

Prevention of Harm and the Cultivation of Wellbeing:

Tamariki, Rakatahi, and Mātua Whaikaha

Integrative Literature Review



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

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

Author

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

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Kōrero Whakamārama

Kāi Tahu dialect has been used when writing in te reo Māori. This means that the ng is replaced with a k (for example, whakarongo is changed to whakaroko). We have underlined the k whenever this convention has been applied.

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Kā Whakamārama/Glossary

Ableism: Is a socially constructed belief system that values certain bodies and minds based on what is considered normal, productive, and desirable. Groups that fit within these ideals have societal privilege over those who may not fit within society's construction of normal.

Child abuse: The harming (whether physically, emotionally, or sexually), ill-treatment, abuse, neglect, or deprivation of any child or young person (Oranga Tamariki Act, 1989).

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, 2024).

Disability: This review utilises the definition of disability set out in the UNCRPD, which includes "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" (United Nations, 2006, Art. 1).

Harm: Events or circumstances that decrease the wellbeing of a child, such as physical abuse, sexual abuse, emotional abuse, neglect, serious differences, harmful behaviours, cumulative harm, family violence, or an inability or unwillingness to care (Oranga Tamariki, 2019).

In care: Defined as being subject to a custodial order or legal agreement under the Oranga Tamariki Act in the care or custody of the Chief Executive of Oranga Tamariki (Oranga Tamariki, 2023).

Intersectionality: A framework used to highlight the interaction of multiple identities within an individual and how this can compound the effects of marginalisation (Carastathis, 2016).

Learning disability: An alternative to the term intellectual disability. It is the term preferred by self-advocates within the learning disability community in Aotearoa.

Oranga Tamariki: Ministry for Children, a government organisation that works to support “any child in New Zealand whose wellbeing is at significant risk of harm now, or in the future” (Oranga Tamariki, n.d.).

Out of Home Care (OOHC): A living arrangement in which a child is removed from the custody of their immediate family members or legal guardians. There are multiple options for OOHC placements, such as residential care, adoption/guardianship, foster care, and relative/kinship care (Cheng, 2023).

Prevention: For Oranga Tamariki, prevention is for those at risk of harm, preventing the need for statutory care, protection, or youth justice response. For tamariki and rakatahi in care or regularly coming to the attention of Oranga Tamariki, prevention is avoiding future harm through therapeutic or restorative responses (Oranga Tamariki, 2021).

Reasonable accommodation: Refers to “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms” (United Nations, 2006, Art. 2).

Wellbeing: Wellbeing includes meeting your everyday living needs and achieving your long-term developmental potential. Wellbeing is not only an absence of harm but also the presence of a positive mental, social, and physical state (Smith et al., 2021).

Kā whakamārama – Te Reo Māori¹

Aotearoa: Aotearoa New Zealand.

Hauora: Māori philosophy of wellbeing and health.

Kaimahi hauora: Health worker.

Kaitiakitanga (kaitiakitanga): Guardianship, stewardship.

Mana: Enduring, indestructible power of the atua (ancestor with continuing influence) which is inherited at birth.

Manākitanga (manākitanga): Hospitality, kindness.

Mātua whaikaha: Disabled parents.

Rakatahi (rangatahi): Young person.

Rakatahi whaikaha (rangatahi): Disabled youth.

Tino rākatahi (tino rangatiratanga): Self-determination, sovereignty, independence, and autonomy. The term is rooted in a Māori worldview, and there is no one English term that fully encapsulates its meaning. Tino rākatahi speaks to Māori control over Māori lives (Te One & Clifford, 2021).

Tamaiti: Child (singular).

Tamariki whaikaha: Disabled children.

Takata whaikaha (tangata whaikaha): Disabled person.

Tākata whaikaha (tāngata whaikaha): Disabled people.

Tauira: Student.

Tauira whaikaha: Disabled student.

Te Tiriti o Waitangi: The Treaty of Waitangi - New Zealand's founding document.

Whānau: Immediate and/or wider extended family (Walker, 2011).

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

Kupu Rāpoto/Acronyms

ASD: Autism Spectrum Disorder.

DBI: Donald Beasley Institute

FQOL: Family Quality of Life Approach

NZDS: The New Zealand Disability Strategy 2016 - 2026

OT: Oranga Tamariki

OTSI: Oranga Tamariki Strategic Intentions 2021 - 2025

PBLS: Positive Behaviour for Learning School-wide

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

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

YAL: Young Adult List

1 – Ka Kupu Whakataki/Introduction

Oranga Tamariki is undergoing significant transformation, including how disability services are conceptualised and delivered by the Ministry and in partnership with tamariki, rakatahi and mātua whaikaha, and their whānau.² An important component of this transformation is developing and implementing prevention policy and strategies. While there is some uncertainty around what ‘prevention’ is, efforts are underway to better understand the roles and responsibilities of prevention delivery. The prevention of harm to children raises important questions for Oranga Tamariki, including when and how Ministry involvement should occur; what the necessary linkages are to wider government services and supports; and what the critical components of effective and appropriate preventive services and supports are for children and their families/whānau.

In October 2023, Oranga Tamariki commissioned the Donald Beasley Institute (DBI) to undertake an investigation into prevention in relation to disabled tamariki, rakatahi and mātua whaikaha, and their whānau. The purpose of this review is to consider prevention and wellbeing literature within a Te Tiriti o Waitangi and disability rights-based framework, and to better understand effective design, development, and implementation of prevention strategies and initiatives for tamariki, rakatahi and mātua whaikaha, and their whānau, who are at risk of engagement with care and justice settings.

² Disabled children, young people and parents, and their family.

2 – Ka Pātai Rakahau/Research Questions

As outlined in the project brief, this integrative review is specifically oriented towards academic and other relevant literature focused on:

- primary level prevention
- holistic wellbeing
- barriers to prevention services
- intersectionality
- the prevention of tamariki and rakatahi whaikaha coming into care
- the prevention of the tamariki of mātua whaikaha coming into care
- the prevention of tamariki and rakatahi whaikaha coming into the youth justice system
- prevention that supports the holistic wellbeing of tamariki, rakatahi and mātua whaikaha, and their whānau

As such, the reviewed literature centres on the following research questions:

1. What is the definition and framing of ‘prevention’ in the context of tamariki, rakatahi and mātua whaikaha and their whānau?
2. How might prevention approaches support ‘a good life’ for tamariki, rakatahi and mātua whaikaha and their whānau?
3. Are there systemic prevention initiatives (nationally or internationally) that demonstrate successful outcomes?
4. What prevention system and service disparities affect tamariki, rakatahi and mātua whaikaha and their whānau (that is, what prevention services are they not receiving)?
5. How can prevention be more effective for tamariki, rakatahi and mātua whaikaha and their whānau, and Oranga Tamariki kaimahi?
6. What are effective ways of designing and implementing strategies to prevent tamariki, rakatahi and mātua whaikaha and their whānau from engaging with Oranga Tamariki?

3 – Whanoka Pono/Values

This integrative literature review is based on the following documents and principles:

- Te Tiriti o Waitangi
- United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
- 2016-2026 New Zealand Disability Strategy (NZDS)
- The Social and Human Rights Models of Disability.

Kā Mātāpono (DBI Research Values) also underpin this important work:

- Whakatinana – Honouring Te Tiriti o Waitangi through our practice
- Whakarakatira – Being Respectful
- Whakawhanaukata – Being Relational
- Whakamana – Being Ethical
- Whakawhirinaki – Being Accountable
- Whakakotahi – Being Inclusive
- Whānau – Through uplifting whānau our journey will be one of prosperity.

4 – Te Aramahi/Methodology

An inclusive and diverse team of disabled and non-disabled researchers conducted this integrative literature review. The integrative literature review method is an approach that allows for the inclusion of both empirical literature and ‘grey’ literature. Grey literature is literature produced by governments and non-governmental organisations, academia, businesses, service providers, and industry (Lawrence, 2012; Whittemore & Knafl, 2005). This inclusive approach to literature reviews has greatly benefited the development of evidence-based practice and policy (Whittemore & Knafl, 2005).

Initially, the research team began by searching for both academic and grey literature via Google Scholar and a range of academic search engines, as well as Google, which generated a wide range of research related to many academic disciplines, as well as grey literature. Once the core literature was identified, the research team reviewed abstracts and titles and scanned each text for relevance. Literature that was viewed as relevant was read in full. Emphasis was placed on research that utilised a disability lens and prioritised the lived experiences of tamariki, *rakatahi* and *mātua whaikaha*, and their whānau. Key findings and study details from relevant literature were entered into a data chart before thematic analysis was undertaken to identify key themes across the literature.

4.1 – Strengths and limitations

The greatest strength of this literature review is that it was led by a team of diverse, experienced, disabled researchers, representing a range of identity and cultural groups. This ensured that various perspectives shaped and informed the final review, with the core values (section 3) and accountability to the disability community being prioritised at every stage of the review process. A second key strength was the volume of academic and grey literature, particularly in wellbeing and disability.

5 – Instructive conventions, policies, frameworks, and models

Outlined below are key conventions, policies, frameworks and models relevant to the area of prevention and disability in Aotearoa New Zealand.

5.1 – Te Tiriti o Waitangi

Oranga Tamariki have a responsibility to honour Te Tiriti o Waitangi as the founding document of Aotearoa New Zealand. They have expressly committed to giving effect to the principles of Te Tiriti o Waitangi through partnership, protecting tamariki and rakatahi Māori from harm, addressing disparities, and implementing their obligations under section 7AA,³ which recognise and provide practical commitment to the principles of Te Tiriti o Waitangi (Oranga Tamariki, 2021).

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

The UNCRPD is an international agreement that sets out what governments must do to ensure that disabled people have the same human rights as everyone else (United Nations, 2006). In 2008, the New Zealand Government became one of the first countries to ratify the UNCRPD, before further indicating its commitment by ratifying the Convention's Optional Protocol in 2016. Relevant articles of the UNCRPD highlight the right of disabled children to the enjoyment of all fundamental freedoms on an equal basis with other children, including freedom from violence and abuse (Article 7). Article 16 requires states parties to take "all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse" (United Nations,

³ At the time of writing this integrative literature review, Section 7AA of the Oranga Tamariki Act 1989 was proposed for repeal (see [Oranga Tamariki \(Repeal of Section 7AA\) Amendment Bill](#)), and multiple urgent Waitangi Tribunal inquiries that specifically relate to the rights, will and preference of tamariki Māori and tamariki whaikaha Māori were underway.

2006). Given that tamariki and rakatahi whaikaha who enter care and youth justice are known to frequently experience harm (Baidawi & Piquero, 2020; Euser et al., 2015), Article 16 is relevant to prevention efforts.

5.3 – New Zealand Disability Strategy 2016-2026

The New Zealand Disability Strategy (NZDS) guides the work of government agencies, including Oranga Tamariki, on all issues affecting disabled people. The NZDS aims to help realise the rights of disabled people by supporting the implementation of the UNCRPD (Office for Disability Issues, 2016). The underpinning principles of the NZDS are the Te Tiriti o Waitangi, the UNCRPD, and ensuring disabled people are involved in decision-making that impacts them. The NZDS recognises the importance of disabled families being supported to be healthy and well (outcome 3), of them being treated fairly and equitably by the justice system (outcome 4) and of safeguards being put in place for those who may be at risk of violence and abuse. The NZDS requires that decision-making on issues regarding justice, violence and abuse prevention and human rights is informed by robust data and evidence (Office for Disability Issues, 2016).

5.4 – The United Nations Convention on the Rights of the Child (UNCRC)

The UNCRC was adopted and opened for signature and ratification in 1989, and New Zealand ratified the UNCRC on 6 April 1993 (Ministry of Justice, 2020). Article 19 addresses prevention from harm and recognises that such harm can occur within the family and when a child is in Out of Home Care (OOHC). It requires state parties to “take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardians(s) or any other person who has care of the child.” UNCRC requires “effective procedures for the establishment of social programmes to provide necessary support for the child and for those who have the care of the child, as well as for other forms of prevention” (United Nations, 1989).

5.5 – United Nations Declaration of Indigenous People (UNDRIP)

The UNDRIP is a universal framework of minimum standards for the survival, dignity and well-being of the indigenous peoples of the world. It elaborates on existing human rights standards and fundamental freedoms, as they apply to the specific situation of indigenous peoples. Article 21 of the UNDRIP articulates indigenous peoples' right to the improvement of their economic and social conditions, and that States shall take effective measures and, where appropriate, special measures to ensure continuing improvement of their economic and social conditions. This includes particular attention to the rights and special needs of indigenous elders, women, youth, children and disabled people (United Nations, 2007).

5.6 – Oranga Tamariki Strategic Intentions 2021-2025 (OTSI)

Within the OTSI, it is noted that there are increasing calls for whānau to be supported earlier rather than later through community-led responses that are enabled by statutory agencies. As stated in the OTSI, “the best strategy for prevention is enabling and strengthening family, whānau, hapū, and iwi to provide safe, stable loving care for tamariki. For this, we will enable communities to put in place the support, the solutions, and the services they know will work for their people to prevent tamariki coming to our attention” (Oranga Tamariki, 2021, p. 15).

5.7 – Whanaketia – Through pain and trauma, from darkness to light (final report of the Royal Commission of Inquiry into Abuse in Care)

Following a six-year inquiry, in July 2024 findings from the Royal Commission of Inquiry into Abuse in State Care (2024) were released to the public. Included in the scope of the inquiry were the experiences of tamariki, rakatahi and mātua whaikaha who had experienced abuse in state care between 1950 and 1999. The report consists of 16 volumes outlining the context in which abuse occurred, what happened, why it happened,

specific case studies, survivor experiences and recommendations. Of particular note to this literature review is:

- Care Safety Principle 5 of the recommendations, which states that prevention should be embedded in the leadership, governance and culture of all State entities (and indirect care providers) involved in the care system.
- Recommendation 121, which states that the government should support and adequately invest in programmes for children, young people and adults who are in care or are at risk of being placed in care as well as parents, whānau and caregivers.
- Recommendation 122, which states that the government should support and adequately invest in abuse and neglect prevention programmes, including for those who may be at risk of perpetrating abuse and neglect.
- Recommendation 128, which states that all public awareness, training and education programmes to identify and prevent abuse and neglect, and address prejudice and discrimination (including ableism and disablism).

5.8 – Other relevant frameworks, models, and approaches

5.8.1 – Social and human rights models of disability

The social model of disability highlights that individuals with impairments are disabled by socially constructed barriers that limit their ability to fully participate in society (Oliver, 2013). The social model of disability shifts the root cause of disability from the individual to society, and through this shift, the model has become a powerful tool for advocacy. The human rights model of disability holds that disabled people have the same human rights that are guaranteed to non-disabled people (Johnstone, 2001). The rights-based model challenges the barriers to support that disabled children who have experienced abuse face (Franklin et al., 2020). It also emphasises the empowerment of disabled people as active stakeholders (Miller & Ziegler, 2006). In combination, the social and human rights models of disability can be used in the area of prevention to both highlight, and to remove barriers.

