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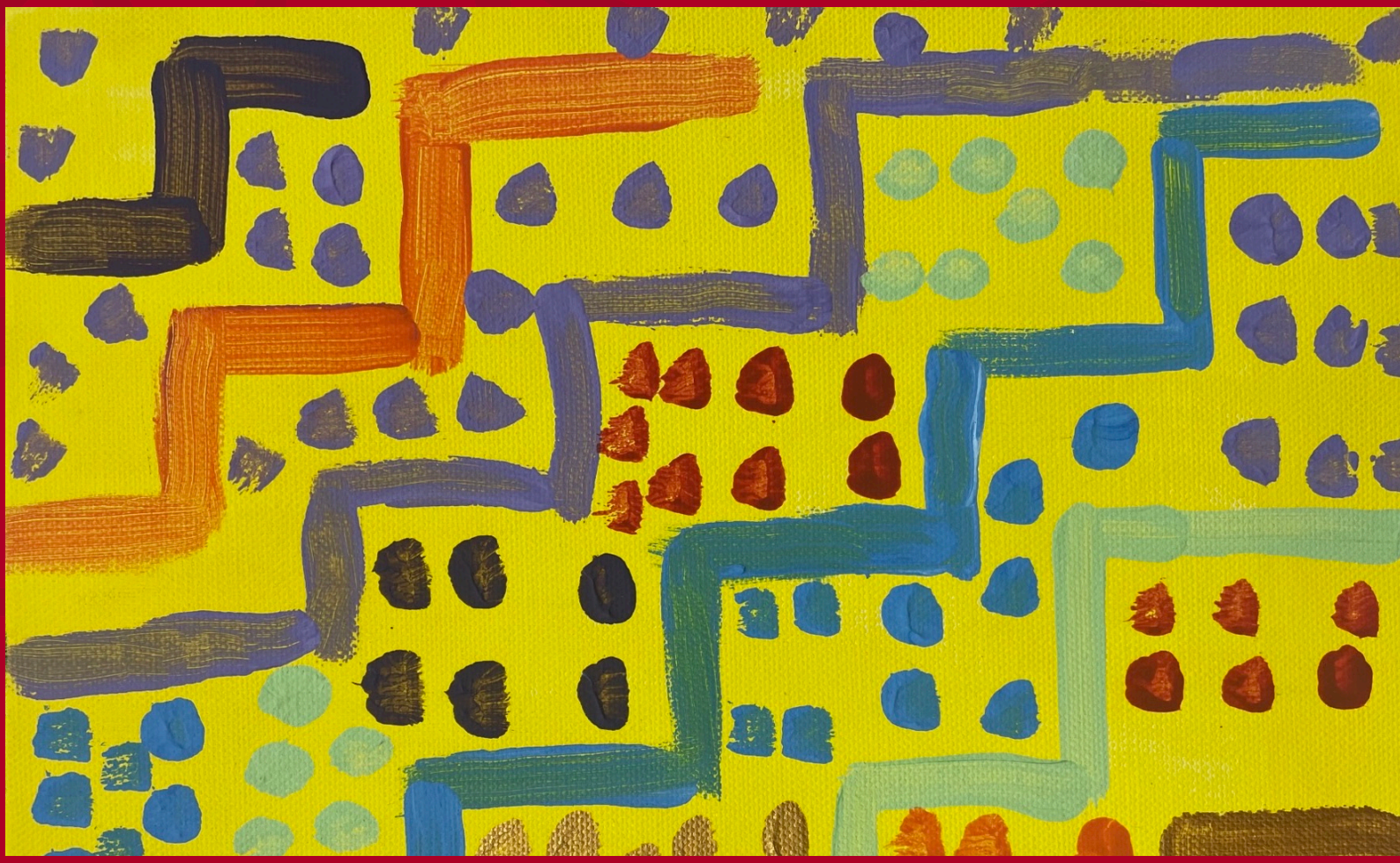

The Meaning of 'Family' in a Multicultural Context:

Disabled People's Perspectives on Article 23 of the UNCRPD

Kā Whakamihi / Acknowledgements

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Whakarakatira te tākata,
ahakoa ko wai, ahakoa nō hea.

Respect and treat all with dignity,
irrespective of who they are and
where they come from.

Author: Donald Beasley Institute (DBI). The DBI is an independent charitable trust that conducts disability research and education. The DBI is committed to ethical, inclusive, and transformative research and projects that promote the rights of disabled people.

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Kōrero Whakamārama: We apply the Kāi Tahu dialect when writing in te reo Māori, that includes Kāi Tahu specific words and replacing the ng with a k.

Project Artwork: Jeffery Oliver

Tohu description: The DBI's tohu depicts the round shape of a wharerau, a temporary shelter once built at mahika kai sites (food gathering areas). The top of the wharerau sits above the earth with a rau (lined pit) below. As a place of shelter and story sharing, the wharerau reflects the DBI's commitment to working respectfully alongside whānau whaikaha to share and grow knowledge and understanding.

Ihiraki / Table of Contents

Kā Whakamārama / Glossary

Ableism: The system of assigning value to people's bodies and minds based on societally constructed ideas of normality, productivity, desirability, intelligence, excellence, and fitness (Lewis, 2022).

Collectivist culture: A culture where individuals are tightly integrated in groups and the interests of the group are prioritised over individual interests (Hofstede, 2001).

Disability: "[T]hose who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (United Nations, 2006, Art. 1).

Disability justice: "The cross-disability (sensory, intellectual, mental health/psychiatric, neurodiversity, physical/mobility, learning, etc.) framework that values access, self-determination, and an expectation of difference. An expectation of difference means that we expect difference in disability, identity, and culture. To be included and part of society is about being able to be our "whole self" (all of our identities together). Disability Justice includes space for self-care, reflection, and hard discussions" (Ortiz, 2012).

Disablism: "Discriminatory, oppressive or abusive behaviour arising from the belief that disabled people are inferior to others" (Miller et al., 2004, p. 9).

Social ecological model: This model illustrates the interplay between a variety of levels of influence, for example, societal, community, relational, and individual levels (Brofenbrenner, 1979; Terry, 2014).

Eugenics: Theories and practices that support reproduction among favoured groups of people (positive eugenics); while restricting the reproductive autonomy of groups deemed "unfit for parenthood", and a threat to the advancement of the gene pool (negative eugenics) (Powell, 2022, p. 1857).

Formal supports: Formal support refers to the formal and/or paid relationships a disabled person has, such as support workers, caregivers, respite, professional and specialist services, and so on (Collings et al., 2017).

Human rights model of disability: This model holds that disabled people have the same human rights as non-disabled people (Harpur, 2012; Johnstone, 2001).

Individualistic culture: A culture that is based on valuing the needs of an individual over the community (Hofstede, 2001).

Natural supports: “People who are not disability providers but who provide support to people with disabilities to participate independently in employment or community settings” (Duggan & Linehan, 2013, p. 201).

Queer: Describes sexual and gender identities outside of heterosexual norms. Queer is rooted in politics and can be used in reclamation by those most marginalised within the LGBTQIA+ community (Gender Minorities Aotearoa, n.d.).

Rainbow: Another term for LGBTQIA+ people and families (Gender Minorities Aotearoa, n.d.).

Social model of disability: This model identifies the root cause of disability to be socially constructed barriers that limit disabled people’s ability to participate in society on an equal basis with others (Oliver, 1990).

Twin-track approach: “A twin-track approach is about making sure mainstream services and supports are inclusive of, and accessible to, us and that services and supports that are specific to us as disabled people are also available. This approach is not about having to choose between the specific or mainstream option; rather it is about having the right access to the right high quality support or service, at the right time and in the right place” (Office for Disability Issues, 2016, p. 21).

Universal design: “The design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design” (United Nations, 2006, Art. 2).

Kā Whakamārama – Te Reo Māori[1]

Aotearoa: New Zealand.

Kupu: Word.

Mātua whaikaha: Disabled parents.

Rakatahi (rangatahi): Younger generation, youth.

Tākata Tiriti (Tāngata Tiriti): Non-Māori, who belong to Aotearoa New Zealand by right of Te Tiriti o Waitangi (Network Waitangi Otautahi, 2023).

Tākata whaikaha Māori (Tāngata whaikaha Māori): Māori disabled people.

Tākata whenua (Tāngata whenua): Local people, hosts, indigenous people - people born of the whenua, that is, of the placenta and the land (where their placenta is buried and where their ancestors lived). Tākata whenua possess whakapapa that locates them within a tribal system (Mead, 2016) and a kinship network across space, place and time (Karetū, 1990). Using the whakapapa principle - where all spiritual and material things originated in Te Korekore (Royal, 2003) - tākata whenua can trace their genealogy to the first woman Hineahuone, who was fashioned out of clay by Tāne (ātua).

Tamariki: Children.

Tauiwi: Foreigner.

Tāwhirimātea: Atua Māori of wind and storms.

Te ao Māori: The Māori world, including language, protocols and customs based on values such as manaakitaka, kaitiakitaka, whanaukataka and rakatirataka (Mead, 2003). Māori rakatirataka was affirmed in He Whakaputanga o te Rangatiratanga o Nu Tireni on October 28 1835 and te Tiriti o Waitangi on February 6 1840 (Waitangi Tribunal, 2014).

Te reo Māori: Māori language.

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[1] Unless specified, definitions have been sourced from Te Aka Māori Dictionary.

Tīpuna: Ancestors, grandparents.

Whaikaha: To have strength, be strong enough. Disabled - a usage created within the Māori disability community.

Whānau: Extended family, family group, a familiar term of address to a number of people. A group of whānau with shared whakapapa form a hapū (kinship group) - the primary economic and political unit of traditional Māori society (Durie, 1994). In the modern context the term is sometimes used to include people who may not have any kinship ties to other members.

Whānau hauā: Collective understanding of disability within te ao Māori (Hickey & Wilson, 2017).

Kā Whakamārama – Moana-nui-a-Kiwa[2]

Aiga: Aiga is a word in the Samoan language, loosely translated to ‘family’, consisting of a wide family group of blood and marriage, or even adopted connections who all acknowledge the matai (head of the family) (Iosefo, 2020).

Alofa: Love (Anae, 1998).

Fa’aaloalo: Respect (Anae, 1998).

Fa’aSamoa: Samoan culture (Ledoux-Taua’aletoa, 2013).

Loto maualalo: Humility, humble.

Soālaupule: “[T]to share your authority, mandate” in any given setting (Ualesi et al., n.d., p. 3).

Tautua: Service (Anae, 1998).

[2] Unless specified, definitions have been sourced from the Pasefika Polynesian Dictionary.

Kupu Rāpoto / Acronyms

ASH: Acceptable Standard of Health

DBI: Donald Beasley Institute

DPO: Disabled People's Organisations

EGL: Enabling Good Lives

LGBTQIA+: Lesbian Gay Bisexual Trans Queer Intersex Asexual plus

NGO: Non-Governmental Organisation

NZDS: New Zealand Disability Strategy 2016 - 2026

NZSL: New Zealand Sign Language

RCOI: Royal Commission of Inquiry

RFP: Request for Proposal

UN: United Nations

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

1 Ka Kupu Whakataki / Introduction

Article 23 (Respect for Home and the Family) of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) affirms the right of disabled people to be part of, and establish their own home and family. Even so, research consistently shows that disabled people experience discrimination in relation to relationships, marriage, reproductive health, forming a family, and establishing a home (Vikström et al., 2020). Furthermore, family, whānau, aiga and close supporters of disabled people can experience significant financial, physical, and emotional challenges when caring for their disabled family member, and upholding their rights, will, and preference (Donald Beasley Institute, 2022).

Conducted during a period of socio-political uncertainty, this research is aptly timed. For example, while carrying out this research the final report from the Royal Commission of Inquiry into Abuse in Care evidenced how disabled New Zealanders were historically separated from their family and whānau through statutory interventions, while also experiencing significant violations of their human rights (Royal Commission of Inquiry into Abuse in Care, 2024). Simultaneous to the release of the RCOI's findings, unexpected changes to disability legislation and policy by the New Zealand Coalition Government were beginning to directly impact disabled people's enjoyment of Article 23 of the UNCRPD.

With the disability rights mantra, 'nothing about us, without us' at its core, this research is designed to facilitate a disability-led conversation about the right to respect for home and family. Specifically, it seeks to understand disabled people's perspectives on, and experiences of Article 23 of UNCRPD, within the unique multicultural landscape of Aotearoa New Zealand. In order to explore disabled people's diverse perspectives in relation to home and family, this research is guided by three key questions:

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

The report begins with an overview of relevant conventions, policies, reports and models. Findings from an integrative literature review are then summarised, before findings from a questionnaire and qualitative interviews with disabled people and their family, whānau, aiga and close supporters from a wide variety of cultures and backgrounds are explored. Key themes and research impacts are discussed, before recommendations and concluding comments are made.

2 Kā Mātāpono / Values

The Donald Beasley Institute is an independent charitable trust that conducts disabled-led and inclusive disability research. Kā Mātāpono (DBI Research Values) underpin this important work:

- Whakatinana – Honouring Te Tiriti o Waitangi through our practice
- 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.

Image description: Within the tohu, kōwhaiwhai (shapes) depict patterns representing the DBI's whakapapa (history), mātāpono (values), mahi (work), and commitment to whānau whaikaha (disabled people and their families).

3 Te Aramahi / Methodology

A diverse team of disabled and non-disabled researchers conducted this research across three key phases: 1) an integrative literature review; 2) a questionnaire; and 3) qualitative interviews. The research received full ethical approval from New Zealand's national Health and Disability Ethics Committee (Ref 2022/FULL/12434).

