ORANGA TAMARIKI
Ministry for Children

EVIDENCE CENTRE
TE POKAPŪ TAUNAKITANGA

# Good practice for disabled tamariki and rangatahi in care

## LITERATURE REVIEW

The Oranga Tamariki Evidence Centre works to build the evidence base that helps us better understand wellbeing and what works to improve outcomes for New Zealand's children, young people and their whānau.

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# Glossary

**Breaking point**: When whānau-carers feel physically and emotionally unable to provide care for tamariki whaikaha.

**Care:** Any supports or services that are received by tamariki whaikaha either informally (via natural supports) or formally (via funded supports and services), regardless of the setting.

**Complex disability:** Disabled child/young adult, who also has either multiple disabilities, a serious, ongoing medical condition and/or behaviour that requires a high level of support (Complex Care Group, 2020, para. 1).

**Disability:** Persons with disabilities include those 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. (Article 1 – Purpose) (United Nations, 2006).

**Integrative literature review:** An inclusive form of literature review, integrative reviews bring together theoretical data and empirical literature of all kinds. This approach also allows the inclusion of legislation, policy, and other technical reports.

**Kinship care:** Care by extended family member

**Natural supports:** Informal social and practical support provided by whānau, friends or other community members.

**Out-of-home care (OOHC):** Any form of care in which a tamaiti whaikaha predominantly lives away from their whānau in an alternative setting with an alternative caregiver(s), and that this arrangement is overseen by a child protection agency. The out-of-home placement may have occurred at the instigation of the whānau, or due to care and protection concerns raised by an outside party or child protection agency.

**Relinquishment:** The act of passing responsibility for the care of tamariki whaikaha to the State. A more recognised term in Aotearoa New Zealand is voluntary out-of-home placement.

**Respite**: Opportunity for whānau-carers to take a break from their caring responsibilities.

**Whānau-carers:** Family members who are the primary carer(s) for tamariki whaikaha.

# Kupu Māori (Māori word definitions)

**Aotearoa:** Aotearoa New Zealand

**Kaiako**: Teacher

**Kaiārahi:** Guide, escort, counsellor, conductor, leader, mentor

**Kaimahi hauora**: Health worker

**Kaitiakitanga**: Guardianship, stewardship

**Mahi:** Work

**Mana:** Enduring, indestructible power of the *atua* and is inherited at birth

**Manākitanga**: Hospitality, kindness

**Tamaiti:** Child (singular)

**Tamariki whaikaha and rangātahi:** Disabled children and youth

**Tāngata whaikaha:** Disabled Person

**Tauira Model**: Student Model

**Te Ao Māori**: Māori world view

**Tuakana:** Senior, older brother of brother or older sister of sister

**Teina:** Younger brother of brother, younger sister of sister

**Whānau**: Family

# Abbreviations

**CYPFA:** Children, Young Persons and Their Families Act

**EGL:** Enabling Good Lives

**IDI:** Integrated Data Infrastructure

**IF:** Individualised Funding

**ODI:** Office for Disability Issues

**OOHC:** Out-of-home care

**OT ACT:** Oranga Tamariki Act

**MSD:** Ministry of Social Development

**NGO:** Non-governmental organisations

**NZDAP:** New Zealand Disability Action Plan

**NZDS:** New Zealand Disability Strategy

**PMLD:** Profound and multiple learning disabilities

**SDM:** Supported decision-making

**SED:** Serious Emotional Disturbance, or mental health/ psychosocial disabilities

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

**UNCRC:** United Nations Convention on the Rights of the Child

**VEOHRC:** Victorian Equal Opportunity and Human Rights Commission

# Introduction

## Ko te ahurei o te tamaiti arahia o tātou mahi

## Let the uniqueness of the child guide our work

Tamariki and rangatahi whaikaha[1] (disabled children and young people) in Aotearoa New Zealand are some of the most disadvantaged members of our society, experiencing inequity across all areas of their lives (Murray, 2018; Wynd, 2015; Neuwelt-Kearns et al., 2020). Tamariki whaikaha are critically disadvantaged in the care they experience and support they receive. They also consistently fail to receive adequate attention within research, policy, and practice (Hwang, 2018). In Aotearoa New Zealand, there is growing recognition of the need to both increase understanding of the experiences of tamariki whaikaha in care and to resolve the issues that negatively impact them.

An example of this can be seen in the NZ Disability Action Plan 2014-2018 (NZDAP), which called for a review of voluntary out-of-home placement for disabled tamariki in Aotearoa New Zealand (Office for Disability Issues, 2014).

Under priority 8a of the NZDAP – Reduce the number of disabled children and adults who are victims of violence, abuse, or neglect – there was a requirement to: *Review the current care and support processes for disabled children who are (or are likely to be) subject to care under the Children, Young Persons and Their Families Act 1989 to establish whether they are being treated equitably and fairly, and in their best interests and, if not, to provide advice on changes needed to legislation, operational policy, operational delivery and/or monitoring and enforcement* (Office for Disability Issues, 2014). In 2015, the Ministry of Social Development (MSD) became the lead agency for this work, which was conducted by the Disabled Children Project[2] – a working group convened to lead the mahi.

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[1] In this report the abbreviated term *tamariki whaikaha* denotes both tamariki whaikaha and rangatahi. The te reo term is inclusive of children and young people of all ethnicities and cultures. Where tamariki Māori are directly considered, clarification is provided.

[2] Access further information about the Disabled Children Project at: [The disabled children: voluntary out-of-home placement review - Ministry of Social Development (msd.govt.nz)]

The primary focus of the Disabled Children Project was to review sections 141 and 142 of the then Children, Young Persons and Their Families Act (CYPFA) 1989.[3] Sections 141 and 142 of CYPFA applied to tamariki whaikaha, whose whānau could not meet their support needs and consequently sought 'voluntary' out-of-home placement in state care for them. Unlike their non-disabled peers entering care, tamariki whaikaha experienced a different pathway into, across, and out of care under ss 141 and 142, and had fewer rights and protections at all stages of their journey. Having this alternative pathway and inequity in the child protection legislation of Aotearoa New Zealand was significantly out of step with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006).[4]

This review included a submission process and associated analysis (Ministry of Social Development, 2015) and qualitative research with young adults who had entered care under a s 141 or 142 pathway (Mirfin-Veitch & Conder, 2015). Informed by the review, in 2019 ss 141 and 142 of the Oranga Tamariki Act were repealed, determining that all tamariki whaikaha should be subject to the same systems and receive the same protections as their non-disabled peers in care.

# Literature review outline

In March 2021, Oranga Tamariki commissioned the Donald Beasley Institute (DBI)[5] to develop a literature review focused *on identifying good practice for disabled tamariki and rangatahi in out-of-home care (OOHC)*. The literature review is intended to inform

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[3] The Children, Young Persons and their Families Act (1989) had its title repealed and was renamed the Oranga Tamariki Act in July 2017. Refer to: Oranga Tamariki Act 1989 No 24 (as at 14 July 2017), Public Act Contents – New Zealand Legislation .

[4] Aotearoa signed and ratified the UNCRPD in 2007 and 2008, respectively (Stace & Sullivan, 2020, p. 23). Taking these actions carried an obligation to give expression to all UNCRPD Articles, including the obligation to repeal legislation that makes a distinction between disabled and non-disabled people within the law.

[5] The Donald Beasley Institute is an independent charitable trust that conducts disability research and education: www.donaldbeasley.org.nz.

future planning and decision-making in relation to improving disability services and support provisions and considered three primary topics:

Models and systems: What identified good practice models and systems are there for disabled tamariki and rangatahi in out-of-home care, and importantly [for] their whānau?

Service and supports: What kinds of services and supports are considered good practice for disabled tamariki and rangatahi in out-of-home care?

Participation and voice: What enables and empowers disabled tamariki and rangatahi to fully participate and have a voice in decisions about their care?[6]

Discussion with Oranga Tamariki prior to the project commencing further defined the specific scope of the brief as being *"where there are no care and protection issues, or care and protection issues are not the main reason for determining whether a child needs to be taken into care."*[7]

To this end, Oranga Tamariki identified a list of policy-related secondary questions focused on their specific and most pressing evidence needs concerning tamariki whaikaha and their whānau in the above situation.

1. What leads tamariki and rangatahi with complex disabilities [to enter] out-of-home care?
2. What kinds of services and supports are considered good practice for enabling tamariki and rangatahi whaikaha to be cared for by whānau[8] thus preventing the need for out-of-home [care]?
3. What are the different residential (live-in) options for tamariki and rangatahi whaikaha and who cannot be cared for at home, and how effective are these in terms of outcomes?

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[6] Note that the original order of these three primary topics was revised by the DBI team in order to better meet the aims of the literature review.

[7] Personal communication, Oranga Tamariki, 8 April 2021.

[8] For the purposes of this report the term whānau is used synonymously with family and denotes the primary carer(s) of tamariki whaikaha.

4. What are the best ways to maintain family and whānau connections when tamariki and rangatahi whaikaha are in out-of-home care?
5. What supports can enable tamariki and rangatahi whaikaha to return home?
6. What kinds of services and supports are considered good practice for enabling tamariki and rangatahi whaikaha to return home after being placed in out-of-home care?[9]

A final and foundational question was:

7. How can a social model of disability be applied in a care and protection system?

The commissioning document also specified the *literature review should also examine, where appropriate and possible, subjects of importance to disabled tamariki and rangatahi in New Zealand, such as indigenous and Māori models or systems of care.*

In response to these questions, the care journey is explored and presented as three parts within the findings section to inform contemporary policies and practices that have the potential to: prevent tamariki whaikaha entering care; ensure appropriate delivery of OOHC in situations where this **last resort action** has to occur; and demonstrate commitment to family and whānau reunification.

## What do we know about disabled tamariki and rangatahi in care?

Oranga Tamariki *does not have an easy way of identifying disability for children in care and so has limited visibility over the extent to which children and young people in care are living with impairments* (Oranga Tamariki, 2020, p. 4). An attempt to address this critical information gap recently occurred via research using the Integrated Data Infrastructure (IDI).[10] This research identified *1 in 10 tamariki (children) aged 0-17 with*

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[9] An additional question relating to the support needs of disabled parents was posed but was accepted as outside the scope and focus of the current review.

[10] The Integrated Data Infrastructure (IDI) refers to an extensive database of linked data from government agencies, Stats NZ surveys, and non-government organisations. For more information refer to: www.stats.govt.nz/integrated-data/integrated-data-infrastructure/.

*current or previous Oranga Tamariki involvement have at least one indicator of disability* (Oranga Tamariki, 2020, p. 8).[11]

This research is instructive in that it offers insight into the 10 percent of tamariki and rangatahi whaikaha who can be reliably identified.[12] However, the acknowledged and significant undercount makes it an unreliable measure of the true prevalence of disability experienced by the total population of tamariki engaged (in some way) with Oranga Tamariki. As noted in the report, this research *excludes children and young people with an unknown and/or unmet need, such as those who have impairments that are not yet diagnosed, who do not meet thresholds of funding, or who are not in contact with services* (Oranga Tamariki, 2020, p.5). For this reason, the research should only be utilised as a prevalence measure of those tamariki and rangatahi engaged with Oranga Tamariki and who have a formally diagnosed, and more complex disability.

In this regard, the research is instructive within the context of the current literature review as the cohort of tamariki whaikaha aged between 0-17 known to be in out-of-home care, tamariki with a primary diagnosis of intellectual disability were by far the largest group (87%). Tamariki with autism as their primary diagnosis were the next largest group (11%) and tamariki identified as having a physical, sensory, or neurological impairment only comprised 3% of the total cohort of tamariki whaikaha in care (Oranga Tamariki, 2020, p. 17).

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[11] It is acknowledged that research has reported vastly different estimates of disability amongst the population of tamariki and rangatahi engaged with Oranga Tamariki. For example, in the 2018 transitions cohort study it was suggested that the prevalence of disability amongst the transition cohort could be approximately 75%, when including psychosocial disability. Forty-seven percent were suspected to have a disability, or had a disability diagnosis. (www.orangatamariki.govt.nz/assets/Uploads/About-us/Research/Latest-research/transtion-needs-survey/Transition-Cohort-Needs-Assessment-Stage-2-Survey-Results.pdf). It must be noted however, that the focus of this literature review is on the small and specific subset of tamariki whaikaha who have diagnosed complex disability.

[12] Disability was identified via three administrative datasets within the IDI: The Child Disability Allowance (Ministry of Social Development), Ongoing Resourcing Scheme (Ministry of Education), and Disability Support Services (Ministry of Health).

Sixty-six percent of tamariki whaikaha in out-of-home care were also identified as having high or very high support needs (Oranga Tamariki, 2020, p.18.) affirming the focus of the current literature review – tamariki whaikaha with complex disabilities whose entry into care is more strongly determined by insufficient supports being available to them and their whānau, rather than overt care and protection issues.

## What is the scope of this literature review?

This literature review is underpinned by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) definition of disability.

*Persons with disabilities include those 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. (Article 1 – Purpose)* (United Nations, 2006).

This definition recognises the full range of impairments disabled people (including tamariki and rangatahi whaikaha) experience. It also acknowledges the social model of disability, which recognises that a person is disabled by socially constructed barriers.

