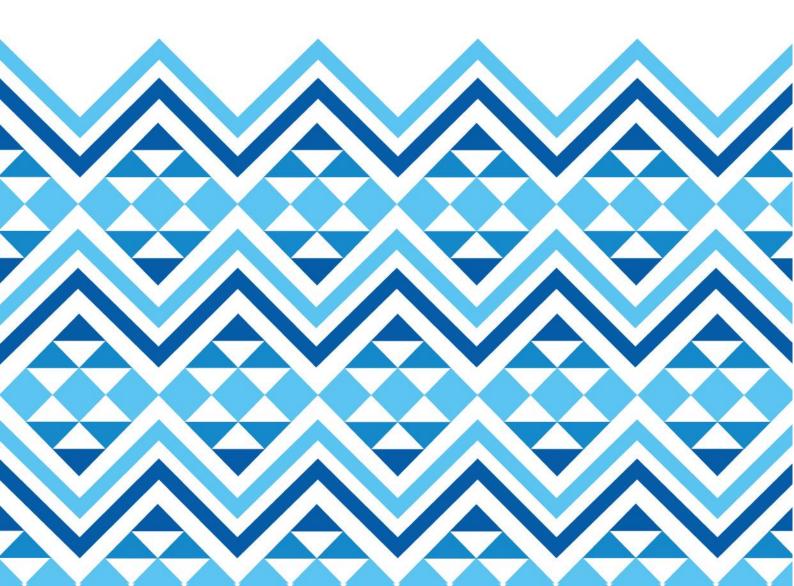


New Zealand Government

Primary Health Needs of Children and Young People in Care

Oranga Tamariki Action Plan In-Depth Needs Assessment Report

June 2023



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Acknowledgements

The members of the Oranga Tamariki Youth Advisory Group 2022.

Endorsements

Chief executives of the Social Wellbeing Board endorsed this assessment in June 2023.



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EXECUTIVE SUMMARY

A higher duty of care

The 4638¹ children and young people living in care have the same right to primary health² as any other child or young person growing up in New Zealand. By taking these children and young people into care, however, the State has accepted a higher positive obligation, which is to provide day-to-day care of the child or young person,³ which includes responsibility for meeting their health needs. But the health needs of children and young people in care are high and complex to address, while they bump into system barriers that are sometimes invisible – opportunities to promote and improve health and wellbeing in time to make the biggest difference for this population are being missed.⁴ This assessment considers how the Oranga Tamariki system is currently meeting the primary health needs of New Zealand's most vulnerable children and identifies areas for system-wide attention at a time of health sector reform.

Children and young people in care have arguably the poorest health and wellbeing of any population in New Zealand and fewer protective factors for health. Children and young people in care were hospitalised for avoidable reasons at twice the rate of the general population in 2020, bypassing the primary health system and indicating a failure in addressing their primary health needs. Care placement itself is a risk factor for health, especially for children and young people with a high rate of placement instability. Placement breakdowns can seriously impair health and wellbeing, interrupting the wider system of support around the child.⁵ At worst, placement instability can delay or even deny critical interventions for health and disability-related needs and lead to unplanned placement exits without ongoing primary health support.

Despite the State's higher obligation, children and young people in care generally rely on accessing the primary health system on the same basis as any other New Zealander, except that they are children, often with poor health, high support needs, and there is a high prevalence of trauma. Of the population, 68% are Māori and 17% are Pacific; populations which have significant health disparities and additional barriers. They also acquire additional barriers to healthcare specific to their care status, including that they often move frequently and are cared for by people who do not know them well, which means that their critical health information is unreliable and often inaccessible. Unlike other vulnerable groups, however, they are invisible in the health system as there aren't systematic ways of sharing information.

The main government support for the health of children and young people in care is production of a gateway assessment, which focusses on identifying a range of needs including health needs, but which is a specialist tool that largely by-passes the primary health system. Oranga Tamariki, the Ministry of Health, and the Ministry of Education plan to

¹ Of 4638 in care as at December 31, 2022, 1855 were in family placement, 705 in foster care placement, 432 returned home, 112 in independent living, 84 in youth justice residences, 479 with care providers and 671 in other placement types.

² For the purposes of this assessment primary health encompasses health that is addressed at home and in the community and is inclusive of community health.

³ Oranga Tamariki (National Care Standards and Related Matters) Regulations 2018, r16 (a).

⁴ Some US research refers to the population of children and young people in care as the most vulnerable population in the US in terms of health.

complete a review of the gateway assessment by the end of the year. The current report highlights specific issues that can be considered by the review, such as timeliness and integration with ongoing primary and community healthcare, as well as concerns about the framework for assessment and scope for devolution to Māori partners.

Key findings

This assessment report provides a strategic overview of the current primary health needs of children and young people in care as well as the Oranga Tamariki system's response. The report should also be read in conjunction with other Oranga Tamariki Action Plan in-depth needs assessments, in particular the companion assessment on the health needs of young people transitioning out of care.

The key findings arising from the assessment are:

- Children and young people in care, and their whānau and caregivers, need health and wellbeing information and support in their homes, schools and communities that is confidential, non-judgemental, goes at their own pace and is independent from Oranga Tamariki. They also need additional support for continuity and coordination of healthcare.
- Despite the higher legal obligation to address the health needs of this population, primary health is currently a low government system priority and is not being addressed systematically. By the time the Oranga Tamariki system is focussing on the health of a child or young person in care, health related needs are often manifesting as a crisis.
- Children and young people in care face multiple barriers to primary healthcare, including that they are not identifiable in the health system and there is no guidance on how to deliver services to this population. Children and young people in care may be de-prioritised, re-traumatised or receive ineffective healthcare, increasing life-long avoidant behaviour.
- There is a lack of an accountable interagency framework and implementation guidelines which set out a common purpose and roles and responsibilities for the promotion of the holistic health and wellbeing of children and young people in care. There is currently no shared definition or approach, which leads to different understandings of the requirements and system incoherence.