Phase One: Integrative Literature Review

An integrative literature review method was used to locate and analyse existing research. This review method allows for the inclusion of literature that is both peer-reviewed academic literature and 'grey' literature.[3] Exploring a wide range of literature adds depth to the development of evidence-based practice and policy (Whittemore & Knafl, 2005).

A broad range of literature was reviewed, including academic databases, peer-reviewed articles, United Nations documents, textbooks, government reports, non-governmental organisation (NGO) reports, and media articles. Search terms included (but were not limited to) disability (disabilities, disabled), impairment, family, whānau, aiga, adoption, natural supports, and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, CRPD, Convention). Each resource was systematically searched for materials containing different combinations of search terms, and relevant materials were analysed.

Phase Two: Questionnaire

Informed by the findings from the integrative literature review, phase 2 of the research sought the broad engagement of disabled people and their family, whānau, aiga and close supporters through a questionnaire.[4] Participants were recruited through the DBI's extensive disability networks, Disabled Persons Organisations

[3] Grey literature includes documents produced by governments and non-government organisations, academia, businesses, service providers, and industry (Lawrence, 2012; Whittemore & Knafl, 2005).
[4] The questionnaire was delivered in a range of accessible formats and languages including plain English (online, Qualtrics), Te Reo Māori, NZSL, Easy Read, plain text, large print and audio.

(DPOs), disability organisations, disability service providers, and other relevant organisations. During this phase of data collection, more than 81 responses were received (31 more than the original scope of 50). Of the 81 questionnaire participants, 42 identified as disabled, six as D/deaf, and 26 as family, whānau, aiga, or close supporters, and one 'other'.[5] Participant ethnicities were New Zealand European/ Pākehā (52); Māori (3); Māori and Pākehā or another ethnicity (10); and other ethnicities such as Indian, Fijian, Chinese, Danish, Irish, Scottish, Samoan, Welsh, South American, and unspecified (11). Regarding gender, questionnaire participants identified as female (50); male (19); gender diverse (5); and one participant preferred not to say. The disabilities represented amongst the participants were D/deaf and hard of hearing; physical disability; neurodivergence; psychosocial disability; learning disability;[6] chronic health; and blindness or vision impairment. Many participants had coexisting disabilities. The age range of the participants was 18 to 65+.

The questionnaire was designed to ask participants about their perspectives on their right to respect for home and the family, culture, and the role of support workers in a family context.

Phase Three: Qualitative Interviews

During the third phase of data collection, 14 qualitative interviews were conducted with disabled people and their family, whānau, aiga and close supporters. Participants were recruited through the DBI's extensive disability networks, Disabled Persons Organisations (DPOs), disability organisations, disability service providers, and other relevant organisations, and maximum variation sampling was used to ensure a diverse range of disability groups, cultures and family contexts were represented amongst the participants.

The 14 interview participants identified as: Pākehā/New Zealand European/ New Zealander; Māori; British; European; Samoan; and Cook Island Māori. Regarding

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[5] Participants had multiple identities, meaning the total does not always equate to 81. For example, some participants identified both as disabled people and a family member or support person of a disabled person.

[6] Learning disability is an alternative term to describe intellectual disability. It is the term preferred by self-advocates with learning disabilities in Aotearoa New Zealand.

gender, interview participants identified as female (9); male (4); and non-binary (1). The disabilities represented amongst the participants were D/deaf; physical disability; psychosocial disability; learning disability; chronic health; and blindness. Some interview participants had coexisting disabilities. The age range of the participants was mid-20s to mid-60s.

The interview questions were informed by phases one and two of the research, and engagements were conducted via Zoom and in person. Each interview was recorded and transcribed into a verbatim transcript, before being analysed alongside phase one and two findings. All data were compared and contrasted, noting emergent trends and patterns to identify significant themes, and directions for future investigation.

Strengths and limitations

A key strength of this research is that it was led by a team of diverse disabled and disability researchers, representing a range of identity and cultural groups. This ensured that various perspectives shaped and informed the final report, with the DBI's mātāpono (values) and accountability to the disability community prioritised at every stage of the research process. This was particularly important given that the purpose of this project was to explore the meaning of respect for family and home for disabled people and their family, whānau, aiga and close supporters. A second key strength was the volume of data. The number of people wanting to participate in this research exceeded expectations, leading to a large body of data and evidence.

A limitation of this study is that it cannot be asserted that all relevant literature was identified, despite extensive searches being undertaken. Relevant research may not have been located or integrated for a range of reasons including because it was: unpublished; unavailable through the chosen databases; not written in English; not considered to align with the core values of this research; or catalogued under search terms that were not used in this study.

4 Kaupapa Here Matua / Instructive Conventions, Policies, Reports and Models

Outlined below are key conventions, policies, reports and models that are relevant to disabled people's right to respect for home and the family in Aotearoa New Zealand.

Te Tiriti o Waitangi

Te Tiriti o Waitangi is the foundational document of Aotearoa New Zealand, which established a formal relationship between Māori and the Crown, and recognised two spheres of authority - Māori tino rakatirataka and Crown kāwanataka (Waitangi Tribunal, 2024). Article 2 of te Tiriti o Waitangi provides Māori with tino rakatirataka (chiefly authority) over the land and taoka (treasures such as cultural practices, language and customs. Te Tiriti o Waitangi affirms the importance of Te Ao Māori (Māori world views), which includes the holistic health and wellbeing of tākata whaikaha Māori and whānau hauā (Ingham et al., 2022; Rolleston et al., 2022).

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The UNCRPD is an international agreement between the United Nations (UN) and signatory governments aimed at progressively realising the human rights of disabled people. It sets out what governments must do to ensure that disabled people have the same human rights as everyone else (United Nations, 2006). In 2008, the New Zealand Government became one of the first to ratify the UNCRPD, before further indicating its commitment by ratifying the Convention's Optional Protocol in 2016. Article 23 of UNCRPD refers to respect for home and the family. It requires governments to eliminate discrimination against disabled people in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others (United Nations, 2006).[7]

New Zealand Disability Strategy 2016-2026

The New Zealand Disability Strategy (NZDS) guides the work of government agencies on all issues affecting disabled people. The NZDS aims to help realise the

[7] For the full text of Article 23 of the UNCRPD please refer to Annex A.

human rights of disabled people by supporting the implementation of the UNCRPD (Office for Disability Issues, 2016). The underpinning principles of the NZDS are Te Tiriti o Waitangi, the UNCRPD, and ensuring disabled people are involved in decision-making that impacts them. The NZDS recognises disabled people as members of family and whānau (Office for Disability Issues, 2016).

Enabling Good Lives (EGL)

Enabling Good Lives (EGL) is a disability support vision and approach co-developed by disabled leaders and the New Zealand Government to articulate how to implement and uphold the human rights of disabled people (Enabling Good Lives, n.d.). It was established with the recognition that the traditional disability support system was not achieving what was promised within the UNCRPD. The EGL approach is underpinned by eight principles and a funding model: self-determination; beginning early; person-centred; ordinary life outcomes; mainstream first; mana enhancing; easy to use; and relationship building. While the EGL approach to funding (personal budgets) has been successfully piloted in three regions in Aotearoa New Zealand with the intent of being delivered nationally, in August 2024 the New Zealand Government 'paused' its expansion of the EGL approach (Whaikaha - Ministry of Disabled People, 2024).

Whanaketia – Through pain and trauma, from darkness to light Whakairihia ki te tihi o Maungārongo (final report of the Royal Commission of Inquiry into Abuse in Care)

In July 2024, the Royal Commission of Inquiry into Abuse in Care (2024) final report was made public. Included in the inquiry's scope were the experiences of disabled children and adults who experienced abuse in state care between 1950 and 1999. The report consists of 16 volumes outlining the context in which abuse occurred, what happened, why it happened, specific case studies, survivor experiences and recommendations. Of particular note to this research is the finding that the families of D/deaf and disabled children were actively encouraged to place their children into state care. This led to the segregation of D/deaf and disabled children from their family. For D/deaf and disabled Māori and Pacific children and young people, separation and isolation from their whānau and aiga was followed by deprivation and

the denial of their cultural and collective identities (Royal Commission of Inquiry into Abuse in Care, 2024).

Social and human rights models of disability

The UNCRPD and NZDS are underpinned by the social and human rights models of disability. The social model identifies the root cause of disability as being socially constructed barriers that limit disabled people's ability to participate in society on an equal basis with others (Oliver, 2013). The social model critiques the medical model of disability, which holds that "a person's functional limitations (impairments) are the root cause of any disadvantages experienced" (Crow, 2010, p. 125). The social model shifts the focus from the individual to broader societal barriers, and as a result, has become a powerful tool for disability advocacy. In addition, the human rights model holds that disabled people have the same human rights as non-disabled people (Harpur, 2012; Johnstone, 2001). Both models challenge the barriers that disabled people face when becoming parents and starting families (Libesman, 2023), and can be used to highlight and remove barriers in this area.

5 Arotake Mātākōrero / Literature Review Summary

The first phase of this research was an integrative literature review. The purpose of the review was to understand how the notion of 'family' is constructed within literature, and to provide the basis for the data collection phases of the research. Included in the reviewed literature was research pertaining to the meaning of family, respect for home and the family, and the realisation of Article 23 of the UNCRPD for disabled people and their families.

Analysis of the literature indicated that 'family' is a topic of interest across many disciplines and fields (Zvonkovic et al., 2006). The review also revealed that non-traditional forms of families are more common; with divorce and remarriage becoming increasingly prevalent, resulting in many iterations of what are broadly referred to as 'blended families' (Pool & Du Plessis, 2017). There has also been a significant increase over time in the number of families with parents who are not formally married to each other, single-parent families, and families involving non-heterosexual relationships (Henaghan et al., 2013).

There are also significant differences in how the term 'family' is understood by different communities and cultures in Aotearoa New Zealand, especially in the context of Māori and Pākehā/Tauiwi (Pool, 2013). For disabled people, the complexities associated with disability are deeply impacted by culture (and vice versa), including experiences of discrimination when being part of, and establishing partnerships and their own home and family (Vikström et al., 2020). However, there was little literature specifically addressing disabled people's conceptualisation of family (Halder et al., 2014).

While the integrative literature review uncovered a sizable literature in health and social care policy and practice regarding families that include disabled children, there was relatively little literature on disabled people's experiences of family life and parenting. With the exception of the body of research focused on parenting by

people with a learning disability,[8] there was also a lack of research on disabled people's experiences of parenting and services, parenthood, and broader roles and relationships (Clarke & McKay, 2014). A recent study from Aotearoa New Zealand investigated key factors that underpin high-quality disability support with regards to the interplay between disabled people, family and support workers (for example, trust, communication, and flow), and acknowledged the need to further explore the intricate interplay of context and mechanisms that drive positive outcomes for disabled people (Bourke et al., 2024). This review also highlighted the scarcity of research on how disabled people conceptualise and understand 'family' and 'home', and the everyday implications for disabled people when Article 23 of the UNCRPD is either upheld or denied. However, the literature did highlight that for disabled people the experience of family and home influences, and is influenced by, the experiences of disability, health, and wellbeing (Ahlström & Wadensten, 2011; Jones, 2020; Selander & Engwall, 2021). Culture also has a strong influence on home and family, which has significant implications for a multicultural nation like Aotearoa New Zealand. Six key areas of interest from the integrative literature review are summarised below.

5.1 Defining 'family'

Family is the building block of communities and cultures (Pryor, 2005). The 'scientific theory' of family is based on the nuclear family as an institution for nurturing children (Skalnik, 2006). According to this definition, family is a bounded social unit with a shared place and emotional ties between family members (Havigerová et al., 2013). However, understandings of 'home' and 'family' differ between families and culture (Vikström et al., 2020) and the concept of the 'nuclear family' has been critiqued for being too narrow to include broader definitions, such as those held by non-western cultures (Tautolo et al., 2020). According to the United Nations' recommendations in Principles and Recommendations for the 1970 Population Censuses (United Nations, 1970), family is defined as:

> [M]embers of the household who are related to a specified degree, through blood, adoption or marriage. The degree of relationship used in

[8] For example, see Conder et al. (2010).

> determining the limits of the family is dependent upon the uses to which the data are to be put and so cannot be precisely set for world-wide use. A family cannot comprise more than one household; a household can, however, consist of more than one family, of one family together with one or more non-related persons, or entirely of non-related persons. In practice, most households are composed of a single family consisting of a married couple without children or of one or both parents and their unmarried children. It should not be assumed, however, that this identity exists.

'Family' may also refer to the 'extended family' or 'joint family', which includes a couple with not only their minor children but also their married children, their families, and other relatives as well. A common theme among the varying definitions is the role of law or custom in regulating families. Throughout history, Aotearoa New Zealand has witnessed legal and conceptual changes of 'family' (Henaghan et al., 2013), with new and updated legislation being enacted to reflect increasing diversity. The current conceptualisation of family, according to the Families Commission Act 2003 is inclusive of any group of individuals related by marriage, civil union, blood, or adoption, or an extended family, two or more persons living together as a family, and a whānau or other culturally recognised family group (Parliamentary Counsel Office, n.d.).