The UNCRPD definition of disability is included here to purposefully highlight the diversity of tamariki whaikaha within the Oranga Tamariki system in Aotearoa New Zealand both currently, and in the future. The definition is inclusive of the spectrum of formally recognised, suspected, or hidden disabilities. It encompasses physical, mental, intellectual, or sensory impairments, including neurodiversity and mental distress regardless of cause.[13]

However, while this inclusive definition of disability underpins this work, tamariki and rangatahi with complex disability are the primary focus of this brief. As outlined in the introduction and background to this report, the origins of this literature review link back to the programme of work that commenced with the review of sections 141 and 142 of the CYPFA and to the Oranga Tamariki goal of determining *the most appropriate*

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[13] The researchers acknowledge a range of definitions are used within disability and disability-related legislation and policy within Aotearoa.

*outcomes for disabled tamariki who may require a care and protection placement*. An interrelated goal of the agency is to *develop new pathways and standards for placements and to support whānau to remain caring for their tamariki and rangatahi*.[14]

Oranga Tamariki recognises that attention is required to determine appropriate care for this group, who frequently find their way into care due to whānau being unable to access the necessary support, rather than more overt care and protection issues. For this reason, the key emphasis of this work is on the evidence relating to tamariki and rangatahi with complex disability and their whānau – who are most closely represented by the 10 percent of disabled individuals who were able to be identified through the prevalence study mentioned earlier (Oranga Tamariki, 2020). While beyond the scope of this literature review, the pathway into care for tamariki whaikaha also occurs as a result of overt care and protection concerns. Recent American research confirmed that tamariki whaikaha are at an increased risk of experiencing maltreatment, for example abuse and neglect, and that this maltreatment can cause disability (Legano et al., 2021).[15]

In Aotearoa New Zealand, complex disability has been defined by the national advocacy organisation for this group of disabled people as any:

> *Disabled child/young adult, who also has either multiple disabilities, a serious, ongoing medical condition*[16] *and/or behaviour that requires a high level of support (Complex Care Group, 2020, para. 1).*

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[14] The specific text within the commissioning document for this project.

[15] It is worth noting that several the critical elements of support and assistance for whānau carers highlighted throughout this literature review are aligned with methods and strategies identified by Legano et al. (2021) in the context of maltreatment and other overt care and protection breaches experienced by tamariki whaikaha. Further exploration of the care and protection pathway for tamariki whaikaha in this context is warranted.

[16] Given the different pathways and services required by children who have a serious, long-term health condition and no other disability, literature relating to this specific OOHC context has not been included.

Within the international literature, a range of terms and descriptions are used to denote complex disability, including people with cognitive impairments; people who are non-verbal; people who are profoundly disabled, severely disabled, or who have profound and multiple learning disabilities (PMLD); as well as disabled people with intensive support needs or high and complex needs (Moss, 2017, p. 7). In this report, the term complex disability is used, except when directly quoting research that uses an alternative (but synonymous) term.

In setting the scope of this literature review, the difficulty of determining widely understood and accepted definitions of care, and out-of-home care (OOHC) was also noted. Following the repeal of sections 141 and 142 of the Oranga Tamariki Act, the Act no longer sets out a specific pathway to OOHC for tamariki whaikaha. However, one of the common ways tamariki whaikaha and rangatahi currently enter care is when “the parents or guardians or the persons who have the care of the child or young person are unable to care for the child or young person” as set out in s 14(1)(b) of the Act (Oranga Tamariki, 1989). Sections 139 and 140 of the same Act also provide a temporary pathway to the care system for those tamariki or rangatahi defined in s 14(1)(b). While OOHC care arrangements often are initially intended as a temporary measure, data on the duration and permanency of such placements for tamariki whaikaha is limited.

It is acknowledged that definitions of care and out-of-home care are many and varied. A pragmatic approach was taken to meaningfully conceptualise care and OOHC in the context of this work. To reflect cultural and jurisdictional diversity in the literature, **care** is determined to be any support(s) or services that are received by tamariki whaikaha either informally (via natural supports) or formally (via funded supports and services), regardless of the setting. **OOHC** is determined to be any form of care in which a tamaiti whaikaha predominantly lives away from their whānau in an alternative setting with an alternative caregiver(s), and that this arrangement is overseen by a child protection agency.[17] In the context of Oranga Tamariki, kin-care can fall into this category, however, it is strongly acknowledged that in Aotearoa New Zealand, whānau is a

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[17] The out-of-home placement may have occurred at the instigation of the whānau, or due to care and protection concerns raised by an outside party or child protection agency.

broad term, inclusive of a family network wider than the nuclear family unit. Tamariki and rangatahi may live with whānau other than biological parents for parts or for all of their lives. These whānau-centred arrangements and relationships are outside Oranga Tamariki jurisdiction and do not constitute OOHC.

At present there are several options for OOHC placements in Aotearoa New Zealand. Placement types include emergency, respite, transitional, family home care with professional caregivers or staff, permanent care (home for life), and adoption. There are also care and protection (and youth justice) residences. However, it is not clear where the tamariki whaikaha and rangatahi who are the focus of this literature review (those with complex disability) are most often placed, what options are (or are not) currently offered, or how tamariki whaikaha with complex disabilities feel about where they have been made to live.

# Methodology

# Conceptual framework

Aotearoa New Zealand has existing legislation, convention, policy, as well as strong Te Ao Māori and disability models, that if understood and implemented, have the potential to provide a contemporary bicultural and rights-based framework to guide the care and protection of tamariki whaikaha. The most important and instructive of these are presented here to demonstrate an existing, strong platform for policy makers and practitioners in this space, and to ensure key questions were answered in a manner responsive to the unique cultural context of Aotearoa New Zealand. The framework is mapped here to make our approach and influences explicit, and discussed again later in the report.

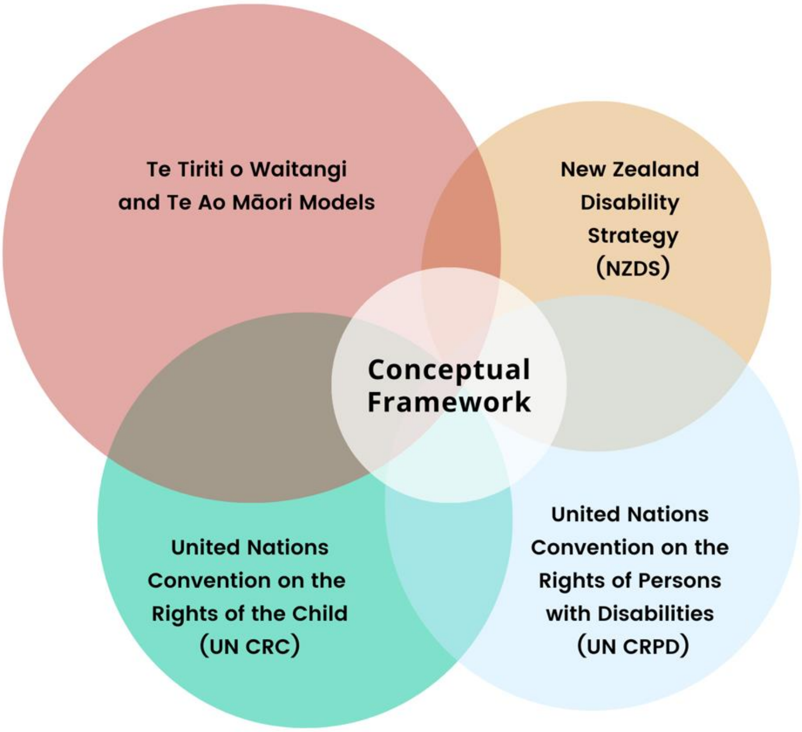

Figure 1. Conceptual Framework

## Te Tiriti o Waitangi

Through its recognition of the unique position Māori hold as tangata whenua of Aotearoa New Zealand, Te Tiriti o Waitangi took primacy within this work, as it should within any information gathering exercise intended to guide policy and practice delivered by the state. In the case of the current research, identified literature was analysed for alignment with Te Ao Māori philosophies and understandings to enable recommendations for indigenous or bicultural policy and practice to be made. As a preliminary step, a range of seminal Te Ao Māori frameworks and models used within the education, health, and social sectors (and beyond) to promote culturally responsive practice were explored.[18] The next step was to identify specific Te Ao Māori models that could inform the framework being developed to meet the aims of the current literature review. The identified models should not be perceived as the only relevant options.

## Tauira Model

The Tauira Model was conceptualised for the specific purpose of this literature review. At its core, it embraces the concept of us all being lifelong students who draw on what we have learnt from the past, what we are learning in the present, and what we want to learn in the future. In te reo Māori, *tauira* means student, example, template, apprentice, model, or pattern. The kupu tauira encompasses many meanings, such as:

- *Tau* – connector, a string or cord, something that fastens, a season or year, an age, to sing, a chant, to settle or abate.
- *Ira* – life principle, gene.[19]

In the Tauira Model, kaimahi hauora (those who deliver care) are conceptualised as lifelong students of their 'practice'. This is a positive and proactive stance that ensures the kaimahi remains open to new learnings from many sources but predominantly from

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[18] As holistic models sourced from mātauranga Māori (Māori knowledge), these included models such as Te Whare Tapa Whā, developed by Mason Durie, The Meihana Model by Suzanne Pitama, Te Wheke Model by Rose Pere, Mana Enhancing Approach described by Leland Ruwhiu (1999), Tikanga Māori Model by Hirini Moko Mead (2003), Kaupapa Māori Theory (G. Smith, 1990; L. Smith, 1997; Pihama, 2001; Pohatu, 2005). Information about these and other Te Ao Māori models can be found at: www.rangahau.co.nz/rangahau/ and www.rangahau.co.nz/ethics/166/.

[19] This translation was sourced from John Moorfield. Te Aka Online Māori Dictionary: Retrieved May 5 2021.

those in their care. The model encourages kaimahi to self-reflect and welcome learning that may come from inappropriate or ineffective care and in this way generates space to create individualised ways of working that affirm those in care and their whānau as ‘kaiako’ (teachers) of their ‘practice’.

The Tauira Model/Framework embodies the tuakana-teina relationship and offers a fluidity that allows student/teacher (carer/cared for) to learn from each other and acknowledges that when there is clear and overt acceptance of this power in the relationship, ‘best practice’ is achieved for both. This approach recognises that the appropriateness and quality of care is best determined by the those receiving it.

## Kaitiakitanga and Manākitanga models

It was also important to draw direction from the Kaitiakitanga and Manākitanga Models that give expression to Te Ao Māori understandings and conceptualisations of care. These models are well recognised and highly respected within the social work context in Aotearoa New Zealand.

While articulating how Māori worldviews provide innovative ways to approach social work, Taina Whakaatere Pohatu (2003) stated:

> *At its most basic yet most profound level, kaitiakitanga is about fulfilling the vital obligation for ‘taking care of’. Placing kaitiakitanga obligations within Te Ao Māori requirements of safe space, respectful relationships, absolute integrity and well-being lays out the environment upon which taking care of can be constantly assessed (p.12).*

When approached with an understanding of both Kaitiakitanga and Manākitanga (lifting one’s mana), best practice becomes about cherishing and nurturing mana. To pursue the wellness of mana is crucial when seeking to work in a way that could be considered as demonstrating ‘good or best practice’. To know what mana is for those with whom we work (in this case tamariki whaikaha and their whānau) and to know what it is for ourselves (Ramsden, 1990), enables us to transform practice in culturally relevant and positive ways.

## Māori-centred practice

Attention was also paid to key messages contained within the recent report, *Māori Centred Social Work Practice Brief* (Oranga Tamariki, 2021), which explored Māori-centred, mana-enhancing social work practices that preference Te Ao Māori, Indigenous and Bicultural world views, specifically in relation to assessment.

A Māori-centred approach, as stipulated in this practice brief, is consistent with the obligations Oranga Tamariki has towards Te Tiriti o Waitangi, their statutory functions, and mana tamaiti objectives and values. Essential attributes of a Māori-centred approach is an all-encompassing philosophical foundation, grounded in Te Ao Māori concepts of wellbeing and care (Oranga Tamariki, 2021). Māori remain in the centre of the management of their care at every stage, their values and aims are prioritised as enrichment targets of wellness (similarly to the Tauira and Manākitanga Models mentioned above). Pre-eminent Māori researcher and theorist Mason Durie agrees, noting that a Māori-centred approach to service design necessitates that Māori design and deliver the processes within mainstream settings in response to the dominance of mainstream processes and methods of service (Hollis-English, 2015).

The key principles of mana-enhancing practice have been identified in the Māori Centred Social Work Practice Brief (2021) as:

- *Valuing Te Ao Māori concepts of wellbeing and cultural identity.*
- *Understanding historical relationships embedded in Te Tiriti o Waitangi.*
- *Relationships defined by authenticity, respect, integrity, and dignity.*
- *Emphasising the roles of whakapapa and cultural narrative in healing processes.*
- *Reaffirming and supporting whānau self-determination* (Oranga Tamariki, 2021 p. 5).

A mana-enhancing approach is conveyed through a willingness to hear the perspectives of tamariki, whānau, hapū and iwi and to activate their articulated needs, and has been embedded more over recent years through the development and commitment by Oranga Tamariki to improving outcomes for tamariki Māori, their whānau, hapū and iwi.

In summary, the framework prioritises Mana Tamaiti (ensuring participation in decision making), Manākitanga (preventing entry into care or custody), Whakamana Tangata placing with whānau, hapū and iwi, Manawhenua-Kaitiakitanga (supporting identity and belonging), Mana Motuhake-Rangatiratanga (leaving custody or care). Progress toward these outcomes is regularly reported by Oranga Tamariki in s 7AA reports.[20] The mana-enhancing approach sets out a blueprint for care, which if applied to all tamariki (and their whānau), including tamariki whaikaha with complex disabilities, provides the 'practical strategies' that practitioners frequently working with this group seek.