We also know that health needs are often not met in time to make a difference to the family's ability and willingness to continue to care for a child. Some enter care and protection principally because the family do not have supports to care for their child at home, and we know that this dynamic can drive the need for additional care and protection in many others. The needs of those at risk of entering care are being addressed separately in an in-depth needs assessment on early risk factors.

This report has been informed by collaboration with former members of the Oranga Tamariki Youth Advisory Group and has valued lived experience as part of the information gathering and assessment process. The views profiled in this assessment are not new and relate to health issues for this population which are well supported in the international literature and available relevant domestic research, data, and other evidence.

Focus areas

Across government there are already significant initiatives underway that are expected to address many of the issues raised by this report for children and young people involved with Oranga Tamariki. These include priority areas under the Child and Youth Wellbeing Strategy, actions under the Oranga Tamariki Action Plan, the transformation within the health system including reviews of Well-Child Tamariki Ora programme and School-Based Health Services, as well as the Oranga Tamariki Future Direction Work Programme.

Meeting the primary health needs of this small population in the care of the State is an important litmus test of the health reforms. We consider that it is critical to support system collaboration on the reforms and to remain connected at the national, regional, and local levels as the health reforms are implemented. We identify five focus areas at the conclusion of this report, including the accountability framework, increased health and wellbeing supports and services for children and young people in care, including support that is independent from Oranga Tamariki, a review of the system approach to trauma-based care, and a step change in data and information-sharing.

Agencies will report back to the Social Wellbeing Board within three months with a roadmap of how focus areas will be addressed, including the agencies responsible and initial timeframes, as well as other work to address specific primary healthcare issues raised in this assessment.

Voice of the Child

"I want to blossom as my true self, no side ulterior motives, no government nametags and no slapping it back in my face." – Care-experienced young person

Children and young people in care want a more holistic child-led whānau-centred approach to health and wellbeing and feel that their care status had a negative impact on their health, which has also undermined their autonomy and their agency. Care-experienced youth that engaged on this report wish to start by affirming that care status is a risk factor for health. They say that transactional experiences in the mainstream health system were common, or they avoided it, unless they had continuity of care and long-term relationships: *"Chuck them in the depression folder, or anxiety folder, and put them on meds that all the bro's are on too. A quick fix"*. They see the role of the Oranga Tamariki system as about empowering them to be independent, to exercise their rights, and build on their strengths. They want all the people in their support system to understand trauma and effective ways to respond to their trauma symptoms, whether that is whānau, caregivers, social workers, teachers, or doctors, and they want access to effective trauma support when they need it.

They also said that they wanted more, and much better quality, primary and place-based healthcare, starting with more in-home support to promote their health and wellbeing and that of their caregivers and whānau, and to help them to feel safe to access more services. When they talk about their health, they want confidential relationships with wrap-around providers who are independent from Oranga Tamariki, who know their history, and understand them. They do not get enough support for oral health and sexual and reproductive health. They prioritise connections that are long-lasting, non-judgmental and that are empowering: according to some young people we spoke to, *"there is a massive trust barrier... a fear that children will be ripped away"*. They want to make informed choices and decisions about their health and wellbeing and to go at their own pace.⁶

Children and young people in care say there is greater need to support health literacy and respect child sovereignty in the case of children and young people in care because of their complex whānau and caregiving arrangements. Challenges can include being cared for by people that do not know them well or who may not make good decisions. One young person described being prevented from accessing health services because their father had threatened a health professional. She was also prevented by her parents from accessing the Independent Child's Benefit while pregnant: "*I was living off \$20 a week while my mother was obtaining family tax credits and I was not even living at home.*" Whānau-based approaches needed to take account of the rights of the child or young person and promote accountability: not all whānau had the emotional regulation to be able to communicate and make good decisions. Another explains: "*On the marae it was always kaumatua, pakeke, and rangatahi. We've lost that a bit. It's important to bring back the voice of rangatahi.*"

⁶ Please see the <u>Independent Children's Monitor Report 2020/21</u>, and the <u>Follow up to What Makes a Good</u> <u>Life Report by the Office of the Children's Commissioner 2019</u>, which contain extensive quotes from careexperienced youth, as well as Youth2000 surveys, which were used to corroborate and understand the views shared by individuals for this assessment. This report also drew on unpublished engagement with careexperienced youth for the School-Based Health Services Review and testimony of the Royal Commission of Abuse in Care.

PART A: Purpose

Under the Children's Act 2014, the purpose of the Oranga Tamariki Action Plan is to "indicate how the chief executives of the children's agencies will work together to improve the wellbeing of the core populations of interest" to Oranga Tamariki. The Action Plan requires in-depth assessments of housing, education and health needs of children and young people. This report provides a strategic overview of the primary health needs of children and young people in care and examines how the Oranga Tamariki system is meeting these needs.