While Aotearoa New Zealand has two officially recognised cultures - Māori and Pākehā - it is also home to many diverse peoples (Dam, 2017). With normative and colonial understandings of 'family' having evolved over time, families take on many shapes and forms in Aotearoa New Zealand. Some examples include stepfamilies; single-parent families; families headed by unmarried partners; families headed by same sex partners; multigenerational households; adoptive, foster and whangai families; and more (Crib, 2009; Superu, 2015). For disabled people, their experience of family, whānau, aiga and home is not only impacted by culture, but also their experiences of disability, health and wellbeing. This includes the intimate role of support workers within the home, and their engagement with disabled and non-disabled family members (Ahlström & Wadensten, 2011; Jones, 2020; Selander & Engwall, 2021).

5.1.1 Whānau hauā, whaikaha and whānau

Conceptualisations of disability in te ao Māori differ to Western perspectives. Two commonly referenced Māori models of disability include the whānau hauā and whaikaha models. The kupu (word) ‘hauā’ originates from Tāwhirimātea, who is the atua (god) of wind and who brings breath to the world (Bennion Law, 2022). Whānau hauā refers to the idea that the impact of disability is balanced through whānau working together (Hickey & Wilson, 2017). Whaikaha acknowledges the strength of disabled people. It is a more recent term, created by tākata whaikaha Māori (Māori disabled people) to reflect a strength-based approach to the way disability is conceptualised (Whaikaha – Ministry of Disabled People, n.d.). In addition, Reo Hāpai (2020) translates whaikaha as meaning “to have strength, to have ability, otherly abled, enabled. A word created within the Māori disabled community.”

Whānau is an all-encompassing concept that plays a significant and central role in Māori culture (Collins & Hickey, 2006). While whānau is considered the closest concept to family in Māori culture (Ministry of Social Development, 2004), it transcends Western concepts of family, and includes whakapapa to hapū, iwi, tīpuna or ancestors, and whenua (Walker, 2011). In traditional Māori society, the primary economic unit was the hapū - a kinship group formed by a collection of whānau who whakapapa to a common ancestor (Durie, 1994). The principle of whanaukataka (kinship) encapsulates the Māori worldview that a person’s wellbeing is closely associated with the wellbeing of their kinship group, and an individual's actions were viewed as the actions of their kinship group (Royal, 2003; Waitangi Tribunal, 2014). Hapū, and whānau by extension, were the supreme authority in traditional Māori society (Durie, 1994). In this way, many aspects of Māori values and norms have been described as collectivist (prioritising the needs of a group or society over the needs of the individual) in contrast to the individualistic values and norms of pākehā society (Brougham & Haar, 2012; Hook, 2007; Hickey & Wilson, 2015; Tassell et al., 2010).

While still underpinned by Māori values such as whanaukataka and manaakitaka,[9] the term ‘whānau’ has evolved in modern times and taken on different meanings (Durie, 2003). For example, as highlighted by Hickey and Wilson (2015):

> Whānau may also be made up by those with a common purpose of experience, such as those with similar disabilities like kapo or turi. These whānau are referred to as kaupapa whānau, whose members provide caring, support and nurturing roles that traditional whānau provide. The collective orientation of the Māori whānau means its members also have associated responsibilities and obligations to manaaki other members and the whānau as a whole (p. 86).

While the relationship dynamics between tākata whaikaha and whānau hauā Māori and whānau have not been widely investigated (Collins & Hickey, 2006), disability-led and kaupapa Māori research has brought together whānau hauā, tākata whaikaha and whānau perspectives on whānau and disability. This growing body of research has included topics such as (but not limited to): whānau wellbeing; the diverse realities of Māori and whānau hauā; the interchangeable, yet subtle differences between household, whānau and family; Indigenous disability identities; Māori and disability support options; health and wellbeing; amongst others (Collins & Hickey, 2006; Hickey & Wilson, 2015; Ingham et al., 2022; Waimarie Nikora et al., 2004).

Of particular relevance to this research are discussions around individualistic cultural perspectives on the right to respect for home and the family, and collectivist cultural perspectives (Hofstede, 2001). For example, individualism, more than collectivism, is focused on personal rights (such as universal human rights) and goals rather than an individual’s obligations toward the collective (van Hoorn, 2015). As summarised by Wilson and Hickey (2015, p. 91), “Policies for determining the rights of disabled persons need to include a Māori worldview of wellbeing and disability to better meet

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[9] Manaakitaka is to extend aroha (love and compassion) and is found in acts such as helping, encouraging or supporting one another: “It is one of the most important concepts to Māori people as it secures the strength of our whānau (families) and communities” (Te Pā Tū, 2024). As highlighted by Hirini Moko Mead (2016) “All tikanga are underpinned by the high value placed upon manaakitanga - nurturing relationships, looking after people, and being very careful about how others are treated” (p. 33).

the needs of whānau hauā. Continuance of a universal approach will perpetuate inequities for whānau hauā."

5.1.2 Tagata Sa'ilimalo and aiga

Diverse ethnicities make up Pacifica communities in Aotearoa New Zealand (Ministry for Pacific Peoples, 2022). Therefore, a variety of definitions and conceptualisations of family and disability exist within these communities. Recognising the unique experiences and understandings of disability, Tagata Sa'ilimalo is a framework created by Pacific disabled people in Aotearoa New Zealand. Tagata means person or people, and sa'ilimalo means the pursuit of success:

> … an aspirational vision of the pursuit of success underpinned by sheer determination and sustained by the collective vitality of Pacific peoples. It is a vision that reflects the hopes of the disability community to imagine better for their future. The Tagata Sa'ilimalo vision is inclusive of all Pacific peoples in Aotearoa and all disability types (Tōfā Mamao Collective, 2022, p. 5).

Pacific notions of family also extend beyond the Western notion of the 'nuclear family unit' (Tautolo et al., 2020). In many Pacifica populations families live in multi-generational households (homes housing multiple generations) and multi-family households (homes housing multiple families) (Koloto & Katoanga, 2007; Ledoux-Taua'aletoa, 2013; Pene et al., 2009). Furthermore, the "central element in fa'aSamoa (Samoan culture) is the aiga (family)." Within the aiga "giving and receiving tautua (service), fa'aaloalo (respect) and alofa (love) are crucial" (Anae, 1998 cited in Ledoux-Taua'aletoa, 2013, p. 18). In Samoan culture, the term aiga is used for kinship in all its dimensions: "It is inclusive of nuclear family, extended family as per the Western understanding. Aiga also incorporates descent groups, blood relatives, relatives by marriage and adopted relatives (Meleisea, M. & Schoeffel, P. cited in Adair, V. & Dixon, R. 1998)." (Ledoux-Taua'aletoa, 2013, p. 18). In this sense, the concept of aiga reflects many of the values of whānau Māori, with Pacific cultures also being considered collectivist (Ministry for Pacific Peoples, 2018).

For many Tagata Sa'ilimalo, Pacific identity is central to their lives and that of their families and carers. In other words, disability is a subset of cultural identity (Tuvale, n.d.). Tagata Sa'ilimalo are also uniquely tied to the family collective, with the term

‘Tagata Sa’ilimalo’ referring both to an individual and to the family and community surrounding that person. Within the family collective, tagata sa’ilimalo are understood to “both give and receive support” (Tōfā Mamao Collective, n.d.).

5.1.3 Disability and family in Pākehā society

Western social and family traditions in Aotearoa New Zealand primarily originate from British Colonisation. The family traditions of Anglo and European-origin New Zealanders (pākehā) are significantly different from many family traditions found in Māori and Pacific communities, as well as other immigrant communities such as Asian populations (Metge, 2014). In Aotearoa New Zealand, the Western concept of family has traditionally referred to the social unit comprising a husband, wife, and their children. Based on marriage and biological parenthood, the modern Western family is typically united by affection and the obligation to care for and support each other, as well as a common identity and shared common residence (Metge, 2001). In Pākehā communities family often plays a central role in nurturing individuality, providing emotional and financial support, and realising members’ potential. In general, there is a sense of responsibility for transferring values and cultural knowledge to the next generation(s) (Pryor, 2005).

While more traditional forms of families are still prevalent in Aotearoa New Zealand, other forms of families are increasingly becoming common. For example, traditional class-based or gender-based boundaries are dissolving, and families with a variety of structures are taking shape. Statistically, a typical pākehā family in Aotearoa New Zealand continues to take on a nuclear family structure with extended family living separately. However, with divorce and remarriage becoming increasingly prevalent, step-parents and step-siblings are present in many families, and there has been an increase in the number of families with unwed parents (Pool & Du Plessis, 2017).

Disability is also characterised by Western understandings in pākehā society. The medical model of disability, which perceives disability as a physical disease or illness located in an individual has gradually been replaced with the social model of disability, which emphasises the removal of barriers that prevent disabled people from full inclusion in society (Shakespeare, 2013). Accordingly, a range of formal disability support services are offered to enhance the independence of disabled people. However, family often continues to play a critical role in their everyday lives,

and for many disabled people family is their only source of support for everyday tasks (Olson et al., 2005) as well as liberation and self-determination (Shakespeare, 2014). In doing so, parents and other family members act as advocates and guide disabled people in the pursuit of their individual interests (Brennan et al., 2016).

5.1.4 Immigrant perspectives on disability and family

Family dynamics in migrant communities are both similar to, and distinct from, the wider community (Vertovec, 2007). For many immigrants, family is a social institution that provides a foundation in which children learn how to navigate and fit into society. Family theorists contend that immigrant families are open and dynamic and are susceptible to changes, just like non-immigrant families. However, unlike other families, immigrant families sustain more social pressure to conform and fit into mainstream society (Anderson and Blinder, 2021).

Empirical evidence indicates that the success of immigrant children and subsequent socioeconomic attainment are determined by their educational aspirations and by parental involvement and capacity to provide them with opportunities and support. This has been explained by the fact that a close familial relationship can function as a protective factor against negative forces resulting from oppositional subculture, weak family bonding, and disruptive family processes (Burns, 2019).

In Aotearoa New Zealand, migrant families can be significantly impacted by immigration policies. Disabled people are particularly subjected to ableist immigration policies, such as the Immigration Act 2009 and Acceptable Standard of Health (ASH) policy, which prioritises individuals and families unaffected by disability or health conditions, and restricting those who are affected by disability from immigrating to, or joining their family in Aotearoa New Zealand. Such policies actively prevent disabled people from obtaining the required visa to enter the country, or obtaining residency if they are already in Aotearoa New Zealand (Ayoubi & Nazari Orakani, 2022). Discriminatory policies assess visa and residency applications on the basis of an estimated cost of health and education services disabled people might use in a five-year period. This has had a substantial impact on disabled migrants and their families. Over the years, the Immigration Act 2009 and ASH has discriminated against many disabled people and their families by preventing them from migrating, and separating families between Aotearoa New Zealand and their

country of origin, leading to many disabled people and their families being forced to leave the country (Kelly-Costello, 2022).

5.1.5 LGBTQIA+ communities, disability and family

While LGBTQIA+ and rainbow families are the same as all families, they can experience prejudice and stereotyping related to the notion that rainbow identity, and raising children in rainbow families, constitutes a social deviation from normality (Golombok, 2015). The concept of ‘family’ has been a major focus for rainbow activists due to mainstream social attitudes that deny same-gender partners from creating tangible family relationships (Tasker et al., 2018).

Family support is important for the individual and relational health and wellbeing of the rainbow community. Rainbow disabled people experience specific challenges resulting from their intersecting identities such as higher rates of isolation, discrimination, and violence when compared to non-disabled people. Furthermore, there is a prevalent societal view that disabled people do not or should not have intimate/sexual relationships or gender identity (Toft et al., 2020). It is important to understand how family support may have changed in response to the recent major shifts in family dynamics, and more specifically following the structural changes that legalised marriage for same-sex couples in many Western countries (Cortina & Festy, 2020).

6 Kiteka / Findings

Having reviewed academic, grey, international and national literature regarding disability, home, family and culture, the data collection phases of this research sought to contribute to the literature and identified gaps by engaging with a diverse array of disabled people about their perspectives on the right to respect for home and family. In this chapter, findings from the questionnaire and qualitative interviews detail six key themes and related sub themes regarding the perspectives of disabled people and their family, whānau, aiga and close supporters on disability, home and family, including: my family; my roles and responsibilities; my culture; my supports; my aspirations; my home; and barriers to home and family.

6.1 My family

The first key theme detailed who participants considered their family to be, and included common characteristics of family. As noted in the reviewed literature, the United Nations' definition of family is a group of people who share the same household, and connection through blood, marriage or adoption (United Nations, 1970). However, little attention has been given to the additional, and sometimes complex relationships disabled people experience in their everyday lives, and what this means for their human rights under Article 23 of the UNCRPD.

As might be expected, however, often the first thing that came to mind when participants were asked who they considered their family to be, were their immediate family members, with participants frequently referencing biological connections and blood ties:

> Think family means blood in that way. I think it does, means kind of related by blood. And I think that's kind of family unit. That's what I think of when I hear the word or you know, I see the word or see the sign [for] 'family'. And I think that could include cousins and uncles and aunties and all of that. (Interview participant)

This response, unsurprisingly, reflects both the United Nations' definition as well as Western, colonial and nuclear concepts of family, and the traditional social unit

consisting of parents and their biological children, and other immediate blood relations.