## Whāia Te Ao Mārama

A disability – Te Ao Māori lens was also embedded in this work. Importantly, this work was informed by *Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan*. Whāia Te Ao Marama is *a "culturally anchored approach to supporting Māori with disabilities (tāngata whaikaha) and their whānau*" (Ministry of Health, 2018, p. 1), and is particularly relevant to this literature review as it outlines the Ministry of Health's commitment to improving outcomes for tāngata whaikaha through the provision of health and disability services.

Underpinned by Te Tiriti o Waitangi, the UNCRPD, and the principles of Enabling Good Lives,[21] the overall vision expressed in Whāia Te Ao Mārama is that tāngata whaikaha pursue a good life with support. The plan is visually expressed through a torino (double spiral) where each element of the torino represents a specific goal. *Te Rangatira* expresses the goal of tāngata whaikaha having choice and control over their lives, and the opportunity to take leadership; *Te Ao Māori* expresses the goal of tāngata whaikaha connecting with and contributing to whānau, hapū and iwi; Te Ao Hurihuri represents the goal of tāngata whaikaha being part of modern society and their wider community through social networks, employment, and access to services;

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[20] www.orangatamariki.govt.nz/assets/Uploads/About-us/Report-and-releases/Section-7AA-Report/S7AA-Improving-outcomes-for-tamariki-Maori.pdf.

[21] The Enabling Good Lives principles are self-determination; beginning early; person-centred; ordinary life outcomes; mainstream first; mana enhancing; easy to use; relationship building. www.enablinggoodlives.co.nz/about-egl/egl-approach/principles/.

and Ngā Tūhonohono conveys the goal that tāngata whaikaha freely experience connection between Te Ao Māori and Te Ao Hurihuri in a way that maintains their mana. Given this conceptualisation emerged from the thinking of tāngata whaikaha themselves, and refers directly to the dimensions or aspects that are necessary to the delivery of culturally responsive health and disability services, it offers strong guidance for supporting tamariki whaikaha and their whānau.

## Whānau Hauā Model

Finally, Hickey and Wilson's (2017) model was drawn on as an Indigenous Māori framework that acknowledges the impacts of ongoing colonisation and contemporary influences that are oppressive and discriminatory to Indigenous disabled people. Whānau is described as family from whakapapa or as kaupapa whānau (those who share similar traits or purpose) and hauā is broken into hau being the wind that lifts and assists whānau members who have a disability. This model describes an Indigenous disabled person's holistic worldview that focuses on the collective.

Whānau Hauā spreads across historical and contemporary contexts and acknowledges that these contexts can impede the ability of the individual to meet their health needs. Obtaining and sustaining wellbeing is a collective response not just the action of the individual. Whānau Hauā differs from the social model of disability because whānau – the collective – works together to restore the equilibrium of their whānau members living with a disability. This model also reiterates that the individual is defined by their whānau and whakapapa rather than as an individual with a disability. Whānau Hauā manage disability, according to Huhana and Wilson (2017), as part of their daily life as opposed to it being "central to an individual's identity or everyday life" (p. 86). The collectivism approach is a protective and cohesive method to managing disability in changing, and at times denying, environments that have not recognised the significance of cultural identity to growth and wellness.

All the Te Ao Māori models drawn on have a natural synergy, including similar core principles, but each brings different insights to this mahi.[22]

## United Nations Convention of the Rights of Disabled Persons (UNCRPD)

As a States party to the UNCRPD, Aotearoa New Zealand has an obligation to progressively realise the full range of human rights conferred by the Convention; all of which apply equally to disabled children and adults and encompass, in some areas, their whānau and close supporters. Several UNCRPD articles have relevance in the context of the specific questions responded to via this literature review, including Articles 1, 3, 4, 7, 12, 14, 16-17, 19, and 23.[23]

## United Nations Convention on the Rights of Children (UNCRC)

Similarly, as a States party the New Zealand Government has an obligation to implement the range of children's rights set out in the UNCRC. All the articles in the UNCRC apply to everyone under the age of 18 regardless of their disability, ethnicity, culture, gender, sex, or class. The specific articles in UNCRC that have relevance for this literature review include Articles 1, 2, 3, 4, 5, 6, 9, 12, 17, 18, 19, 20, 21, 23, 25, and 27.[24]

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[22] The authors do not intend the Te Ao Māori models here to be seen as an exhaustive list of models and approaches with the potential to guide culturally responsive policies and practices with tamariki whaikaha and their whānau.

[23] Article 1: Purpose; Article 3: General Principles; Article 4: General Obligations; Article 7: Children with disabilities; Article 12: Equal recognition before the law; Article 14: Liberty and security of the person; Article 16: Freedom from exploitation, violence, and abuse; Article 17: Protecting the integrity of the person; Article 19: Living independently and being included in the community; Article 23: Respect for home and the family. Refer to www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html for further detail.

[24] Articles 1 and 2: Everyone has rights; Article 3: What's best for you; Articles 4, 5, and 6: Making your rights a reality; Article 9: Living with your family; Article 12: Having your say; Article 17: Your right to information; Articles 18, 19, and 20: Your rights at home; Article 21: Your rights if you are adopted;

The UNCRPD and UNCRC work together to underpin the policy, legislation and practice that impact tamariki whaikaha, as reflected in the amendments to the Oranga Tamariki Act (1989) in 2019.[25] Strongly recognising the right to legal agency for disabled children and adults asserted within Article 12 of both conventions, an amendment to s 11(2) of the Oranga Tamariki Act enforces greater commitment to facilitating young children's participation in and views about the legal proceedings that relate to them. This includes the provision of accommodations that support active engagement, particularly regarding communication.[26]

## New Zealand Disability Strategy 2016-2026 (NZDS)

Aotearoa New Zealand has had a disability strategy since 2001. All iterations to date have been developed around the overarching goal of Aotearoa New Zealand being:

> …*fully non-disabling society – a place where people have an equal opportunity to achieve their goals and aspirations, and all of New Zealand works together to make this happen.* (Office for Disability Issues, 2016, p. 6).

In the latest NZDS, three principles and two approaches are seen as critical to its success. The three principles are respect for and implementation of:

- Te Tiriti o Waitangi
- the UNCRPD, and
- ensuring that disabled people are central to decision-making that affects them.

The NZDS also advocates the need to invest in both long-term, whole of life supports and services, as well as twin-track supports and services, best achieved through a

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Article 23: Your rights if you have a disability; Article 25: Your rights in foster care; Article 27: You have the rights to good standard of living. Refer to www.occ.org.nz/childrens-rights-and-advice/uncroc/uncroc-basics/ for further detail.

[25] The 2019 amendments also strengthened the duties imposed on the chief executive of Oranga Tamariki in relation to obligations to Te Tiriti o Waitangi. Refer to https://nzfvc.org.nz/news/changes-under-oranga-tamariki-act-1989-effect-1-july-2019 for an overview of the amendments.

[26] Specific detail relating to s 11(2) of the Oranga Tamariki Act (1989) is at: www.legislation.govt.nz/act/public/1989/0024/latest/whole.html#DLM149450

combination of mainstream and disability specific approaches (Office for Disability Issues, 2016, p. 6). While all eight current strategy outcomes are applicable to tamariki whaikaha, Outcome 7: Choice and Control is particularly relevant to this literature review, and includes the following assertion:

> *Our views as children and those of our families, whānau and carers will be considered when choices are made about what supports and services we receive and what works best for us. There will also be respect for the evolving capacities of disabled children, ensuring their input into decisions that affect them* (Office for Disability Issues, 2016, p. 36).

The NZDS is given practical expression via the New Zealand Disability Action Plan 2019-2023 (NZDAP) which identifies current efforts to transform the disability support system (Ministry of Health) and efforts to promote supported decision-making (Ministry of Social Development) as work programmes intended to give greater choice and control (Office for Disability Issues, 2019. p.8).

## Literature search method

Having established both the Te Ao Māori and rights-based foundations required for this literature review, an Integrative Literature Review methodology was implemented to identify the literature and other required resources. This method was selected due to the DBI's awareness of the limited base of current, peer reviewed literature addressing good practice for tamariki whaikaha in OOHC – both nationally and internationally. Therefore, given the diversity of the questions, and the likelihood that the academic literature would not provide comprehensive or culturally relevant answers to them, an integrative review method was deemed appropriate.

As the most inclusive form of literature review, integrative reviews can facilitate a wide understanding of phenomena of concern through the combination of theoretical data and empirical literature of all kinds (Whittemore & Knafl, 2005). Fundamentally, this approach also allows the scope of reviewed literature to extend beyond peer-reviewed and academic articles, to include 'grey' literature. Grey literature refers to information produced by governments, academia, businesses, service providers, non-governmental organisations, and industry, that is not commercially published and/or where publishing is not the primary activity of the producing body. This includes but is not limited to technical and project reports, working papers, discussion papers, manuals, information sheets, and conference papers (Lawrence, 2012).

When using the integrative review methodology, there are generally four questions that a reviewer seeks to answer while reviewing a body of knowledge:

1. What is known?
2. What is the quality of what is known?
3. What should be known?
4. What is the next step for research or practice? (Russell, 2005, p. 1).

Given the stated intention to use this work to improve the quality of care experienced by tamariki whaikaha in the care of Oranga Tamariki, this approach was most likely to generate information with the potential to have practical utility for both policy and practice.

Data collection was approached in two ways. Peer reviewed academic articles published between 2011 and 2021 were identified through a systematic search strategy.[27] This was achieved via searching academic databases between March and May 2021. The academic databases consulted included: Web of Science; Australia/New Zealand Reference Centre; PsycINFO; Academic Search Premier; Google Scholar; Scopus and Proquest. The search terms included:

- Children or adolescents or youth or child or teenager
- Multiple and complex needs
- Family support or family inclusion or family involvement or family engagement

Further search terms were developed due to a low number of relevant results, these included:

- Multiple and complex disabilities
- Disability

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[27] Older references are used on occasion if there is a specific reason for doing so. Where this occurs in the text it is acknowledged.

- Disabled children or disabled young people or children with disabilities
- State care
- Case management
- Out-of-home care or foster care or kinship care or residential care or looked after children or child welfare or child protection
- Relinquishment
- Reunification
- Indigenous
- Native

Due to the varying terms used to describe tamariki whaikaha, multiple terms related to disability and the topic of this brief were attempted. For example, multiple and complex needs is a term used to describe multiple situations unrelated to disability. New and additional search terms were found by using keywords that were included in relevant articles as well as terms identified in titles. A hand search was then conducted using a snowball method (Wohlin, 2014), which involves searching the reference sections of relevant articles to collect missing articles that were either indexed incorrectly or used terms that were different to our own and had therefore not emerged within the initial searches. Google searches were also conducted to reach other articles that had not yet been found. The Google searches included ‘children with multiple and complex disabilities in out-of-home care’ and ‘support for parents with children with multiple and complex disability’.

Grey literature was identified more intuitively, beginning with key legislation, conventions, strategies, policies, key reports and extending into other areas such as websites of government organisations (for example, Oranga Tamariki, Ministry of Health, and Ministry of Social Development) and independent organisations (for example, CCS-Disability Action and Child Poverty Action Group).

## Data analysis

Both academic articles and grey literature were scanned for relevance by reading through titles and abstracts. Literature identified as relevant was marked as such and read in full. Key findings and study details from relevant literature were entered into a data chart. Thematic analysis was undertaken to identify key themes in the literature that had the potential to inform or answer the research questions.

## Limitations

There are several limitations to this research, which are presented here for the benefit of the reader, and to contribute to their understanding of the findings and discussion.

Preliminary discussions with Oranga Tamariki to determine the parameters of this literature review led to shared agreement that the mahi would consider OOHC for tamariki with complex disability. This decision acknowledged an immediate goal held by Oranga Tamariki to increase their responsiveness to this cohort. It was acknowledged that entry into OOHC for this group often occurs in response to whānau crisis, and typically sees tamariki with complex disability placed in residential care settings rather than in whānau or foster-care, as is more typical in the case of both their non-disabled peers and peers with less complex impairments. In taking this emphasis, it was difficult to locate academic and other literature instructive for the aims of the brief. This was due to a lack of empirical research relating to children (and adults) with complex disability in general, and their experiences of OOHC in particular. The reasons people with complex disability are 'left-out' of research are multi-faceted and their exclusion is frequently commented on in disability literature. In the context of this work, it meant that it was hard to achieve a strong (research) voice for tamariki with complex disability themselves as the focus of the mahi.

Given the specific focus, an integrative review was determined to be a methodological approach that would provide the best chance of being able to draw in relevant data. Even so, a systematic approach to searching the literature and other resources is still required. By setting the search parameters that are outlined above, it is acknowledged that relevant data may inadvertently have been missed. For example, confining the search period to 2011-2021 will have eliminated some potentially relevant data sources. Further to the challenge of locating appropriate data, the overarching and more specific questions posed by Oranga Tamariki did not easily align with the research evidence. For example, while a reasonable amount of data spoke to the questions about what leads to OOHC and supports and services that could assist whānau-carers 'before care', there was very little evidence of evaluated OOHC settings or reunification approaches. And finally, some research that was instructive to the questions posed in the literature review focused on tamariki with identified disabilities than tamariki with complex disability. Where such research has been included, efforts have been made to indicate this.

Most critically, working within the agreed parameters of the research, illustrated the acute lack of Indigenous research relating to tamariki whaikaha in OOHC. While we have highlighted how existing Te Ao Māori models and approaches respond to key themes and issues identified through the research, it is acknowledged that the data used to develop this literature review is predominantly Eurocentric in orientation.