5.8.2 – Māori models of disability and wellbeing

Incorporating cultural understandings of disability is crucial when discussing wellbeing. In te ao Māori, there are two primary models of disability – the whānau hauā and the whaikaha models. Regarding the whānau hauā model, whānau refers to family from whakapapa, which Karetu (1990) describes as the glue that connects people through a broader kinship-network to place and space; and hau refers to the wind that uplifts disabled whānau members. Acknowledging the ongoing impacts of colonisation and its oppressive and discriminatory effects on Māori disabled people is central to the whānau hauā model. This requires further acknowledgement of the disadvantages caused by ableism and colonialism, which inhibit the ability of disabled people to have their needs met. Therefore, wellbeing is a collective responsibility (as opposed to an individual responsibility), predicated on working together to restore the balance between whānau and disabled people (Hickey & Wilson, 2017).

Tākata whaikaha is a strengths-based disability model that acknowledges the strengths of Māori and is widely recognised throughout Aotearoa New Zealand (as is illustrated in the title of Whaikaha – Ministry of Disabled People). Matua Maaka Tibble (Ngāti Porou) felt uncomfortable with the term 'disabled' and its association with deficit-thinking, and therefore suggested the term 'whaikaha' or 'tākata whaikaha' better reflected the strengths of disabled people (Whaikaha – Ministry of Disabled People, n.d.). In addition, Reo Hāpai (2020) translates whaikaha as meaning "have strength, to have ability, otherly abled, enabled. A word created within the Māori disabled community."

There are a range of Māori health and wellbeing models that can underpin discussions about tākata whaikaha, whānau, and wellbeing. For example, Mason Durie's Te Whare Tapa Whā uses a wharenui (meeting house) and its four walls to describe the various aspects of well-being, including physical, spiritual, and emotional health (Rochford, 2004). As Rawson's (2016) research illustrates, Te Whare Tapa Whā also emphasises familial relationships and cultural practices, and that te reo Māori and tikanga (protocols) are integral in providing a sense of belonging that contributes to positive health and wellbeing. According to the model, each wall represents a complementary dimension of wellbeing, including: taha wairua (spiritual); taha hinengaro (psychological); taha tinana (physical);

and taha whānau (familial/relational), which collectively complement each other and ensures balance and strength are maintained. Furthermore, whenua (land) forms the foundation of the wharenu (Rochford, 2004).

Other relevant models include the tauira, kaitiakitaka, and manākitaka models. The Tauira model embraces the concept that all people are lifelong learners who draw on past, present, and future learning experiences. The term tauira means template, apprentice, model, or pattern. The model conceptualises care workers (kaimahi hauora) as lifelong students who are self-reflective and critical of their experience of inappropriate or ineffective care and affirm those in care and their whānau as potential 'kaiako' (teachers). The tauira model embodies the tuakana-teina relationship where the student and teacher (carer/cared for) learn from each other, there is an overt acceptance of this power dynamic, and the appropriateness and quality of care is determined by those in care (Donald Beasley Institute, 2022). The kaitiakitaka and manākitaka models support the understanding and conceptualisation of care through a te ao Māori lens and are recognised and highly respected by scholars in the Aotearoa New Zealand social work context (Napan & Connor, 2023). Kaitiakitaka pertains to the obligation of 'taking care' (Pohatu, 2003), whereas manākitaka refers to uplifting one's mana. Understanding mana from the perspective of those that one works alongside, and what it means to yourself (Ramsden, 1993) enables the transformation of practice in culturally responsive and positive ways (The Education Hub, 2023).

5.8.3 – Pacific models of disability and wellbeing

Much like Māori models, there are a range of disability, health, and wellbeing models originating from cultures throughout the Pacific. One example is the tagata sa'ilimalo model, which was designed by Pacific disabled people in Aotearoa New Zealand. Tagata means person or people, and sa'ilimalo means the pursuit of success, and this model is described as:

... an aspirational vision of the pursuit of success underpinned by sheer determination and sustained by the collective vitality of Pacific peoples. It is a vision that reflects the hopes of the disability community to imagine better for

their future. The Tagata Sa'ilimalo vision is inclusive of all Pacific peoples in Aotearoa and all disability types (Tōfā Mamao Collective, 2022, p. 5).

Another example of a Pacific health and wellbeing model is the Fonofale model of health, which has its roots in Samoan culture and language. In 1995, Fuimaono Karl Pulotu-Endemann developed the Fonofale model of health in consultation with a variety of Pacific Island communities throughout Aotearoa New Zealand – including Samoan, Cook Island, Tongan, Niuean, Tokelaun and Fijian peoples – in regards to what factors they believed best determined good health. The Fonofale model uses the various parts of a Samoan house (fale) to symbolise different elements of health: the floor symbolises family and is connected to gafa (genealogy); the roof symbolises cultural values; the four pou (posts) in between the roof and the floor symbolises spirituality, and physical and mental health and the 'other', which represents 'other' determinants such as gender, sexuality, age, and socio-economic status. The fale is affected by a broader range of dimensions, such as the environment, context, and time, which can also affect health (Pulotu-Endemann, 2001). Similarly, the Fonua model is a Tongan health framework, which holds that life harmony can only be maintained when health issues are addressed through five dimensions: sino (physical); 'atamai (mental); laumalie (spiritual), kaingal (community), and 'atakai (environmental). In addition to the five dimensions, there are four phases in the natural order of Fonua: kumi fonua (search, explore, navigate new fonua); langa fonua (form, build and construct); tauhi founua (maintain and sustain); tufunga fonua (reform and re-construct); as well as tauhi va (maintaining the relationship) and liliu (change - Fonua accepts change as natural) (Tu'itahi, 2007 & 2009 cited in ActionPoint, 2018).

5.8.4 – Safeguarding approach and framework

In broad terms, safeguarding is a preventative approach to child protection that focuses on minimising or eliminating harm to all children. Within the disability sector it also refers to a disability-specific approach to the prevention of the abuse of disabled people. In Aotearoa New Zealand, the Safeguarding Framework (New Zealand Disability Support Network, n.d.) was developed by the New Zealand Disability Support Network to "establish a common understanding and consistent approach to help promote, protect and enhance the rights of disabled people and protect people against abuse" (New

Zealand Disability Support Network, 2020, para. 1). This framework sets out a spectrum of safeguards from personal, relationship and community safeguards through to disability and community services and system safeguards. The framework has three focus areas: *Being Aware*, *Being Heard*, and *Being Responsive*, with guiding principles that include prevention (New Zealand Disability Support Network, 2020).

5.8.5 – Inequality framework

An inequality framework investigates axes of inequality as a spectrum of disadvantage, not dichotomous groups, and acknowledges intersectionality to see how these axes overlap. Keddell and Davie (2018) note that an inequality framework:

“provides balance to the current ‘social investment’ policy approach that targets individuals and families for service provision, with little attention to how structural inequalities impact on system contact... A nuanced conceptual framework needs to be developed to explore the interaction of social, economic and environmental inequalities in family resources, with patterns of policy and service priorities, resources and practices to produce outcomes (p. 1).

5.8.6 – Family Quality of Life approach (FQOL)

An FQOL approach provides a perspective on how social services, such as Oranga Tamariki, can holistically and comprehensively evaluate a family to determine their needs. This approach facilitates the effective planning of supports or interventions based on identified needs, as well as allowing them to effectively evaluate how successful those plans were after they were implemented. The FQOL approach recognises that disability impacts the family as a whole, and therefore, support must holistically serve the entire family (Beigel et al., 2012).

5.8.7 - Oranga Tamariki wellbeing frameworks

Within Oranga Tamariki there are a range of frameworks and kaupapa tuku iho that embed holistic approaches to oranga and hauora. Te Toka Tūmoana - Tangata Whenua and Bicultural Principled Wellbeing Framework, for example, was developed by Child,

Youth and Family (CYF) for internal use by practitioners. Grounded in Te Tiriti o Waitangi (1840), Pūao-Te-Ata-Tū (1988) and the Child, Young Persons and Their Families Act (1989), Te Toka Tūmoana responded to CYF's priority to "work together with Māori" embedded in their Mā Mātou, Mā Tātou Strategic Plan (2012) (Oranga Tamariki, 2021b). Outlined in this bi-cultural wellbeing framework are three takepū (mana ahua ake o ngā mokopuna, te ahureitanga, and tiaki mokopuna); three puna (te ao hurihuri, mokopuna ora, and te ao kōhatu); and five pou (upholding and protecting the rights and interests of Māori, hearing and acting on the voices of Māori, reducing disparities for tamariki Māori and their whānau, supporting and facilitating mana tamaiti, and valuing the Māori evidence base) (Eruera et al., 2021).

6 – Kiteka/Findings

According to International Human Rights Law, tamariki and rakatahi whaikaha “for the full and harmonious development of his or her personality, should grow up in a family environment, in an atmosphere of happiness, love and understanding” (United Nations, 1989, preamble) and “shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child” (United Nations, 1989, Art. 9).

Despite these inherent human rights, research shows that tamariki and rakatahi whaikaha are at higher risk of entering care than their non-disabled peers due to maltreatment (Lightfoot et al., 2011) and relinquishment (Hill, 2017; Ng & Rhodes, 2018), and that they are disproportionately represented in youth justice facilities (Anns et al., 2023; Lount et al., 2017; Lynch, 2016). Another group of people at the intersection of disability and child welfare services are mātua whaikaha (disabled parents and caregivers), with research showing a higher rate of child removal from this population than non-disabled parents and caregivers (Beltran-Castillon & Mcleod, 2023; Libesman et al., 2023).

The findings detailed in this review seek to understand strategies and interventions that can help prevent tamariki and rakatahi whaikaha, and the children of mātua whaikaha, from engaging with care or youth justice settings. Informed by national and international examples, findings are categorised according to key research questions, and include: defining and framing prevention and wellbeing from a disability perspective (Questions 1 and 2), successful care and youth justice prevention strategies (Question 3), systemic disparities (Question 4) and recommendations for designing and implementing effective prevention strategies (Questions 5 and 6).

6.1 – Defining prevention and wellbeing

Relevant foundational question/s:

- Question 1: What is the definition and framing of ‘prevention’ in the context of tamariki, rakatahi and mātua whaikaha and their whānau?
- Question 2: How might prevention approaches support ‘a good life’ for tamariki, rakatahi and mātua whaikaha and their whānau?

Key insights:

- Primary prevention includes initiatives targeted at the general population; preventing maltreatment before it occurs; and preventing tamariki and rakatahi from entering care and justice settings.
- Secondary, early, or intensive prevention includes initiatives targeted at tamariki, rakatahi, and mātua whaikaha and their whānau who are at high risk of engagement with care settings.
- Primary and secondary-level prevention aligns with the disability sector’s twin-track approach.
- The ecological model of disability violence and abuse is a useful framework for not only understanding why abuse occurs, but how to prevent it from occurring in the future.
- There is no universally accepted definition of wellbeing. A Tiriti o Waitangi and rights-based approach enables tamariki, rakatahi, and mātua whaikaha and their whānau to develop their own definition.
- Prevention approaches must focus on cultivating wellbeing at each ecological level, as defined by tamariki, rakatahi, and mātua whaikaha, and their whānau.
- Enabling Good Lives (EGL) is a disabled person-led approach that is useful for framing prevention and wellbeing strategy development. EGL enables tākata whaikaha and whānau to have greater choice and control in their lives and has been suggested as a single principles-based system for application throughout the work of all government agencies, including Oranga Tamariki.

The first objective of this literature review was to explore key definitions and framing of ‘prevention’ and ‘wellbeing’ from a disability perspective, and how these understandings

might support ‘a good life’ for tamariki, rakatahi, and mātua whaikaha and their whānau. To do this, the first collection of findings provides an overview of the various levels of prevention, before aligning these with the twin-track approach to disability. The ecological model of disability violence and abuse is presented as a potential framework for understanding why abuse occurs, as well as its prevention, before the definition of wellbeing is discussed and explored from a disability perspective. Finally, Enabling Good Lives is highlighted as a disabled person-led approach that can be used to inform prevention and wellbeing strategy development.

6.1.1 – Defining prevention, the twin-track approach and pathways to care

Prevention refers to an action or set of actions designed to stop something before it occurs. In the context of child abuse and neglect, prevention includes a range of actions, interventions, or strategies aimed at reducing risks or threats to a child’s health and wellbeing (NAPCAN, 2024). According to the literature, prevention can be categorised according to risk levels, specific populations, and the continuum of engagement with services. This includes primordial prevention (risk factor prevention), and four or five level framings (such as quaternary prevention), which provide important contextual considerations. However, the most widely used prevention framework is the three level framework where *primary level* or universal prevention is focused on the general population to prevent maltreatment before it occurs, *secondary level* prevention targets early or intensive prevention support towards individuals or whānau in which maltreatment is more likely or emergent (high-risk), and *tertiary level* prevention responds to whānau where maltreatment has already occurred (or has been indicated) (Blakey et al., 2012; Bromfield & Holzer, 2008; Oranga Tamariki Evidence Centre, 2018).⁴

Primary and secondary levels of prevention align directly with the twin-track approach of disability – an internationally recognised model that ensures mainstream services are inclusive of, and accessible to, disabled people, and that services specific to disabled people are also easily accessed (Office for Disability Issues, 2016). Importantly, disabled

⁴ According to the project brief, the focus of this literature review is primary and secondary levels of prevention, and not other levels of prevention.

people should not have to choose between the specific or mainstream options; rather it is about having the right access to the right high-quality support or service, at the right time and in the right place (Office for Disability Issues, 2019). When compared with the prevention levels identified above, there was a clear alignment in framing:

- **Track 1** of the twin-track approach (primary level): Universally designed prevention strategies and initiatives targeted at the general population (that is, they are inclusive of, and accessible to, tamariki, rakatahi, and mātua whaikaha);
- **Track 2** of the twin-track approach (secondary level): Disability-specific prevention strategies and initiatives targeted at high-risk tamariki, rakatahi, and mātua whaikaha, and their whānau.

When considering primary and secondary level initiatives aimed at preventing tamariki and rakatahi whaikaha from entering care or justice settings, it was also important to consider the potential pathways to engagement, including:

- **The care and protection pathway:** where tamariki and rakatahi whaikaha, or the tamariki of mātua whaikaha, are placed into care due to safety and wellbeing concerns (Oranga Tamariki, 2023).
- **The relinquishment pathway:** where whānau-carers engage with Oranga Tamariki due to them reaching a breaking point in providing day-to-day care to their tamariki and rakatahi whaikaha (Donald Beasley Institute, 2022).
- **The youth justice pathway:** where tamariki and rakatahi whaikaha engage with Oranga Tamariki when they have committed an offence and have become involved in the “youth justice service arm of Oranga Tamariki” (Oranga Tamariki, 2021c, p. 6).