However, participants also drew attention to the rich, albeit sometimes complex, tapestry of family networks that extended beyond traditional Western concepts, including cross-generational family members. For example, some Māori participants spoke about family in terms of whānau and whakapapa, which included all extended family through blood ties and relational commitments (such as marriage or in-laws), as well as ancestors:

> My family is my husband and children, my parents, in-laws, siblings, nephew, aunties and all ancestors. (Questionnaire participant)[10]

Similarly, cultural differences were found in Pacific participants' conceptualisation of home and family. One participant shared the critical role that extended family members played in their life:

> I've been blessed to have, as well as my, my own biological mother, you know, I had two aunties and two uncles who became matriarch and patriarch of my family when my parents weren't around, with culture and stuff, when Mum and Dad moved back to [Island] to look after my grandmother. (Interview participant)

Participants shared that aiga comes before all else, with aiga being a central value of the community alongside collectivism and communitarianism, spirituality, reciprocity, and respect. Much like the Māori values of whanaukataka and manaakitaka, these values created a shared sense of responsibility to care for each other, including tagata sa'ilimalo:

> So my, 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 aunties and uncles who are part of that ecosystem of support. (Interview participant)

[10] While questionnaire responses have been presented as written in the form, some grammar and spelling edits have been made to improve clarity and ease of reading.

With regards to other identities represented amongst the participants, for participants from LGBTQIA+ communities, families were also considered as those who shared connections that were not blood or by marriage, but who shared identity in a familial way. This is sometimes referred to as ‘chosen’ family (Jackson Levin et al., 2020):

> Both like a rainbow identity and disability have been a huge marker in shaping what I think family is. [...] And then I think that created a really great framework for them to understand, 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. (Interview participant)

> I am estranged from much of my blood family. My family are in an anti-queer religion so they are not safe for me. I consider it more meaningful to consider family to be the people who show me care and freely given love, and who take the time to be an active presence in my life. (Questionnaire participant)

> Knowing family has no specific look families can be chosen (rainbow /trans community). (Questionnaire participant)

Similarly, a shared disability identity was considered by some participants as a marker of family, as well as pets:

> My adopted kids and birth child, husband, my mum, step dad, brothers and their families, sister and her family, the bigger extended family of whānau living with FASD and other neuro-divergent conditions, pet rabbit is also our family member. (Questionnaire participant)

> My whānau includes my partner, our beautiful dog, some close friends who are also in rainbow relationships and raising their children + fur babies, and some close friends who are also disabled that are around my age. These are the people I feel safe to have in my home. [...] My

> rainbow family and disabled friends are my safe place in an unpredictable world. (Questionnaire participant)

6.1.1 Characteristics

As well as identifying who participants considered their family to be, two common characteristics were identified as being central to family. These were consistent across the participants, regardless of ethnicity or identity.

Family are those who provide support

Reflecting literature detailing values that are central across different cultures (for example, manaakitaka in Te Ao Māori, tautua in Pacific cultures, and support for independence in Pākehā cultures), the provision of support (emotional and practical) was a strong theme for many participants, many of whom shared the view that family are those who provide support to disabled family members:

> Blood relatives, immediate family and extended, friends. Family is more than just blood, it's those that are in your life as a constant support and friend. (Questionnaire participant)

> My partner is immensely supportive, both practically and emotionally. I actually want more non-family support, especially with housework, so it's not all dumped on her. (Questionnaire participant)

Family are those who make me feel safe

As described in the literature (Pain, 2000; Price, 2002), safety was also a key characteristic of home and family:

> Well, my husband is, he's my safe place. (Interview participant)

6.2 My roles and responsibilities

The second key finding highlighted the significance of family roles and responsibilities. While anecdotal and academic literature suggests that disabled people are often perceived as dependents and recipients of support and care (Fine & Glendinning, 2005), participants highlighted the important roles they played in their respective families:

> I'm just here. I'm just the Dad. Really, I can't really think of any specific quality that I think is most important. Just being there. And being a Dad, it's the most important thing to me - being present. Being in their lives. (Interview participant)

Within this finding, two sub themes highlighted the characteristics of participants' roles and responsibilities within their families. In addition to their family role (for example, 'Dad'), participants consistently reflected on being a contributor and a reciprocator.

6.2.1 Contributor

When discussing their families, participants repeatedly emphasised that they were involved and contributing members of their families - whether in familial roles, leadership roles, or task-oriented roles (such as being a responsible pet owner). Importantly, these roles were no different from the roles filled by other non-disabled family members, even though participants sometimes needed extra support and accommodations to fulfil these roles effectively:

> [...] be here for them and be involved. I take the [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. We just do things together. And when they were little, I would carry them when they're tired, and all that sort of thing. (Interview participant)

Some participants highlighted how cultural and moral values superseded notions of disability, and the impact this had on their role in the family:

> We grew up in the church. And as part of being part of being part of the church environment, you know, there were certain roles, responsibilities that are usually handed to people of young age, and, you know, in a lot of ways, my family, you know, made it work, they were advocating that, you know, that I, too, was able to undertake some of those roles within the church, despite my disability. And so, then, you know, I've had advocacy and education around the things that I can versus things that I need support to be able to do, has always been a part of my, has always been a part of my life. (Interview participant)

Importantly, participants felt that their experience of disability should not be a barrier to carrying out family roles and responsibilities - they wanted to be treated like everyone else in the family, and expected to contribute like everyone else:

> So, disability wasn't really a thing until it was, you know, until it was obvious, like, I'd walked into something or tripped over something or something like that. But outside of all of that, on the most part, you know, I was treated like, like everybody else. My family. My family never really saw my disability as a barrier to carry out roles within the family. (Interview participant)

6.2.2 Reciprocator

The second sub theme that was discussed in relation to family roles and responsibilities was reciprocity, which was found consistently throughout the different cultures represented in this research. As has been highlighted in previous research (Meltzer & Muir, 2022; Mauldin & Saxena, 2018), participants noted that reciprocity between themselves and non-disabled family members was important:

> [...] respect the needs of everybody in the home as they all contribute to every person’s successes. While I have a disability, my family support me to manage my independence as much as I support them to manage theirs. (Questionnaire Participant)

> My family are who, for the most part, I can rely on to try to help me & visa-versa. (Questionnaire Participant)

The importance of reciprocity was not just limited to immediate family members. For example, several participants shared the importance of paying forward the support they receive to the wider community:

> That the whole thing around love and respect, and, you know, being able to reciprocate those cultural values in the space. (Interview participant)

> [Respect is being] a valued member of society with contributions to be made to immediate and wider society. (Questionnaire participant)

6.3 My culture…

The third key finding is related to culture, which can have a significant impact on the goals, values, beliefs, and patterns of behaviours of individuals and families, including in relation to home and family environment (Bámaca-Colbert et al., 2019). While there is no single universally accepted definition of culture (Apte, 1994) it is generally used to describe assumptions and values, orientations to life, beliefs, policies, procedures and behavioural conventions that are shared by a group of people, and that influence (but do not determine) each member's behaviour and their interpretations of the 'meaning' of other people's behaviour (Spencer-Oatey, 2008). Within this theme participants discussed a range of sub themes, including the impact of culture on perceptions of: home and family; disability; support; and Deaf culture.

6.3.1 Home and the family

The first sub theme related to cultural perceptions of home and family. Family dynamics refer to the patterns of interactions among family members, relatives, their roles and relationships, and the various factors that shape these interactions (Jabbari et al., 2023). Because family members often rely on each other for emotional, physical, and economic support, cultural differences can result in significant variations in family dynamics and interactions. In line with the literature, participants shared that culture plays a significant role in their understanding of, and interactions within, home and family. For example, when one interview participant of Māori and Samoan descent was asked if culture impacts what they think about home and family they responded:

> Yes. Most definitely. From an early age, we were delegated tasks to do in the family that we must be sure to do. I guess it built up our early skills. I know, it was quite tough for our ways, the family beliefs. And we started young and so we knew what was expected of us. We knew what we were doing. We knew what was expected in terms of activities. Yeah, that was all very, very real. Let me give you an example. Let's

> say when we were three, four or five, you know, we learned how to garden the weeds. Pull out the weeds, plant seeds, we knew how to do things like washing up, helping out with the family, with food, caring for each other, cutting out meat and vegetables. We knew we had to do all these things. (Interview participant)

Similarly, when answering the question ‘What does respect for home and the family look like in your culture/community?’ another questionnaire participant highlighted the central role of manaakitaka in their whānau and relationships:

> As a Māori family we respect each other by loving and showing that we care helping those one 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. (Questionnaire Participant)

6.3.2 Disability

The second sub theme considered cultural perceptions of disability. The impact of culture was described as extending beyond participants’ understanding of home and family, to the way that disability is perceived and responded to within their immediate and wider family and community:

> They [whānau Māori] are much more accepting, very much more accepting than my, I would say my more Western-oriented family. The Māori people are much more, they don't have a bigger problem with it [disability] as other people do. So, there again, for me, it's much easier to associate with my local whānau than it is for me to associate with other family, my mother's family who are very, very, very, very distant. You know, they don't accept it [disability] very much, very greatly at all. But my father's family have no problem with it [disability], really they don’t. (Interview participant)

When asked to elaborate on the cultural differences they were referring to, this interview participant explained that their whānau Māori responded differently to disability than their Pākehā family and colleagues did:

> I would say first they see me as a person. That's what they definitely see that they're, you know, they take into consideration my disability, if I have to go somewhere. That's taken into consideration. But otherwise, they treat me pretty much as they would treat anybody else. And that's definitely a cultural thing here. Because I see, even see that with my colleagues throughout purely Westernised there's a huge difference in the way that they treat you. The people around me at work who are Māori, they have a completely different understanding of disability. (Interview participant)

Reflecting on different cultural approaches to disability, another interview participant noted:

> There always needs to be a balance between values, cultural values within the family, versus I guess the, the Western perspective. I guess, you know, in terms of how set disability or how people with disabilities are perceived when, or the, the assumption and role within the family. [...] For example, my parents, through their cultural lens, didn't want me to go to school camp, because of my disability and the fear of, you know, falling, injuring myself. And, out of all of my aunties and uncles and all of my family, I only have one Māori auntie, an auntie who was brought up here in Aotearoa and gave a different perspective to my parents, you know, about letting me go to camp and if I fall I fall, if I injured myself, I injured myself. (Interview participant)

Another interview participant of Samoan descent shared that in their aiga, a disabled family member had been given a chief title:

> They actually call [family member] ‘Savaiinaea’, which in our family is a high chief title, even though it's not bestowed upon him through the ceremonial process, but that for me is a sign of respect. Family meetings, church sessions, my [family member is] always seen as Savaiinaea. He's given that title. And it's not a mockery one. It's actually an acknowledgement of the tautua [service] that my mum has provided for the family, but also just because it's [family member], they

> see him as a leader in their own eyes, because he's unique in what he's had to lead and the life that he's lived. He is the high chief in our family with a disability. That's what makes him special and loved and respected. He doesn't need to have the skill of speaking high Chief language, has presence and just being alive this long is what our family see. And that's not just me, it's my extended family because they acknowledge it all the time. And it's really humbling to see and to hear, because we know that it's a really important process of higher chief titles when they're bestowed upon you.

As highlighted in these excerpts, understandings of disability are often influenced by culture, and as a result, impact disabled people's relationships with home and family.

6.3.3 Values

When thinking about the impact of culture on home and family, participants also referred to the importance of cultural values:

> A family passes on values and supports each other, same culture. My husband and I are both Deaf. So, we are very similar. And we have quite a close link. We are deeply embedded in the Deaf community and it works very well. (Interview participant)

> [Respect for home and the family] means respecting the cultural values of our home e.g. alofa (love), fa'aaloalo (respect), loto maualalo (humility). (Questionnaire participant)

One Deaf interview participant also emphasised the role of family in instilling cultural values, highlighting "supporting family members" as an important value that ensures "the same culture" is continued. Other participants also spoke about home and family as an environment where cultural values could be learned and passed on. For example, several participants shared how the value of "keeping one's promise" was passed onto them from their parents, and how they are making sure to observe this value in their interactions with their own child. This was particularly important for an interview participant with a learning disability:

> Participant: If I promise it, I've only ever let, I've only let [child] down once, only once. Because I took him somewhere. I said, look, [child's name removed], I'm sorry. But something's come up. I can't, but you promised. Yes, I know, [child], I'll make it up to you. And I always made it up to him.
> Interviewer: So that's a really important thing for you in terms of being a mum that when you say you're gonna do it, you do it?
> Participant: We do it.
> Interviewer: And was that part of your family, were your mum and dad like that?
> Participant: When they said something, they did it.