Finally, the findings of this literature review were restricted by time limitations.

# Findings

## Have tamariki whaikaha had a voice in research and other discussions about out-of-home care?

It is appropriate to commence the findings by considering the extent to which tamariki whaikaha have been present in the academic and other literature about OOHC. As outlined in the conceptual framework for this literature review, the two United Nations Conventions require the New Zealand government take into consideration the rights of tamariki whaikaha when developing law and policy that impacts them (Ministry of Justice, 2020). In line with these conventions, and as mentioned earlier, section 11 (2)(c) of the Oranga Tamariki Act 1989 requires Oranga Tamariki to provide support for tamariki and rangatahi with different communication needs to express their view (Oranga Tamariki Voices of Children and Young People Team, 2020).

Tamariki whaikaha were rarely the primary voice within research about OOHC, with a more comprehensive body of research available relating to the experiences of non-disabled tamariki and rangatahi in care. While there is a risk that the experiences and needs of tamariki whaikaha may be lost or missed by generalising experiences of all tamariki (Conder et al, 2015), understanding their shared experiences and views is also important. For example, through a comparison of literature it became clear that both disabled and non-disabled tamariki report a need for support when they are sharing an opinion or making a decision (Oranga Tamariki Voices of Children and Young People Team, 2020; Oranga Tamariki Voices of Children and Young People Team, 2021).

Tamariki whaikaha have asserted that involving them in decisions about their OOHC care creates transparency and trust. As Crettenden et al (2014) found, in the absence of transparency and clear communication, tamariki whaikaha[28] felt rejected by their whānau. Tamariki whaikaha in care in Aotearoa New Zealand agree with this international research stating that adults were not honest about their care arrangements (Oranga Tamariki Voice of Children and Young People Team, 2020).

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[28] The terms tamariki whaikaha and whānau-carer (as defined for this evidence-brief) are used throughout the findings even when discussing international literature. In this way mana is held for the language of Aotearoa. The only exception is when a direct quote is included.

Adults and professionals who had relationships with these tamariki and rangatahi shared frustration that there was a lack of information provided by Oranga Tamariki that communicated directly to tamariki and rangatahi (Oranga Tamariki Voice of Children and Young People Team, 2020).

To effectively communicate, understand and act on the views and opinions of tamariki whaikaha it is important to recognise their diverse communication style and needs. Tamariki whaikaha have highlighted that their behaviour is part of their communication (Oranga Tamariki Voice of Children and Young People Team, 2020). They also shared that physical cues, such as eye contact from adults, are important for them to know and feel that they are being listened to (Oranga Tamariki Voice of Children and Young People Team, 2020). Another critical aspect of the communication highlighted by tamariki whaikaha was to simply ask for their view and not to assume what they were thinking or feeling (Oranga Tamariki Voice of Children and Young People Team, 2020).

Mirfin-Veitch & Conder (2015) reported a lack of participation by rangatahi whaikaha who were in OOHC prior to the repeal of ss 141 and 142 of the Oranga Tamariki Act 1989. This research also highlighted that rangatahi remained in residential services even when they aged out of Child, Youth and Family care due to lack of opportunities to express a desire for or to experience other ways to live.

Finally, international research has shown that the participation of tamariki whaikaha in decision-making is often influenced by the actions and attitude of both their whānau and professionals. This highlighted a need for resources for decision-making to be available, as well as ongoing support for the decisions they ultimately make (McNeilly et al, 2015). Irish research also identified that it was common for social workers to assume that tamariki whaikaha lacked capacity to make their own decisions, which hindered their participation in matters that were directly related to their own lives (Kelly et al 2016).

Such findings above are contrary to Article 7 of UNCRPD, which recognises the rights of disabled children (United Nations, 2006), Article 12(2) of the UNCRC which assures the rights of child “to be heard in any judicial and administrative proceeding affecting the child” (United Nations, 1989), and Article 12 of the UNCRPD requires that state parties provide appropriate support for disabled people in exercising their legal capacity (United Nations, 2006). Supported decision-making (SDM) is identified within the convention as the mechanism or strategy by which disabled children and adults can express that capacity (Mirfin-Veitch, 2016). SDM is an established approach to decision-making that assists people to shape their own decisions, particularly when they have been assumed to lack the mental capacity to do so. If understood and implemented, SDM has the potential to elevate the voices and facilitate meaningful participation of tamariki whaikaha in decisions that impact on their lives – including decisions about care.

The remainder of the findings are presented in three sections reflecting the journey into care; being in care; and getting out of care, experienced by many tamariki whaikaha and their whānau.

# The journey into care

The journey into care section considers two secondary questions:

1. What leads tamariki and rangatahi with complex disabilities [to enter] out-of-home care?
2. What kinds of services and supports are considered good practice for enabling tamariki and rangatahi whaikaha to be cared for by whānau thus preventing the need of out-of-home [care]?

## Breaking point

Superseding all other factors, the experience of 'breaking point' was a central theme instructive to both questions being analysed. Breaking point refers to circumstances where whānau-carers feel that the pressures of day-to-day caring have become unsustainable, and that an alternative care arrangement is urgently required. Mencap, a UK-based organisation, has conducted extensive research in this area and offers the following definition:

> *Breaking point is a physical and emotional crisis where the persistent lack of short break services and the endless pressure of providing intensive care finally*

> *take their toll. It is a dreadful situation for families, which causes pain and despair, and, often, irreparable damage* (Mencap, 2006, p. 7).[29]

In Aotearoa New Zealand, breaking point has been reported as affecting family and whānau-carers for many years. For example, research exploring families' earlier decisions to seek institutional care for disabled family members found that OOHC was most-often sought when a single, final event tipped the balance from a family coping, to no longer being able to manage (Mirfin-Veitch, Bray & Ross, 2003). Research designed to explore why families sought permanent OOHC for children with very high support needs also identified a range of factors that, in combination, led to such decisions (Carpinter, Irwin & Rogers, 2000). More recently, research conducted by Milner et al. (2016) focused on the respite care experiences and needs of whānau-carers. They found that six out of every ten respondents had felt like they were at breaking point. It is important to note that the pressure of caring is also experienced by Māori whānau-carers of tamariki whaikaha. Bevan-Brown (2013) referred to the earlier work of Collins and Wilson who had highlighted that while caring is widely understood as intrinsic to Te Ao Māori, Māori whānau are negatively impacted by a lack of resources. Therefore, assumptions should not be made about their need for formal support and services. In the Australian context, Green et al. (2020) considered how to increase early intervention supports and services to Aboriginal and Torres Strait Islander tamariki whaikaha and their whānau-carers in recognition of both the pressures of care, and barriers to access they are known to experience.

## Relinquishment as a pathway into care

In an Australian context, the impact of whānau-carers reaching breaking point in the absence of effective support is described in research analysing the act of *relinquishment*. Relinquishment, a term common within Australian literature, describes situations where parents 'surrender' the day-to-day care of their child to the state

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[29] It is acknowledged that both the Mencap (2006) and the later Mirfin-Veitch, Bray & Ross (2003) and resources fall out of the prescribed literature search period 2011-2021 however they are included here as they are particularly relevant.

(Ellem et al., 2016; Nankervis et al., 2011a; 2011b; Ng, & Rhodes, 2018; Victorian Equal Opportunity & Human Rights Commission [VEOHRC], 2012).

The act of relinquishment is the ultimate expression of 'I can't do this anymore'. The extreme and seemingly unresolvable sense of being unable to meet a child's needs can lead family and whānau to surrender; usually by leaving their child in the care of a respite facility and not returning to collect them. Venues and other agencies such as schools, hospitals, Department of Human Services offices, or emergency services (VEOHRC, 2012) have also been reported as sites of the relinquishment of tamariki whaikaha (and adults). As this indicates, relinquishment is often an unplanned action, which occurs in the context of unstable circumstances and in the absence of person- or whānau-directed, stable support(s) and services being in place. In Australia, the unplanned nature of relinquishment typically results in the tamaiti whaikaha needing to be accommodated in respite facilities designed for short-term stays. This contributes to an acute shortage of respite services and an even greater degree of unmet respite need within the disability system (Nankervis et al., 2011a; 2011b).

It seems clear that relinquishment occurs in response to whānau-carers of tamariki with complex disabilities experiencing crisis (breaking point). For example, Ellem et al. (2016) found that Australian family members were typically under extreme levels of stress when they made the decision to relinquish care. It is also important to note that although whānau experienced some immediate feelings of alleviation following relinquishment, this relief was diluted by the trauma of turning over care of a loved one, resulting in feelings of grief, guilt, and anxiety. For many whānau, relinquishment is a last resort option that is contemplated over time and actioned only when they feel they have exceeded their capacity to cope (Ng & Rhodes, 2018).

## The build-up to breaking point

Several factors were identified as contributing to whānau-carers reaching breaking point. In a report published by the VEOHRC (2012)[30], family and other close carers reported *financial pressure* as a factor in decisions regarding relinquishment as they struggled to accommodate the costs and time associated with day-to-day care of their

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[30] VEOHRC refers to the Victorian Equal Opportunity and Human Rights Commission.

disabled family member. Retaining employment was reported to be challenging, as was navigating the costs associated with *"medication, specialised therapies and equipment, additional costs for respite and other services not fully funded, and education costs"* (p. 29).

*Stress and isolation* were also reported as contributing to thoughts or actions relating to relinquishment, including negative health impacts such as high rates of anxiety and depression, coupled with exhaustion and lack of sleep. A lack of sleep was particularly pronounced when tamariki whaikaha require vigilant attention 24 hours a day for reasons related to safety, or when their care includes highly medicalised interventions (VEOHRC, 2012).

As has consistently been reported throughout the literature since the 1990s, another factor contributing to relinquishment decisions is related to family and whānau-carer concerns for the *siblings* of tamariki whaikaha. Concerns were two-fold; the first being that in meeting the needs of tamariki whaikaha, whānau-carers felt they had little capacity for other members of their whānau. The second related to the risk of sibling's physical safety in cases where complex behaviours were present (Ng & Rhodes, 2018). On some occasions, decisions to relinquish tamariki with complex or aggressive behaviour were reported as being based on these unresolved safety concerns. Of all contributing factors mentioned by whānau-carers, the feeling of *"coming up against a brick wall"* when trying to access help and running out of options was the most common characteristic shared by parents who had relinquished the day-to-day care of their tamaiti whaikaha (VEOHRC, 2012, p. 30).

## A pattern of unmet need

In the above-mentioned VEOHRC report, characteristics of the *support context* were also identified as factors leading to relinquishment. The authors described the disability system in Australia as being crisis-driven with support only becoming available to families at the point of crisis. The service system was reported as being inconsistent, fragmented, and difficult to navigate, as well as lacking coordination and planning, such as a sustainable and flexible family-centred approach (VEOHRC, 2012).

Similarly, Aotearoa New Zealand-based research by Milner et al. (2016) found that there was an acute shortage of quality respite, even though respite requests and usage was escalating. Parents reported a lack of support from schools due to children being suspended and expelled, which generated additional demands. Issues observed in the disability services workforce were also identified, including a lack of well-qualified, consistent staff within services, a paucity of staff available to provide support, and significant skill gaps. Finally, engaging with government agencies, together with feeling conflicted over how to respond to, and resolve, their support requirements and those of their tamariki whaikaha were reported as factors contributing to whānau-carer stress within the support context (VEOHRC, 2012).

In a further Australian study, Nankervis et al. (2011a) found three themes relating to the relinquishment of care. The first theme concerned the personal characteristics of tamariki whaikaha, including the intensity of support, need, age, and their ability to communicate. In particular, high medical needs, adolescence and the absence of accessible communication created additional challenges for whānau-carers. The second theme involved characteristics regarding the family dynamic, which were psychological distress, parental expectations, relationship breakdowns, single parent households and the desire to lead a ‘normal’ life. The third theme involved characteristics attributed to the support context relating to the availability of appropriate supports, and in particular respite services. Nankervis et al. also identified that an (unplanned) relinquishment was sometimes deliberately used as a vehicle for obtaining permanent out-of-home accommodation.

## Psychological and physical wellbeing

While the relinquishment literature provides a particular framework for analysing the journey to out-of-home placement, a wider body of research also considers the challenges experienced by whānau-carers, including pressures that have potential to lead them to breaking point. The alignment between research findings related to each of these bodies of work is striking. For example, Crettenden et al. (2014) explains that the decision parents make to locate out-of-home placements (in a planned way) generally occurs after a period of stress accumulation, which leads to the whānau-carer(s) reaching breaking point. With research indicating that a deterioration of parental psychological wellbeing can lead families to place their children in the care of others, albeit reluctantly, the importance of tending to the psychological wellbeing of the whole family or whānau is evident (Cramm & Nieboer, 2011).

Whiting (2014) also found that caring for children with complex disabilities can affect psychological and physical wellbeing of parents and other family members, and as also noted by Crettenden et al., (2014) this put whānau-carers at an increased risk of stress, anxiety, depression and marital tensions. Milner et al. (2016) reported that whānau-carers often experience poorer health and wellbeing outcomes. Whānau-carer stress was also identified by Cramm and Nieboer (2011), which appeared to be exacerbated in circumstances where tamariki whaikaha also experienced depression or anxiety. These researchers also noted that restricted social activities strongly affected whānau-carer stress, which was perceived to be linked to whānau-carers feeling a lack of control in their day-to-day lives (Cramm & Nieboer, 2011).