6.1.2 – Ecological Model of Disability Violence and Abuse

Another model that has been useful in the framing of prevention and wellbeing is the ecological model of disability violence and abuse (Sobsey & Calder, 1999; Hollomotz, 2009; Fitzsimons, 2017). The model draws on the World Health Organization’s violence prevention model, which is used internationally to inform violence and abuse prevention. In the context of disability, the ecological model is commonly used as a framework for

exploring and understanding the interrelatedness of factors that both impact disabled people and create environments where violence and abuse can occur. The ecological model explores these factors at the individual and relationship/relational levels (microsystem levels), the community level (exosystem), and the societal level (macrosystem) (Hollomotz, 2009). This model was recently used to analyse the experiences of disabled survivors in the Royal Commission of Inquiry into Abuse in State Care (Mirfin-Veitch et al., 2022). While not specific to tamariki and *rakatahi*, the application of the model to stories told by disabled survivors of state care identified the following antecedents of abuse and violence:

- **Individual level:** a lack of agency, rights, will and preference, cultural alienation and loss of identity, and denial of personhood;
- **Relational level:** power and decision-making imbalance, and social isolation;
- **Community level:** a lack of access to housing/employment/education, and negative attitudes towards disability, including perceptions of dependency, disabled people only being seen as recipients of services and supports, and as non-citizens;
- **Societal level:** laws and policies that deny personhood rights, segregated systems, limited access to legal and social protections, and negative societal attitudes (Mirfin-Veitch et al., 2022).

In addition to helping understand why abuse occurs, the ecological model of disability violence and abuse can also be drawn on when considering how to prevent violence and abuse experienced by tamariki, *rakatahi* and *mātua whaikaha* (primary and secondary levels of prevention), as well as cultivating wellbeing (Goldson, 2001).

6.1.3 – Defining wellbeing

According to the World Health Organization (2021, p. 10), wellbeing is “a positive state experienced by individuals and societies. Similar to health, it is a resource for daily life and is determined by social, economic and environmental conditions.” As such, this literature review does not adhere to a single definition of wellbeing. Instead, in taking a disability rights-based and *Tiriti o Waitangi* approach, tamariki, *rakatahi* and *mātua whaikaha*, and their whānau have choice and control over how they individually and

collectively define wellbeing according to their social, economic, environmental and cultural conditions. All levels of prevention must therefore include approaches that not only aim to reduce harm, but also cultivate the wellbeing of tamariki, rakatahi and mātua whaikaha, and their whānau, as defined by them.

6.1.4 – Enabling Good Lives

The disability community has long expressed concerns about disability supports and services not working well for tākata whaikaha and whānau due to a lack of choice and control (Ministry of Social Development, n.d.). Developed by the disability community in 2011, Enabling Good Lives (EGL) is an approach that enables tākata whaikaha and their whānau to have a say in their lives, easy access to support and services, and systems-level influence. EGL is based on eight core principles that can be applied in any given situation and have been recommended as a single principles-based system for application throughout the work of all government agencies (Enabling Good Lives, 2024).

The principles are:

- **Self-determination:** Disabled people are in control of their lives.
- **Beginning early:** Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.
- **Person-centred:** Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.
- **Ordinary life outcomes:** Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.
- **Mainstream first:** Disabled people are supported to access mainstream services before specialist disability services.
- **Mana enhancing:** The abilities and contributions of disabled people and their families are recognised and respected.

- **Easy to use:** Disabled people have supports that are simple to use and flexible.
- **Relationship building:** Supports build and strengthen relationships between disabled people, their whānau, and community (Enabling Good Lives, 2024).

Notably, the EGL approach recognises disabled people belong to networks and cultures (for example, family, friends, and communities), which should be respected as being fundamental to identity, belonging and citizenship. Investing in disabled people and their families is central to EGL. As evidenced by the pilot projects in Christchurch, Waikato, and MidCentral region, there are improved outcomes when disabled people, families and whānau have choice and control over their supports and services. For example, benefits included increased autonomy and social connectedness, improved quality of life, and better access to education and employment opportunities, and higher engagement and take up of disability services from the marginalised groups, including disabled Māori and Pacific peoples, in comparison with the current disability support system (Enabling Good Lives, 2024).

EGL is an important disabled person-led initiative that can be used to frame efforts to reduce the disproportionate abuse and violence experienced by tamariki and rakatahi whaikaha and consequential engagement with child protection and justice services. Second, the EGL principles can and should be applied to all strategies and initiatives aimed at cultivating wellbeing for tamariki, rakatahi, and mātua whaikaha in Aotearoa New Zealand.

6.2 – Care prevention strategies

Relevant foundational question/s:

- Question 3: Are there systemic prevention initiatives (nationally or internationally) that demonstrate successful outcomes?

Key insights:

- Despite a consistent demand for prevention initiatives, there were very few practical examples of primary and secondary level initiatives specifically aimed at preventing tamariki, *rakatahi* and *mātua whaikaha*, and their *whānau* from engagement with care settings.
- However, broader research addressing the following areas were identified as positively contributing to tamariki, *rakatahi* and *mātua whaikaha*, and *whānau* wellbeing and general risk reduction:
 - early identification and intervention
 - respite
 - shared care
 - Intensive Family Support/Intensive Family Preservation
 - social support
 - peer support
 - non-caregiving employment
 - professional health and wellbeing support
 - client-led and flexible funding models
 - training and education

According to the social and rights-based models of disability, a disabled person is not more vulnerable to harm because of their disability, but instead because of environmental, structural, and attitudinal barriers (Davy et al., 2024). To reduce the risk of harm, prevention strategies must address environmental, structural, and attitudinal barriers that can lead to care settings. Despite the reviewed literature showing a strong and consistent demand for primary and secondary level prevention initiatives, there were very few

practical examples of initiatives specifically aimed at preventing tamariki, rakatahi and mātua whaikaha from entering care settings. This may in part be due to tamariki, rakatahi and mātua whaikaha not participating in, or being included in data, evidence, monitoring and evaluation target populations of track 1 prevention initiatives (Donald Beasley Institute, 2022), and/or a lack of resources for track 2 prevention initiatives. Instead, the broader literature identifies key factors that are known to reduce the vulnerability of disabled people in general terms, while cultivating wellbeing and contributing to successful outcomes of tamariki, rakatahi, and mātua whaikaha. With this in mind, the next collection of findings draws on national and international literature to identify a variety of systemic approaches that may be useful for primary level prevention efforts, as well as secondary level prevention efforts targeted towards whānau who are at high risk of having tamariki and rakatahi placed in care settings, whether arbitrarily due to safety and wellbeing concerns or by relinquishment.

6.2.1 – Early identification and intervention

Initiatives that support early identification and subsequent interventions for families with tamariki and rakatahi whaikaha have been recognised as being important in the prevention of abuse and neglect (Child Welfare Information Gateway, 2018; Haight et al., 2013) as well as relinquishment (Victorian Equal Opportunity & Human Rights Commission, 2012). In Aotearoa New Zealand, there are various opportunities for the health, safety, and wellbeing of pepī, tamariki and rakatahi to be monitored and referred to health care providers or broader social services. For example, Well Child Tamariki Ora (WCTO) is a primary prevention programme that provides health and development checks to all children from birth to five years of age (Te Whatu Ora, 2023). Secondary prevention programmes, such as Family Start, funded and overseen by Oranga Tamariki, also have a focus on early identification and intervention, and look at the environment of a tamaiti, whānau circumstances, safety, and provides support to whānau who are struggling with challenges or problems that put the hauora, education, and wellbeing of a tamaiti at risk (Oranga Tamariki, 2021a).

Once a child reaches school, Te Hunga Tauwhiro i te Kura – Social Workers in Schools (SWiS), Tauwhiro Taiohi – Youth Workers in Secondary Schools (YWiSS), Tauwhiro

Taiohi – Multi Agency Support Services in Secondary Schools (MASSiSS) and Mana Ake - Stronger for Tomorrow are programmes that provide school-based community social work services for at-risk tamariki and youth to help improve their safety, wellbeing, and educational outcomes. If issues are identified, referrals can be made by the tamariki, rakatahi, or whānau, the school, community, or government agencies (Oranga Tamariki, 2023a). Supporting Fathers, as the name suggests, is an Oranga Tamariki programme aimed at supporting young men who become parents, and the Break-Away School Holiday Programmes is an annual sports and activity-based school holiday programme delivered in high need communities (Oranga Tamariki, 2023b).

However, while research shows tamariki and rakatahi whaikaha are at greater risk of entering care settings, there is limited research or data specifically analysing their engagement with existing primary and secondary early identification services such as those mentioned above, any consequential referrals to health and social services, or whether the services prevent the abuse and maltreatment of tamariki and rakatahi whaikaha. For example, in a recent review of the Well Child Tamariki Ora programme, while “Measures of service coverage, completeness, quality and outcomes showed the programme is persistently underserving Māori, Pacific peoples and whānau living in high-deprivation areas,” and “Data about access to WCTO services and providers and outcomes for whānau of tamariki with disabilities and for pēpi and tamariki in state care is not collected” (Ministry of Health, 2020, p. 15). Furthermore,

although the current programme contributes to health and wellbeing outcomes for many pēpi and tamariki, we need to design, deliver, and resource it differently to promote equity for pēpi, tamariki and whānau who are Māori Pacific, have disabilities, are in state care, or have high needs. This means enabling far more flexible, integrated approaches to delivery that are strengths-based and whānau-led, as well as strengthening the universal components needed to support tamariki health and development (p. 25).

Based on this evaluation, and given that Māori and Pacific peoples experience some of the highest rates of disability (Statistics New Zealand, 2013) and that 1 in 5 disabled

children lived in material hardship (Statistics New Zealand, 2021), it is reasonable to conclude that tamariki and *rakatahi* whaikaha, Pacific disabled children, and disabled children living in high-deprivation areas are less likely to benefit from primary prevention programmes such as WCTO, when compared to corresponding populations (Ministry of Health, 2020). As highlighted by the review, “sector feedback suggests the system needs to change, to deliver both universal and intensive services that are more responsive to the unique needs of these pēpi, tamariki, and whānau” (p. 15), which speaks directly to the potential of the twin-track approach to disability.

In 2019, a review of the tamariki whaikaha experience of the Oranga Tamariki Family Start programme (from the perspectives of social workers) found that 22% of caseloads included families with tamariki (0-4 years) with one or more disabilities. This is compared to the 5% disability rate in children aged 0-4 years in the general population (according to the 2013 Disability Survey), indicating a higher prevalence of disabilities among young children in vulnerable whānau. Whānau of tamariki whaikaha experienced a range of challenges including stress, social isolation, a lack of knowledge about caring for tamariki whaikaha and the supports and services available to them, financial stress and poverty, and a lack of access to health services, transport, and adequate housing. As summarised by the review, the policy implications for Oranga Tamariki emphasised the need for timely, available and well-resourced specialised services, cross-agency early interventions, and coordination between service providers (Oranga Tamariki Evidence Centre, 2019). The review did not seek the perspectives of tamariki whaikaha themselves, or their whānau.

In a 2021 Malatest evaluation of Mana Ake - Stronger for Tomorrow it was noted that tamariki wellbeing was improved through the programme by strengthening regional systems and services to support tamariki and whānau (Malatest International, 2021). While the programme includes professional development for teachers and others on topics directly related to disability (for example, anxiety, learning difficulties, eczema, and so on), the evaluation did not provide details about the experiences of tamariki whaikaha or their whānau participating in the mainstream education context (track 1), or whether the programme had been applied in disability-specific contexts such as specialist schools (track 2). However, given that psychosocial disability itself is considered under the United

Nations' definition of disability, the improvement in wellbeing noted by the evaluation is promising.

With regards to Oranga Tamariki primary and secondary prevention programmes such as SWiS, YWiSS, MASSiSS, Supporting Fathers and Break-Away School Holiday Programmes, there was little literature addressing the effectiveness for tamariki and rakatahi whaikaha, or indications as to why these services might not pick them up, or if they are, why referrals to health and social services as a prevention strategy fail to result in equitable outcomes. For example, in 2019, an Education Review Office (ERO) review of SWiS highlighted that SWiS considers context and underlying triggers that lead to the child's referral to them, before making a plan with whānau and tamariki. This includes understanding what else is needed by whānau, such as support for disability (Education Review Office, 2019). However, further details about the experiences of tamariki and rakatahi whaikaha, or the frontline staff engaging with them, are not provided – again highlighting a gap in administrative and qualitative data and evidence.

6.2.1.1 – Early identification and intervention initiatives for mātua whaikaha

According to international literature, mātua whaikaha experience higher instances of child removal than non-disabled caregivers (Lightfoot, 2022; Pérez-Curiel et al., 2023). In Aotearoa New Zealand, research shows that parents with a learning disability have 13 times the risk of having their child placed in care (Beltran-Castillon & Mcleod, 2023). It is therefore important for primary and secondary prevention efforts to also extend to this population. To prevent the removal of children from mātua whaikaha, early identification and intervention initiatives are required throughout their parenting journey – from the decision to form a family, to supporting the child and wider family throughout their lifetime (Tarleton & Ward, 2007). For example, for parents with learning disabilities, research shows that early interventions should begin before pregnancy occurs, with education and support pertaining to choice and control, contraception, becoming pregnant, and parenting roles and responsibilities. Research also shows that parenting success is largely due to the responsiveness of early formal (track 2) and natural supports: "This responsiveness appeared to be a significant element in the success of their early parenting and it illustrated that careful thought had gone into the assessment of the needs

of these parents. There had been close liaison between all members of the support team” (Conder et al., 2011, p. 111).

For example, in 2020 a review into a complaint made about a discriminatory uplift of a pepī from a wahine whaikaha led to the establishment of a new Oranga Tamariki service broker role to improve services across the regions and the employment of more regional disability advisors. When working with mātua whaikaha, sites are encouraged to contact their regional disability advisor; engage with the wider sector, including the Needs Assessment and Service Coordination Services (NASCS); and engage with the site lawyer if a court process is going to involve disabled parents (Office of the Ombudsman, 2020). However, while the implementation of these roles reflects the recommendations made by research and evidence, further evaluation is needed to understand whether it has resulted in the successful prevention of tamaiti removal from mātua whaikaha.

6.2.2 – Respite

A second, and widely cited, example of a successful prevention strategy was respite. “Whether it is planned or offered during times of crisis, taking a break from the demands of caring for a child with disabilities can help parents reduce stress and the risk of abuse or neglect” (Child Welfare Information Gateway, 2018, p. 10). While respite has long been recognised as a form of OOHC once a family becomes engaged with child protection services, more recent literature has recognised the benefits of respite as a proactive prevention strategy for tamariki and rakatahi whaikaha and their whānau (Donald Beasley Institute, 2016; MacDonald & Callery, 2004; Oranga Tamariki Evidence Centre, 2019; Victorian Equal Opportunity & Human Rights Commission, 2012).

As highlighted in an earlier Oranga Tamariki report, a lack of support for whānau affected by disability can lead to a “breaking point”, as well as subsequent abuse, harm, and/or relinquishment (Donald Beasley Institute, 2022, p. 34). In a 2016 study investigating the respite experiences of caregivers of tamariki and rakatahi whaikaha in Aotearoa New Zealand, for example, six out of ten survey respondents said they had felt close to breaking point and that half of survey participants did not feel they were able to access sufficient respite (Milner et al., 2016).

Research shows that respite can be beneficial to both caregivers and children (Oranga Tamariki Evidence Centre, 2019; 2021). In one literature review, authors refer to this approach as 'contingency driven':

[H]ere respite care is based on the idea of prevention and conceived as part of a planned package of care resources. It is based on partnership with families. Statutory powers need not be invoked as a vehicle for using respite care and its rationale is largely consumer-oriented. The advantages for practitioners in using respite in this context have been discussed above. However, it should be noted that respite as a contingency-driven option would enable practitioners to plan its use strategically within a range of services and over a specified time period. The trust between clients and practitioners might be enhanced by using respite, and the stigma attached to the 'social work visit' might be reduced (Webb, 1990, p. 25).