When reflecting on the role of culture in their experience of disability, home and family, another interview participant summarised:

> You know, and to be honest, it's played the biggest part and when we say culture, both ethnicity culture being Samoan and Pacifica, but also the culture that created the culture of alofa, the culture of love. The culture here is Tāngata Tiriti you know, Tāngata Whenua. So culture has been huge. It's been a foundational characteristic, I suppose. I don't know other words to describe it, but it's been critical alongside spiritual. (Interview participant)

6.3.4 Deaf culture

The fourth sub theme specifically related to Deaf culture. In Aotearoa New Zealand, the Deaf community has its own unique values, rules for behaviour and traditions (Office for Disability Issues, 2021). It is also considered a distinct culture group characterised by sign language, and a range of shared experiences such as visual learning styles, attending Deaf schools, belonging to Deaf societies or clubs, and similar life experiences (Deaf Aotearoa, n.d.). Disability culture and Deaf culture were important topics for Deaf participants, who spoke about distinctive aspects of home and family. For example, one participant talked about the role of verbal and non-verbal communication:

> And so hearing parents make soothing sounds to children. And you know, and then you use soothing words, and then you communicate in a certain way that the child learns to grow up and communicate back in a certain way. But with a Deaf child, they're only feeling the pat on the back. They're only feeling you know, or seeing the mother's face, they're not hearing those soothing sounds, and there isn't that communication that develops sometimes in the same way. And I wonder whether that's enough for Deaf children to develop a lot of those aspects. (Interview participant)

Deaf participants and participants with Deaf family members also spoke about the role of sign language in their home and family:

> We've brought them [children] up with them having Sign Language. We have a better relationship with our children than I think that I had with my parents. I think [partner] has a very good relationship with her [family] because of their communication, it's a much stronger bond than I had with my family. So, I think we've got a similar bond with our children. So, I think having the extra language is very important. (Interview participant)

Another Deaf interview participant also emphasised the role of sign language in enabling stronger relationships between family members:

> But it was interesting when I'd heard my parents say that, he [hearing sibling] had said he'd wished he was Deaf, so he could have been part of that [sign language community]. (Interview participant)

However, Deaf participants also noted the isolation they felt at times, due to the inability to communicate with extended hearing family members in sign language, which also impacted their relationships, reciprocity, and support networks:

> Interviewer: Yeah, how would you say, having no one in your family being able to sign, how has it impacted on the relationships that you've had with them long term?
> Participant: As I've gotten older, we've sort of drifted apart because we don't communicate. Yes. I think sign language is very important if you

> want to keep family together. Especially if there are Deaf people in the family - sign language is just critical. (Interview participant)

Deaf participants also noted that the lack of sign language knowledge can lead to communication challenges in wider family contexts:

> No, not on my side of the family. They [my side of the family] know the odd sign, a little bit, and they can finger spell but they're not signers. Partly because sign language did not really take off in New Zealand until I was in my late teens. Even though we did have sign language, we had it at [Deaf school]. We were signing when we were very small, but did not become part of my education until I was in my late teens. So, it wasn't until then, that my family started trying to learn a little bit. But by then I was already 17/18 and I had already left home and there was no real need to learn to sign so they never really learnt. There was no need to learn to sign. So, my family never really learned that. But [partner], she's younger than I am. And her [family members] sign. She communicates with them and always had that in her life. It was a very different situation. (Interview participant)

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

6.4 My supports

The fourth set of key findings referred to the different types of supports disabled people regularly engaged with, and included four sub themes: natural supports; formal supports; family carers; and care and culture. Support people play a significant role in how disabled people organise themselves and their time, and the opportunities they have. The impacts are wide-ranging, affecting the way in which disabled people plan and conduct their day-to-day activities, the places go or do not go, their ability to participate in society, and what they may or may not be able to do in the short or long term future (Thompson, et al., 2014). Many participants spoke about the importance of support and services in the context of home and family.

6.4.1 Natural supports

Natural supports refer to the informal and unpaid supports a disabled person has access to (Duggan & Linehan, 2013). Not only do natural supports provide disabled people with basic necessities of life, but also support with health care, maintenance, safety, protection, mobility, and fulfilment of family roles (Kashyap, 1989). While the importance of natural supports is not unique to disabled people, many participants indicated that people in these roles provided types of support that were integral to fulfilling their family and home roles and responsibilities. For many of the participants, natural supports were immediate family members such as siblings, parents and grandparents, who provided emotional, financial, practical, child care and household management support:

Emotional support

> 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. (Questionnaire participant)

Financial support

> I know I have financial support from my parents if I need it, I have a lot of love and care from all my family, and I wish I could see them a bit more. (Questionnaire participant)

Practical support

> I have a sister and a mother who are fairly close by me in [location]. So, they're always around [to help]. (Interview participant)

Child care support

> Yep, he's a, he loves his grandad, mostly. Every week he, we try and get every weekend he spends with his grandad. He loves him because in the holidays, they take him out to the movies, he would have been, he's seen two movies over the holidays. (Interview participant)

Household management support

> Well I've been flatting now for just over five years by myself. 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. (Interview participant)

Support from extended family was also identified as important, and was a key feature in responses from Māori and Pacifica participants:

> When I was 15, because of my eye condition being degenerative, I was no longer able to participate in contact sport, because you know, I loved a bit of rough and tumble, [I] wanted to play rugby like my brothers and my cousins, but I couldn't do that because of my sight loss. So you know, with the support of a cousin of mine who was able to help me think outside of the square in terms of what could I do to, sort of be able to stimulate my need for playing contact sports, at the age of 15, I was introduced to Olympic [sport]. And through that support from my family, I was able to compete nationally and internationally. (Interview participant)

A consistent feature of conversations around natural supports was reciprocity (or manaakitaka and tautua) and the importance of paying forward the support participants had received from natural supports, to others. For example, one participant reflected on the reciprocal relationship they had with siblings:

> So I had my older brother, so we never got along when we were younger. But he's only 18 months older than me. So I get the opportunity when I'm up in [place], like a couple winters ago, of going out and helping them on their farm and I love them now, they've given me my only niece so far, on my side of the family. And my younger brother, I've always been there for him. He's always been there for me growing up. (Interview participant)

Similarly, other participants indicated that having natural supports had encouraged them to provide support to others:

> I have cousins that I'm very close to who live in town. And they're always the first people that I contact if I need anything, and they

> contact me often. So I see them often. And they are constantly asking me if I'm alright which has helped me to inspire me to help other people as well. Because, you know, it's paying it back. That's what I believe in. (Interview participant)

> 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. (Questionnaire participant)

6.4.2 Formal supports

The next type of support discussed in the context of home and family was formal supports, which refers to the formal and/or paid relationships a disabled person has, such as support workers, caregivers, respite, professional and specialist services, and so on (Collings et al., 2017). Formal supports play an important role in the lives of many disabled people who rely on these relationships across various aspects of their family and home life, from personal care and home management, to assisting them to participate in the community (Robinson et al., 2021).

Participant perspectives on formal supports were varied, given that some had no access to formal supports, others employed or were provided with support workers, while other participants had support people who spanned both natural and formal supporters (for example, family carers). Given that many disabled people rely on support workers in areas that, for non-disabled people, are usually private domains of their lives, one of the areas this research sought to explore was how disabled people felt about having formal supports enter into these domains. While there was no clear consensus across participants, outlined below the characteristics of formal supports that participants felt were important to fulfilling their home and family roles and responsibilities.

Support workers

In Aotearoa New Zealand, formal support workers provide assistance within a variety of areas including personal care, household management, social activities and employment (Jorgensen et al., 2009). With the exception of one Pacifica questionnaire participant who said their support workers were “treated as family and beloved friends”, participant reflections regarding formal support people (that is, non-

familial support workers) was that they were family-like, but not family. While support workers held unique relationships with participants, participants were also clear about the need for boundaries due to the transactional nature of the relationship:

> I initially like to think of them [support workers] as family. However, I don't cross try not to cross that line in terms of when they leave their house, or when they go out for the weekend. Or do you know, when they're away from me, then they are my employee. And let them have their space. However, I mean, when they're in my home, they're in my home, and I treat them like family. (Interview participant)

> I have a home help but they don’t play any role in my family. (Questionnaire participant)

> Okay, there is boundaries, definite boundaries, but I would be lost without them [...] So not family. But yeah, close, close people. (Interview participant)

> Some of my sons' support workers are almost like family. (Questionnaire participant)

Some participants noted that formal support workers enabled them to fulfil their family roles and responsibilities, as well as pay forward the support they received to others:

> 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. (Questionnaire participant)

> They help to support me in daily tasks and enable me to travel to see my family. (Questionnaire participant)

> But I can discuss family matters with them [support workers] and they support me in my roles in the family. (Questionnaire participant)

Even so, participants also drew attention to the flaws of the disability support and services system (DSS). Participants shared that even though access to support and

having a good relationship with support workers and agencies was important, often these relationships required compromise within their family and home environments.

> 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. (Interview participant)

> They [support workers] are important but cannot be relied on for long-term support. (Questionnaire participant)

Family Carers

The second type of formal care referenced by participants was family carers. In 2020, a change in the New Zealand Public Health and Disability Act 2000 allowed family members to become formal supports for a disabled family member. According to the Ministry of Health (2024), carers are individuals, family, whānau and aiga who provide care for someone close to them "who needs additional assistance with their everyday living because of a disability, health condition, illness or injury." It is estimated that one in every 10 formal disability support roles are carried out by family carers, and that they are more likely to be women, and members of the Māori and Pacific communities (Ministry of Health, 2024). While formal family care arrangements did not feature significantly in the questionnaire and interview responses, it was noted that family carers play an important role in the respite system, especially when there is a lack of access to suitable respite arrangements in the community:

> My Mum, while she was alive, she actually did respite care for the kids she'd like had some for the weekend or whenever which was really helpful because they were old enough. Once I learned about respite care, they were old enough to look after themselves, not babies, so you know 5, 6, 7. So that helped her with a little bit of extra income and it helped me with getting that break. (Interview participant)

Participants also repeatedly noted that respect for disabled people's home and family must extend to respect for their family, whānau, aiga and close supporters:

> Supporting and allowing us to live together as family members and if a family member in the home is providing care and support for disabled family members than paying them for that role as you would if said family member or members was to live in residential care in the community being cared by others often random people who are complete strangers which isn't great for people with a disability such as Autism. (Questionnaire participant)

6.4.3 Care and culture

The third sub theme of ‘my support’ addressed the influence of culture on support. As previously highlighted, culture can have a significant impact on how disability is understood by society, a family, or by an individual. For some participants, it was important to have a support worker from the same culture, or from a culture with a similar understanding of disability and/or cultural and moral values. This was discussed by one Pacifica participant:

> And they [support workers] will become, like, we would bring them into the ecosystem [of care] because there's an expectation of the type of care that we would want them to have and enable [family member] to feel it naturally. So yes, they come in as workers that are paid, yet the total that families give was given unconditionally, it's given without pay, right. And so when support workers come in, in the event we would want them to, we'd probably do some whakawhanaungatanga. I guess assess and just let them know how, what [family member’s] world looks like and we would want to also feel comfortable, because I understand with you know, when you come from a mainstream thinking of level 1, 2, 3, or 4 qualification and this is a criteria that you need to do. So when you do home care or when you do personal care, you must do this - this isn't for us, it's more trusting that we can actually say to them, and they feel that it's initiative driven. We don't want it to be time restricted, which is what support workers are paid for, on a half hour time or on a 15 minute time for changing clothes, that is the weaving of mainstream requirements into our ecosystem of whānau and family.

When asked whether it was important for support workers to be from the same culture as the disabled person, the participant responded:

> It's not ethnic specific. What I'm saying is the skills that we look for is that of family, and whether you're just treating him as your brother, or your son. Those are the qualities that we ask. We will know by looking at [family member's] face, his reactions, whether he's happy, or whether he's just being polite. You know, those are the things and we have been able to understand [family member]. So, is it important that the support workers be [Pacific]? Look, it plays a part, but I get that you know, they're scarce. We're happy just with whoever has the heart of service.

Culture can also impact decision-making processes around a disabled family member's care and support needs. For example, Soālaupule is an inclusive Samoan decision-making process to achieve consensual decisions and outcomes, as well as shared accountability. "Soa" means 'to partner or share'; "lau" means 'your or yours'; and the word "pule" means 'authority' or "mandate". Used together, Soālaupule, can be interpreted as 'to share your authority, mandate" in any given setting (Ualesi et al., n.d, p. 3):

> 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. And that culture is, yes, ethnic specific. But it's also been the culture that we've been raised around with what we've seen, and when I say Soālaupule, that is terminology that is a decision-making process that high chiefs operated. And we do the same thing within our family. And not just high chiefs, what I mean is that we have something similar. So I just want to flag to you here that we have an ecosystem. [...] But in terms of the Soālaupule process, and family sense and cultural sense, it's my obligation to then also advise our family on what's happening with [family member], and I'm talking about our cousins and those that are in his ecosystem of care. So anything they have, or would like to know about [family member's] care comes back to me to be able to answer it in the event my brother cannot. (Interview participant)

6.5 My aspirations

Having reflected on family roles and responsibilities, culture, and supports, the next collection of findings referred to participant aspirations in relation to their home and family. Despite the identified challenges, participants had many aspirations about how they wanted “to be able to live and love how [they] want to” (Interview participant). They spoke about their dreams of marrying and having children, becoming grandparents, and passing on their knowledge and experiences to future generations:

> I'm looking forward to the next part of my family life, which is becoming a grandparent when that eventually happens. That'll add another layer of you know, I guess perception of things to offer the next generation within my family. (Interview participant)

For many participants, remaining present and involved in the lives of their families, particularly in the lives of children, was important.

> I've always told my kids three things that I want them to always be aware of as they grow up. And it's sort of around the values that I've always known, the answer is to always be thankful, be grateful, and be humble. You know, and so, always show humility, always be grateful for what you have, and always be thankful for the things that they're able to pass on and share to others. You know, those are the, those are the kinds of values, morals, you know, and none of that's attached to my disability, is it? (Interview participant)

For one participant, they aspired to be treated with dignity and respect:

> And I believe that we should be treated with respect and dignity. And that is very important for me. (Interview participant)

Other participants provided specific examples of areas where they desired respect. For example, recognition of, and respect for, methods of communication was an area that was highlighted by Deaf participants.

> I would have the expectation that other people would be able to be adaptable. And I understand that some people have no knowledge or no experience of communicating with a Deaf person at all.

A further aspiration was greater choice and control when it came to home and family - something that is not always experienced by disabled people, and in particular, people with learning disabilities. For example, one participant explained how disabled people have some rights, but not on an equal basis with non-disabled people.