## Respite

International and national literature highlights the critical role that respite plays in supporting whānau wellbeing when caring for tamariki with complex disability. Fundamentally, respite offers the opportunity to take a break, relieves stress, and enables whānau-carers to engage in activities that they find personally fulfilling away from their caring role (Nankervis et al., 2011b). Whiting (2014) found that regular access to respite promoted resilience in parents, helping them to continue caring for their children, but also that regular, planned breaks and respite was *“the greatest area of unmet need”* (p. 27). Unmet respite has been flagged in the literature as one of the most significant contributors to whānau-carers’ decisions to (reluctantly) absolve themselves of the day-to-day care of their tamariki (Nankervis et al., 2011b).

In Aotearoa New Zealand, Milner et al. (2016) found that whānau-carers who received sufficient respite were less likely to report feeling close to breaking point. They also emphasised that different whānau have different needs therefore a one-size-fits-all approach to respite, and indeed any other supports, is inadequate and inappropriate. Their findings demonstrate the critical need for whānau to exercise choice and control over service and support options.

Finally, the reviewed literature on respite care issues and solutions highlights that short-term arrangements and responses are ineffective at increasing the resilience and wellbeing of whānau and preventing planned or unplanned out-of-home care (Nankervis et al., 2011a).

## What kinds of services and supports are considered good practice for enabling tamariki and rangatahi whaikaha to be cared for by whānau thus preventing the need of out-of-home [care]?

The literature identifies a multitude of factors that can impact on the capacity of whānau-carers to provide day-to-day care for tamariki whaikaha with complex disabilities. The second follow-up question considers how decisions to seek out-of-home care, either planned or unplanned, can be prevented.

### At a systems level

One of the main risk factors identified as contributing to breaking point was the lack of financial resources provided for whānau affected by disability. However, the reviewed literature did not present a universal model on how to better financially resource whānau-carers to avoid reaching breaking point. It is important to note that regardless of jurisdiction, when tamariki whaikaha enter ‘the system’ either voluntarily or due to care and protection concerns, previously scarce financial resources are quickly made available to the formal services that assume the role of carer. This raises the question of how such resources might be directed to tamariki whaikaha and their whānau-carers earlier, and more equitably.

Ellem et al. (2016) considered that direct funding of assessed needs would ensure greater choice and control for individuals and their whānau-carers; suggesting that whānau would be better placed to retain care of their tamariki whaikaha if they could choose the type of supports relevant to their situation, including how and by whom it is provided. They also suggest that Australia's National Disability Insurance Scheme[31] had the potential to provide this flexibility at a systemic level.

In Aotearoa New Zealand, similar overarching principles are already present in the major policy initiatives Enabling Good Lives and Mana Whaikaha,[32] which aim to transform systems around policy, funding and support accessed by disabled people in Aotearoa New Zealand. Ensuring that tamariki whaikaha with complex disabilities and their whānau-carers are aware of, and able to access, these new person and / or whānau-directed funding systems may provide both adequate funding, and a degree of flexibility with regards to its use. This could decrease the risk of factors known to contribute to breaking point and help prevent out-of-home placement. However, to ascertain whether the potential of these transformative funding systems is being felt by whānau inclusive of tamariki whaikaha with complex disabilities, regular and focused disabled-led and rights-based evaluation is required. It is also important to note that at the time of writing this literature review, EGL and Mana Whaikaha initiatives were not universally available to all disabled people in Aotearoa New Zealand. To maximise the potential of these initiatives for whaikaha tamariki and their whānau-carers engaged with Oranga Tamariki for reasons of care or protection, the various systems involved (particularly welfare, health and education) need to share equal responsibility and to work collaboratively and creatively to meet their needs.

## Future supports for whānau carers

The research that has been drawn on in this section of the literature review has clearly emphasised a need for consistent and meaningful support for the psychological wellbeing of whānau-carers. Nankervis, et al. (2011a) assert that mental health

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[31] The National Disability Insurance Scheme (NDIS) is an Australian initiative which aims to provide disabled people with direct funding for supports and services. The NDIS also provides disabled people with information and connection to local supports and services. For further information refer to: www.ndis.gov.au/understanding/what-ndis

[32] Enabling Good Lives (www.enablinggoodlives.co.nz/) and Mana Whaikaha (manawhaikaha.co.nz/) are major policy initiatives currently being offered in specific regions of Aotearoa. Both initiatives share a fundamental commitment to choice and control, and person-directed supports, and aim to transform the funding, policy and support systems to achieve this.

services should be provided to prevent the development of mental distress and to avoid the level of caring-related pressure that leads to out-of-home placement. The challenge for policy is ensuring equitable access to such services, in a timely and as-needed basis, recognising the episodic pressures associated with long-term care. This challenge is underpinned by the need to identify when whānau-carers are at an acute risk of reduced psychological wellbeing, or when whānau resilience is being undermined to a dangerous level. As proposed by VEOHRC (2012), in circumstances where unplanned relinquishment has occurred reporting the details surrounding the relinquishment within administrative data systems is one way to call attention to the problem and initiate strategies to prevent out-of-home placement.

While unplanned relinquishment has not been identified (publicly) as a major issue in Aotearoa New Zealand, until recently most voluntary out-of-home placements occurred via ss 141 and 142 of the Oranga Tamariki Act. Arguably, the term ‘voluntary’ was an inaccurate one, and whānau-carers were in fact forced to pursue this pathway in the absence of consistent and adequately resourced supports and services. Even so, the repeal of ss 141 and 142 of the Oranga Tamariki Act does not eliminate the potential for tamariki whaikaha to enter care. It is imperative that efforts are made to engage with whānau-carers regularly, meaningfully, and sensitively, particularly those providing the daily care for tamariki whaikaha with complex disabilities. Aotearoa New Zealand has a number of wellbeing frameworks, which could be used to discuss and assess whānau wellbeing, for example, Te Whare Tapa Whā,[33] Te Wheke[34] and Te Pae Mahutonga.[35] These evidence-based actions have the potential to create possibilities for early intervention rather than a crisis model, requiring Oranga Tamariki

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[33] Te Whare Tapa Whā is a Māori health model developed by Mason Durie which symbolises four walls or sides of the wharenui. www.health.govt.nz/our-work/populations/maori-health/maori-health-models/maori-health-models-te-whare-tapa-wha

[34] Te Wheke is a Māori health model developed by Rose Pere which relates to family health. www.health.govt.nz/our-work/populations/maori-health/maori-health-models/maori-health-models-te-wheke

[35] Te Pae Mahutonga is a Māori health model developed by Mason Durie for health promotion, which encompasses Mauriora (access to te Ao Māori, cultural identity), Waiora (environment), Toiora (healthy lifestyles) and Te Oranga (participation in society).www.cph.co.nz/wp-content/uploads/TePaeMahutonga.pdf

to work in partnership with health and disability services when overt care and protection issues, or the need for out-of-home placement arise. Such an early intervention approach could be achieved via universal access to person- and whānau-directed supports currently offered in specific regions (such as EGL and Mana Whaikaha), or through Individualised Funding (IF).[36]

# Being in care

The being in care section of the findings considers two secondary questions.

1. What are the different residential (live-in) options for tamariki whaikaha and rangatahi who cannot be cared for at home, and how effective are these in terms of outcomes?
2. What are the best ways to maintain family and whānau connections when tamariki whaikaha and rangatahi are in out-of-home care?

## Out-of-home care placement options

Research indicates that stable placements are important for the wellbeing of tamariki whaikaha in out-of-home care (Helton, 2011). However, studies suggest that tamariki whaikaha who are cared for in residential care facilities are more likely to experience unstable placements compared to their non-disabled counterparts (Hill, 2012). Kinship care has been identified as one of the most stable placements for tamariki whaikaha (Helton, 2011). Despite this, research from the United States has reported a tendency for case workers to place tamariki whaikaha in non-kinship care (Helton, 2011). Helton (2011) explored whether tamariki whaikaha are more likely to experience instability within their placement when placed with their kin. The stability of kinship care was quantitatively analysed using the Child Protective Service sample within the National Survey of Child and Adolescent Well-being dataset. Findings revealed that kinship care returned the same degree of stability of placement for both disabled and non-

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[36] Individualised funding (IF) is offered via the Ministry of Health and provides disabled people the opportunity to directly manage their own disability supports. IF is available nationwide to any person who is eligible for Home and Community Support Services or Respite Services. For further information refer to: www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/individualised-funding-funded-ministry-health.

disabled tamariki. This challenges the presumption that residential support is required for tamariki whaikaha, and supports the value of kinship care for this group.

The benefits of kinship over other out-of-home placement, such as residential facilities or supported accommodation, relate to the natural elements of whānau, and life within whānau. Friedman and Norwood (2016) explored formal care settings for tamariki whaikaha (although not exclusively those with complex disability). In formal care settings there is often high staff turnover and limited individual attention available to tamariki due to low staffing ratios. Moreover, the regimented schedules and rules of the house limits spontaneous interaction between tamariki whaikaha and their caregivers (Friedman & Norwood, 2016).

In addition to kinship care, researchers have found that 'wraparound support'[37] delivered by a multidisciplinary team is the best practice when supporting both tamariki whaikaha with complex needs and their whānau-carers (Crettenden et al., 2014; Whiting, 2013). This includes trauma-informed support and therapy which enhances the ability of tamariki whaikaha to maintain mental wellbeing (Buchanan et al., 2019). This type of approach is also reflective of the principle-based approach in Aotearoa New Zealand, Enabling Good Lives, which recognises the importance of a person-centred approach and the seamless delivery of support across different disciplines (Enabling Good Lives, n.d.). The importance of the role of key worker has also been highlighted in the literature (Crettenden et al., 2014; Whiting, 2013); as key workers frequently fulfil a vital communication role between various services, whānau-carers and tamariki whaikaha. Effective case management is difficult if there is uncertainty about the length or permanency of the out-of-home care placement. This lack of certainty makes it harder to develop trust and a robust plan and approach to information sharing and support for tamariki whaikaha.

Buchanan et al. (2019) highlighted the responsibility of OOHC providers to support and maintain the connection between tamariki whaikaha and their whānau-carers. One key factor that enables or restricts the ability for whānau to stay connected with

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[37] Wraparound support in the context of services designed for tamariki and rangatahi is generally understood to be when services and professionals work together to provide supports that are tamariki- and whānau-centred, and are comprehensive, holistic and collaborative.

their tamariki in out-of-home placement is proximity. Being placed in OOHC arrangements far away from their whānau can result in tamariki whaikaha losing vital whānau connection (Crettenden et al., 2014). Distance often creates financial, transport and time pressures that make it difficult for whānau to regularly visit their loved one.

## Tamariki whaikaha and whānau experiences of out-of-home placement

As outlined earlier, the reviewed literature focuses more heavily on the reasons why whānau-carers seek OOHC or more overtly relinquish care rather than on the experiences of tamariki whaikaha themselves (Crettenden et al., 2014). Literature that considers the experiences of OOHC for non-disabled tamariki and rangatahi suggests that they would have had better lives if they had been enabled to stay with whānau. Experience in OOHC placements is often associated with higher risks of low academic and social outcomes (Cheung et al., 2012; Jackson & Cameron, 2012). To explore the experiences of OOHC for tamariki with multiple and complex disabilities including those with high health needs, Crettenden et al. (2014) conducted qualitative research that included tamariki, whānau carers, case managers, accommodation and service managers.

In this study, seven whanau-carers reported experiencing improvements in the behaviour and health of their tamaiti through a more managed routine in out-of-home placement. They also shared that they were able to have more quality time together as a family (Crettenden et al., 2014). At the whānau level, the quality of information sharing was identified as a primary factor in whether a care placement was considered positive. Whānau-carers expressed frustrations about having to repeatedly share the same information and history with different parties involved with their tamariki. It was also found that information sharing both prior to, and after entering, care was seen as crucial but difficult to achieve if an OOHC placement has occurred due to a crisis. Participants reported instances of communication failure, resulting in tamariki whaikaha not having access to important belongings, or being given unsuitable food to eat.

These types of experiences include some of the factors that contributed to the negative perceptions expressed by tamariki whaikaha who were also interviewed for this study. Only one person reported that they valued their greater independence and freedom, and only two others noted that they were able to engage in activities they enjoyed. Three out of four tamariki whaikaha interviewed expressed anger about their living situation, and for one, feelings of inferiority. Case managers who participated in the study also reported that tamariki whaikaha often did not receive any explanation as to why they were being placed in OOHC. This led to a lack of understanding or acceptance of their situation, as well as a sense of grief, loss, and rejection by their whānau and society. Finally, Crittenden et al. (2014) reported that whānau-carers initially experienced guilt and grief when tamariki whaikaha went into OOHC, but that these feelings subsided over time. However, whānau whose tamariki showed poorer long-term outcomes and ongoing behavioural issues continued to feel guilty and concerned about having placed tamariki in care.

# The journey out of care

This final section of the findings considers two secondary questions.

1. What supports can enable disabled tamariki and rangatahi to return home?
2. What kinds of services and supports are considered good practice for enabling disabled tamariki and rangatahi to return home after being placed in out-of-home care?

## What is reunification?

According to Baker (2007), ideas of permanence rest on the principle that children in OOHC should be returned home to whānau-carers and, where this is not possible, should be able to grow up in ‘substitute’ whānau. Such ideas are based on the premise that stability in children’s lives leads to better outcomes. As research shows, however, the path to permanency and reunification is particularly difficult for tamariki whaikaha who experience a range of inequities throughout their OOHC journeys.