Literature about the specific experiences and needs of families affected by disability notes that unique respite characteristics are known to improve the outcomes of tamariki and rakatahi whaikaha, and their whānau. These include:

- **Planned respite:** While respite is commonly used as an emergency response, the literature noted the benefits of respite being a planned, co-designed, proactive prevention strategy (Victorian Equal Opportunity & Human Rights Commission, 2012; Webb, 1990).
- **Respite choice, control, and flexibility:** Families have noted the importance of ensuring the availability of a variety of flexible respite contexts and being able to choose between them. These might include facility-based respite, in-home respite, matched family placement, holiday programmes, after-school programme, and so on (Milner et al., 2016; Oranga Tamariki Evidence Centre, 2019; Victorian Equal Opportunity & Human Rights Commission, 2012).
- **Specialised respite:** For many whānau, respite services do not adequately cater to the specialist health, behavioural, and safety needs of their tamariki and rakatahi whaikaha (Milner et al., 2016). As such, families should be able to choose between mainstream (track 1) and specialised (track 2) respite services, both staffed by

people highly skilled in behaviour work (Victorian Equal Opportunity & Human Rights Commission, 2012).

In the context of Aotearoa New Zealand, the disability support system enables some whānau to access funding for respite. After being assessed and approved by a Needs Assessment Service Coordination (NASC), some whānau can access a subsidy called Carer Support, which can be used to provide a full-time carer with a break from their caring role. It reimburses some of the costs of care and support for the takata whaikaha while taking a break. A full-time Carer is a person who provides more than four hours per day unpaid care to a takata whaikaha, for example, the parent of a tamaiti whaikaha (Whaikaha – Ministry of Disabled People, n.d.). Carer Support funding, however, has also been affected by the March 2024 changes to Purchasing Guidelines, leaving whānau-carers with less flexibility, choice, and control over their respite options.

A further example of an evaluated respite programme is demonstrated in the United Kingdom, where local authorities can apply for short break funding to offer programmes for tamariki whaikaha. The short breaks can include daytime or overnight care in the home or elsewhere, educational or leisure activities outside the home, or services to assist whānau in the evenings, at weekends and during the school holidays. Rather than requiring the local government grants to fund short break programmes, which can be inequitable and ignored, central government funding ensures access across local communities. Some local authorities collaborate with whānau to co-design short break programmes that are then delivered by partner organisations with existing infrastructure and capabilities. An evaluation of the programme showed that tamariki whaikaha demonstrated significant early improvements, while most whānau cited feeling supported, reduced stress, increased time to care for other family members, increased time for non-caring employment, and improved general wellbeing of the whānau (IFF Research, 2023).

6.2.3 – Shared care

In one study investigating the nature, extent and causes of relinquishment, shared care was one of the most cited models of prevention by whānau participants. This is where a tamaiti whaikaha lives at home several days a week and in a supported or whānau-based placement for the remainder. While shared care is often used as a strategy for OOHC

arrangements and for reunification purposes, research indicates that it should be explored as a primary and secondary prevention strategy (Victorian Equal Opportunity & Human Rights Commission, 2012). For example, in a Northern Ireland-based study on disability, safeguarding and state care, respondents (whānau) indicated a need for more shared care options to help safeguard tamariki whaikaha whose parents require more intensive support and longer breaks from their caring role (Kelly & Dowling, 2015). As noted in a Victorian Equal Opportunity & Human Rights Commission report, specific cultural meanings of 'shared care' for Indigenous communities should also be considered in shared care arrangements (Victorian Equal Opportunity & Human Rights Commission, 2012).

Regarding mātua whaikaha, research on shared care arrangements for parents with a learning disability was limited. This is likely because parents with a learning disability are more likely to lose custody of their tamariki, rather than be offered support such as shared care (Tøssebro et al., 2017; Pacheco et al., 2021). While research shows that it is beneficial for tamariki in foster care to stay in touch with their biological parents (Atwool (2013) cited in Adolfsson et al., 2021), research also shows that parents with a learning disability are rarely supported to understand and navigate the relationship with their tamariki after they enter care settings (Pacheco et al., 2021; MacLeod et al., 2022). In Australia, a peer support programme called "Parents on the Outside" was developed to support parents with a learning disability whose tamariki have entered the foster system. This programme was later implemented in Sweden (Adolfsson et al., 2021). A small qualitative study analysing the impact of the programme highlighted that peer support initiatives have the potential to enhance a sense of belonging for parents with a learning disability, and increase their ability to understand and manage their circumstances. This supported them to take on the parenting role as 'visiting parents' (Adolfsson et al., 2021).

6.2.4 – Intensive Family Support/Intensive Family Preservation

Intensive family support (IFS) and intensive family preservation (IFP) programmes have been used as primary prevention strategies worldwide. These programmes aim to prevent unnecessary out-of-home placement of tamariki through intensive, on-site intervention, and to teach whānau new problem-solving skills to prevent future crises. They are

characterised by small caseloads, short duration of services, 24-hour availability of staff, and the provision of services primarily in the whānau home or another environment familiar to the whānau (Intensive Family Preservation Services, n.d.).

In Aotearoa New Zealand, an example of a secondary level IFS/IFP prevention initiative (that is, an initiative targeted towards high-risk whānau) can be found in the Intensive Response initiative. In 2019, the New Zealand government approved \$31.6 million over four years to establish a new IFS/IFP approach for tamariki at risk of harm, and their whānau. The approach recognises that whānau who become involved with Oranga Tamariki often do not get the support they need. As a result, a secondary level prevention response is provided to ensure that whānau, families and tamariki are supported to thrive at home (Oranga Tamariki, 2023c). However, it is unclear what impact this primary prevention programme will have on the high rate of tamariki and rakatahi whaikaha Māori entering care settings.

In Aotearoa New Zealand, a track 2 secondary level IFS/IFP prevention initiative (that is, a disability-specific initiative targeted towards high-risk whānau with tamariki and rakatahi whaikaha) includes the Intensive Wrap Around Service (IWAS), which aims to support whānau and tamariki whaikaha who are at risk of entering out-of-home care (CCS Disability Action, 2022). Funded by the Ministry of Health and primarily delivered by CCS Disability Action, funding for IWAS comes from a single national budget and is allocated according to the urgent and ongoing need of tamariki and rakatahi whaikaha and their whānau. Allocated funding can be used for community support workers, respite care, shared care, behavioural support/psychologists, coordination of other services and supports, counselling for the tamaiti or whānau, community activities, equipment, and so on. The approach reflects a client-led and flexible funding model (see section 6.2.7) with additional coordination support. In 2015, a review of the service engaged 60% of whānau who have access to the service. Of these, 83% shared that receiving IWAS support has significantly improved their lives. As highlighted in the report, “67% of families said they “would not have been able to keep their child at home without the service.” However,

information about how to access the service is difficult to find (personal communications, 21 March 2024).⁵

More broadly, international literature regarding the efficacy of ISF/IFP programmes is mixed due to limitations on research strength, conflicting findings about outcome impacts, and cost-saving capacities (Schweitzer et al., 2015; Bezeczky et al., 2020). Similarly, while there is some evidence about the effectiveness of IWAS in Aotearoa New Zealand (personal communication, 21 March 2024), accessible data remains limited.

6.2.5 – Social support

In Aotearoa New Zealand, a recent study highlighted the complexity of relationships for mothers raising autistic children, and the missed opportunities they had to develop positive relationships, including friendships. For example, participants reported a significant decrease in the quantity and quality of their social ties and relationships, including relationships ending prematurely. The negative impact of losing personal and social relationships was reported to be associated with a lack of support and funding for wellbeing tools such as relationship counselling (Priestly et al., 2022).

Social support was also identified in a USA-based study as a critical factor for reducing the negative psychological effects of raising a tamaiti with autism spectrum disorder (ASD) as well as other disabilities. Informal support particularly, such as that provided by friends and whānau (also referred to as natural support), has been shown to be effective in reducing stress among mothers of tamariki with ASD. Research showed that mothers often first turn to their spouse, then extended family, and then other parents of tamariki whaikaha when seeking support: "Based on these results, it would seem advisable for interventions to focus on strengthening each of the informal social supports specifically because each of the sources are associated, either directly or indirectly, with unique sources of benefit for the mother" (Ekas et al., 2010, p. 1282). Additionally, the authors suggest developing interventions that increase optimism amongst families, such as cognitive behavioural therapy (CBT).

⁵ This review was conducted by Sapere Research Group in 2015. It is not currently publicly available but was shared through personal communication.

As highlighted by Child Welfare Information Gateway (2018, p. 9), “Connecting parents to services such as social support groups and respite care may allow them to better understand their own mental and physical well-being and reduce stress, improve attachment, and reduce the risk of maltreatment.” Moreover, strong social networks have been identified as a protective factor for tamariki and *rakatahi* whaikaha from abuse and neglect (Robinson & Graham, 2021). Social networks may be able to detect abuse and neglect at an early stage, even when tamariki and *rakatahi* whaikaha are unable to express themselves or their experiences (Robinson & Graham, 2021).

6.2.5.1 – Peer support

A further aspect of social support that was reported to cultivate wellbeing was caregiver peer support (Ekas et al., 2010; Nankervis et al., 2011). While there are a variety of international examples of caregiver peer support organisations, in Aotearoa New Zealand, Parent to Parent is a model that matches parents of tamariki whaikaha with trained volunteer Support Parents who have a child or family member with the same or a similar disability, health impairment, or are experiencing a similar issue (Parent to Parent, n.d.). Through peer support models, “Parents can share their experiences in a supportive group setting and trade information on resources, address issues related to their children’s disabilities, and create informal support networks” (Child Welfare Information Gateway, 2018, p. 10).

6.2.5.2 – Non-caregiving employment

A further research project conducted in Croatia explored how the employment status of whānau-carers of tamariki and *rakatahi* whaikaha contributes to whānau wellbeing (Tokić et al., 2023). For example, parents whom the Croatian government paid to care for a tamaiti whaikaha had a wellbeing status similar to unemployed parents. However, parents with full-time or part-time employment were healthier and more satisfied with their lives. One of the cited reasons was that employment offers respite from the responsibilities of caring for a tamaiti whaikaha. Parents with non-caregiving employment were also more likely to have a greater level of social support when compared to unemployed parents and parents in paid caregiving roles. Despite the challenges of balancing caregiving responsibilities and employment, this research suggests that employment plays an

important role in the wellbeing of parents/caregivers and the wider family (Tokić et al., 2023).

6.2.6 – Professional health and wellbeing support

Related to the services offered by intensive family support (IFS) and intensive family preservation (IFP) programmes, was a more general body of literature regarding the impact of professional support for whānau affected by disability. One Australian study found that having access to professional support was a key factor in promoting positive family outcomes and wellbeing (Davis & Gavidia-Payne, 2009). Delivering family-centred services in a supportive and respectful manner while treating parents as active partners in the care of their tamaiti whaikaha was found to contribute positively to family outcomes. Providing information to parents and delivering services in a coordinated and comprehensive way also promoted positive whānau outcomes. While family income was a predictor of positive whānau outcomes, family income was no longer a factor when both extended whānau and professional support were considered. These findings demonstrate that personal resources are less important to whānau wellbeing than having access to adequate formal support (Davis & Gavidia-Payne, 2009).

Another aspect of social support identified in the literature was telehealth (Kelson & Dorstyn, 2023), which is defined as “health care delivered using digital technology where participants may be separated by time and/or distance” (NZ Telehealth Forum & Resource Centre, n.d.). Whānau-carers of tamariki and rakatahi whaikaha are known to experience higher rates of psychosocial distress due to caring responsibilities, and often have little time to access support. Telehealth allows whānau-carers to choose when and how frequently they access support, such as counselling. While evidence indicates positive outcomes when carers access telehealth, data on the long-term benefits is limited (Kelson & Dorstyn, 2023).

6.2.7 – Client-led and flexible funding models

Globally, there has been a shift from government-managed funding to consumer or client-led approaches that enable tākata whaikaha to exercise their human rights (Foley et al., 2020). With research consistently showing that individualised funding can have a positive

impact on disabled people's quality of life, client satisfaction, and safety (Fleming et al., 2019), client-led and flexible funding models that cultivate wellbeing for tamariki and rakatahi whaikaha and their whānau should be considered as a key element of any prevention strategy. For example, in the review of the Family Start programme, social workers reported that the most helpful services and supports for whānau with tamariki whaikaha were the Child Disability Allowance (62%), the Early Learning Payment (40%), Speech-language Therapists (36%), Early Childhood Education (33%), and Child Development Services (31%):

Direct monetary transfers (such as the allowances above) were seen as particularly helpful for families because many face poverty and deprivation. They help with additional costs related to their children's disabilities and sometimes the parents'/caregivers' disabilities. Many parents/caregivers are full-time carers of children with complex disabilities and need multiple sources of financial help (Oranga Tamariki Evidence Centre, 2019, pp. 3-4).

In Aotearoa New Zealand, Individualised Funding (IF) is a type of person-directed funding from Whaikaha – Ministry of Disabled People that gives tākata whaikaha and their whānau more choice in how they are supported to live their lives. This includes respite services to help carers take a break, such as facility-based respite, Carer Support, and In-home support. IF increases choice and control about who provides support, and how, and when it is used (Whaikaha – Ministry of Disabled People, n.d.). However, in March 2024, changes were made to IF Purchasing Guidelines – effective immediately and without community consultation – restricting what tākata whaikaha and whānau-carers could spend their flexible funding packages on. This led to distress across the disability sector, including for whānau-carers of tamariki and rakatahi whaikaha – some of whom described being close to “breaking point” (Ridout, 2024).

The literature also points to the challenges associated with flexible funding models. For example, delays in accessing and receiving funds, overly complex and bureaucratic processes, general lack of clarity, inconsistent approaches to delivery, unmet information needs, and hidden costs or administrative charges, which “can be [a] source of considerable concern and stress” (Fleming et al., 2019, p. 2). For example, in the

Aotearoa New Zealand study investigating the experiences of mothers of autistic children, participants reported that the funding system was complex, leaving them feeling anxious, stressed, and disenfranchised. This included an unwelcoming, oppressive and complicated assessment process and that individualised funding criteria failed to consider the holistic needs of whānau (Priestly et al., 2022).

6.2.8 – Training and education

Globally, initiatives aimed at training and educating caregivers, professionals and tamariki and rakatahi whaikaha in abuse prevention have had some success (Nankervis et al., 2011; Keen et al., 2010; Starc et al., 2014). For example, Family Connection – a USA-based initiative that draws on an international evidence-based programme called Positive Parenting Program (Triple P). Within Triple P, Stepping Stones is an evidence-based curriculum that is specific for parents of tamariki whaikaha. Informed by a strengths-based approach, the Stepping Stones curriculum helps parents manage problem behaviours and developmental issues common in tamariki whaikaha, while also helping parents to encourage positive behaviours, cope with stress, develop close relationships with tamariki and teach tamariki new skills (Child Welfare Information Gateway, 2018). As highlighted in a literature review on disability, respite, and relinquishment, “evidence indicates that the effects of these programs [for example, Triple P] are maintained after the intervention has ceased, the reduced stress experienced by the family can have a flow on effect for risk of relinquishment” (Nankervis et al., 2011, p. 158). Another example is ENVISAGE in Australia – a parenting programme specifically targeted at parents of tamariki with early-onset neurodiversity. This is a co-designed and co-led programme for new parents that provides skills, knowledge, and social networks. Participants in the programme reported improvement in family function and confidence in their parenting (Miller et al., 2023). Research shows that parents with tamariki who have higher needs (including disabled children) are more likely to seek parenting training and programmes. Furthermore, a child's level of need is likely to be reflected in the retention of skills learned in parenting programmes (Britto et al., 2022).