> Yeah, I think in some respects that we do, but there's, we have like if you put everyone in one circle, like everyone, we all have those same controls. But then you've got an extra circle on the outside which is disabled people and another circle which are intellectually disabled people, and different circles have other different things and in our own circle, like for us the physically disabled, we have we need to be able to have those choices of other things that people normal people just wouldn't even think about. (Interview participant)

Other participants talked about their aspirations for choice and control over their lives, especially in relation to home and family. If they wanted to be in a relationship, get married, or have children, they believed their choices should not be restricted by disability:

> I think it's up to a person's choice, I think it's up to a person to know whether they want to have that relationship. 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. (Interview participant)

When asked what would enable greater choice and control in their family and home lives, several participants mentioned having access to personal budgets (Enabling Good Lives) and individualised funding:

> I have individualised funding. So I use that to pay for my support workers coming in. Which is great. Because I love, with individualised funding, I've loved being able to pick and choose and control my own. (Interview participant)

Some participants spoke about being able to fulfil relevant family roles, instil family values, and encourage cultural understanding:

> Respect between a parent and a child and vice versa. And the relationships, sort of the cultural relationships, are very fundamental things that still continue in my family. (Interview participant)

Other participants talked about disability-related aspirations such as inculcating understandings of disability onto the next generation:

> Yeah, the language of disabilities always bothered me. I mean, I've never seen myself as a disabled person. I see what I've got as having an impediment. I mean, it's something I've got to work around all the time. You know, I can't get in the car. I need a van with a hoist. You know, I've got to go on flat surfaces. But it's not a disability to me, per se, it's an impediment. And I've tried to explain that to my son too; I said I don't have a bad time. I have a very good time, most of the time. You know, other people might see this as a disability, I don't particularly. Inside, I am still me. So that's what I am doesn't particularly bother me greatly. Somebody else has a problem with it, that's up to them. (Interview participant)

6.6 My home

The next key finding and related sub themes emerged from discussions around ‘home’. For participants, characteristics of home ranged from tangible features, such as physical accessibility, to intangible features such as emotional and cultural safety, and respect.

My home is… accessible

According to the literature, disabled people often associate the meaning of ‘home’ with mobility and independence of movement (Imrie, 2016). When participants spoke about home, they frequently referred to physical accessibility:

> Well, [home] is a place where I'm strong. So for many years, I stayed in places which were more suited to able bodied people. Now I stay in a place which is run by [organisation]. And it's a rarity to find this place because it's flat. It's got a roll in shower, it's got bars to grab. (Interview participant)

While some participants reflected on the benefits of accessibility, other participants mentioned the lack of accessible housing options, and the negative impact this had on their sense of home.

> There's so many people out there with wheelchairs and stuff, [and] there's not enough housing that are made to be wheelchair accessible. I'm lucky I was moved into my home, because I was going to be having my first operation and because I can't balance on crutches. So I needed be in a wheelchair for three months. But I still, I still have steps up to my door that I have to use to get inside. I have to like, shuffle my bum up the steps for every operation that I had, but because housing is so limited for accessible housing, you can't just get transferred or move into a private rental that's suitable because there's not enough out there. (Interview participant)

Accessibility also went beyond the physical environment, for some participants. For instance, accessible communication was a significant characteristic of home for Deaf participants:

> My [partner] is Deaf. But all my [children] can hear and our house is a signing house. Even though I speak well, at home, it's all signing. So, we're really in the Deaf community, not in the hearing community.

My home is… safe

For several participants, home is a place where they felt physical, psychological, and economic safety; somewhere they could escape and rest:

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

> Home is definitely my place to relax and be free to not hide my pain. (Questionnaire participant)

> Home is a chance to escape from a disabling world for me. It's set up to my needs as best I can. It means I don't have to be in a constant state of alert. (Questionnaire participant)

Safety was also mentioned by an interview participant from the queer community:

> Safety being a keyword. And also, like in our homes or places where we live in, we are inherently more vulnerable, we are naked there, we are unwinding our thoughts and feelings at the end of the day. And so 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. (Interview participant)

My home is… where I am respected

Participants also believed that home is where they are respected.

> Everyone should have a home, and its a huge deal to be welcomed into anybodies sacred and safe place. People with disabilities, are often more vulnerable as we need extra assistance in everyday life, so being invited into your home shows a huge amount of trust. This should be respected by anyone and everyone that is invited in. (Questionnaire participant)

As articulated extensively throughout questionnaire responses, respect for home and family included:

- **Respect for time:**
    - Just to honour the people whom you interact with and respect their space and time.
    - Take time to get to know me and how my home works.
- **Respect for space:**
    - I expect people to ask first if they visit, for example, and prefer not to have them in some rooms of the house.
    - Being considerate of personal space and boundaries in the home.
    - The ability to be house proud or house kept nice to have visitors and be able to host without feeling embarrassed.
- **Respect for rules and boundaries:**

- Understanding if things are different to how you'd do things in your own home, remembering that just because someone is blood, doesn't give them automatic right to be part of your life.
- Listening and responding. Checking in before acting. Consulting. Including.
- For me it means respecting the way I choose to interact with my family or the way I live in my home, even if it’s not the way you live.
- Respect boundaries, respect is earned and not just given.

- **Respect for disability, energy and capacity:**
  - Not burdening the host.
  - Offer to make your own cup of tea so I don't have to worry about carrying it or dropping the mug.
  - It also means that if we ask you to show up for us, it's not with the expectation that you can rock up whenever because my need for rest doesn't allow for that. Courtesy means a lot and that's sometimes staying away.

- **Respect for culture and values:**

  - Honour the home rules and kaupapa of the family.
  - Treating everyone as worthwhile and equal. Respect for values, issues, decisions made.

- **Respect for choice, control and autonomy:**

  - Choosing who we live with and where we live. [...] It means not being under extra supervision or surveillance because you are a disabled parent!
  - That we can define who our family are. That we get to choose our support workers and who comes into our houses. That we have the ability to move if we don't feel safe in our living environments. That services for domestic violence support are accessible and we know how to get help if we need it. That we are loved but that we still have our autonomy, that love is not an excuse to take that away, there is dignity in our own ability to make decisions even if some of them turn

out to be bad; We/they have agency. It means keeping your intentions in check, regardless however well-meaning you are!
- Accept that person with disability and their whānau are the drivers of the support required and the activities that happen in the home. Do with not for.

- **Respect for identity:**
    - In rainbow family it means not making assumptions.
    - Respect who I am. Person coming into my home takes note of how I live and respects that. I don't think that it is really a Pākehā concept. But for me it means non-judgemental family support.
    - Respect diversity and don’t be judgemental.
- **Respect for supports, services, resources and accommodations:**
    - To respect a disabled person means they are enabled to enjoy life and have a good quality of life and have the right resources and accessibility to live comfortable with their family and can express their needs and wants.
    - To respect their right to live in their own home with their family and their children if they have them with adequate and appropriate support to enable them to live in the community and look after and live with their children if they have them and offer additional support if child is also disabled and don't write us off as being unable to care for our children just because we need additional support just support us.
    - Disabled people should receive any financial support they require to be able to live peacefully and confidently in their own home with their family.
    - It means having support or not from disability support services.
- **Respect for family, whānau, aiga and close supporters of disabled people:**
    - It means seeking, listening and valuing their input. It means acknowledging the "natural authority" (Kendrick) of close family. Part of

this is the history of involvement families have had of fighting for/advocating for their disabled children. As a very close relative - mother - I expect to be informed about what is happening as I am my adult children's greatest advocate. I expect that agencies will make it easy for me to be involved by providing an environment that welcomes me. For example, agencies will be responsive to my communication attempts.

- Ensure that the home meets the needs of the disabled person, and the family as a whole.
- This means to accept without negative stigmatism or preconception, disabled people and their families; It means to recognise that family members, especially parents, have the deepest understanding of the disabled person's needs, abilities and aspirations and should be involved closely in decision-making concerning the welfare of the disabled person.

6.7 Barriers to home and the family

Throughout participant responses, barriers to realising disabled people's right to respect for home and the family were evident. These included: barriers to roles and responsibilities; barriers to cultural expressions of disability, home and family; barriers to support; and barriers to home and family aspirations.

Barriers to roles and responsibilities

While participants felt strongly about their roles and responsibilities within their families, they also spoke about barriers to the fulfilment of these roles. For example, many participants reported barriers in the form of negative attitudes and assumptions regarding what familial roles they could and could not (or should not) fulfil:

> You also need to stop with the assumptions because a lot of people assume wrongly, and assumptions can lead to real clashes with both parties in any situation, about our ability or our understanding; for example, they assume that we cannot be a mother [or] we cannot have a family [or] be in relationships. (Interview participant)

> Two years ago, a taxi driver picked me up. I got in the taxi and then he folded my chair up and put it in the boot. I said, “we're going to go and get my son,” and he looked at me and he said, “You have a son?” I said, “Yes, he's over, it was then 12,” and he was shocked. He said “I didn't know you were able to do that.” (Interview participant)

As reported in the literature (Devkota, 2017), it is not uncommon for families and communities to have fears about disabled people passing on conditions and impairments to their child/ren, which was also confirmed by participants. For example, one interview participant recalled the advice that was given to their mother by a health professional:

> When I was first diagnosed as a child, my doctor, whichever doctor it was, said to my Mum, “You need to get her into genetic counselling so she won't have kids to pass this on.” (Interview participant)

A similar experience was shared by another interview participant, regarding members of their wider disability community:

> I've come across people in my life who have been labelled, because they wanted to get married and both of them had intellectual disabilities. There was a fear that they were going to have children who were going to have intellectual disabilities, that they weren't going to be able to support their children as parents with an intellectual disability, all of that kind of stuff. So yeah, I believe there was a lot of - there still exists a lot of discrimination around people with disabilities getting married and having families, you know, in the end, really, previous generations that I know of, in the blindness community, you know, they all got married within their own community, you know. There was no encouragement to get married outside of your blind community. (Interview participant)

A lack of access to supports, services and accommodations needed to fulfil family roles and responsibilities was also experienced by participants:

> As disabled people we want to live full lives which means being able to have partners and children of our own and to be supported in those

> roles. I am not well supported by the system to be a mother. An example of this is not qualifying for any home help or meal prep. I also only qualify for personal care for myself despite having young dependent children who require personal care. [...] 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. (Questionnaire participant)

For example, an interview participant recalled the difficulties they had when attending a parent's support group:

> As a Deaf mother, it's been very difficult because of resources, [there is] no support for Deaf mothers. It's very hard for me to be involved with parents' groups. Very harsh. When I first became a Mum, it was really hard for me to join mainstream parents' groups, because there was no access to sign language. I was the only Deaf woman, they were all hearing. And it was very hard for me to fit, and for everyone else to understand my perspective, my journey, and the challenges, it's really hard for me. [...] When I look back, in terms of the mothers' group, when I first became a mum, it was quite hard for me because some of them [other mothers] were not so nice, actually, because it felt like I was the only one who was being labelled as a disabled person. And they didn't really understand in terms of the barriers that I faced and I grew up with and that I was quite used to these barriers. So yeah, it was not easy. (Interview participant)

A further interview participant noted that when their disability progressed with age, a lack of supports and services meant they could not fulfil their grandparent role, which had affected their relationship with their grandchild:

> During that time I had two grandchildren. One of them, I don't have the same bond with because I wasn't able to physically do anything with him, that I was with the older two. (Interview participant)

Barriers to cultural expressions of disability, home and the family

Barriers to cultural expressions were primarily discussed in relation to the impact of dominant western conceptualisations of disability, home and family, as well as colonisation in Aotearoa New Zealand and the Pacific:

> Until the age of 32 I was totally in the English culture. This for me is a journey that I've undertaken myself to learn about my whānau and people. Because my father was of the generation of people who had the Māori beaten out of them when they were in school. They weren't allowed to speak te reo. And his father took on an English name, because it was easier for English people to talk to somebody who had an English name than it was to have a Māori name. [English name], a fancy name. So yeah, for me growing up, I grew up as a little English boy. And certainly from the age of about [early 30s] that I started embracing my father's [Māori] culture. (Interview participant)

> Because my background is Māori and Samoan, which means that my whānau have been through hard times already. They know what it's like to be discriminated against, same as I'm discriminated against. So we have a very clear understanding of how we can fit together easily. (Interview participant)

> I come from two cultures [Fijian/Indian] that were so terribly colonized & have such strong religious issues that I am not sure how to answer this with hope. I don't think there's respect in our communities for home/family, especially for disabled people, purely because we are driven by capitalism & we are measured against paid productivity. (Questionnaire participant)

More specifically, one interview participant described the tension between the current disability supports and services system in Aotearoa New Zealand, and the way Article 23 of the UNCRPD is interpreted according to different cultures:

> [W]hilst we have enduring power of attorney, it was a real mission to talk about how we, what that meant to us. And we were only doing it because it was a legal requirement for funders and hospitals to talk to us, when an actual fact the enduring power of attorney is such a like, even that process is so disconnected from Pacifica just does not in any

> sense, like I find it offensive, to be honest. But those are the things that we try and work towards. 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. It's, we have never felt empowered to be able to, you know, for [family member], at every point, we've had to justify, provide a rationale, fit into their reporting mechanisms, because it was just to find the providers reason, and we've just been so far out from it. (Interview participant)

For this participant, these challenges were underpinned by the individualistic nature of disability policy and practice in Aotearoa New Zealand, and the exclusion of perspectives from collectivist communities:

> To be honest, and this is, and I'm answering this based on our experience with [family member], it's so far disconnected, and it does discriminate. Because the reason that is and what I've found in the last year or so, is that EGL is all individual. And that's cool. Like, like, I want it noted that might fit for some families, because it's very individualistic. And so when you look at disability, we're conditioned to just look at that person, but from our perspective, in terms of [family member]'s family and us, we are [family member], we, as his family, are him. And when you go and try and weave all that together, the immediate reaction is well, no, it's actually individual. [...] And this is what I'm finding, is that people just quote the Treaty, they quote you know, United Nations, or whatever, EGL, but there's nothing that actually brings our voice into it that actually talks of collectivism. [...] I don't disagree with EGL. Absolutely, that's great for some, but it was never written by a Pacifica person.