## Reunification – what are the risks?

While reunification is often cited as the key goal of OOHC, there are several factors that have been identified as risking delay or preventing reunification. These can include, but are not limited to:

- Court orders
- Multiple placements
- Behavioural problems
- Neglect
- Poverty and disadvantage
- Ethnicity
- Parental rejection
- Parental mental health
- Parental abandonment
- Parental absence
- Changes in family configuration
- Substance issues (Delfabbro et al., 2015; Fernandez & Atwool, 2013; Mendes et al., 2013).

When considering these risks from a disability perspective, it is likely that delayed or prevented reunification is magnified for whānau affected by disability. For example, in Aotearoa New Zealand research shows that whānau affected by disability are likely to experience intersecting disadvantages, and many of the risks identified above, to a greater level than whānau unaffected by disability.

## What does international research say about reunification for tamariki whaikaha?

It has been well established that tamariki whaikaha in OOHC are at an increased risk of experiencing negative outcomes whilst transitioning from OOHC into reunification or alternative permanent arrangements. For example, international research over three decades shows that tamariki whaikaha with experience of OOHC are less likely to achieve reunification with their whānau-carers than non-disabled tamariki (Akin, 2011; Baker, 2006; Connell et al., 2006; Cleaver, 2000; Courtney, 1994; Courtney & Wong, 1996; MacDonald, et al., 2016; Romney et al., 2006; Rosenberg & Robinson, 2004); are more likely to reside in non-kin foster care for longer periods of time than their non-disabled peers (Cleaver, 2000; Romney et al., 2006; Rosenberg & Robinson, 2004); and for tamariki with learning (cognitive) and/or psychosocial disabilities, the chances of achieving reunification are even lower (Becker et al., 2007; Connell et al., 2006; Landsverk et al., 1996; McDonald et al., 2007; Romney et al., 2006).[38]

Research by Akin (2011) for example, showed tamariki whaikaha in OOHC experienced a decreased likelihood of reunification and guardianship by approximately one-third when compared to non-disabled tamariki in OOHC. Children with SED (Serious Emotional Disturbance, or mental health/ psychosocial disabilities) had one tenth of a chance of reunification when compared to children without SED.

> *In combination, findings that observed disabilities and mental health problems as risk factors of reunification were especially worrying. They lead to speculation about biological families struggling to meet their children's physical health and mental health needs. These findings suggest that child welfare practice must recognize disabilities and mental health problems as potential obstacles of permanency, particularly reunification and guardianship* (Akin, 2011, p. 1008).

On the other hand, when tamariki whaikaha do transition from OOHC, procedures often fall short. This is in part the result of a lack of planning, the provision of inadequate information, and a lack of consultation with the tamariki whaikaha and their whānau-carers (Mendes & Snow, 2013; Priestley et al., 2003; Rabiee et al., 2001).

> *Key staff in children's services often knew very little about the options available to young disabled people leaving care. Social workers without a background in disability issues often felt that they did not know where to go for more information, and this problem was compounded by a lack of communication or joint working between service providers* (Priestley et al., 2003, p. 881).

As summarised by Mendes et al. (2013), research shows that not only do transitioning tamariki whaikaha have additional needs relating to physical, intellectual, sensory,

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[38] Some of the literature cited here falls outside of the investigation period but has been included to highlight that it has been well and long-established that tamariki whaikaha are significantly disadvantaged in terms of access to reunification.

communication and/or psychiatric conditions, but they also experience higher rates of bullying, abuse, and exploitation; are at higher risk of mental health conditions; experience negative attitudes towards their disability/ies; and have unequal access to services and supports. As a result, the risk of re-entry into OOHC following reunification is high. According to Font et al. (2018), this may also be because caseworkers struggle to identify and address whānau-carers multiple and often complex needs.

While research on tamariki whaikaha experiences of OOHC, transition and reunification in Aotearoa New Zealand is sparse, anecdotal evidence suggests that they continue to experience inequitable outcomes in their care journeys, reflecting the international research cited above. As such, it is possible, and beneficial, to consider not only international studies on improving the outcomes of reunification for tamariki in general, but to also reflect on how reunification processes and policies can be developed from disability rights and bicultural frameworks to improve the chances of success.

## What supports can enable tamariki whaikaha and rangatahi to return home?

First and foremost, it is important to acknowledge that under Article 4.c of the UNCRPD, the New Zealand Government must "take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes" (United Nations, 2006). While there is little literature on tamariki whaikaha experiences of OOHC and reunification in Aotearoa New Zealand, Article 4 holds that existing Oranga Tamariki policies must be inclusive and accessible to all people who engage in their services. In other words, effective implementation of Article 4 means that there is little need for segregated policies regarding tamariki whaikaha reunification with families and whānau.

However, the UNCRPD and NZDS also recognise that some tamariki whaikaha who do enter OOHC as a last resort will need extra support to ensure successful reunification can happen. Drawing on the literature above, these supports have been categorised according to the three key stakeholders of the reunification process –

tamariki whaikaha, OOHC workers, and families and whānau – as well as the UNCRPD articles that obligate progressive realisation in these areas.

**Supports for tamariki whaikaha:**

As highlighted throughout the reviewed literature, a key risk factor of reunification is tamariki whaikaha not receiving appropriate diagnosis, primary health care, specialised and culturally responsive health care, and disability supports during OOHC. As such, practitioners have recommended that all tamariki whaikaha receive full, timely, funded, evidence-based health and disability assessments, as soon as they enter OOHC, to avoid delaying or preventing reunification:

> *Greater attention is needed to ensure social work practice is age-differentiated and culturally appropriate, and that children's needs related to disabilities and mental health problems are fully addressed. As children enter foster care they should be screened for immediate and urgent medical and mental health needs. Following the guidelines of the American Academy of Pediatrics (2002) "all children in foster care should receive comprehensive physical and mental health and development evaluations within one month of placement" (p. 539). In addition to comprehensive assessment, permanency will be facilitated by connecting children and families to evidence-based services that address their disabilities and mental health needs* (Akin, 2011, pp. 1009-1010).

It is also important that health and disability supports and services for tamariki whaikaha extend beyond OOHC, and into the reunification process. In their research on the experiences of tamariki whaikaha leaving OOHC and transitioning into adult life, Mendes et al. (2013) provides a series of recommendations that can also be applied to reunification including:

- *Reliable and accessible data on the number of young people with a disability in and leaving OOHC to facilitate effective leaving care planning for this group.*
- *Greater collaboration and joint planning between child protection and disability services.*
- *Specialist allied health assessments at the beginning of a young person's 'journey' through OOHC.*

- *Appropriate allied health assessments, to determine their skills, capacity and readiness for transition prior to leaving care.*
- *Ongoing monitoring and support.*
- *Accurate data on outcomes for young people with a disability leaving care to inform policy and practice development* (pp. 48-49).

As these recommendations suggest, support services for tamariki whaikaha must be provided in a timely manner, and be responsive to their individual needs. Furthermore, tamariki whaikaha should be at the centre of all decisions that affect them:

> *Disabled care leavers should be at the centre of all decisions relating to their transition to adult life to facilitate meaningful, self-determined life choices. Information about their rights, eligibility for services and post-care options must be accessible and person-centred; pathway planning should be undertaken well in advance of leaving care to facilitate self-determined choices, meaningful supports for post-care lives and clear pathways to specialist support* (Snow et al., 2016, p. 87).

**Supports and training for OOHC workers:**
Another key factor influencing reunification are the resources allocated to training and supporting OOHC workers in disability awareness, particularly while co-creating care plans and reunification processes with tamariki whaikaha and their families and whānau. For example, in their research with tamariki whaikaha (learning disabilities) MacDonald et al. (2016) provided a number of suggestions to ensure OOHC workers are sensitive towards the rights, needs, will and preferences of tamariki whaikaha and young people who are in OOHC and/or who are transitioning to adult life, reunification or alternative permanence. These included:

- *Training for child protection officers, residential workers and foster carers in recognizing and responding to intellectual disability and trauma.*
- *Recruitment and training of specialist foster carers to provide placements responsive to complex needs of young people with intellectual disability who have experienced trauma, including small caring loads; commitment to long-term engagement; and funding and resources to support placement stability.*

- *Targeted responses to young people with intellectual disability transitioning from care to adult life, including extended transition planning early, and*
- *Regular planning meetings; inclusive planning processes; and supportive communication practices; extended care orders and/or tailored transitional accommodation and support; and extended post-care support (holistic, flexible and responsive to crisis), including support to manage and/or build significant relationships, address gaps in personal skills and resources and access and sustain valued adult roles (p. 65).*

Other organisations and practitioners have also long supported the call to ensure care workers have adequate knowledge of disability and disability rights (see for example: *Child Welfare League of America, 1988;* Meyers et al., 1999; Rosenberg & Robinson, 2004; *Landsverk, Burns, Stambaugh, & Reutz, 2006, 2009*; and Akin, 2011).

From a disability rights perspective, the training of OOHC workers in disability awareness and rights is reiterated throughout the UNCRPD. Under Article 4.i of the UNCRPD, the New Zealand Government is obligated to *“promote the training of professionals and staff working with persons with disabilities in the rights recognized in the present Convention so as to better provide the assistance and services guaranteed by those rights”* (United Nations, 2006).

**Supports for families and whānau-carers (during OOHC and reunification):**
Finally, much of the cited literature speaks to the lack of support, knowledge, respite, and resources families and whānau receive when caring for tamariki whaikaha, which can lead to neglect and abuse resulting in OOHC. Under the UNCRPD, this indicates a failure to uphold Article 23.4, which states that *“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.”*. Additionally, the poor outcomes experienced by tamariki whaikaha do not reflect the aspirations of Outcome 7 (Choice and Control) of the NZDS:

> *When we are young, our families, whānau and carers will be supported to help us grow up. Our views as children and those of our families, whānau and carers will be considered when choices are made about what supports and services we receive and what things work best for us. There will also be respect for the*

> *evolving capacities of disabled children, and ensuring their input into decisions that affect them* (Office for Disability Issues, 2016, p. 36).

As was highlighted in the Desperate Measures report (VEOHRC, 2012), family, whānau-carer, and disability supports must be in place for reunification processes to be meaningful and sustainable:

> *Some families reported intense pressure to take their child home at the point of, and soon after, relinquishment. They did not see this as a genuine attempt at reunification; instead they saw it as a government department trying to avoid its responsibilities when it was unable to find a placement and, in particular, trying to avoid another child ending up in respite full time. [...] For those who were able to build a relationship of trust with the department, reunification was possible when an effort was made to engage with the family and the practical supports were provided to ensure the child's return home was viable: "The first two weeks sets the groundwork towards reunification… we know this from the work with child protection, but it is equally applicable to relinquishment. It is crucial to maintain and build relationships, keeping the family connected and start to build solutions [sic], so that rather than parents feeling they are on their own, parents feel able to take their child home with the support needed for it to work* (p. 47).

A rights-based approach holds that supports must be provided to families and whānau to ensure that the rights of the tamaiti whaikaha can be met within the family and whānau environment. Support must be provided early, be intensive, and designed to build capacity within whānau-carers:

> *Early intervention and intensive outreach support to families experiencing complex disadvantage to build parenting capacity and address presenting needs (e.g., intellectual disability [parent and/or child]; mental illness; intergenerational abuse, neglect and child protection involvement; domestic violence; drug and alcohol abuse; homelessness; and unemployment)* (MacDonald et al., 2016, p. 64).

Finally, whānau-carer supports must be culturally responsive, as highlighted recently in the Wai 2575 report:

> *The stress that was experienced by Whānau Hauā and whānau around inadequate or inaccessible funding was a strong indicator that while the Crown has delineated lines of disability funding, for all whānau that participated in these interviews it was simply not enough to provide for appropriate care. The reality of already being on the poverty line that is disproportionally experienced by Māori throughout New Zealand has a significant compounding effect when Māori are also living with disabilities* (Kaiwai & Allport, 2019, p. 3).

## What kinds of services and supports are considered good practice for enabling tamariki whaikaha to return home after being placed in OOHC?

With regards to good practice services or supports for tamariki whaikaha to return home after OOHC, there were few concrete examples or models. Instead, the literature widely acknowledges that more research is needed to evaluate the effectiveness of services and supports through a disability rights lens before it can be considered ‘good practice’. However, one model that is being explored in Victoria Australia is the Shared Care model. The shared care model is dependent on relationships, timeframes, and staff awareness of trauma:

> *Shared care through Family Options was identified as positive and planned means to assist reunification. However, relationships in these arrangements need to be handled sensitively and parents given time to recover from the trauma of relinquishment. Departmental representatives and Family Options service providers we interviewed were highly attuned to these sensitivities* (VEOHRC, 2012, p. 47).

Other practical suggestions that are being explored in Australia include a holistic support framework for tamariki whaikaha (with learning disabilities) who are transitioning from OOHC into adult life, including:

- *Therapeutic support responsive to the needs of intellectual disability.*
- *Learning support to build personal skills and knowledge for meaningful participation in adult life roles, relationships, and achievement of personal goals.*

- *Relationship support to build and sustain supportive relationships with family, caregivers and community members for long-term connection and belonging; and to manage and/or end difficult or abusive relationships.*
- *Inclusion support to participate in community life, including access to opportunities (e.g., participation in meaningful roles and decision making) and resources (e.g., material, services, and relationships)* (MacDonald et al., 2016, pp. 65-66).

A further study on care leavers with learning disabilities in Australia and Northern Ireland also recommended establishing a clear definition of disability within care policies*:*

> *As a starting point, a clear definition of disability in policy and practice guidance would improve identification of this group of care leavers and service planning to meet their needs. The UNCRPD provides the basis for a shared understanding of disability, with an inclusive definition that acknowledges bodily impairment and disabling barriers in society. Aligned with the need for a clear definition of disability, eligibility criteria for access to aftercare services and adult disability or mental health services should be transparent and address barriers in access to services for those with borderline or moderate levels of disability, for whom social workers have ongoing concerns about vulnerability in emerging adulthood.* (Snow et al., 2016, pp. 86-87).