At a community level, it is also beneficial for frontline staff and professionals to be trained to recognise maltreatment of tamariki and rakatahi whaikaha, while promoting positive societal attitudes towards them. This includes:

- ensuring community members are aware of the heightened risk;
- helping others see tamariki and rakatahi whaikaha as valued and unique individuals;
- promoting the inclusion of tamariki and rakatahi whaikaha in everyday life; and
- encouraging communities to share the responsibility for the wellbeing of tamariki and rakatahi whaikaha (Child Welfare Information Gateway, 2018).

Training and education can also extend to tamariki and rakatahi whaikaha themselves: “Teaching children with disabilities about the risks of abuse and neglect, as well as improving their ability to advocate for themselves, can help reduce maltreatment among this population” (Child Welfare Information Gateway, p. 11). As such, the Child Welfare Information Gateway recommends prevention strategies that involve tamariki at risk of maltreatment in group-based educational opportunities regarding abuse and neglect; supporting effective communication skills of tamariki whaikaha; and reducing their social isolation.

6.3 – Youth justice prevention strategies

Relevant foundational question/s:

- Question 3: Are there systemic prevention initiatives (nationally or internationally) that demonstrate successful outcomes?

Key insights:

- Tamariki and rakatahi whaikaha are disproportionately represented within the youth justice system, both in Aotearoa New Zealand and internationally.
- Successful initiatives within schools that can prevent the exclusion of tauira whaikaha from school (and thus from being more likely to enter the youth justice system) focus on transforming school systems and environments to enable positive tauira behaviour and conflict resolution.
- Mentoring programmes are an effective prevention strategy that can increase wellbeing. Programmes that operate on a one-to-one basis, at the pace of rakatahi whaikaha, focus on building a strong relationship, and are responsive to the needs of tamariki whaikaha are effective.
- Police training to effectively identify a person's disability can be a preventative factor. Early identification can prevent an escalation of conflict and lead to early diversion away from youth justice systems.
- Comprehensive disability training for justice professionals is critical. Initiatives such as the Mental Health Intervention Project and Crisis Intervention Training can increase knowledge and the use of diversion.
- Once tamariki and rakatahi whaikaha are engaged in youth justice systems, they must receive reasonable accommodations to enable them to engage effectively. Initiatives such as the Young Adult List (YAL), the modifications provided by the current Youth Court, and specialist disability advocacy services can be effective at such secondary prevention efforts.

High numbers of rakatahi whaikaha have been found to enter the youth justice system. In the United Kingdom, a seminal report identified very high rates of neurodivergent young

people within custody. For example, people with a learning disability were found to represent 23% to 32% of young people in custody when they make up only two to four per cent of the general population (Hughes et al., 2012). Studies focusing on prevalence rates in Aotearoa New Zealand, have also identified that even though young autistic people have lower rates of proceedings against by police than those without autism (Bowden et al., 2021), young adults with ADHD are significantly more likely to interact with the criminal justice system (Anns et al., 2023). Young male offenders and remandees have also been found to have high rates of auditory and language difficulties (Lount et al., 2017). There has also been ample acknowledgement and insights from professionals highlighting the over-representation of young disabled people within the youth justice population (Gibbs & Sherwood, 2017; Lynch, 2016). For example, Principal Youth Court Judge Andrew Becroft noted that there is a “sky high disproportionate prevalence in the New Zealand youth justice system” of young people who are neurodiverse (Lynch, 2016, p. 8).

Rakatahi who enter care settings are far more likely to become involved in youth justice and have been termed ‘crossover children’ (Baidawi & Piquero, 2020, p. 803). This pathway has also been termed the “care to custody pipeline” (Zhang, 2022, p. 149). For example, in England and Wales it was found that around 50% of the tamariki in custody had been in care at some point in their lives (Prison Reform Trust, 2016). In Aotearoa New Zealand, 97% of tamariki and 88% of rakatahi who had been referred for a youth justice Family Group Conference (FGC) had been the subject of a report of concern to Oranga Tamariki relating to their welfare (Reil et al., 2022).

Research shows that when tamariki and rakatahi whaikaha experience both care and youth justice settings they are likely to experience “greater cumulative maltreatment and adversity, earlier out-of-home care entry and offending onset, more caregiver relinquishment and residential care placement, and a greater volume of charges” (Baidawi & Piquero, 2020, p. 816). The link between tamariki in care and rakatahi entering youth justice, and the poor outcomes for crossover children highlights the importance of a two-pronged prevention approach that focuses both on entry into care settings and entry into youth justice settings.

Many strategies and innovations discussed in this section will likely have a preventative effect on rakatahi entering youth justice. Building the capacity of family, whānau, and carers through the provision of support has been shown to increase the stability of relationships within the home and to reduce the likelihood that rakatahi whaikaha will engage with youth justice (Oatley & Gibbs, 2020). However, investment in youth justice-specific prevention strategies and initiatives is also critical, and working with legal professionals and schools is required to identify and support tamariki and rakatahi whaikaha. It also means transforming legal processes to accommodate tamariki and rakatahi whaikaha and provide wraparound services, which can prevent the matter from escalating and rakatahi from becoming involved and entrenched within the justice system.

The following collection of findings draws on national and international literature to identify a variety of approaches that have proved helpful to rakatahi at risk of entering youth justice settings. This section will provide a brief overview of prevention strategies in this field. It is important to note, however, this topic requires a dedicated piece of work that delves deeply into the context surrounding tamariki and rakatahi whaikaha and their involvement in youth justice systems, and why and how such entanglement occurs.

6.3.1 – Early interventions within schools

High rates of tauira whaikaha experience disciplinary school exclusion (including suspensions and expulsions) compared to non-disabled tauira (Kervick et al., 2019; Mendoza et al., 2019; Sullivan et al., 2014). Strict school discipline and exclusion practices increase the likelihood of rakatahi becoming involved with the youth justice system (Mendoza et al., 2019). This is likely why primary, intermediate, and secondary schools were the most prevalent settings for primary prevention initiatives discussed within the youth justice literature. Schools were noted as offering an existing infrastructure to implement early intervention programmes. For example, the Principal Youth Court Judge, Andrew Becroft, highlights education as a preventative factor against youth offending, noting that “teachers are ‘firstline crime fighters’ with the best chance of helping youths out of a cycle of crime” (Dyslexia Foundation, n.d., para. 13).

6.3.1.1 – Positive Behaviour for Learning School-Wide (PBLS)

A specific model that has been developed for reducing behavioural issues within schools is the Positive Behaviour for Learning School-Wide (PBLS) model. PBLS focuses on transforming the environment, systems, and practices of a school to increase tauira positive behaviour choices rather than attempting to change the tauira (Ministry of Education, n.d.). The model consists of a school-wide framework that can take at least three to five years to implement. The implementation takes schools through a tiered process with tier one reviewing the support systems and processes across the entire school that impact all tauira (primary, track 1 level prevention). Tier two (secondary, track 2 level prevention) puts in place interventions for tauira who need additional behaviour and learning support and tier three (also secondary, track 2 level prevention) looks at more individualised and intensive support for tauira whose needs are not met by tiers one and two and who exhibit highly challenging behaviours (Ministry of Education, n.d.).

The PBLS model has been evaluated internationally (mainly in the United States) and has found to be effective for tauira whaikaha through improving educational outcomes, reducing rates of suspension and expulsion, addressing behaviour support needs, and preventing exclusionary discipline (Bradshaw et al., 2012; Loman et al., 2018; Meyer et al., 2021; Simonsen et al., 2021; Grasley-Boy et al., 2022). The implementation of this model has also led to increased positive behaviours and emotional regulation by tauira whaikaha (Bradshaw et al., 2012). The Ministry of Education has promoted the PBLS model within Aotearoa New Zealand, which is called School Wide. The Ministry of Education published an evaluation of this model in 2015, which, though not explicitly referring to disability, emphasises the positive shifts in practice and outcomes due to this model (Boyd & Felgate, 2015).

Though the outcomes of the PBLS model look promising, some studies have found that implementing this model alone may not address all equity issues within schools (McIntosh et al., 2018). Some theorists have suggested that further steps may be needed, such as increased professional development for teaching staff and adopting formal policies that explicitly address equity within school disciplinary practices (Skiba et al., 2011). Nevertheless, the engagement with the PBLS model within New Zealand schools represents an opportunity for Oranga Tamariki to collaborate with the Ministry of

Education to implement PBLS programming for tamariki and rakatahi whaikaha, and continue to facilitate its adoption across Aotearoa New Zealand.

6.3.1.2 – Restorative justice

A further tool that has been found to improve school environments for tamariki and rakatahi whaikaha is restorative practice (also referred to in the school-focused literature as restorative approaches and restorative justice) (Kervick et al., 2019). Restorative practice within education systems:

[E]ncompasses a variety of relational processes that create intentional opportunities for building trust, connections, and understanding within a community. In a classroom, this can look like whole-class community building circles, the use of affective statements, small group conferencing when an issue arises, and formal restorative conferences to address and repair harm (p. 590).

Traditional approaches to school discipline have tended to draw on the medical model of disability, which places individual responsibility on students and families to respond to difficult or challenging behaviours. Kervick et al. (2019) argue that restorative practice principles implemented within a whole-school approach can address the discipline inequities experienced by tauira whaikaha and shift the emphasis toward the environment the tauira is situated within (similar to the PBLS model, and in alignment with the social and rights models of disability, and community level response within the socio-ecological model). Through negotiation and mediation, rather than disciplinary methods such as suspension and expulsion, both parties can move forward without experiencing unnecessary exclusion. Such processes must be implemented utilising track 1 universal design principles to ensure accessibility for all tauira. Adopting such practices can mitigate disciplinary inequities that often drive tamariki and rakatahi whaikaha out of school and into youth justice settings (Kervick et al., 2019).

6.3.2 – Mentoring programmes

Mentoring programmes generally match a mentor to a tamaiti and rakatahi. The aim is to build a trusting and respectful relationship, enabling the tamaiti and rakatahi to achieve their goals (Oranga Tamariki, 2022). In Aotearoa New Zealand, Oranga Tamariki currently refers tamariki and rakatahi to mentoring programmes (Oranga Tamariki, 2022). Research has shown that connecting rakatahi to mentoring programmes is an effective strategy for preventing “delinquent” behaviour that can bring them into contact with youth justice systems (Tolan et al., 2013). Canadian research has also found that tamariki and rakatahi whaikaha participation in mentoring programmes can improve their engagement in education and employment, transitions into adulthood, social connection, and psychosocial health and wellbeing (Lindsay & Munson, 2018). Mentoring programmes can be conducted in schools or independent mentoring organisations (Bradley, 2016; Mills & Thomson, 2018).

An example of a successful mentoring programme is SEND, a programme for tamariki with special educational needs and disabilities (SEND) in Wakefield, United Kingdom. The programme aims to achieve post-pandemic engagement or re-engagement of SEND tamariki with their social, recreational, educational, and professional lives. Utilising a one-to-one mentorship program, meetings take place in the whānau home, and at their pace, to ensure comfort and to better support the whānau. A second family worker also helps explain the intervention to the parents (IFF Research, 2023). A second example is the *Pro Se: Speech & Debate* programme. The programme was developed from a collaboration between the RIYS Diversion Programme and Cornell University, and offers virtual mentorship and additional education in speech, debate, and self-advocacy to rakatahi whaikaha who have current or prior involvement in the youth justice system. Data from the pilot programme was positive, with over 80% of the participants progressing toward their goals or successfully graduating from the programme (Sergio & Saleh, 2023).

As noted in the literature, mentoring programmes must be responsive to and inclusive of the specific needs of tamariki and rakatahi whaikaha. For example, a peer mentoring programme in England specifically focused on autistic students emphasised the development of social competence, meaning the skills needed to form meaningful

relationships and manage social interactions (Bradley, 2016). Social competence has been found to enable young autistic people to learn communication skills to better develop friendships (Bradley, 2016). After implementation in five mainstream secondary schools, an evaluation of the programme showed positive impacts on autistic students' self-esteem and social satisfaction, as well as decreased levels of bullying experienced by the students. The study concluded that the mentoring programme positively impacted the students' well-being (Bradley, 2016).

6.3.3 – Early identification of disability by justice professionals

When tamariki and rakatahi whaikaha come into contact with frontline justice professionals, such professionals must have screening methods to ensure effective identification of disability. Effective identification will likely improve engagement between legal professionals and tamariki and rakatahi whaikaha and can prevent escalating conflicts (Gibbs, 2022). This is important, as interactions between tamariki and rakatahi whaikaha and justice professionals can sometimes escalate due to a lack of understanding of their disability-specific needs. For example, advocates have described encounters where a young person reacts to a triggering action, leading to conflict, which can then lead to charges (Snydman, 2022). Early identification can prevent this conflict and indicate to frontline workers that the young person requires accommodations such as not being touched, modified communication, breaks, a sign language interpreter, a support person, and diversion programmes (Dowse et al., 2021).

Effective de-escalation and providing accommodations after early identification can prevent tamariki and rakatahi whaikaha from becoming involved in the criminal justice system and can improve justice outcomes (Holland et al., 2023). Australian research has highlighted the difficulties justice professionals face when identifying disability, especially when individuals have an “invisible disability” such as a learning disability (Australian Human Rights Commission, 2014; Dowse et al., 2021). For example, a systematic review of the international peer-reviewed research on police engaging with individuals with a learning disability who are alleged offenders recommended specialised disability awareness training to improve police skills in identifying people with a learning disability

and upskilling police to support and communicate effectively with them (Gulati et al., 2020).

An example of such training can be seen in a partnership between the Tasmania Police in Australia and the Brain Injury Association of Tasmania. The partnership aims to improve disability identification for police to recognise and respond inclusively to disabled people. Part of this initiative involved the Brain Injury Association of Tasmania providing identification cards to people with an acquired brain injury (The National Assistance Card, n.d.). This card includes personal details, a nominated contact number and information about their disability to better inform police they engage with (Australian Human Rights Commission, 2014). A data sharing agreement is also being trialled with Tasmania Police where National Assistance Card cardholders will have their personal identity record flagged in the Police database. Therefore, if Police are contacted regarding a cardholder, they will have access to that cardholder's information prior to the call-out enabling an informed and appropriate response (National Assistance Card, n.d.a). Though this initiative appears promising, a comprehensive evaluation could not be identified.