Barriers to support

While many participants acknowledged the different types of support they had when it came to their family and home lives, most reported they currently do not receive enough support:

> I wish that I was able to get more physical help but 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. (Questionnaire participant)

For example, when thinking about formal and informal support and care arrangements, participants noted several types of barriers. For Deaf participants, communication was referenced as a primary barrier:

> I know that it can be difficult as a Deaf person to talk to someone who might not understand me for a start in sign language, and might not understand my challenges. And, so I haven't had that access to those supports. (Interview participant)

Deaf participants also reflected on the challenges of accessing appropriate sign language interpreters, for example, when sensitive family or legal issues needed to be discussed. For these participants, reliance on interpreters meant family matters were sometimes exposed in a way that was uncomfortable because there was a chance that an interpreter may become “too much involved with a certain person” and “knows so many aspects of a Deaf person's life.” Challenges in communication were also evident in Deaf participants’ access to natural supports, particularly when they could not communicate with family members in sign language:

> We don't mix much with my brothers and sisters who are hearing mainly because [partner] finds it very difficult. She’s a signer and the way she was brought up, her [family members] both sign so she always had sign language in her life but my family were oral and so they don't sign so [partner] finds it very hard to socialise with them so we don't mix with my family very much anymore. (Interview participant)

Another barrier to accessing support within the context of home and family were the extra skills and knowledge participants felt they needed to navigate the disability support and services system:

> I certainly feel that unless you are a little bit outspoken and push back a bit you could quite easily fold. And I think that there's a lot of people out there who do just that. I have an example where I'll use my mother,

> because she's recently had [medical event] in the last two years. And she, I feel she won't, doesn't fight back a lot of the time and say what she needs to the people that she needs to say it to, doctors, you know, anyone who can possibly be able to help or this profession or a group that can help her. I say, Well, why don't you approach them or talk to them? "Oh, I don't want to, it's too hard. It's, you know, I'm not entitled to it." And I'm like, well, you don't know, if you're not entitled to these things until you ask. So yeah, I think there's a lot of people that just don't get that opportunity, or feel that there's a sense of their own personal worth, to get out, be and ask these questions. (Interview participant)

Other participants reflected on the challenges of managing relationships with support workers and their families. In particular, it was noted that having support people come into the privacy of the home also had an impact on those they lived with:

> And one difficult thing that I found hard to navigate as a young adult flatting was negotiating privacy with those appointments in the home, when the shared spaces are shared spaces. And also you don't necessarily talking about all the things there. (Interview participant)

> Yeah, although even with my partner, he gets overwhelmed by the support workers that come. And so the relationship with them and him is also something that I have to navigate around like, I try to arrange them to come when he's not there. Because he gets overstimulated. It's a lot of compromise, right. It's just it's relationship. Energy. It's a good one. So it's, it's not just you and the [support] person. Yeah. It's you and the people in the home. There's things that are not like, oh, we could do the appointment at home or at night. I literally need you to do something in my home with me. So like you need to be in my home. And so that changes things at home. (Interview participant)

Barriers to aspirations

Findings from the questionnaire and interviews also showed that participants experienced challenges when working towards their aspirations. For example, as

was highlighted in the reviewed literature, many disabled people face assumptions about their ability to, or appropriateness of establishing a home and forming a family. Several participants talked about such assumptions and expectations as being barriers to their aspirations:

> The other thing is, you also need to stop with the assumptions, because a lot of people assume wrongly and …. have as assumptions about our ability or our understanding, for example, they assume that we cannot be a mother, we cannot have a family, be in relationships. (Interview participant)

Another participant spoke about similar assumptions and expectations around disability, home and family:

> I feel the issues and discrimination against some of those things, “Oh well, you have a disability, so therefore you're not normal, therefore you don't need or want family and home and work”. (Interview participant)

As summarised by an interview participant:

> [W]hen I worked in the wider world, there was massive discrimination. And people look at you, people 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.

7 Kōrerorero / Discussion

This research seeks to broaden understandings of respect for home and the family, as articulated in Article 23 of the UNCRPD, from the multicultural perspectives of disabled people living in Aotearoa New Zealand. Many of the findings were unsurprising, and reflected the everyday roles, responsibilities, expectations, pressures, concerns, and joys of any other family or individual. However, as shared by participants, there are also nuances to disability, home and family; complexities that can only be understood through lived experience. The following discussion focuses on four broad themes that emerged throughout the conversations with participants: aspirations - same, but different; the intersections of culture, disability, home and family; natural supports and reciprocity; and formal supports - family-like, but not family. The findings are then discussed within the context of the Enabling Good Lives principles, before the potential impact of the research is explored, followed by recommendations for the progressive realisation of disabled people's right to respect for home and the family.

7.1 Aspirations: Same, but different

One of the most prominent themes found throughout participant responses was that they, or their disabled family member, experienced the same aspirations as anyone else - namely relationship, respect, and safety. However, these desires were almost always shaped and influenced by societal attitudes, systems and environments that were inherently ableist or disablist, individualistic, and that conformed to dominant Western ideals. While blatant discrimination was not reported by participants, the identified barriers indicated underlying prejudices and harmful ideologies throughout Aotearoa New Zealand that can, and do, inhibit disabled people's experiences of home and family. Take, for example, one participant who shared they wanted to start a family with their partner. While the couple's desires to form a home and family were not unlike their non-disabled peers, fulfilling those desires was hindered by attitudes, systems and environments that subtly, yet persistently, inhibited their aspirations:

> Obviously, our family, my partner, and I have been thinking lots about what being parents would look like. And we've been thinking about things from even like, like, parental leave, there's no like, different level

> or entitlement for disabled people. When, like, making babies and raising babies is different for us and has more barriers. We also might need additional appointments or support to make our family, or after you've had baby, raising baby. There's more, can be more admin we need to do even just in terms of looking at rights and entitlements if you're a person in employment. (Interview participant)

While the findings of this research confirmed that participants had the same aspirations regarding home and family as non-disabled people, the barriers they faced were unique and systemic. These barriers are well-documented within the literature, particularly medical model practices that hinder the reproductive freedoms of disabled people (Mitchell & Snyder, 2003). Such practices have historically created significant barriers for disabled people when establishing families - from engaging in relationships that are necessary to form a family, to accessing information, training, family planning, and parental support (Fitzgerald & Withers, 2013). As this research has shown, disabled people continue to experience systemic barriers that impede their ability to carry out home and family responsibilities, in contradiction with Article 23 of the UNCRPD.

7.2 The intersection of culture, disability, home and family

A second key theme was the intersection of culture, disability, home and family. Not only did culture inform participants' understanding of home and family, but also of disability. For example, Pākehā participants and participants of European descent tended to describe family as being blood relations and immediate family members. For Māori and Pacifica participants, concepts of family, whānau and aiga were much broader, and also included the wider community, natural world, and ancestors.

Within these unique cultural contexts, perceptions of disability and a disabled family member’s roles and responsibilities were also considered. For example, Māori and Pacific participants drew attention to Western (individualistic) approaches to disability and support, which often embody values such as independence and self-reliance (Humphrey & Bliuc, 2022). On the other hand, collectivist cultures, as was highlighted by Māori and Pacific participants, tend to focus more on whānau and aiga, and each member’s contributions and shared responsibility to support and

maintain the group's wellbeing. According to Sullivan et al. (2012), the collectivism-individualism dichotomy holds that some cultures foster thought and behaviour primarily oriented to the maintenance of the social group and interpersonal relationships, while other cultures encourage individuals to behave in ways that maximise their own self-interest and expression. Throughout the questionnaires and interviews the importance of servitude (for example, manaakitaka and tautua) in collectivist communities was also emphasised, which formed the basis for the provision of care and support for specific members of whānau and aiga, including disabled people.

For other identities represented amongst the participants, culture also impacted perceptions of disability, family and home. For example, Deaf participants described family as primarily being blood relations, while drawing attention to the importance of Deaf culture, Deaf community and sign language in the context of home and family, particularly in regards to communication and relationships. Participants who identified as LGBTQIA+ also extended their definition of family to include those with shared queer and disability identities, with home being a place where they felt safe in their identity.

These findings highlight the intrinsic link between culture, disability, home and family. They also demonstrate the importance of applying a collectivist lens to what has traditionally been interpreted as individual human rights by considering the impact of culture on the interpretation and implementation of Article 23 of the UNCRPD in Aotearoa New Zealand.

7.3 Natural supports and reciprocity

According to many participants, natural supports played a significant role in the home environment and beyond. While participants reported living in a variety of different family structures, a significant characteristic of 'family' was those who provide support. In particular, family support (natural support) was integral to realising disabled people's right to respect for home and the family.

When discussing natural supports and the right to respect for home and the family, conversations almost always turned to the relational value of reciprocity, or the exchange of things with others for mutual benefit. Within the context of this research,

participants from all cultures and identity groups linked reciprocity to being able to receive support, as well as giving support in return. For example, Māori participants referred to experiences and perspectives that align with the value of manaakitaka, and Pacifica participants spoke of tautua, with the framing of Tagata Sa'ilimalo embodying the collective approach to "both giv[ing] and receiv[ing] support" (Tōfā Mamao Collective, n.d.). As such, natural supports were not considered to be one-sided relationships, but a relational exchange within a familial context. For example, participants talked about being available and present for their family members when they needed support or having a valued role within their family.

However, it was also noted that the ability to participate in a reciprocal exchange or mutual support was often impacted by participant's access to formal or paid supports. One of the main barriers to respect for home and the family was the lack of culturally responsive support participant's experience under the current disability support and services system to meet their family and home-related needs - including the expectation of reciprocity or mutual support within natural support relationships in any given culture. For example, while care and support was often provided by natural supports (unpaid family, whānau or aiga), some participants felt that they lacked the necessary formal supports to reciprocate something of mutual value that aligned with their cultural values. As a result, the risk of perpetuating the notion that disabled people are dependent and one-sided recipients of care and support was heightened.

7.4 Formal supports: Family-like, but not family

Most participants who could access formal supports described them as family-like, but not family. It was unclear, however, whether collectivist and individualistic cultural expectations had an impact on this perspective (further research is needed). Even so, formal and paid support people played a critical role in the lives of participants who relied on such supports for varying aspects of their home and family life. These findings are in line with current literature describing the pivotal role support workers have in supporting disabled people's independence, social connectedness, and participation in the community (Bourke et al., 2024; Robinson et al., 2021; Thompson, et al., 2014). Unlike natural supports, however, formal supports were considered transactional in nature, with no expectation for reciprocal exchange or in

some cases. As discussed in section 7.4.2, formal supports were instead considered a tool that enabled participants to not only fulfil their familial roles and responsibilities, but to reciprocate the care and support they received from natural supports (such as family, whānau and aiga).

7.5 Enabling Good Lives

The findings of this research, along with the discussion themes, can be easily linked to the eight principles of the Enabling Good Lives (EGL) approach. The disability community has long expressed concerns about disability supports and services not working well for disabled people and their families due to a lack of choice and control (Ministry of Social Development, n.d.). Developed by the disability community, Enabling Good Lives (EGL) is an approach that enables disabled people and their families to have a say in their lives, easy access to support and services, and systems-level influence. EGL is based on eight core principles that can be applied in any given situation and has been recommended as a single principles-based system for application throughout the work of all government agencies (Enabling Good Lives, 2024). This includes the government's work to progressively realise home and family obligations contained in Article 23 of the UNCRPD. Below are six of the most relevant EGL principles as they directly relate to participant responses.

Self-determination: Disabled people are in control of their lives

Throughout the questionnaires and interviews, participants articulated the importance of exercising choice and control over how they define disability, family and home, particularly in relation to cultural values, roles and responsibilities.

Beginning early: Invest early in families and whānau to support them and build community and natural supports

Natural supports (such as family, whānau and aiga) were identified as crucial to realising the right to respect for home and the family. However, natural supports were not considered one-way relationships nor defined by dependence and reliance. Reciprocity was a key factor in natural support relationships, whether this was offering something of value back into the relationship, through the fulfilment of family

roles and responsibilities, through caring for other family members, or paying it forward to other people in the participant's wider family and community.

Person-centred: Disabled people have supports that are tailored to their individual needs and goals

Both natural and formal supports were experienced differently by different participants, according to culture and identity. There was no one-size-fits-all for what support looked like in the context of home and family. However, all participants noted that disabled people, and indeed all people, require supports to achieve their home and family roles, responsibilities and aspirations.

Ordinary life outcomes: Disabled people are supported to live an everyday life [such as] having a home and family - like others at similar stages of life

Disabled people have the same everyday aspirations as others, such as having a home and family. However, a lack of formal supports was identified as a barrier to filling these everyday aspirations.

Mana enhancing: The abilities and contributions of disabled people and their families are recognised and respected

This principle was particularly evident in discussions around reciprocity and natural supports. While the experience of disability sometimes impacted the fulfilment of family roles and responsibilities, the abilities and contributions of disabled people were recognised, respected and valued by families, or there was an aspiration for recognition and respect. Conversely, the importance of recognising, respecting and valuing the contributions of natural supports was also highlighted.