# Discussion

This literature review has explored the care experiences of tamariki whaikaha and their whānau-carers through an integrated review of national and international literature. The brief was intended to provide evidence relating to three foundational issues that are central to, and impact on, OOHC for tamariki whaikaha and their whānau carers:

- Models and systems: What identified good practice models and systems are there for disabled tamariki and rangatahi in out-of-home care, and importantly [for] their whānau?
- Service and supports: What kinds of services and supports are considered good practice for disabled tamariki and rangatahi in out-of-home care?
- Participation and voice: What enables and empowers disabled tamariki and rangatahi to fully participate and have a voice in decisions about their care?

In the following discussion, the research findings related to the six secondary questions are drawn on to respond to these foundational issues, with the intention of offering meaningful direction for policy and practice in this area.

## Models and systems

One of the primary motivations for this literature review was to collect and analyse existing grey and academic literature pertaining to good practice models and systems regarding OOHC that could be applied to tamariki whaikaha and their whānau-carers. However, while the reviewed literature generously articulated the risks, challenges, and barriers experienced by tamariki whaikaha and their whānau-carers, it has not been so generous in suggesting good practice models and systems that might be replicated or integrated into the Aotearoa New Zealand care system.

This is an appropriate finding, as it reflects the kaupapa of the task at hand. As Atwool (2021) concludes, Aotearoa New Zealand has a tendency to import ‘evidence-based’ models from abroad. However, international evidence-based models are often not appropriate for Aotearoa New Zealand’s unique, bicultural context.

Even so, as presented in the discussions above, the reviewed literature has revealed ways in which better supports can be provided to whānau-carers of tamariki whaikaha to prevent relinquishment. In cases where OOHC is implemented as a **last resort option**, the review has indicated that wrap-around supports and services for the tamaiti and their whānau-carers are imperative throughout their care journey including during reunification efforts, and/or to support alternative permanent placements.

As such, we find it fitting to return to the models that have underpinned this review, and which can provide a platform from which good practice Aotearoa New Zealand-specific models of care might be developed in the future.

## Te Ao Māori models, and toward a bicultural approach

This literature review was developed using Te Tiriti o Waitangi as a guiding framework, and drew more specifically on the Tauira Model, Kaitiakitanga and Manākitanga Models, the Oranga Tamariki Framework for Improving Outcomes for Tamariki Māori, their Whānau, Hapū and Iwi, Maori Centred Practice, Whāia Te Ao Marama – the Maori Disability Action Plan, and Whānau Haua Models.

From the evidence generated through this mahi, the importance and relevance of these approaches is clear when seeking to be responsive to tāngata whaikaha and tamariki whaikaha. Te Tiriti o Waitangi obliges the State to work in partnership with tāngata whenua. In the case of Oranga Tamariki, the imperative for swift movement to bicultural systems, policies, and practices has been recently and firmly established (Oranga Tamariki, 2020).

Biculturalism in Aotearoa is constructed upon the formal relationship between Māori and Pākehā in Te Tiriti o Waitangi – The Treaty of Waitangi. Te Tiriti is the 'covenant which commits us to a bicultural Māori-Pākehā society' (Department of Social Welfare,1985, p. 8). The New Zealand government began to invest in biculturalism in the late 20th century when Eurocentrism or mono-culturalism was questioned in government policy and systems that were widely acknowledged as biased towards Pākehā. O'Reilly and Wood (1991) described biculturalism in Aotearoa as *the co-existence of two distinct cultures reflected in society's customs, laws, practices and institutional arrangements, with both cultures sharing control over resources and decision making*. And with reference to the importance of moving toward a bicultural society, Mataira (1995) predicted, *collective knowledge perceived evenly in a society will contribute to the betterment of all* (1995, p. 10).

In the 21st century, achieving an authentically bicultural society and system(s) continues to challenge many organisations and individuals. Transforming biculturalism theory into bicultural practice is, as Crawford (2016) highlighted, about understanding and honouring relationships, focusing on the implicit rather than the explicit, and accepting a need for open and consistent reflection.

Working in a bicultural manner incorporates Māori language, tikanga and cultural knowledge in governments and institutions. It is also centred on a commitment to social justice for Māori and understanding of the significance of mana whenua in all negotiations and public actions. The key value-based connectors that underpin all Māori models are whanaungatanga (connections, relationships); pono (beliefs); aroha (love and caring); whenua and the taiao (land and environment); whānau (family); hapū and iwi, (whakapapa); and tino rangatiratanga (autonomy to make your own decisions). Hollis-English (2015) stated that the personal awareness of the above concepts assists social workers better implement these values within their practice.[39]

The cycle of inquiry into what is best practice for Māori and how to transform Te Ao Māori philosophies, values and models into practice appears to be less challenging for those delivering care than it is for those responsible for those managing large systems of care. Prior to the latest Oranga Tamariki framework for *Improving outcomes for tamariki Māori, their whānau, hapā and iwi*,[40] there have been other Te

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[39] Te Ao Māori values principles, such as integrity, respect, honesty, consistency, commitment are transformed into action by Māori social workers within their professional practice (Tate & Paparoa, 1986; Tate, 2010). Tate and Paparoa (1986) reiterated that values originating from Te Ao Māori flow seamlessly from workers' personal to their professional lives. Māori social workers have frequently described they implement these values through tikanga (customary) processes such as karakia (blessings), kaitahi (having a shared meals together), whānau hui (gathering of whānau), attending meetings at the Marae and utilisation of whakapapa connections to gain and sustain rapport with the individuals and whānau with whom they work. However, this connection from theory to practice is not innate or 'natural' to all and requires support from education providers, organisations/services, and professional peers in order that people are able to learn, understand, and apply (Tate, 2010).

[40] Refer to: www.orangatamariki.govt.nz/about-us/how-we-work/outcomes-framework/

Ao Māori frameworks and approaches recommended to Oranga Tamariki as a way of evolving their practice and enhancing improved outcomes for all whānau. For example, the Māori Advisory Unit Report in 1985 investigated the capacity of the Department of Social Welfare to meet the needs of Māori through their service provision and called for Māori for equity in management, and service delivery that is not racist and oppressive. In 1988 the Puao Te Ata Tū (Day Break) report undertaken by the Ministerial Advisory Committee explored the Department of Social Welfare from a Māori perspective, resulting in 13 recommendations to the Department of Social Welfare and other institutions to progress bicultural knowledge and practice. Furthermore, the 1988 Royal Commission on Social Policy report – Ngā Kohinga Mai No Ngā Pūtea i Whakairia ki Ngā Tahuhu o Ngā Whare Tūpuna – stressed that issues affecting Māori need to be viewed in context beyond the individual and whānau to be inclusive of hapū and iwi.

In the current context, Matthew Tukaki, Chair of the Ministerial Advisory Board, Oranga Tamariki recently asserted *a need for Oranga Tamariki to not just develop strategies that enable and empower tamariki, whānau, and communities but to operationalise those strategies into action on the ground.*[41]

When applying a Te Ao Māori lens to the research findings presented here, the relevance and utility of the models and frameworks referred to in the introduction to this section become clear. At its heart, the *Tauira Model* encompasses the tuakana-teina relationship whereby carers and those cared for learn from each other. In the context of OOHC research, whānau-carers, and tamariki whaikaha call for formal services such as Oranga Tamariki to listen, and to learn from them as the experts on their own lives. Relatedly, *Kaitiakitanga* and *Manākitanga* Models are instructive as they give primacy to safe and respectful relationships that enhance mana. Again, strong themes emerged from the research that demonstrated the need for tamariki whaikaha and their whānau-carers to be valued and their physical and emotional wellbeing to be nurtured as a way of preventing OOHC. These ways have been overtly recognised and developed into a mandated outcomes framework for tamariki Māori,

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[41] *Kahu Aroha – Hipokingnia ki te katoa – Embrace with the cloak of love, embrace all within it. The initial report of the Oranga Tamariki Ministerial Advisory Board*, Wellington. July, 2021, p. 6.

as reported in the recent Section 7AA report (Oranga Tamariki, 2020). In this framework, Mana Tamaiti (ensuring participation in decision making), Manaakitanga (preventing entry into care or custody), Whakamana Tangata placing with whānau, hapū and iwi; Manawhenua-Kaitiakitanga (supporting identity and belonging), Mana Motuhake-Rangatiratanga (leaving custody or care), are the central pou. Section 7AA provides both the tangible principles and specific ways of working that uphold the needs of tamariki whaikaha Māori. Based on findings from the literature, it is also responsive to the needs of tamariki whaikaha more broadly, as it seeks to establish a biculturally responsive approach.

The related *Māori-centred Models* within social work practice emphasise several core components, including the need to reaffirm and support whānau self-determination. This speaks to the recurring theme of lack of voice, choice, and control, where whānau-carers feel as though they are forced into extreme measures regarding the care of their tamariki whaikaha, due to lack of services and supports, and tamariki whaikaha not being active agents in those decisions. The vision of *Whāia Te Ao Marama* symbolised by a torino (double spiral) emphasises the need for tāngata whaikaha to be able move fluidly between Te Ao Māori and Te Ao Hurihuri, at their own choosing and with their mana intact. Tāngata whaikaha with complex disability are included in this vision, which in the context of OOHC requires a commitment to bicultural systems, policies, and practice. Finally, the Whānau Hauā model reiterates the need for a collective, whānau-based approach to meeting the needs of tamariki whaikaha with complex disability. In the case of tāngata whaikaha in particular, there must be overt recognition of their cultural identity as their primary identity.

These and other **existing or future** Te Ao Māori models offer a strong foundation for future policy and practice designed to meet the needs of tāngata whaikaha. Given their synergies with the findings of the literature review, **they also have the potential to meet the needs of all tamariki whaikaha**, regardless of their cultural heritage or identity, thus creating the pathway to bicultural responses to their care and protection needs.

## Implementation of the Social and Human Rights Models of Disability

Question 8 of this literature review asked *[h]ow can a social model of disability be applied in a care and protection system?*

Both the NZDS and the UNCRPD are guiding documents founded on the social model of disability, each recognising that people with impairments are disabled by socially constructed barriers – that is, ableist attitudes, systems, structures, and environments. It is the responsibility of society to remove those disabling barriers in order to achieve equality and equity for all people, including the disability community (Oliver, 2013; Shakespeare, 2017).

In the case of tamariki whaikaha, the social model is an effective tool for identifying the barriers experienced throughout all aspects of their lives, including during OOHC. However, while the social model is a useful descriptive and investigative device that can be used to determine socially constructed barriers and identify where policy reform is needed (Lawson & Beckett, 2021), the solution to these barriers is more likely to be achieved through the application of a bicultural, human rights framework.

A human rights framework of disability, also known as the 'rights model of disability' is a prescriptive model of disability policy:

> *Accordingly, the focus of the human rights model is not the concept of disability. Rather it provides guidance (and requirements) on policy responses to disability. Consequently, it can be viewed not as a model of disability but as a model of disability policy* (Lawson & Beckett, 2021, p. 364).

The rights-based model holds that equality for tamariki whaikaha is a human right. The model is based on empowerment, referring to the participation of tamariki whaikaha as active stakeholders, together with the accountability of people in positions of power, such as Oranga Tamariki and the New Zealand Government (Miller & Ziegler, 2006).

As such, the question should be extended beyond *[h]ow can a social model of disability be applied in a care and protection system* to include, *how can the social model of disability be integrated into care and protection systems, while upholding International Human Rights Laws obligations through the implementation of a rights and Bicultural framework*? **It is possible to realise the rights, needs, will and preferences of tamariki whaikaha in OOHC in Aotearoa New Zealand using the social model as**

**the foundation, the rights model as the justification, and a bicultural framework as an all-encompassing expression of Te Tiriti o Waitangi.**

This literature review has identified and explained key Te Tiriti o Waitangi and human rights principles that Aotearoa New Zealand has an obligation to uphold for our tamariki, including tamariki whaikaha. These principles are reiterated in the New Zealand Disability Strategy, and underpin emerging system(s) and policy initiatives such as Enabling Good Lives and Mana Whaikaha, which outline aspirations and outcomes for all disabled people that uphold their human rights. Understanding of, and commitment to, these fundamental documents should be accepted as the first, critical and foundational step toward operationalising a way of working with tamariki whaikaha with complex disabilities and their whānau-carers.

The second critical step is listening to the experiences and wisdom of tamariki whaikaha and their whānau-carers, who hold many of the solutions to the challenges associated with preventing OOHC, ensuring that it only occurs as a last resort, and that OOHC always includes a plan for whanāu reunification.

The third is to value and implement Aotearoa New Zealand and international research that has consistently identified key issues and associated responses that can guide practice to be responsive to the needs of tamariki whaikaha and their whānau-carers. All issues identified in the reviewed literature are aligned with a social model approach to the identification of barriers. Taking a human rights-based lens to these barriers, grounded in the UNCRPD, provides a way to respond to the breaches of human rights experienced by tamariki whaikaha and their whānau-carers. All this action can occur against the overarching backdrop of Te Ao Māori models, both universal and disability focused, which share similar values, and seek to achieve similar outcomes.

## Services and supports

Perhaps the most common and most anticipated theme found in the reviewed literature concerned the services and supports available to tamariki whaikaha and whānau-carers while navigating care systems. More specifically, the literature detailed the negative consequences caused by the *lack* of supports and services experienced by this population. In response to the secondary questions, supports and services were considered across the three major stages of the care journey: pathways into care, OOHC, and reunification.