6.3.4 – Training and education

It has been noted that one of the main barriers to preventing tamariki and rakatahi whaikaha from entering the youth justice system is the lack of education on disability available to, and targeted at, justice professionals (Oatley & Gibbs, 2020; Ellem & Richards, 2018). In the USA, the National Disability Rights Network, have noted that tamariki and rakatahi whaikaha can often be arrested by police for behaviour that appears concerning but is actually harmless. Training of justice professionals can prevent such negative interactions (National Disability Rights Network, 2019). Justice professionals being better informed about disability is likely to improve engagement with tamariki and rakatahi whaikaha and therefore decrease the risk of harm to tamariki and rakatahi whaikaha who do engage. For example, police officers have expressed frustration at the lack of resources available to them and at being expected to respond to situations they feel unequipped to manage, for example responding to those experiencing a mental health crisis (Australian Human Rights Commission, 2014).

An example of direct training for legal professionals is the Mental Health Intervention Project that was implemented in the Australian territories. In this project, local law enforcement officers, service providers and health workers would meet regularly to discuss potentially at-risk locals. Many of these rakatahi had emotional, behavioural, or psychosocial disabilities, or were neurodivergent. By having prior knowledge of who they may be engaging with, police learned to implement strategies to better respond to their needs upon engagement or implement early intervention strategies to prevent engagement from needing to occur. For youth justice, these representatives should include school personnel to identify at-risk students (Australian Human Rights Commission, 2014).

Another training programme found to be effective is the Crisis Intervention Team Training Model (CIT) that originated in the USA. The intensive training to justice professionals provides them with the skills to de-escalate situations involving individuals experiencing mental distress or psychosocial disability. It also provides them with further knowledge as to how to divert these individuals from involvement in the justice system (Doulas & Lurigio, 2010, 2014; Ellem & Richards, 2018). CIT for rakatahi with mental illness is:

designed to ensure that youths with mental illness receive the assessment and treatment services needed to prevent recidivism and preclude further penetration into the justice system. With the advent of youth CITs, law enforcement officers are now becoming the critical links between schools and community resources, as their involvement is pivotal for deflecting youths with mental illness from the juvenile and adult criminal justice systems (Doulas & Lurigio, 2010, p. 242).

CIT has been implemented throughout the USA, including Texas, Chicago, and Denver. The Children in Crisis programme in Denver, for example, operates under three criteria: recognising mental illness, responding appropriately, and providing resources for follow-up care for rakatahi experiencing distress and crises. It consists of a 45-hour curriculum where police learn about trauma, common mental illnesses, and effective response tactics (Doulas & Lurigio, 2010). Adult-focused CIT has been found to be effective in

decreasing arrests and use of force and in increasing referrals to mental health services (Compton et al., 2014; Watson et al., 2017).

A study that evaluated a child focused intervention called Crisis Intervention Teams for Youth (CIT-Y), which consisted of 40 hours of training, 24-hour accessibility to mental health services and community collaboration, found that CIT-Y was feasible in the US counties where it was conducted and was acceptable to the officers who took part. The outcomes showed that 86% of the police officers who participated had positive changes in their knowledge and attitudes toward rakatahi with psychosocial disability and described increased knowledge of community resources for rakatahi (Kubiak et al., 2019).

6.3.5 – Accommodations and additional support once rakatahi become involved in the justice system

Once tamariki and rakatahi whaikaha are engaged in the youth justice system, they are entitled to receive accommodations that enable them to engage effectively. The Australian Human Rights Commission (2014) noted that “The Convention on the Rights of Persons with Disabilities … clearly states that people with disabilities must be provided with necessary modifications and adjustments to obtain effective access to justice” (p. 10). Such accommodations, according to the definition of prevention currently used by Oranga Tamariki, can be understood as tertiary-level prevention efforts.

6.3.5.1 – Youth Court, Rakatahi Courts, Pasefika Courts, and the Young Adult List

Modifications to the traditional court process to ensure accessibility and the provision of extra support have been found to improve outcomes for tamariki and rakatahi whaikaha who have become involved with the justice system. Such modifications have been made in the Youth Court and the Young Adult List (YAL) in Aotearoa New Zealand (Clasby et. al 2022). Youth Court processes that have been noted as effective for rakatahi with a neurodivergence include increased screening for disability, the provision of a Youth Forensic Service nurse as well as Education Officers (which can mean disability is identified more often), and the increased use of Section 333 health assessor reports, which assist justice professionals to better understand the young person to inform decision-making (Lynch, 2016). Professionals working with rakatahi with Foetal Alcohol

Spectrum Disorder (FASD) have spoken highly of the youth justice system in its response to these rakatahi, emphasising its ability to screen for FASD, focus on the underlying needs of the rakatahi, and provide helpful interventions (Sherwood, 2020).

A youth justice initiative that has increasingly become available to rakatahi Māori and Pasefika rakatahi who have admitted to charges are Kā Kōti Rakatahi (Rakatahi Courts) and Pasefika Courts. Rakatahi Courts are held on marae, observing te ao Māori and tikaka Māori. Kā Kōti Rakatahi have been in existence for approximately 15 years, and there are currently 15 courts in operation. Similarly, Pasefika Courts observe Pasefika cultural processes and are typically held in churches or community centres. Access to the courts for Pasefika rakatahi is very limited at present, with only two courts in operation – both based in Tāmaki Makaurau. The courts are designed to ensure Māori and Pacifica rakatahi are active participants in their own legal matters and processes, and to also enable whānau, aiga and the community to be involved.

A 2012 evaluation of Kā Kōti Rakatahi reported many positive outcomes, including high attendance, rakatahi feeling welcome and respected, showing positive attitudes, and taking responsibility for their offending, establishing connections with their marae, and taking on leadership roles. Whānau, agencies, and marae communities also reported positive outcomes including: whānau feeling better supported in their parenting role and as having better whānau relationships; agencies having the opportunity to develop networks and relationships, and to increase their cultural competency, and marae communities as being able to uphold the mana of rakatahi, while still holding them accountable (Kaipuke Consultants, 2012). While Kā Kōti Rakatahi and Pasefika Courts provide innovative and culturally responsive approaches to preventing tamariki and rakatahi from entering the justice system, further research is needed to understand the specific experiences of tamariki and rakatahi whaikaha and their whānau.

Finally, the YAL was first trialled in the Porirua District Court but is now also implemented in the Gisborne District Court and Hamilton District Court (Ministry of Justice, n.d.). The YAL is targeted towards rakatahi aged between 18 and 24, ensuring their engagement in the District Court is tailored to their needs and they are connected to community support. The YAL was developed and implemented after judges noticed that rakatahi between the

ages of 18 and 24 experience particular challenges and need quality support when engaging in court processes. Judges, such as Judge Walker and Judge Becroft, also noticed that many rakatahi engaging in the justice system were neurodivergent and experienced mental distress, which created significant barriers to their participation in court processes (Johnson, 2021).

Adjustments made within the YAL process include simple screening processes that can identify potential disabilities, the use of plain language, checking that the rakatahi understands what is happening, and a change in the architecture of the courtroom to ensure accessibility and whānau involvement (Johnson, 2021; Clasby et al., 2022). The YAL also ensures engagement with the community by providing support from community services, therefore providing essential wrap-around services. For example, representatives from services such as MSD's Community Link, which provides access to services such as service volunteer programmes, finding employment, benefit support, and services around health and housing can be present in the court (Johnson, 2021). While the YAL is not targeted at rakatahi engaged in the Youth Court, it highlights interventions that are effective for rakatahi involved in court processes.

In 2021, a short-term outcome evaluation of the YAL initiative in the Porirua District Court showed early promise, with YAL participants and key stakeholders reporting largely positive experiences (Paulin et al., 2021). Rakatahi who had participated in the YAL noted that they found the process easier to understand, they appreciated the respect shown to them by the judge, appreciated being referred to interventions they needed, and noted that the experience made them think more deeply about their future and make positive changes in their life. Key stakeholders felt that rakatahi were given increased opportunities to be referred to service providers who could support them to acquire new skills and qualifications. They also noted that the initiative gave justice professionals access to more extensive information about young defendant's disabilities than they otherwise would have (Paulin et al., 2021). In 2022, a further evaluation of the YAL occurred. Recommendations that could further improve the court experience and increase access to justice for neurodivergent rakatahi were identified, including a need for neurodivergence education and screening within the court environment (Clasby, et.al., 2022).

6.3.5.2 – Advocacy services

Rakatahi have reported a lack of advocates who can interact with justice professionals when they do come into contact with youth justice systems (Australian Human Rights commission, 2014). Advocacy is “based on principles of empowerment and is used to ensure that disadvantaged groups are aware of their rights and are assisted to secure them” (Collings et al., 2018, p. 165). Disability advocacy within legal proceedings can potentially improve outcomes for tamariki and rakatahi whaikaha due to the provision of legal advice, representation, and knowledge of diversion opportunities. This advocacy and support can better ensure justice-involved youth are receiving the ideal outcomes within their proceedings (Australian Human Rights Commission, 2014).

While there was no literature that spoke to the effectiveness of such interventions for tamariki and rakatahi whaikaha, the research has highlighted the benefits of independent legal advocacy for mātua whaikaha (disabled parents). For example, an Australian study interviewed parents with a learning disability who had engaged in care and protection proceedings and who had accessed a specialist legal advocacy programme. The programme was based in a community legal centre that specialised in supporting people with a learning disability who are involved in the justice system. Parents who engaged with these services felt a strong need for advocacy due to confusing court processes, feeling unheard and experiencing a sense of powerlessness within proceedings. The participants emphasised how having an independent advocate from a programme specialised in disability advocacy helped them to understand the process, ensured that the court took their disability into account and helped to build a bridge between them and the court (Collings et al., 2018). A similar legal advocacy service in the United Kingdom was also found to be effective for mātua whaikaha with a legal professional noting that “[t]he service better prepares clients, gives them a better understanding of the issues and allows their views to be better represented” (English, 2010, p. 27).

In Aotearoa New Zealand, youth advocates and lay advocates are appointed for rakatahi in the Youth Court. A youth advocate is a trained lawyer, while a lay advocate is a person with mana or standing in the young person’s community (Ministry of Justice, n.d.a). Oranga Tamariki already works alongside lay advocates to facilitate their involvement

with rakatahi (Oranga Tamariki, 2024). The above literature argues for the provision and engagement with advocacy services that cater to the specific needs of tamariki and rakatahi whaikaha, with advocates being trained to work effectively with this population.

While positive initiatives and innovations continue to occur in the youth justice context, Principal Youth Court Judge John Walker (Caught in the Act, 2022) commented in a recent editorial: “It may be time for the Oranga Tamariki Act to require the assistance of a lawyer before any statement by a young person is admissible in Court” (p. 4). Judge Walker’s remarks centre on his view that all young people, and tamariki and rakatahi whaikaha in particular, should have the highest level of legal advice and representation throughout the legal process - not just while in court. The Oranga Tamariki Act requires a nominated person to be present during questioning of a young person, and while they are making statements. However, individuals undertaking the role of nominated person may not have a comprehensive understanding of the legal rights of a young person, nor how or when to intervene when those rights have been breached. Such legislative revision may ensure more equitable access to justice for tamariki and rakatahi whaikaha.

6.4 – Systemic disparities

Relevant foundational question/s:

- Question 4: What prevention system and service disparities affect tamariki, rakatahi and mātua whaikaha and their whānau (that is, what prevention services are they not receiving)?

Key insights:

- There is little data or evidence regarding the systemic disparities tamariki, rakatahi and mātua whaikaha experience when accessing primary level prevention services, especially from a lived experience perspective.
- By drawing on wider disability research, it is possible to gain a broad understanding of barriers takata whaikaha experience, and how these may lead to primary level prevention system and service disparities experienced by tamariki, rakatahi and mātua whaikaha.
- Identified barriers include:
 - a lack of data
 - inconsistent risk threshold interpretation and implementation
 - distrust
 - exclusion from education systems
 - a lack of education and training in disability
 - overburdened disability, health, and social services systems
 - a lack of access to referrals and diagnosis
 - complex information and systems
 - social isolation, and
 - a lack of tamariki friendly services for parents with psychosocial disabilities

While research shows tamariki, rakatahi and mātua whaikaha are at greater risk of engagement with care, protection and justice services, there was very little research specifically addressing the disparities they experience when engaging with existing

primary level prevention programmes. Further research from a Tiriti o Waitangi and disability rights-based lens is required to fully understand where the gaps in services are for tamariki, rakatahi, and mātua whaikaha engaging (or not engaging) with initiatives known to reduce the risk interactions with care and justice settings and/or cultivating wellbeing. However, it is possible to draw on broader literature to identify key barriers to disabled people's general engagement in health and wellbeing strategies.

Lack of data: A common and persistent message throughout the reviewed literature was the lack of data and evidence regarding tamariki, rakatahi, and mātua whaikaha engagement in primary prevention initiatives (Child Welfare Information Gateway, 2018; Health and Disability, 2023; Ng & Rhodes, 2018; Royal Commission of Inquiry into Abuse in Care, 2021; Victorian Equal Opportunity & Human Rights Commission, 2015). As highlighted in a previous Oranga Tamariki report (Donald Beasley Institute, 2023), collecting current and accurate data on why tamariki whaikaha enter care can inform what community-based supports can and should be provided to families and whānau to prevent the past from being repeated. This has the potential to progress the goals of the Oranga Tamariki Outcomes Framework, particularly, “[c]hildren are safe and flourishing in their homes” (Oranga Tamariki, 2021, p. 18). Such information can also support the prevention of disproportionate abuse experienced by tamariki whaikaha. Data and evidence are crucial to understanding systemic disparities experienced by tamariki, rakatahi, and mātua whaikaha.

Risk thresholds: As noted by Kelly and Dowling (2015), it is important to interrogate risk thresholds for child protection through a disability lens. For example, in an Ofsted report entitled ‘Protecting Disabled Children’, it was recognised that neglect is not always recognised in time, because it does not reach the risk threshold:

In many of the child protection cases examined by inspectors, where neglect was the key risk, children had previously received support as children in need for a long time. Despite the lack of improvement for the child there were delays in recognising that the levels of neglect had met the threshold for child protection. In many of these cases the impact of poor parenting on the child was not clearly seen and the focus on the child was lost (Ofsted, 2012, p. 4).

Further research by Taylor et al. (2014) highlighted that thresholds for triggering action in the Scottish child protection system were higher for tamariki and rakatahi whaikaha than for non-disabled tamariki and rakatahi, and that there can be variance across protection service's interpretation of levels of significant harm, with some issues being perceived as family support rather than child protection concerns. Similarly, in a UK-based study by Stalker et al. (2010), findings showed that:

- social workers who develop close working relationships with carers can sometimes empathise with the demands they experience and may be reluctant to make a formal child protection referral if they witness "a wee bit of neglect or whatever" (p. 18);
- some social workers appear to be more tolerant of carers assaulting a disabled child than a non-disabled child;
- different organisations may have differing understandings of acceptable 'thresholds'. For example, schools sometimes raise early concerns, which social workers may perceive as premature.