Relationship building: Supports build and strengthen relationships between disabled people, their family, whānau, aiga and community

This EGL principle speaks to the desire of participants to fulfil everyday family roles and relationships, to reciprocate something of value, and to be present and participating in their home, family, community, according to their culture and values. For this to be achieved, participants identified the importance of ensuring appropriate, affordable and accessible formal supports were in place to continually

build and strengthen relationships between themselves and their family, whānau and aiga, natural supports, and the wider community.

7.6 Research impact

This research has created space for an important conversation to begin: a conversation that directly affects disabled people and their whānau, aiga and close supporters, disability supports and services, and policy and practice. Moreover, this research provides insight, guidance and direction for duty-bearers on the right to respect for home and the family. Duty-bearers are entities or individuals with a particular obligation or responsibility to respect, promote and realise human rights and abstain from human rights violations (Inter-agency Network for Education in Emergencies, n.d.). It is commonly used to refer to State actors (for example, the New Zealand government), but non-State actors can also be considered duty-bearers (for example, disability support services). Rights holders are individuals or social groups that have particular entitlements in relation to duty-bearers - in this case disabled people.

As this research demonstrates, disabled people are at heightened and continued risk of being perceived as passive recipients of care, rather than rights holders (United Nations Human Rights Office of the High Commissioner, 2014). While much work has already been done to ensure that supports and services are delivered in culturally responsive ways,[11] this research highlights that there is significant room for improvement when it comes to understanding, respecting and realising disabled people's right to respect for home and the family in a way that aligns with their cultural values. Importantly, this research contextualises Article 23 of the UNCRPD within the unique socio-political environment of Aotearoa New Zealand. As the findings show, even defining home, family, and disability can be a nuanced and complex task, particularly amidst dominant Western and individualistic interpretations, systems and ideologies. Therefore, it is the responsibility of duty bearers to progressively realise the rights contained within Article 23 with these complexities at the forefront of their thinking.

[11] For example, see Te Roopu Taurima and Vaka Tautua.

Perhaps the most critical and urgent impact of this research concerns the delivery of disability supports and services in a way that upholds te Tiriti o Waitangi, human rights obligations under the UNCRPD, and the EGL principles. At the time of conducting this research, the landscape of DSS was undergoing drastic changes, particularly regarding the March 18 changes to Purchasing Guidelines, the independent review of the disability support system, and the New Zealand Government's response to the review's findings (Whaikaha - Ministry of Disabled People, 2024). These changes have, and will, curtail the flexibility (and as a result, choice, control and aspirations) afforded to disabled people, including when accessing the supports participants identified as being crucial for exercising their right to respect for home and the family.

While the focus of this research has been home and family, these recent policy changes also have the potential to negatively impact other human rights contained in the UNCRPD, such as disabled people's right to be involved in their community (Article 19), right to social participation (Article 26), and right to an adequate standard of living and social protection (Article 28). For instance, the March 18 changes to Purchasing Guidelines effectively limit disabled people's ability to pay for support workers' travel for reasons that are unrelated to work or education. Not only has this started to negatively impact disabled people's employment, recreation, and social opportunities (Carers New Zealand, 2024), but also important family, whānau and aiga commitments (for example, attending tangi and fulfilling familial and cultural roles and responsibilities).

As this research has shown, when it comes to home and family, many disabled people need and want the same things as their non-disabled peers. However, the realisation of disabled people's right to respect for home and the family requires a concerted effort from various actors (including the New Zealand Government as a duty-bearer) to create an effective and culturally responsive "ecosystem of support" (Interview participant).

7.7 Recommendations

In light of the findings and insights, outlined below are recommendations for ensuring the progressive realisation of Article 23 of the UNCRPD in Aotearoa New Zealand.

The findings are framed according to the social-ecological model of disability (Bronfenbrenner, 1979; Terry, 2014), which identifies different levels of influence and courses of action that can help remove the barriers participants experienced when accessing their right to respect for home and the family.

1 - Societal level:

To respond to the barriers identified by participants, it is essential to understand how social structures impact and shape disabled people's experiences of the right to respect for home and the family. This requires recognising that the way society works and is structured is framed by privilege and power embedded in economic, political and social policies and practices that focus on the dominant and most 'productive' members of society (Donald Beasley Institute, 2020). These 'larger' societal structures are based on inherently anti-human rights ideologies, expressed through laws, policies, and systems that give some people access to power and privilege while marginalising others (Donald Beasley Institute, 2020). Outlined below are four societal-level ideologies that underpinned the barriers identified by participants, and key recommendations for challenging these often deeply embedded and harmful beliefs.

<table>
<tr><th>Ideology</th><th>Recommendation</th></tr>
<tr><td>Ableism: The system of assigning value to people's bodies and minds based on societally constructed ideas of normality, productivity, desirability, intelligence, excellence, and fitness (Lewis, 2022).</td><td rowspan="2">Universal Design: "The design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design" (United Nations, 2006, Art. 2).

Twin-track approach: "A twin-track approach is about making sure mainstream services and supports are inclusive of, and accessible to, us and that services and supports that are specific to us as disabled people are also available. This approach is not about having to choose between the specific or</td></tr>
<tr><td>Disablism: "Discriminatory, oppressive or abusive behaviour arising from the belief that disabled people</td></tr>
</table>

are inferior to others" (Miller et al., 2004, p. 9).	mainstream option; rather it is about having the right access to the right high quality support or service, at the right time and in the right place" (Office for Disability Issues, 2016, p. 21). **Social and rights models of disability:** Recognising disability through the interaction between environment and person's impairment. Uphold the rights of disabled people by removing environmental and attitudinal barriers as well as providing support to access to all areas of human rights (see section 5). **Disability Leadership:** "We have opportunities and are supported to be leaders or role models in whatever field or level we may choose. Leadership for us includes doing great things on behalf of our country or at a national level, and also doing everyday ordinary things for ourselves, our families, whānau or communities. For example, we can be leaders in employment, through voluntary work or at a political level, both locally and nationally" (Office for Disability Issues, 2016, p. 38). **Disability Justice:** "The cross-disability (sensory, intellectual, mental health/psychiatric, neurodiversity, physical/mobility, learning, etc.) and intersectional framework that values access, self-determination, and an expectation of difference. An expectation of difference means that we expect difference in disability, identity, and culture. To be included and part of society is about being able to be our "whole self" (all of our identities together).
Eugenics: Theories and practices that support reproduction among favoured groups of people (positive eugenics) while restricting the reproductive autonomy of groups deemed "unfit for parenthood" and a threat to the advancement of the gene pool (negative eugenics) (Powell, 2022, p. 1857).	
Colonialism: Pursuing, establishing and maintaining control of, and exploitation of, people and of resources by a foreign group (Moewaka Barnes & McCreanor, 2019).	

	Disability Justice includes space for self-care, reflection, and hard discussions" (Disability Activist Collective, 2010, para. 1). **Te Tiriti Justice:** Recognising the original intent of rakatira Māori who signed Te Tiriti o Waitangi (Museum of New Zealand Te Papa Tongarewa, n.d.). The Waitangi Tribunal (2014) concluded that Māori did not cede sovereignty, but rather intended to share power and authority with the Crown (within their separate spheres of influences - the rangatiratanga and kāwangatanga spheres). The promise of Māori tino rangatiratanga is outlined in Article 2 of Te Tiriti o Waitangi.

2 - Community level:

Realising disabled people's right to respect for home and the family requires duty-bearers to be competent in their roles and confident in their human rights responsibilities. At the community level duty-bearers are the State - including all ministries and branches of Government - as well as society (OHCHR, 2014). The community level represents the places and structures that already exist or are formed by society when people come together, participate and contribute (Donald Beasley Institute, 2023). For the purpose of this research, this includes, but is not limited to, organisations in the disability support and services system and health system (that is, community-level duty-bearers that participants identified). To fulfil their responsibilities under Article 23, community-level duty-bearing actors and organisations must have training and awareness in:

- Te Tiriti o Waitangi
- Disability rights (social and rights models of disability, disability justice)
- Diverse cultural interpretations of disability, home and family
- Supported Decision-Making (SDM)

- Enabling Good Lives

Furthermore, to fulfil family roles and responsibilities, disabled people must be provided with flexible, well-resourced formal supports. This was particularly evident in the questionnaire responses, with many participants noting that they needed more funding, formal supports and flexibility for Article 23 to be realised in their lives.

3 - Relational level:

The relational level of the ecological model invites and enables critical consideration of power and control in the relationships disabled people have with family, whānau, aiga, peers, intimate partners, and others in their day-to-day lives (Donald Beasley Institute, 2023). The participants of this research identified interpersonal relationships as influencing their right to respect for home, and, that family included family, whānau, aiga, and other natural supports. Formal supports, such as disability support workers and health workers, were also considered to be important interpersonal relationships, and were family-like but not family.

When considering the human rights responsibilities of formal supports, that is people in paid roles who have real or perceived power and influence in their relationship with disabled people, it is recommended that they too, like actors at the community level, have training and awareness on Te Tiriti o Waitangi, disability rights, cultural responsiveness, supported decision-making, and the EGL principles. For natural supports, however, their duty-bearer responsibilities are not often as clear or openly acknowledged. According to the literature, and in the context of this research, two main groups of natural supports have duty-bearing responsibilities - primary legal and care duty-bearers (for example, parents and legal guardians of disabled children and adults) and family-carers (family members who are formally paid to support their disabled family member) (Nampewo et al., 2022).

Unpaid natural supports such as family, whānau, aiga, peers, and intimate partners, can also hold positions of influence and power, and therefore also have a responsibility to uphold the human rights of the disabled person they are in relationship with. This responsibility is reflected in Article 29 of the Universal Declaration of Human rights, which states: "...everyone has duties to the community in which the free and full development of his personality is possible." This translates

into the duty of individuals to: respect, promote and protect human rights; exercise their rights responsibly; and recognise they also have general duties to others and their community (such as the disabled person they are in relationship with) (Human Rights Commission, n.d.).

It is therefore recommended that any effort to improve attitudes toward disabled people's right to respect for home and the family at a societal and community level, also includes targeted education and awareness for natural supports in non-legal or formal carer relationships with disabled people. Again, this includes training and awareness in the key areas identified above.

4 - Individual level

The centre of the ecological is the individual level - the disabled person, or rights holder. Many of the barriers participants experienced in their right to family and home stemmed from the harmful ideologies identified above, which placed the burden and fault of disability on the individual. For example, the belief that a disabled person should not have children if there is a risk of passing the disability onto the child (medical model of disability/eugenics), if they are perceived as lacking cognitive capacity (cognitive ableism), or if having a child will cause burden at a relational, community or society level. However, as shared by participants, not only do they have the same home and family aspirations as non-disabled people do, but their right to respect for home and the family is embedded in international human rights law, signed and ratified by the New Zealand Government in 2008.

For disabled people's rights to be realised, they too must be empowered with education, awareness, and understanding of their right to respect for home and the family. Therefore, duty-bearers must make a concerted effort to ensure the availability of accessible resources, funding, training and education for disabled people to improve their human rights knowledge, particularly their human rights under Article 23.

8 Kupu Whakamutaka / Concluding Remarks

This research has initiated an important and timely conversation about disabled people's conceptualisations of family, whānau and aiga in Aotearoa New Zealand, and the right to respect for home and the family. As the findings show, disabled people continue to experience significant barriers in relation to home and family, raising concerns about the realisation of their human rights as guaranteed by the UNCRPD. Moreover, recent changes to government policies regarding disability supports and services and Enabling Good Lives have undoubtedly put disabled people's right to the enjoyment of Article 23 at an even greater risk, with further harmful changes expected in the future.

This report began by outlining instructive conventions, policies, reports and models that contributed to the underlying assumptions of this research, and disabled people's right to respect for home and the family. A summary of key findings from an integrative literature review then situated the research in a broader context of existing literature by exploring definitions of family and Māori, Pacifica Pākehā, immigrant and LGBTQI+ perspectives on disability and family. Key findings from questionnaires and interviews with disabled people and their family, whānau, aiga and close supporters were then presented. The findings were framed to articulate participant reflections on 'my family'; 'my roles and responsibilities'; 'my culture'; 'my supports'; 'my aspirations; 'my home'; and barriers to home and the family. Finally, four prominent themes that emerged across the findings were discussed, including the everyday aspirations of participants regarding family and home; the intersections of culture, disability, home and family; natural supports and reciprocity; and the role of formal supports. Finally, the research impact was explored, along with recommendations for the progressive realisation of Article 23 of the UNCRPD.

This research, however, is just the beginning of the conversation and further research is required; in particular, research that deepens understanding of disability, home and family from different (non-Western, non-individualistic) cultural perspectives. As has been highlighted, there is still much work to do before disabled people in Aotearoa New Zealand can fully enjoy their right to respect for home and the family - particularly in a way that reflects their values and honours their cultural

interpretations of disability, home and family. This research provides disability-led evidence that supports efforts to urgently advance work in this area, including greater investment and flexibility in disability supports and services, particularly in respect to the elimination of discrimination against disabled people in all matters relating to marriage, family, parenthood and relationships. It is, therefore, crucial that the conversation continues at all levels of the social-ecological model, and specifically in spaces where duty-bearers, such as the New Zealand Government and disability supports and services, have the power and ability to enhance disabled people's aspirations for their home and family.

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

9 Tohutoro / References

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Annex A: Article 23 – Respect for home and the family

1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:

a) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;

b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;

c) Persons with disabilities, including children, retain their fertility on an equal basis with others.

2. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.

3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.

4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be

separated from parents on the basis of a disability of either the child or one or both of the parents.

5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.


DONALD
BEASLEY
INSTITUTE