Like the other in-depth assessments, this report is designed to highlight system challenges and opportunities where further work is needed by the children's agencies of government. Since the introduction of the Oranga Tamariki Action Plan, however, we note that both the health system and disability system have been transformed and are currently undoing major change. The disability system is no longer part of the health system, recognising the need for a social and rights-based model of disability, moving away from a medical model. Across government, there are already significant initiatives underway that are expected to address many of the issues raised by this report for the wider Oranga Tamariki population. These include priority areas under the Child and Youth Wellbeing Strategy, actions under the Oranga Tamariki Action Plan, the New Zealand Disability Strategy, and the Pae Ora (Healthy Futures) Act 2022. In addition, Oranga Tamariki is rolling out its Future Direction Work Programme and a practice approach which promotes a holistic approach to health and wellbeing and its own Disability Strategy.

Methodology

This report was produced from February to May 2023, with a focus on partnership with careexperienced youth, interagency collaboration, rapid research, and stakeholder engagement. The process included a review of available literature, data, and documents, and conducting focus groups with shared care and health providers, social workers, caregivers and other Oranga Tamariki kaimahi, including regional disability advisers, health and education advisers and clinical staff. An interagency working group supported scoping of the project and provided review of the report, including officials from Manatū Hauora - the Ministry of Health, Te Aka Whai Ora - the Māori Health Authority, Te Whatu Ora - Health New Zealand, as well as Oranga Tamariki. In addition, a focus group on mental health with officials, clinicians and mental health providers was held and interviews were conducted with health officials, including services related to oral health, early years, general practitioners, schoolbased health services, and immunisations.

There is currently no agreed interagency mechanism for defining, understanding, or monitoring the health and wellbeing of children and young people in care, or primary health in particular, and no agreed measures. We have used the Oranga Tamariki (National Care Standards and Related Matters) Act 2018 ("the <u>National Care Standards</u>"), which includes a definition of health and sets out standards for children and young people in care, to help structure a rapid inquiry into a large and complex area of individual and collective rights and government action. However, there are several issues with the Standards, namely that they: were not designed as an interagency platform, focus on minimum standards, have limited health content, and do not have measures or provide guidance on how the standards should be implemented. Accordingly, we use the Standards while acknowledging that many stakeholders in the system are pursuing a more aspirational and holistic approach to the health and wellbeing of children and young people in care. Primary health in this report excludes specialist services and is centred on health and wellbeing promotion⁷.

⁷ Health promotion is the process of enabling people to increase control over, and to improve, their health.

The health and wellbeing of this population is highly complex and relates to wide-ranging areas of government, including the primary and community health sector. Manatū Hauora has provided a definition of the primary and community healthcare sector to support the framing in this report:

The primary and community healthcare sector is complex and wide-ranging, covering a broad range of services including diagnosis and treatment, health education, counselling, disease prevention and screening. Many types of services and practitioners are involved, including Māori and Pacific providers, mātanga rongoā and rongoā service providers, general practitioners, pharmacists, midwives, allied health professionals, dentists and dental therapists, aged care and home care workers, nurse practitioners, community and practice nurses, district nurses, community mental health services, and public health nurses. Services are delivered through a wide variety of provider types. Including private companies, charitable trusts, incorporated societies, partnerships and sole traders, and some public provision by Te Whatu Ora. Across these there is a mix of for-profit and not-for-profit business models and a wide range of philosophies, scale and scope of services, and models of care.⁸

In addressing health, many stakeholders emphasised the importance of wellbeing promotion to improve health and that a child or young person's overall health and wellbeing is heavily shaped not just by engagement with primary healthcare services but by other protective factors for health and wellbeing. These protective factors can include whānau wellbeing, identity, and engagement in culture, physical, creative or community activities, connection with friends, peers and mentors and engagement in education among other factors. Currently data is not collected against such a framework. Accordingly, the assessment explores primary health needs using the limited population-specific data that exists.

The development of this report was constrained by several other factors, including the twomonth research, engagement and analysis phase, the ability to secure multidisciplinary personnel dedicated to the project, and the paucity of New Zealand research on this specific population. This impacted:

- The ability to engage further to what is noted above, including with:
 - Children those under the age of 14 years old.
 - Oranga Tamariki priority populations disabled children, young people, and families and Pacific children, young people and families.
 - a wider range of Māori and iwi whānau, partners and providers
 - a broader and more nationally representative sample of Oranga Tamariki kaimahi and primary care specialists involved in the provision of primary health care.
- The level of data that was able to be gathered on a wide range of topics, noting the invaluable assistance of the Oranga Tamariki Evidence Centre and subject matter experts from Oranga Tamariki and health agencies in the time available.

This report values lived experience and uses quotes and insights from care-experienced youth gathered through engagement. Quotes included without attribution in this report have been provided and authorised by the relevant members of the Oranga Tamariki Youth Advisory Group 2022. We have relied on local multidisciplinary expertise and international research and assumed that the significant health disparities or barriers experienced by children as well as Māori, Pacific, and disabled people in New Zealand are relevant also to Māori, Pacific and disabled children in care. Given consistency across comparable countries and where New Zealand evidence exists, we have also assumed that international research is relevant to New Zealand.

This review was not a Kaupapa Māori review, preventing full and effective participation by Māori, although endeavours were made to support engagement with Māori care-experienced

⁸ Manatū Hauora definition of the primary and community health sector 2023.

youth and shared care providers, to engage with Te Aka Whai Ora – the Māori Health authority, to consider Māori models of health and wellbeing, and to draw on the Waitangi Tribunal's extensive work in this area. We also note the lack of disaggregated data in relation to Māori, and which supports understanding Māori models of health, including limited data on whānau health and that this is not a Māori health needs assessment.⁹

Scope

The assessment focusses on children and young people in care – namely, the 4638 who are in the custody of the chief executive of Oranga Tamariki¹⁰. The government has accepted additional obligations to address the health needs of children and young people in care who can often face specific barriers arising from their care status. However, the trajectory of the health of this population also serves as a barometer for effectiveness of the system as a whole and offers insights and opportunities for system learning relevant to all children and young people involved with the Oranga Tamariki system.