Distrust: Tākata whaikaha and whānau distrust of public institutions (including Oranga Tamariki) is well documented (Bollinger, 2024; Calgaro et al., 2022; Donald Beasley Institute, 2022; Human Rights Commission | Te Kāhui Tika Tangata, 2021). As highlighted in Te Kahu Aroha, "Some whānau don't trust the system enough to ask for the help that is available. This reinforces the system's inability to prevent harm" (Te Kahu Aroha, 2024, p. 63). For example, parents with a learning disability often feel judged on their ability to raise their tamariki (Theodore et al., 2018), and have subsequent fears about seeking help from support services in their community. As a result, they may avoid seeking help (Collings et al., 2017; Raising Children Network Australia, 2024), and engaging in primary and secondary level prevention strategies. Māori distrust towards Oranga Tamariki has also been documented (Oranga Tamariki Evidence Centre, 2020; Te Kahu Aroha, 2024; Whānau Ora Commissioning Agency, 2020), which may be exacerbated for tamariki, rakatahi and mātua whaikaha Māori, and their whānau. Tākata whaikaha in Aotearoa New Zealand have also expressed distrust in frontline legal professionals such as police, with Tākata whaikaha having lower levels of trust in police than non-disabled people (Statistics New Zealand, 2020).

Exclusion from education systems: While legally permitted to attend their local school, tamariki and rakatahi whaikaha continue to experience exclusion from mainstream school settings, as well as absenteeism due to health and disability factors (Kervick et al., 2019; Mendoza et al., 2019; Sullivan et al., 2014). In a report regarding monitoring of the UNCRPD access to education was identified as a key issue for tamariki and rakatahi whaikaha, noting that “[e]xclusion, isolation and bullying remain significant issues for children and youth. Education-related complaints continue to make up a large proportion of disability complaints to the Human Rights Commission” (Independent Monitoring Mechanism, 2014, p. 8). For example, access to Early Childhood Education (ECE). Research shows that attending high-quality ECE leads to positive life outcomes such as education, health, wellbeing, emotional, and social skills (Office for Disability Issues, 2022). However, recent research from Aotearoa New Zealand showed that tamariki whaikaha, especially tamariki with complex disabilities, are more likely to experience barriers when enrolling in ECE. This means there may be fewer touch points for identifying and addressing wellbeing concerns (Tokić et al., 2023).

Lack of training and education: Social workers and other frontline staff such as youth workers, family-support workers and police often do not have sufficient training in disability rights and awareness (Hedgepeth-Smith, 2023; Milner et al., 2016; Simpson et al., 2022; Royal Commission of Inquiry into Abuse in Care, 2021; Victorian Equal Opportunity & Human Rights Commission, 2012; Child Welfare Information Gateway, 2018). As a result, they can be ill equipped to support and/or respond to tamariki, rakatahi and mātua whaikaha, and their whānau (Simpson et al., 2022). As such, there is risk that prevention responses are developed and delivered in a way that is not aligned with the social and rights models of disability. Parents and carers of tamariki and rakatahi whaikaha have noted that there is a lack of knowledge about disability in both the education and social assistance workforce and a persistent stigma that “remains deeply embedded in the public mind about disability, particularly intellectual disability” (Child Poverty Action Group, 2015, p. 24).

Practitioners supporting tamariki, rakatahi whaikaha and their whānau have also highlighted a lack of disability knowledge when responding to abuse and neglect experienced by tamariki and rakatahi whaikaha (Simpson et al., 2022). Practitioners have

shared that it is sometimes unclear whether the experiences of tamariki and rakatahi whaikaha is a child protection issue, or a disability issue related to lack of support provided to the whānau. Moreover, they reported there were situations where they could not respond to experiences of harm due to the high needs of tamariki and rakatahi whaikaha and the lack of options available to them such as out-of-home-care (Simpson et al., 2022).

Legal professionals such as lawyers and police have also expressed a lack of knowledge and training regarding disability (Hedgepeth-Smith, 2023; Eadens et al., 2015). In a U.S. study that interviewed 188 police officers 84.1% noted that they have received none or only minimal education and training regarding disability (Eadens et al., 2015). In Aotearoa New Zealand, lawyers have identified the need for increased disability education around learning disability highlighting the need for increased education around relevant legislation, as well as how to better communicate with people with a learning disability. They have noted the importance of individuals with a learning disability being involved in the development of this training and also highlighted the need for police to engage in further education as police were seen as being very under-educated in disability (Mirfin-Veitch et al., 2014).

Overburdened disability, health, and social services system: When referrals to social, health, and wellbeing services are made, the wait time can be long, particularly for disability-related services such as diagnosis of neurodivergent conditions, and for takata whaikaha living in regions where services are not readily available (Donald Beasley Institute, 2022). Young autistic people and their families have described finding the process of obtaining a diagnosis as stressful, with an average time spent on a wait list of 5.3 months (Eggleston et al., 2019). In a scoping literature review that explored barriers tamariki and rakatahi experience when accessing mental health services, it was found that long wait times was the barrier most commonly cited (Anderson et al., 2017). The literature indicates that long wait times can negatively impact whānau engagement with services and can have negative effects on health outcomes (Te Pou, 2022). Parents and caregivers of tamariki and rakatahi whaikaha have also noted the difficulties faced when attempting to access services in Aotearoa New Zealand, with education support being highlighted as especially difficult with parents experiencing “horrendous” difficulties

obtaining “just a basic level of support” for their tamaiti (Child Poverty Action Group, 2015, p. 23).

Lack of access to referrals and diagnosis: An underfunded disability and health system can be a barrier for whānau who cannot afford travel to specialists (often in another city) to receive diagnosis and treatment or specialised services – also known as post code lottery (Donald Beasley Institute, 2022). Parents of tamariki whaikaha have described difficulties with obtaining a formal diagnosis for their tamaiti, describing expensive assessment processes (Child Poverty Action Group, 2015). Furthermore, primary prevention programmes as well as primary and secondary referral services can be inaccessible to takata whaikaha. For example, counselling services may not be accessible to people with learning disabilities (Evans & Randle-Phillips, 2018; Siddell, 2022) or neurodivergence (Jones et al., 2024), or people who use NZSL (Donald Beasley Institute, 2022). Financial and transport barriers can also negatively impact disabled people’s access to health and wellbeing services. Regarding the justice system, the literature suggests a lack of access to screening and assessment for rakatahi whaikaha who become involved with the criminal justice system in Australia and in Aotearoa New Zealand (McCarthy & Duff, 2019). A significant challenge for adopting screening and assessment tools within youth justice is the lack of validated tools that can be used with rakatahi (McVilly et al., 2019).

Complex and hard to use information and systems: “People with disabilities and their whānau and carers are likely to interact with multiple support systems and experience barriers to regularly accessing and benefitting from quality health and disability services” (Ministry of Health, 2020, p. 17). In Aotearoa New Zealand, research has shown that takata whaikaha often lack levels of health literacy that are required to navigate complex health and wellbeing systems. This is due to system shortcomings in maintaining and promoting health literacy for takata whaikaha (Donald Beasley Institute, 2022a).

Takata whaikaha have also reported that disability supports and services are overly complex, inconsistent (for example, disparities between ACC and MoH supports), and lack readily available and accessible information, resulting in many communities missing out (Donald Beasley, 2022; in print 2024). In a study that analysed New Zealand’s welfare

system, takata whaikaha spoke of difficult and onerous processes for obtaining welfare support as well as pressure to frequently re-establish eligibility, which impacted well-being (The Welfare Advisory Group, 2018).

Social isolation: New parents are known to seek social support when a tamaiti whaikaha is born. However, research shows there is less social support available for parents of tamariki whaikaha when compared to parents of non-disabled tamariki. For example, extended whānau who would usually provide social support for new parents often do not have sufficient training or knowledge about disability, and as a result feel unable or less motivated to provide support (Tokić et al. 2023). Social isolation is even more acute for whānau of tamariki whaikaha with challenging behaviours (Brennan et al., 2020). Combined with lack of support from wider whānau and the exclusion from ECE and education systems that would usually naturally provide parent and caregiver networks, some parents with tamariki and rakatahi whaikaha experience social isolation. This further impacts their well-being (Tokić et al. 2023). With regards to mātua whaikaha, a recent report on loneliness indicated that takata whaikaha are amongst the most isolated and lonely populations in Aotearoa New Zealand (Helen Clark Foundation, 2020). Research exploring the social contexts of parents with a learning disability has consistently identified social isolation as impacting their lives (Mirfin-Veitch & Asaka, 2024, in press).

Lack of child-friendly services for parents with psychosocial disabilities: Parents with psychosocial disabilities also featured in the literature, with one USA study finding that mothers with serious mental illness were almost three times as likely as other mothers without serious mental illness to have come to the attention of the child welfare system or to have lost custody of their tamariki (Park, et al., 2006). For this population, barriers include:

- Adult mental health services not identifying consumers who are parents and subsequently not being responsive to tamariki, parenting and whānau needs.
- Organisations often do not have adequate whānau and tamariki friendly policies and procedures.
- The adult mental health workforce lacks skills and knowledge about whānau, tamariki and parenting.

- The workforce needs to increase encouragement of consumers to include whānau and dependent tamariki in treatment of the ill parent including the provision of psycho-education (Maybery & Reupert, 2009).

6.5 – Recommendations

Relevant foundational question/s:

- Question 5: How can prevention be more effective for tamariki, rakatahi and mātua whaikaha and their whānau, and Oranga Tamariki kaimahi?
- Question 6: What are effective ways of designing and implementing strategies to prevent tamariki, rakatahi and mātua whaikaha, and their whānau from engaging with Oranga Tamariki?

Key insights:

- According to the literature, effective prevention strategies for tamariki, rakatahi and mātua whaikaha and their whānau are accessible, holistic, built on trust, well resourced, evidenced- and strengths-based, delivered by qualified and experienced staff, and collaborative and coordinated.
- Designing and implementing effective primary and secondary level prevention strategies can only be achieved in close consultation with tamariki, rakatahi and mātua whaikaha and their whānau. This also extends to monitoring and evaluation processes.
- The design and implementation of prevention strategies should reflect the twin-track approach by ensuring that strategies targeted at broader population groups are inclusive and accessible and that disability-specific prevention strategies are available.
- The social-ecological model provides a useful framework for understanding factors that contribute to maltreatment and risk at individual, relational, community and societal levels, as well as effective prevention responses at these levels.

The final two questions this literature review looked at were the ways in which prevention strategies and initiatives can be more effective for tamariki, rakatahi and mātua whaikaha

and their whānau, as well as effective ways of designing and implementing strategies designed to their involvement with Oranga Tamariki (and justice settings).

6.5.1 – Key elements of effective prevention strategies

Outlined below are key elements of effective prevention strategies, as suggested by the literature. These have been framed to complete the sentence ‘an effective prevention strategy is’: accessible, holistic, built on trust, well resourced, evidence-based, strengths-based, delivered by qualified and experienced staff, and collaborative and coordinated.

6.5.1.1 – Accessible

For a prevention strategy to be considered effective for tamariki, rakatahi and mātua whaikaha, they must be able to access it. Parents of tamariki and rakatahi whaikaha have reported that information about support and services for their tamariki and rakatahi is critical (Kralj, 2012 cited in Starc, 2014). In 2018, the Ministry of Social Development, in partnership with Disabled People’s Organisations (DPOs) developed the Accessibility Charter. Endorsed by at least 40 Chief Executives, the Accessibility Charter documents the Chief Executives’ commitment to delivering on Article 9 – Accessibility of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The Charter requires Oranga Tamariki to commit to working towards ensuring that all information intended for the public is accessible to everyone, and that tamariki, rakatahi, and mātua whaikaha can interact with services in a way that meets their individual needs and promotes their independence and dignity. This includes accessible web content, as well as forms, correspondence, pamphlets, brochures, and other means of interacting with the public are available in a range of accessible formats including electronic, New Zealand Sign Language, Easy Read, braille, large print, audio, captioned, and audio described videos, transcripts, and tools such as the Telephone Information Service (Ministry of Social Development, 2018).

6.5.1.2 – Holistic

While services often focus on tamariki and rakatahi whaikaha and their immediate whānau, or mātua whaikaha and their tamariki, experts recommend a whole-of-family

approach that also includes siblings, and other family members (Achola & Greene, 2016; Davis & Gavidia-Payne, 2009; Keddell et al., 2021; Fry, 2022). For example, within the family quality of life and family systems theory frameworks, approaches to interventions for tamariki, rakatahi and mātua whaikaha are holistic and include the whole whānau. Family-centred practice emphasises that all whānau are unique and must be supported as such, and that parents are the experts on their tamariki and must be central to their care. Receiving a higher level of family-centred services have been shown to cultivate wellbeing and decrease stress amongst whānau (Bhopti et al., 2016). As demonstrated in Davis and Gavidia-Payne's findings (2009), whānau reported an increase in their quality of life and wellbeing when they received a higher level of family-centred practice, especially when they were engaged as partners, provided with coordinated and comprehensive care and information, and when care was supportive and respectful. Whānau showed greater FQOL when they had increased support from extended whānau (addressing social isolation barriers) (Bhopti et al., 2016). Overall, having professional support was one of the highest indicators of FQOL. Although whānau income was positively correlated with FQOL, that significance reduced when extended whānau support and professional support were considered. This is important as it signifies that when whānau are adequately supported, personal resources matter less (Davis & Gavidia-Payne, 2009).

6.5.1.3 – Built on trust

In 2018, a review of the Machinery of Government (MoG) from the perspectives of takata whaikaha drew attention to key features, referred to as 'mana, self-determination and voice' to ensure takata whaikaha have their voice heard within the MoG arrangements (Department of The Prime Minister and Cabinet, 2018; Machinery of Government Review Working Group, n.d.). Of note, Point Five details the importance of trust:

Partnership between disabled people and government is built on trust, mutual respect and a shared purpose. Partnership involves government working with disabled people to develop arrangements that enable disabled people to access the best possible life opportunities and services available to them. Having a partnership between disabled people and government ensures both

parties can engage as equals based on a common understanding that is built on mutual respect and trust. This emphasises the need for co-design, co-decision and collaboration throughout all stages of the process (Machinery of Government Review Working Group, n.d., p. 7).

Trust was also referenced throughout the literature including the importance of social workers and health practitioners building trusting and respectful relationships with whānau (Simpson et al., 2022); improving organisational culture, including by ensuring relationships of trust and collaboration across the system (Ministerial Advisory Board Disability Report, 2022); and taking a tino rangatiratanga by Māori, for Māori, with Māori approach (Whānau Ora Commissioning Agency, 2020). As highlighted by the Royal Commission of Inquiry into Abuse in Care recommendations (2024, Care Safety Principle 3 point ii), “care providers [should] engage in open communication with whānau and support networks about their abuse and neglect prevention approach.” Furthermore, research indicates that trusting relationships are a key factor in safeguarding tamariki and rakatahi whaikaha from harm (Robinson & Graham, 2021) and preventing them from coming into care (Baxter et al., 2023).

6.5.1.4 – Well-resourced

Research shows that disadvantage and reduced wellbeing experienced by tamariki, rakatahi, and mātua whaikaha and their whānau can be mitigated by increasing their access to personal, economic, material, social and community resources (Savage et al., 2014). Material resources can help facilitate initial and ongoing access to supports that contribute to the prevention of harm and cultivates wellbeing for tamariki, rakatahi, and mātua whaikaha and their whānau (Sapiets et al., 2023). An example of a material resource is individualised and flexible funding. This enables tamariki, rakatahi, and mātua whaikaha and their whānau to direct and design the supports they access and provides the potential for them to increase opportunities to develop wider relationships and connections in the community. This approach can help reduce the risk of tamariki and rakatahi whaikaha, or the tamariki of mātua whaikaha, entering care (Robinson, 2014; 2014a), and is a key recommendation of the guidelines on deinstitutionalization, including in emergencies (Committee on the Rights of Persons with Disabilities, 2022).