Findings revealed that at all stages of the care journey, the absence of accessible, adequate, and affordable supports and services were the most significant barrier to tamariki whaikaha and whānau-carer wellbeing. The findings provide strong evidence that services and supports must be oriented and committed to enhancing the wellbeing of tamariki whaikaha and their whānau-carers and give primacy to whānau. This literature review has highlighted that OOHC is not a preferred option for either party, and Article 23 of the UNCRPD should be used to guide all and any situation where OOHC is being posed as a support option of last resort. Article 23(3) provides a very clear instruction that tamariki whaikaha have equal rights with respect to family life, stating that […] *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.***[42] (United Nations, 2006).

## Pathways into care

When considering the reasons why tamariki whaikaha might go into care, the lack of health and disability support services provided to both the individual and their whānau was cited as the main reason for relinquishment. This reflects wider research that shows disabled people in general lack the supports and services needed to lead full, meaningful, and dignified lives,[43] as articulated under the UNCRPD. It is therefore unsurprising that whānau caring for tamariki whaikaha, particularly those experiencing intersectionality and compounding risk factors, feel that relinquishment – seeking OOHC – is their only option. More specifically, reviewed literature indicated that a lack of financial support, whānau-carer psychological distress, concerns for sibling safety,

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[42] Emphasis added.

[43] For example, see Disabled Persons Organisation (DPO) Coalition monitoring reports: www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/nzs-monitoring-framework/monitoring-reports-and-responses/reports-from-convention-coalition/

and the absence of regular periods of respite were major contributing factors in relinquishment decisions, and thus OOHC.

With this in mind, when answering Question One, the reviewed literature required reflection on the lack of services and supports that are available so that whānau-carers can continue to care for tamariki whaikaha and rangatahi at home. However, by identifying the contributing risk factors, it is possible to start to piece together areas for improvement, such as increased financial support for whānau caring for tamariki whaikaha at home, systems for identifying whānau who are at risk of breaking point, psychosocial support for primary caregivers, safety supports for all whānau members, and consistent respite that is both easily accessed and affordable.

## Out-of-home care

When whānau-carers reach breaking point in terms of their caring roles, OOHC appears to be the predominant option for tamariki whaikaha. Since the repeal of sections 141 and 142 of Oranga Tamariki Act 1989 in 2019, tamariki whaikaha enter into the care of Oranga Tamariki through the same pathways as other tamariki. While there is a mention of specialised support for tamariki whaikaha (Oranga Tamariki, 2020), options for OOHC for tamariki whaikaha are currently unclear.

International research shows that kinship care is one of the most stable OOHC options, and can create positive outcomes (Helton, 2011). However, tamariki whaikaha are less likely to be placed with extended family (Helton, 2011). While there is no research on the prevalence of kinship care for tamariki whaikaha or tāngata whaikaha in Aotearoa New Zealand, it is important that there is equal commitment to these ‘remaining’ with whānau.

Regardless of their placement, the importance of wraparound support has been recognised in the literature. That is, individualised support offered by a multidisciplinary team (Buchanan et al., 2019; Whiting, 2013). Through the flexibility and collaboration of multiple skills within a team, wraparound supports can cater for the needs of tamariki whaikaha. This model of practice resonates with the EGL principles that underpin disability support services in some parts of Aotearoa New Zealand (Enabling Good Lives, n.d.). It also appears to be the intent of the Wraparound

Intensive Individualised Support for Children, Young People and their Families/ Whānau Service. This initiative represents a collaboration between the Ministry of Health and Oranga Tamariki, however at the time of writing, no detailed information about or evaluation of the service was able to be sourced.[44]

To ensure efficient coordination between team members, Crettenden et al. (2014) highlight the importance of communication and information sharing. It was also emphasised that without clear explanation of the purpose of OOHC, tamariki whaikaha felt rejected from their whānau. Clear communication and information sharing is important for smooth service provision as well as in fostering positive relationships between tamariki whaikaha and whānau-carers (Crettenden et al., 2014).

## Reunification

The third stage of the care journey was investigated under Questions Six and Seven: what supports can enable tamariki whaikaha and rangatahi to return home, and what kinds of services and supports are considered good practice for enabling tamariki whaikaha and rangatahi to return home after being placed in out-of-home care?

Much like the other two stages of care, the reviewed literature demonstrated a concerning lack of supports and services provided to both tamariki whaikaha and their whānau-carers during care planning, and reunification procedures. It was noted that globally, a lack of disability supports and services meant that tamariki whaikaha were much less likely to achieve reunification, particularly those with complex learning (intellectual) and psychosocial disabilities. For those who were reunited with whānau, or placed in an alternative permanent arrangement, the processes took much longer than it did for other non-disabled children in care settings. Further to this, care workers often failed to provide accessible planning and reunification information in a timely manner. As a result, re-entry into care following reunification was disproportionately high for tamariki whaikaha.

Again, by looking at the barriers, it is possible to establish which supports and services have the potential to positively contribute to enabling tamariki whaikaha and rangatahi

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[44] The service specifications for this initiative can be found at: Shared-Care-Service-Specification-from-1-July-2021.pdf (orangatamariki.govt.nz)

to return home following OOHC. These include early health and disability supports for tamariki whaikaha in OOHC (in preparation for reunification); supports for OOHC workers as rights duty bearers to fulfil their obligations under the UNCRPD; and the implementation of supports and services for whānau-carers as they prepare to reunite with their tamaiti whaikaha (such as financial, psychosocial, safety, and respite supports and services).

## Participation and voice

As already established, the importance of voice and participation of tamariki whaikaha is embedded within two United Nations Conventions[45], which have been signed and ratified by the New Zealand Government (Conder et al., 2016). Under these Conventions, tamariki and rangatahi with complex disabilities have the right to express views on matters that impact them, and for those views to be given due weight (United Nations, 1990; 2006).

Decisions regarding placement in OOHC, however, are often made in a way that fails to uphold their rights. For example, a key factor leading to OOHC includes whānau-carers reaching ‘breaking point’, predominantly due to a lack of services and support. As out-of-home placement should only be a last resort response, consideration of the right of tamariki whaikaha to be heard is likely to be cursory at best, and non-existent at worst. While OOHC may be adequate for meeting their basic needs, it will almost certainly not be responsive to their will and preference (Watson, 2016) as required by Article 12 of the UNCRPD and UNCRC. Fundamentally this is because in most cases OOHC for this particular group of tamariki whaikaha is the only choice available when crisis-point is reached. Furthermore, OOHC settings are extremely limited, with group living in staffed residential services often being the only placement option.

Regardless of the extent to which tamariki whaikaha can express their will and preference regarding their care, their participation in the decision-making processes remains crucial and therefore must be supported (Conder et al., 2016). As highlighted, research grounded in the voices of tamariki whaikaha asserts that when their voices

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[45] United Nations Convention on the Rights of Child, 1989, Articles 12, 13, and 23; United Nations Convention on the Rights of Persons with Disabilities, 2006 Articles 7, 12 and 23.

are reflected in decisions made about them, it creates confidence and a sense of responsibility that can be carried through to adulthood (Oranga Tamariki Voices of Children and Young People Team, 2021). While this particular finding is derived from a survey involving the wider tamariki population it applies equally to tamariki whaikaha.

As also noted earlier, commitment to supported decision-making (SDM) has already been asserted through policy. The 2016-2026 New Zealand Disability Strategy (NZDS) and Disability Action Plan 2019-2023 (NZDAP) support the voice and participation of tamariki whaikaha by aiming to implement SDM practices, especially within the Ministry of Social Development (Office for Disability Issues, 2019). Historically, when an individual was considered incapable of making their own decisions, their best interests were considered by those making decisions for them. However, SDM requires that a person’s will and preference be the centre of the decisions about their life, rather than their best interest alone (Flynn & Arstein-Kerslake, 2014).

Research highlights that while tamariki whaikaha have a voice, they often lack people around them who are willing to listen to them. Without the acknowledgement of voice, participation cannot be realised (Kelly et al., 2016; Oranga Tamariki Voices of Children and Young People Team, 2020; 2021). Across a range of research, tamariki whaikaha have consistently highlighted four factors that enable them to have a voice and participate in matters that influence their lives.

First, they identified trusting relationships as being important. When they feel respected and heard, it enables their voice to come through. They have also shared that body language, eye contact and undivided attention are crucial factors of a good listener (Oranga Tamariki Voices of Children and Young People Team, 2020). Second, limits are often imposed on how much say tamariki whaikaha have in their lives. It is important for them to have support to understand information so that they know the scope of their voice. Third, their voice needs to be taken seriously. Tamariki whaikaha felt that they are often not given choices, and even when they are, their choices are not respected (Conder et al., 2016; Kelly et al., 2016; Oranga Tamariki Voices of Children and Young People Team, 2020). Fourth, it is important to recognise the diverse communication styles and strategies of tamariki whaikaha, and that behaviour is a means of communication which must be listened to (Oranga Tamariki Voices of Children and Young People Team, 2020).

Tamariki whaikaha have also illustrated the importance of maintaining connections with their whānau-carers. Many tamariki whaikaha experience changes throughout their OOHC journey, and their whānau-carers are often the most consistent presence in their lives (Mirfin-Veitch & Conder, 2015). Thus, maintaining and enhancing relationships with whānau can create more positive outcomes and this draws attention to the possibility that if early intervention had occurred, the need for OOHC would greatly be reduced (Mirfin-Veitch & Conder, 2015).

In summary, the key components to enabling and empowering the voice and participation of tamariki whaikaha include consistent trusting relationships, clear information sharing, and supported decision making. Recognising that there will undoubtedly be conflict between the preferences of tamariki whaikaha and their whānau- or formal carers in some cases, the UNCRPD, UNCRC and NZDAP clearly hold that implementing an SDM approach serves to empower and uphold the voice and participation of all disabled people, including tamariki whaikaha.

# Conclusion

A practical expression of this literature review's findings can be found in the foreword of *Improving outcomes for tamariki Māori, their whānau, hapū and iwi – Te whanake i ngā hua mō ngā tamariki Māori, ō rātau whānau, hapū, iwi anō hoki – Section 7AA Report* (Oranga Tamariki, 2020). In her foreword, then Minister for Children, the Honourable Tracey Martin, reflected on why the place of whānau, hapū and iwi, and Māori providers must be recognised saying:

> *Why is quite simple. If we are truly to have a child-centred system then we have to do everything to keep children with their families, because that is what children want. If we are to safely keep children at home then their families need help and they need it earlier. And families are far more likely to accept help, or even to reach out for it – which has to be our aim – if they trust the face at the door* (p. 4).

This statement sums up the implicit and explicit findings and themes of the research and other documents reviewed for the purposes of this mahi. It can also be read as a real-world description of the framework that has been proposed here: a bicultural, human-rights-based approach to tamariki whaikaha who are at risk of, or who enter OOHC as a last resort option.

The reviewed literature has identified key issues and potential responses across all facets of the OOHC journey. It has also outlined a framework that should be used to guide all policy and practice related to OOHC for tamariki whaikaha with complex disabilities to ensure it is responsive to Aotearoa New Zealand's unique cultural context. The framework combines Te Ao Māori models, and both the social and human rights-based models of disability. If applied, it could provide the impetus required to embed fundamental treaty and convention principles, and to develop responsive and enduring models of good practice for meeting the care and protection needs of tamariki whaikaha with complex disability. This includes future research on the specific experiences of tamariki whaikaha and their whānau-carers within the care system, as well as co-designed policies and practices that address the rights, needs, will, and preferences of tamariki whaikaha and whānau who are navigating the current care system.

By embedding a bicultural, rights-based framework into all policies and practice, Aotearoa New Zealand can set its own high bar for international best practice. **Fundamental to any revised policy and practice framework must be a commitment to OOHC being an absolute last resort measure for tamariki whaikaha with complex disability. Furthermore, if OOHC is required it should be both short-term and delivered in a setting and in a manner that is as 'whānau-like' as possible.** These rights are contained within the United Nations Convention on the Rights of Children and the United Nations Convention on the Rights of Persons with Disabilities, and we have an obligation to uphold them.

The approach is also directly compatible with the current Oranga Tamariki purpose *to ensure that all tamariki are in loving whānau and communities where oranga tamariki can be realised*.[46] The associated outcomes framework asserts commitments to achieving the following goals for all tamariki, with particular emphasis on tamariki Māori:

- Tamariki Māori are thriving under the protection of whānau, hapū and iwi;
- Children and young peoples' wellbeing needs are understood and met;
- Children and young people are safe and flourishing in their homes;
- Children and young people do not need to be in care or custody;
- Children and young people in care or custody are safe, recovering, flourishing;
- Children and young who have offended do not reoffend;
- Young people leaving care or youth justice get a good start to their adult lives.

The aspirations and desired practice expressed in the framework with regard to the critical areas of early support, intensive response, care, youth justice and transition mirror the findings presented in this literature review. **Implementing this universal Oranga Tamariki framework alongside the bicultural (disability) rights-based framework articulated in this literature review has the potential to more effectively meet the needs of tamariki whaikaha, and will ensure that no tamaiti whaikaha is left behind.**

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[46] www.orangatamariki.govt.nz/assets/Uploads/About-us/How-we-work/Outcomes-Framework/Outcomes-Framework.pdf

With this in mind, it is appropriate to return to the whakataukī that opened this literature review.

**Ko te ahurei o te tamaiti arahia o tātou mahi**

**Let the uniqueness of the child guide our work**

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