The health needs of the population of young people who are transitioning out of care are being addressed in a companion in-depth needs assessment. We also acknowledge that the government has additional responsibilities for a range of other children and young people, including children under support orders or those who are no longer in the custody of the State, but are on the Unsupported Child's Benefit or Orphan's Benefit.

This report also focusses only on primary health – health that is addressed at home, at school and in communities. Disability supports and services along with specialist health supports and services are outside the scope of this report. Oranga Tamariki, Manatū Hauora - the Ministry of Health, and the Ministry of Education have initiated a review of the gateway assessment, which is a specialist tool that relates to primary healthcare. The current report highlights some specific issues that can considered in greater depth by the Review, such as ownership and inclusion of the child or young person and their family, multidisciplinary collaboration, timeliness, unmet needs for cognitive assessment, information-sharing, and integration with ongoing primary and community healthcare, as well as scope for devolving assessments to Māori partners.

We also know that health and disability needs are often not met in time to make a difference to the family's ability and willingness to continue to care for a child. Some enter care and protection principally because the family do not have supports to care for their child at home, and we know that this dynamic can drive the need for additional care and protection in many others. The needs of those at risk of entering care are being addressed separately in an in-depth needs assessment on early risk factors.

Given the timeframe, the report did not set out to consider the diverse primary health needs of the very many different groups of children and young people in care, such as the specific needs of women and girls, who make up nearly half of the population, rainbow children, who are over-represented in the population, or potentially growing numbers of Asian or migrant children.¹¹ We have, however, included some short reflections on the primary health needs of Pacific and disabled children and young people as two of the Oranga Tamariki Action Plan priority populations. We also commissioned a literature review from the Oranga Tamariki Evidence Centre on the primary health needs of disabled children and young people, which will be released publicly, to support system understanding.

⁹ See <u>Whānau Ora Health Needs Assessment</u> as an example.

¹⁰ As at 31 December 2022. This is the core population of interest under limbs (b)(ii) and a subset (i.e., only those in custody) under (iii) of that definition in section 5(1) of the Children's Act.

¹¹ Compared to the latest estimates in the 2018 census, by 2033 it is projected that Middle Eastern, Latin American and African populations will rise by 68 percent and the Asian population by 48 percent.

In addition, we note that this assessment largely focusses on children and young people in care who are living in care or in foster care placement, either run by Oranga Tamariki or by care providers or other services. However, potentially up to 20% of children and young people in care are living in certain placement types where there may be different barriers to primary health, including those who are living independently or who are in youth justice residential facilities. A further 20% have returned home or do not have a nominated placement type and may be at greater risk of not receiving primary health support and not enrolling in the transitions service.¹²

Definitions

This Assessment employs the following definitions:

Child – person under 14 years old.

Young person – person 14 – 17 years old.

Children and young people in care – children and young people in the custody of the chief executive Oranga Tamariki up to 17 years old, including those in care and those in youth justice.

Disabled child or young person – child or young person who has long-term physical, cognitive, intellectual, neurological, or sensory impairments including neurodiverse conditions such as Fetal Alcohol Spectrum Disorder, Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder, which in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.¹³

Caregiver – a person with whom the chief executive of Oranga Tamariki has placed a child or young person who is in care, with, and who is responsible for caring for the child or young person but does not necessarily have legal guardianship of the child.

Kaimahi or social worker – a person employed by Oranga Tamariki providing social services to children and young people in care.

Health and education adviser – a person employed by Oranga Tamariki to help broker health and education solutions to system barriers.

Shared care provider – a service provider contracted by Oranga Tamariki to deliver care services in respect of children and young people in care.

Primary health – health that is addressed at home or in the community and is not addressed by a secondary or specialised service or in hospital.

¹² Of 4638 in care as at December 31, 2022, 1855 were in family placement, 705 in foster care placement, 432 returned home, 112 in independent living, 84 youth justice residences, 479 care providers and 671 in other placement types.

¹³ Definition adopted by New Zealand as a state party to the Convention on the Rights of Persons with Disabilities, with specific recognition of neurological impairment and disorders which are almost certainly prevalent in the population but not currently identified systematically. This prototype definition has been approved by Oranga Tamariki leadership and developed in collaboration with disabled people, including the disabled community inside and outside the organisation, who seek an approach that is relevant to the population in care. The definition of disability is integral to the social model of disability and the promotion of a rights-based approach.

Health promotion - Health promotion is the process of enabling people to increase control over, and to improve, their health.

Primary health provider – any service provider that provides primary health services in community, from dentists and General Practitioners through to physiotherapists, family planning clinics, pharmacists, and school nurses.