However, there can be additional challenges associated with navigating flexible funding, particularly when information and coordination of supports and services is not accessible or timely (Priestley et al., 2022; Gavidia-Payne, 2020). Therefore, it is important that primary and secondary prevention initiatives are well-resourced in terms of material and information, as well as human resources to coordinate them.

6.5.1.5 – Evidence-based

Research has highlighted the importance of amplifying the voices of tamariki, rakatahi, and mātua whaikaha in prevention strategy design, implementation, monitoring, and evaluation (Baxter et al., 2023; Simpson et al., 2022; Robinson et al., 2014; Taylor et al., 2014). However, there was little research that intentionally included the participation and voice of tamariki, rakatahi, and mātua whaikaha. Collecting data and evidence about tamariki, rakatahi, and mātua whaikaha who are at risk of engagement with, or who are currently engaged with Oranga Tamariki, and the justice system can help to inform prevention strategies and determine their effectiveness. For example, data and evidence can be used to:

- Honour Te Tiriti o Waitangi by informing Oranga Tamariki on how to best support tamariki whaikaha Māori and measure the outcomes of the prevention strategy.
- Prevent abuse by informing Oranga Tamariki about what community-based supports can and should be provided to whānau to prevent maltreatment and relinquishment.
- Inform prevention policy and practice.⁶
- Monitor the progressive implementation of human rights instruments, informing evidence-based policymaking and evidence-based practice.
- Promote and advance current models of disability (Donald Beasley Institute, 2022b).

6.5.1.6 – Strengths-based and trauma-informed

Traditionally, supports and services for tamariki, rakatahi, and mātua whaikaha have been conceptualised using a deficits-based model (Marshall, 2017). Alternatively, the basic

⁶ As noted by recommendation 68.c of the Royal Commission of Inquiry into Abuse in Care (2024).

premise of any strengths-based theory or practice is that every individual, group, and organisation has strengths – including tamariki, *rakatahi*, and *mātua whaikaha* (Kemp et al., 2014). The overarching aim of the strengths-based approach is to improve the lives and wellbeing of users and carers (Department for Health and Social Care, 2019). An example of this can be found in the Oranga Tamariki strengths and needs assessment (Oranga Tamariki Practice Centre, 2019). It is also important for prevention strategies to recognise and promote the strengths of tamariki, *rakatahi*, and *mātua whaikaha* and their whānau (Baxter et al., 2023). Beigel and colleagues (2012) claim that early intervention and prevention can be used to explore and enhance the strength of whānau rather than expose the risks and weaknesses. A key aspect of a strength-based approach is the ability to listen to tamariki, *rakatahi*, and *mātua whaikaha* and uphold their rights (Marshall, 2017).

Trauma-informed practice, on the other hand, focuses on understanding the context of disabled people's experiences. It also invites practitioners to understand how systems of oppression impact the lives of tamariki, *rakatahi*, and *mātua whaikaha* and their whānau. The experiences of tamariki, *rakatahi*, and *mātua whaikaha* and their whānau are inseparable from ableism and disablism (Thomas-Skaf & Jenney, 2021). Prevention approaches must critically analyse and consider the impact of ableism and disablism, while supporting positive realities for whānau (Thomas-Skaf & Jenney, 2021).

6.5.1.7 – Delivered by qualified and experienced staff

Effective prevention strategies include a strong understanding of the risks and context of abuse and neglect for tamariki, *rakatahi*, and *mātua whaikaha* and their whānau, as well as thresholds for activating child protection intervention (Baxter et al., 2023). This knowledge should be shared amongst multi-disciplinary teams and applied attentively and consistently when interacting with tamariki, *rakatahi*, and *mātua whaikaha* and their whānau (Baxter et al., 2023). It is recommended that a single professional (such as a social worker) takes on the role of being the pivotal point for a qualified multi-disciplinary team (Simpson et al., 2022; Prabhakar et al., 2008). Additionally, research shows the importance of listening to the voices of tamariki, *rakatahi*, and *mātua whaikaha* and their whānau to detect and respond to abuse and neglect (Baxter et al., 2023; Flynn &

McGregor, 2017; Robinson, 2014; 2014a; Robinson & Graham, 2021; Taylor et al., 2014). For this to be achieved, practitioners working in child protection services must have training on, and knowledge about, disability. A lack of disability knowledge and training can lead to oversights in detecting and responding to abuse and neglect experienced by tamariki and rakatahi whaikaha, or the tamariki of mātua whaikaha (Simpson et al., 2022; Taylor et al., 2014).

6.5.1.8 – Collaborative and coordinated

Last, but certainly not least, effective primary and secondary prevention efforts are collaborative and coordinated. Tamariki, rakatahi, and mātua whaikaha often experience complex whānau situations that require collaboration from multiple professionals and organisations in order to meet their needs (Fry, 2022; Baxter et al., 2023). Collaborations can be fostered at a systemic level, through a collaborative contracting and commissioning approach. However, these are often limited by a lack of effort on the government's part to create systemic level change, limited pathways for effective recommendations to create system reform, and limited or inconsistent funding (Fry, 2022). Even so, research indicates that having formal and informal relationships and networks of professionals, family and friends are a strong indicator of wellbeing, and also effective at harm prevention at all levels (Ekas et al., 2010; Keen et al., 2010; Moore et al., 2020; Robinson, 2014; 2014a).

As such, one of the key recommendations across the literature was ensuring greater collaboration and coordination between frontline staff, professionals, disability organisations, and government agencies (Donald Beasley Institute, 2022b; Milner et al., 2016; Gibbs, 2022; IFF Research, 2023). However, as noted by Baxter et al. (2023), collaboration and coordination should not solely be between government agencies, but between service professionals as well.

6.5.2 – Designing and implementing prevention strategies: A consultative twin-track approach

The final objective of this literature review was to identify ways of designing and implementing effective prevention strategies designed to prevent disabled children's

involvement with Oranga Tamariki. However, the clearest and most direct response to this question was not found in the reviewed literature, but in Oranga Tamariki Strategic Intentions 2021-2025 (2021, p. 15):

Increasingly there are calls for whānau to be supported earlier, through community led responses, enabled by statutory agencies, that are trusted to step in and support when needed. Prevention can mean different things. For Oranga Tamariki, prevention is for those at risk of harm, preventing the need for a statutory care, protection, or youth justice response. [...] Our belief is that the best strategy for prevention is enabling and strengthening family, whānau, hapū, and iwi to provide safe, stable loving care for tamariki. For this, we will enable communities to put in place the support, the solutions, and the services they know will work for their people to prevent tamariki coming to our attention.

To realise the Oranga Tamariki strategic intention of enabling the disability community to “put in place the support, the solutions, and the services they know will work for [tamariki, rakatahi, and mātua whaikaha and their whānau]” a consultative twin-track approach is required. This expectation is also enshrined in both the UNCRPD and New Zealand Disability Strategy 2016 - 2026, which says Oranga Tamariki should:

- engage in the “the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, [...] shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations” (United Nations, 2006, Art. 4.3);
- “ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right” (United Nations, 2006, Art. 7.3);

- and ensure “that disabled people are consulted on and actively involved in the development and implementation of legislation and policies concerning the outcome area” (Office for Disability Issues, 2016, p. 23).

While the New Zealand government has made some improvements in their engagement with affected communities (for example, see the Department of the Prime Minister and Cabinet's (DPMC) (2022) Policy Community Engagement Tool Second Edition), disabled people with lived experience of a specific subject matter often remain excluded from consultation processes. If they are included, engagement is limited, they are not involved from the outset of development, or their knowledge is subjugated (Francis, 2018). This can lead to disparities in outcomes – whether it be housing (Donald Beasley Institute, 2020), health and wellbeing (Donald Beasley Institute, 2022a), justice (Anns, et. al., 2023; Bowden, 2021), supports and services (Donald Beasley Institute, forthcoming) or any other issue they are affected by. This is particularly true for specific groups within the disability community, such as people with learning disabilities (Petri et al., 2017), as well as those who experience intersecting identities such as tamariki whaikaha, Pacific disabled children, tamariki and rakatahi whaikaha from the rainbow community, tamariki and rakatahi whaikaha from refugee backgrounds and others (Donald Beasley Institute, 2022a; 2022b; 2023; forthcoming).

Involving tamariki, rakatahi, and mātua whaikaha and their whānau at the outset of prevention strategy development, however, aligns directly with Oranga Tamariki's commitment to “community led responses” to prevention (Oranga Tamariki, 2021, p. 15), as well as recommendation Care Safety principles 1-4 and recommendations 126 and 127 of the Royal Commission of Inquiry into Abuse in Care (2024). This includes when designing track 1 prevention strategies targeted at wider non-disabled population groups (for example, the Oranga Tamariki Intensive Response for Whānau Māori) or when designing track 2 strategies specifically for tamariki, rakatahi, and mātua whaikaha (for example, CCS-Disability Action's Intensive Wrap Around Service). While the Oranga Tamariki Disability Advisory Group is a positive example of high-level disability community engagement, literature suggests that proactively consulting with a broad range of tamariki, rakatahi, and mātua whaikaha who have experienced, or who are at risk of experiencing, child protection services or the justice system is an effective way of

developing strategies that can minimise the disparities they currently experience (Baxter et al., 2023; Flynn & McGregor, 2017; Robinson, 2014; 2014a; Robinson & Graham, 2021; Taylor et al., 2014).

More broadly, the literature recommends that consultation of, and engagement with, affected disability communities should be:

- From the outset of strategy development (Francis, 2018).
- Cognisant of Te Tiriti o Waitangi and iwi, hapū and whānau and inclusive of tamariki, rakatahi, and mātua whaikaha Māori (DPMC, 2023).
- Accessible, according to the Accessibility Charter (DPMC, 2023).
- Intersectional (representing a broad and diverse range of life experiences) (DBI, 2022a).
- Well-budgeted and resourced (DPMC, 2023).
- Facilitated by staff who have lived experience and subject matter expertise (Donald Beasley Institute, 2023; DPMC, 2023).
- Consistent and ongoing throughout strategy development, implementation, monitoring and evaluation (Donald Beasley Institute, 2023).

6.5.2.1 – Socio-ecological design

Designing and implementing effective primary level (universal, track 1) and secondary level (disability specific, track 2) prevention strategies should seek to understand and respond to harm and its reduction at different levels of the socio-ecological model (Gorman-Smith, Tolan & Henry, 2000; Tolan, et al., 2003). As was highlighted by research commissioned by the Royal Commission of Inquiry into Abuse in State Care (Mirfin-Veitch et al., 2022), effective prevention efforts must begin by understanding and analysing the social and systemic factors that have, or have the potential to, lead to the maltreatment of tamariki and rakatahi whaikaha at each level of the socio-ecological model, as well as the complex interplay of these factors between the levels. In alignment with the social and rights models of disability, the socio-ecological model enables disability violence and abuse to be understood as a holistic, systemic, and societal issue, rather than as the individual fault of tamariki, rakatahi, and mātua whaikaha and whānau. It also provides a pathway for uncovering more covert forms of disability abuse that may be viewed as less

salient or serious in contrast to other abuses such as physical or sexual violence, while linking abuse to the impact of intersecting disadvantage and marginalisation such as sexism, racism, and so on. The responsibility to respond to abuse, or the potential of, is therefore systemic, and can include transformation of laws, policies, practices, and attitudes that are ableist (Mirfin-Veitch et al., 2022).

Primary and secondary prevention efforts should therefore be designed to respond to individual, relational, community, and societal factors that are known to increase the risk of maltreatment and breaking point. For example, in designing prevention responses the CDC (2022) suggests:

- **Individual:** “Prevention strategies at this level promote attitudes, beliefs, and behaviors that prevent violence. Specific approaches may include conflict resolution and life skills training, socio-emotional learning, and safe dating and healthy relationship skill programs.”⁷
- **Relational:** “Prevention strategies at this level may include parenting or family-focused prevention programs and mentoring and peer programs designed to strengthen parent-child communication, promote positive peer norms, problem-solving skills and promote healthy relationships.”⁸
- **Community:** “Prevention strategies at this level focus on improving the physical and social environment in these settings (e.g., by creating safe places where people live, learn, work, and play) and by addressing other conditions that give rise to violence in communities (e.g., neighbourhood poverty, residential segregation, and instability, high density of alcohol outlets).”⁹
- **Society:** “Prevention strategies at this level include efforts to promote societal norms that protect against violence as well as efforts to strengthen household financial security, education and employment opportunities, and other policies that affect the structural determinants of health.”¹⁰

⁷ As noted in recommendation 121 and 122 of the Royal Commission of Inquiry into Abuse in Care (2024).

⁸ Ibid.

⁹ Ibid.

¹⁰ As noted in recommendation 128 of the Royal Commission of Inquiry into Abuse in Care (2024).

An example of a socio-ecological approach to prevention can be seen in a recent report by Our Watch and Women with Disabilities Victoria (2022). Focused on the prevention of violence against women and girls, *Changing the Landscape* uses the socio-ecological model to highlight that “the interaction between factors at the different levels [are of] equal importance to the influence of factors at a single level” (p. 24). When applied to the notion of prevention being explored in the current review, the socio-ecological model serves to ensure that all levels are prioritised when prevention strategies are being identified or designed. A further Australian study also highlighted the benefits of a socio-ecological approach to understanding the social determinants of tamariki and rakatahi whaikaha and whānau experiences (Sutherland et al., 2022).

7 – Kupu whakamutuka/Concluding remarks

This literature review has responded to six key questions with the potential to inform the Oranga Tamariki approach to developing prevention policies, strategies, and interventions in relation to disabled tamariki, rakatahi, and mātua whaikaha, and their whānau. The review began by defining levels of prevention, before drawing links between prevention and the disability twin-track approach. The ecological model of disability violence and abuse was outlined as a useful model for framing prevention responses at individual, relational, community, and society levels, before the relevance of wellbeing and Enabling Good Lives principles were discussed. The next collection of findings responded to question 3, which sought to identify examples of successful care and justice prevention strategies. Early identification, respite, shared care, intensive family support, social and professional supports, flexible funding models, and training and education were all identified as having the potential to contribute to successful care prevention strategies.

With regards to justice system prevention strategies, early interventions in schools, mentoring programmes, early disability identification by justice professionals, training and education, and additional supports were all identified as contributing to tamariki and rakatahi whaikaha wellbeing and as potential strategies for preventing engagement with the justice system. Systemic disparities were then explored. Although there was little

literature evaluating the primary prevention experiences of tamariki, rakatahi, and mātua whaikaha, a broader body of literature was drawn on to identify common barriers to engagement, and that are likely to lead to disparities in outcomes for tamariki, rakatahi, and mātua whaikaha. Finally, key factors of effective primary and secondary prevention strategies were discussed, before a consultative twin-track approach and ecological framing were suggested as effective ways of designing and implementing prevention strategies for tamariki, rakatahi and mātua whaikaha, and their whānau.

In summary, this integrative literature has demonstrated strong potential for alignment between the Oranga Tamariki approach to developing prevention strategies, policies, and initiatives, and a Tiriti o Waitangi- and rights-based response to tamariki, rakatahi, and mātua whaikaha who are at risk of engaging with child protection services and the justice system.

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