PART B: The Treaty of Waitangi – Te Tiriti o Waitangi

Treaty context

"Whakahokia mai te mana o te iwi ki te iwi, o te hapū ki te hapū, o te whānau ki te whānau, o te tangata ki tōna rau kotahi" Return the authority of the tribes to the tribes, the sub-tribes to the sub-tribes, the families to the families, of the individuals to the individuals representing as they do, the generations of the past and the present. - W Tibble, submission 58, Hui Taumata 1984

"One size fits all doesn't work." – Odele Stehlin

67% of children and young people in care are Māori. Section 7AA of the Oranga Tamariki Act 1987 (the "Act") was introduced as an amendment to the Act in mid-2019. This provision places specific duties on the chief executive of Oranga Tamariki "in order to recognise and provide a practical commitment to the principles of the Treaty of Waitangi (te Tiriti o Waitangi)". Under section 7AA of the Act, the chief executive must ensure that the policies and practices of Oranga Tamariki that impact on the wellbeing of children and young persons have "the objective of reducing disparities by setting measurable outcomes for Māori children and young persons who come to the attention of the department". Oranga Tamariki must also "seek to develop strategic partnerships with iwi and Māori organisations in order to... enable the robust, regular and genuine exchange of information between the department and those organisations."

Te Tiriti o Waitangi (The Treaty of Waitangi) is also included in the principles of the Pae Ora (Healthy Futures) Act 2022 which includes the aim of 'improving the health system for Māori and improving hauora Māori outcomes.' The reforms were informed by a significant recent body of work produced by the Waitangi Tribunal on health (see Box 1). The interagency process that developed this report was supported by engagement with the new

Box 1: Primary health and the Treaty

The Waitangi Tribunal's Hauora: Report on Stage One of the Health Services and Outcomes Inquiry (the Report) 2019 focused on systemic issues and the primary healthcare sector. The Report found that legislative, strategic and policy frameworks, funding arrangements, the way Crown entities are held to account, and the partnerships that the Crown has with Māori, were not Te Tiriti o Waitangi (te Tiriti) compliant and contributed to serious and persistent health inequities for Māori.

The <u>Hauora Report</u> found that "Māori suffer significant prejudice arising from Treaty breaches in the primary health care system."¹ The Tribunal recommended *inter alia* the establishment of a Māori Health Authority to recognise tino rangatiratanga, systematic separate measurement, monitoring and data collection related to Māori health outcomes, and greater priority and partnership with Māori primary health providers.

Addressing health inequities for Māori is one of the underlying reasons for the health reforms. The Pae Ora (Healthy Futures) Act 2022 (the Pae Ora Act) and subsequent health reforms programme is implementing legislative and structural recommendations made by the Waitangi Tribunal, with Whakamaua: Māori Health Action Plan 2020-2025 continuing to respond to legislative and non-legislative recommendations.

The health system has committed to addressing these disparities, such as through the response to the Wai 2757 enquiry, and Whakamaua: The Māori Health Action Plan 2020-2025; and commitments being made as part of the Pae Ora health reforms, including the establishment of the Māori Health Authority. These have implications for how the health system meets the needs for tamariki and rangatahi in care.

Māori Health Authority – Te Aka Whai Ora established under the Act. Health data disaggregated by ethnicity about children and young people in care is limited and does not currently support effective monitoring of health disparities or understanding of Māori models of health, including related to whānau ora. Accordingly, this report prioritised consultation with Māori partners and development of an equity insight through engagement in one region – the Lower South, using lived experience insights to guide inquiry. This included engagement with Ngāi Tahu partners in Otago and Southland, specifically Te Kaika, Waihōpai Runaka and Awarua Whānau and Associates.

Treaty partner views

The Māori groups consulted for this report were generally iwi shared care and/or health providers, most of whom work closely with Oranga Tamariki and have a high level of familiarity with children and young people in care. They emphasised the importance of Māori collective authority to lead, define and address the health and wellbeing of tamariki and rangatahi Māori in care in their rohe. Some objected to the needs-based approach of the National Care Standards and the implication that children and young people had a deficit to be addressed, and the narrow focus on the child's health rather than whānau ora or health of the family. They had different perspectives on the value of engaging on a Crown report. Some were concerned about the timeframe and restrictions of a process that was not kaupapa-based and did not allow full and effective participation by those who were most impacted, especially given the wide diversity of Māori groups.

Māori groups consistently called for the government to prioritise whānau ora – the health of the family – and to take a whānau based approach¹⁴, including to step back and empower Māori-led whānau-based shared care, health, and social service providers, building on their call for a re-imagining of the National Care Standards, as set out at the Whānau Care Whanaungatanga Hui of 22-24 June 2021. Māori groups said they observed a lack of State accountability and effectiveness – court plans did not get fully implemented and some said whānau caregivers felt intimidated by the powers of Oranga Tamariki to take children and young people into care, which restricted capacity to communicate openly about health, including when the system was not delivering for tamariki and rangatahi: *"Whānau caregivers feel powerless, and limited in how much they can be honest and advocate for the children in their care"*.

Māori groups we spoke to identified trauma as the main health priority, including intergenerational trauma, which they said required a trauma-informed whānau-based approach to health. A Māori shared care and health provider explained: *"Trauma manifests in self-harm, self-destructive behaviour, and early sexual initiation. Children often have parents and grandparents who have been in care."* Tupua Urlich, a care-experienced young person, and VOYCE Whakarongo Mai National Care Experience Lead, has spoken publicly about intergenerational transmission of trauma and impact on health at the Māori Hearing of the Royal Commission of Abuse into Care:

I am the second generation on my father's side that have gone into the state care system. My dad and his siblings all went into care. They are all dead now. I am the eldest one left in my whanau, and I am only 25 years old. My father was killed. One of my uncles passed away. He had severe schizophrenia because of his experiences. The intergenerational harm caused by the state was apparent, there was hardly anyone at his tangi. The result of their abuse and trauma and what the state do to our people is present even in death. This mahi is important to me as I am the eldest left in my direct whānau line. You can't say that this isn't connected because it absolutely is."¹⁵

Māori groups also spoke of trauma because of government laws, policies, and actions over time.

PART C: The Health and Wellbeing of Children and Young People in Care

¹⁴ Several reports note that the government's wider support for Whānau Ora has been a success for many whānau. A report by the Controller and Auditor-General in Feb 2023 found that public sector processes and practices need to change to create a more enabling environment to implement these types of approaches where they are appropriate.

¹⁵ Statement of Tupua Urlich for Māori Public Hearing, Royal Commission of Abuse in Care.

Greater needs, poor outcomes

"You need to get to know the rangatahi. You can't change who they are. A lot of health professionals just rely on what the notes say." – Māori care-experienced young person

The 4638¹⁶ children and young people living in care have the same right to primary health as any other child or young person growing up in New Zealand. By taking these children and young people into care, however, the State has accepted a higher positive obligation, which is to provide day-to-day care of the child or young person ^{17,} whether living at home, or with caregivers or in supported accommodation including group homes and residences, which includes responsibility for meeting their health needs. The existing regulatory framework for assessing the primary health needs of this population is the <u>National Care Standards</u>, which defines health needs as including "any current or projected needs" relating to "their physical health (including dental, auditory, and nutritional health, and any health needs related to disability or a long-term condition); and their psychological health, and any assistance needed to recover from the effects of trauma; and their alcohol and drug misuse (if any)."¹⁸

The definition of health focuses on health problems, and to some extent conflates disease and disability reflecting the health and disability system at the time they were written, rather than seeking "the protection, promotion and improvement of health"¹⁹. The framework is also not aligned with Māori models of health, the oranga model of health that guides social work practice or the social model of disability (see Box 2). Whatever the definition, most children and young people entering care have been "exposed to a lack of nurturing care, which impacts significantly on their wellbeing."²⁰ Children and young people in care do not feel they are doing well; those living outside of their family fared worse in every area of wellbeing asked in a Children's Commissioner survey.²¹ Only 51% felt they could "cope when times get hard," (compared to 64% not in care), 58% felt "fit and healthy" (compared to 70% not in care), with 69% feeling they could go to the doctor when they needed to (compared to 84% not in care).

While there is limited system-wide data and research about the health status and trajectories of children and young people in care in New Zealand, research across a range of comparable countries has shown that children and young people in care are consistently "a very vulnerable group with relatively high levels of unrecognised or unmet health needs."^{22 23} Children and young people in care have been classified as a population of children with special health care needs in many of the US States and in England, for example.²⁴ Available evidence indicates that children and young people in care in New Zealand generally have high health needs and very poor health outcomes in adolescence and later life, compared to the general population. At least 80% of children and young people entering care are recorded as having a health need and 66% are recorded as having very high or high

¹⁶ 4638 in custody: 131 are in youth justice custody and 1855 in family placement as at 31 December 2022.

¹⁷ Oranga Tamariki (National Care Standards and Related Matters) Regulations 2018, r16 (a).

¹⁸ Oranga Tamariki Act 2017, s13 (2).

¹⁹ Pae Ora (Healthy Futures) Act 2022, s 3. Goal of the Act.

²⁰ Health Needs of Children in State Care. Duncanson, 2017. P 1.

²¹ 'What Makes a Good Life' Follow Up report of the Children's Commissioner.

²² <u>Health Needs of Children in State Care. Duncanson</u>, 2017. P 2.

²³ According to Kools et al, "children in foster care are the most vulnerable to experiencing poor health compared with any other group of children in the United States." <u>Foster Child Health and Development:</u> <u>Implications for Primary Care (Abstract), 2003</u>.

²⁴ <u>Health Needs of Children in State Care. Duncanson</u>, 2017, p2., and <u>Safeguarding Foster Children's Rights to</u> <u>Health Services</u> by Dicker et al, p.2. 2000.

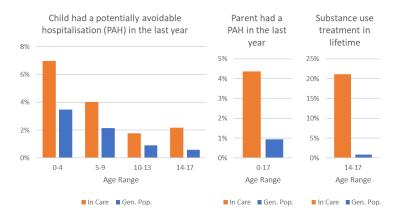
needs.²⁵ Needs are high across all health areas in the National Care Standards, to the extent data is collected (see Box 4).²⁶

The data that exists is focussed on a narrow set of poor health measures linked to the Standards, rather than on monitoring a wider dataset relevant to monitoring and improving the holistic health and wellbeing of the population and the progress towards reducing disparities for priority populations within that group. The shortage of health data across a wider range of indicators has been raised since 2016:

There is an urgent need to improve the range and quality of information on the needs of children, family/whānau and caregivers. Reliable information on the range of indicators is required to measure whether we are making a difference in the lives of children. Better and more accessible information is required on child and family risk factors, and evidence-based practice needs to be implemented by front-line health workforce and other agencies. This is likely to require some investment in the data infrastructure, information technology and workforce skills and training.²⁷

Within the health system, the care status of a child or young person is not captured - the systematic data linkages between the health system and Oranga Tamariki have been described by data officials as "at best weak and at worst non-existent" (see Annex 2). Data within Oranga Tamariki is also generally not readily able to be disaggregated by ethnicity, gender, or region, which means that health needs are not able to be understood, especially given regional health system variations. Oranga Tamariki data is also unreliable and incomplete.

The role primary health plays in preventing a range of avoidable hospital admissions and mortality is crucial and illustrative of failure to address primary health needs.²⁸ New Zealand data shows that children and young people in care were hospitalised for potentially avoidable reasons at twice the rate of the general population in 2020 (see graph below), with both these children and their whānau bypassing the primary health system – a pattern consistent over time. Recent but as yet unpublished New Zealand research also indicates that mortality rates are more than three times as high among children and young people in care than the general population.



²⁵ Children and young people with impairments (orangatamariki.govt.nz)

²⁶ Oranga Tamariki data. See also <u>Health Needs of Children and Young People in Care by Mavis Duncanson</u>.

²⁷ <u>Health Needs of Children in State Care. Duncanson</u>. Duncanson, 2017. p2.

²⁸ Craig E, Adams J, Oben G, Reddington A, Wicken A and Simpson J. The Health Status of Children and

Young People in New Zealand. Dunedin: New Zealand Child and Youth Epidemiology Service, University of Otago; 2013

Box 3: Priority population – Pacific children and young people in care

Around 17% of children and young people in care are of Pacific descent, double that of the general population. Oranga Tamariki has recently completed two reports about their experience (<u>Talanoa Mai Tamaki</u> and <u>Ola Manuia mo ala ma fanau Pasifika</u>). These reports focus on the perspective of Samoan and Cook Island Māori New Zealanders who make up 68% of the general Pacific population: the Pacific ethnicities in care are, however, not recorded, which limits capacity for tailored cultural responsiveness. The reports do not address primary health but identify the high priority placed by many Pacific people on cultural identity and a family-based approach to children and to health. Most also reported religious beliefs relevant to the design of primary healthcare.

Engagement on this assessment identified the need for systematic identification and outreach about the Oranga Tamariki Action Plan as a whole to Pacific populations and to Pacific shared care and health providers on health to improve collaboration. <u>One Pacific community provider</u> said: "OT does not share information adequately and community providers go in blind." Some Pacific health providers suggest interaction with Oranga Tamariki was generally very low. In the reports, many Pacific families emphasise the importance of relationship-based strategies and better information storage, as well as barriers arising from racial discrimination, language difficulties and a lack of Pacific-specific cultural competence in the wider Oranga Tamariki system.

As part of consultations, a Pacific health provider suggested that for Pacific families "primary health was in the luxury category." Poverty and myriad practical barriers rendered the mainstream health system inaccessible for Pacific families: "We have no choice but to take over supporting them to receive the health advice and support they need. One family drove over three hours to fill a basic prescription at a pharmacy for a family member who was released from hospital on a Friday at a time when the local pharmacy was closed and not open over the weekend." Access to funding to support Pacific health for children and young people in care was limited: one provider described receiving \$16,000 for a holiday programme rather than health provision.

Box 2: Priority population – Disabled children and young people in care

Disabled children and young people in care are a priority population in the Oranga Tamariki Action Plan. Under the <u>United Nations Convention on the Rights of Persons with Disabilities</u>, "children and young people with disabilities must have equal access to quality, accessible and appropriate primary health care, and early identification, intervention and specialist disability health services designed to minimise their disability." Persons with disabilities are defined in the treaty as "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". This is often referred to as the social model of disability. In New Zealand, health and disability services work together but responsibility for disability supports sits outside the health system.

The National Care Standards do not address obligations related to disabled children and young people or provide guidance on how to meet the needs of this priority population. There is no data gathered or literature specifically on the primary health care needs of disabled children and young people in care. For the purposes of this assessment, the Oranga Tamariki Evidence Centre commissioned a literature review to help fill the gaps. According to this review, national data shows that the number of children and young people with disabilities under the age of 15 in the general population is 10-11%, but higher for Māori and Māori boys (15% of Māori boys compared to 9% of non-Māori boys). Almost half have multiple needs, with understanding, learning and communication support the most common area. The prevalence of disability is estimated to be anywhere between 47% to 87%, depending on dataset, age of child and definition of disability.

In a commissioned submission the Waitangi Tribunal for Stage Two of the Wai 2575 Health Services and Outcomes Kaupapa Inquiry (Wai 2575), King (2019) describes the limitations of the current data and data collection approaches for identifying tamariki and rangatahi whaikaha, and access to services and supports: "the Crown does not have the appropriate monitoring mechanisms in place to be able to ensure that the health and disability support needs for Māori children and young people with lived experience of disability within its care and protection and youth justice residences are being met.' (King, 2019, p276).

Oranga Tamariki is currently developing a Disability Strategy in collaboration with disabled people. The Strategy aims to embed a social and rights-based model of disability within Oranga Tamariki, grounded within the foundation of te Tiriti o Waitangi. Internal research has been conducted on the voices of disabled children and young people, their caregivers and whānau. It was not possible, to meet with the Oranga Tamariki Disability Advisory Group for the purposes of this assessment. However, health risks and barriers faced by disabled children and young people are likely greatly amplified by being in care. Further direct consultation and research focussing on health is required.

Box 4: National Care Standards and health needs

r13(2)(a) Physical Health, including dental, auditory, and nutritional health.

- Nearly half of children and young people in care have vision, auditory and/or developmental needs. Last year, 43% of children in care who accessed a Before School Check required a referral to address these needs, compared to 32% of the general population.
- Over half of all children and young people in care may have dental health needs. Last year, 18% of children in care under five years old had a dental referral, twice that of the general population. International research suggests the need for dental treatment among those in care across all age groups is much higher.
- Children and young people in care may have high nutritional needs: international
 research suggests they are more likely to experience stunted growth and be
 underweight or overweight. New Zealand data is not collected about the nutritional
 health of children and young people in care, but international research indicates that
 children and young people in care enter care with nutritional deficiencies that are not
 resolved to due to catch up growth and are linked to cognitive development.

r13(2)(a) Long-term conditions and disabilities

- There is reportedly a high prevalence of long-term conditions and disabilities. Systemwide data is unreliable. International research suggests that almost half of children and young people in care have clinical mental health and neurodevelopmental issues – a rate almost four times higher than the general population, which means they are likely prescribed psychotropic medication at a high rate.
- Children and young people in care in New Zealand are hospitalised at a very high rate

 90% of children in care aged ten to thirteen years old have had an emergency department admission in their lifetime, compared to 65% in the general population. 48% of these admissions were avoidable, compared to 24% in the general population. Infectious diseases are the most common cause of hospitalisation among all children in New Zealand.¹ Asthma is the second most common.
- Multiple international studies suggest that children and young people in care have often missed immunisations. See Box 11 on available immunisations data in New Zealand, which suggests immunisations are received at milestone age in 65% of cases.

r13(2) (b) and (c) Psychological Health; and alcohol and drug misuse

 There is a high rate of clinically significant mental health needs and drug and alcohol use. Around 78% of young people in care have accessed mental health treatment, compared to 14% of the general population, and 24% of young people in care have accessed treatment for substance use, compared to 1% of the general population. There is no data of the effectiveness of treatment for the care population and a likely pattern of children and young people attending only initial appointments ahead of scheduled child protection processes.

Prevalence of Trauma

"People need to understand trauma symptoms, don't write me off as a naughty little kid...don't punish." – Māori care-experienced young person

There is almost certainly a high prevalence of complex trauma²⁹ among children and young people in care, which drives health needs during care (see Box 4) and beyond.³⁰ Many have been exposed to child abuse or neglect. Early experience characterised by this type of trauma and stress adversely affects the neurobiology of the brain, and studies have shown that this type of complex trauma underlies many of the health problems experienced by children in care.³¹ In addition, children and young people in care have a trauma in common³² – being removed from their family and for many, frequent changes of location, caregivers, and social workers. Dr Mavis Duncanson, one of the few New Zealand academics with a focus on children and young people in care, described insights from her research in 2016:

Transition into State care often meant that there were abrupt changes in young people's lives, for example, separation from their siblings, living in a different geographical location and having to change school. Few young people reported any support to help them manage the trauma and emotional impact of being removed from their family or being moved from placement to placement.³³

The government has placed a specific obligation on the chief executive of Oranga Tamariki to ensure that support is available to a child or young person "to address any identified need for "assistance to recover

Box 5: Trauma as an invisible need

Trauma results from exposure to an incident or series of events that are emotionally disturbing or life-threatening with lasting adverse effects on a child's functioning and mental, physical, social, emotional, and spiritual wellbeing. Trauma symptoms include flashbacks, loss of bowel and bladder control, disturbed sleep with nightmares, avoidance of people and places, irritability and angry outbursts, hypervigilance and mistrust, lack of positive emotions, digestive problems, headaches and other non-specific pain, loss of appetite or overeating, difficulty with memory, concentration and decision-making, and addictions. Unresolved attachment trauma is directly linked to mental health problems.

Multiple placements and temporary or disrupted relationships with caregivers can also prevent formation of secure attachments and contribute to worsening or the emergence of a wide range of needs. Trauma can also mask needs, generating uncertainty about whether symptoms are mental, physical, behavioural, neurological, or developmental in origin. Often, this means the child does not receive the right support to address disability or avoid unnecessary hospitalisation and ultimately specialist health interventions. At worst, needs are invisible and addressed with discipline and punishment, which re-traumatise the child. International research indicates that very high levels of parent or caregiver relinquishment experienced by young people with ADHD diagnoses increased their risk of being placed in residential care settings and their behaviour being criminalised (see Box 12 on youth offending).

ACC provides treatment for some aspects of trauma, particularly sexual abuse. However, the ACC mental injury system is not connected to the wider health system or Oranga Tamariki. One care-experienced youth also noted that accessing information to make an ACC claim could be challenging in later life for those who were care-experienced. She said many may not wish to pursue a claim until later in life, but engaging ACC relied on accurate historical record-keeping and access to information collected about children when in care.

²⁹ Typically, complex trauma involves repeated incidence of maltreatment over an extended period of time that includes emotional, physical and/or sexual abuse, neglect, and witnessing family violence, which can lead to lifelong difficulties related to self-regulation, relationships, psychological symptoms, alterations in attention and consciousness, self-injury, identity, and cognitive distortions. See <u>Attachment and Trauma in Early</u> <u>Childhood: A Review; The Relationship Between Childhood Traumas, Identity Development, Difficulties in Emotion Regulation and Psychopathology.</u> <u>Emotion regulation difficulties in trauma survivors: The role of trauma type and PTSD symptom severity.</u>

³⁰ Baidawi and Piquero (2021).

³¹ <u>Accessing healthcare as a foster child, by Claire O'Donnell</u>. P 160 Journal of Health Care & Law Policy, 2021.

³² "Although youth who enter into care may already be experiencing symptoms or meet criteria for PTSD (Keller et al., 2010), entry into care can be a significant or even traumatic life experience for this population because of many potential personal, social and environmental challenges, which may influence symptoms." McGuire et al., 2021. The trajectory of PTSD among youth in foster care.

³³ The health needs of children and young people in Care, by Mavis Duncanson, p3.

from the effects of trauma."34 We note that a trauma response needs to include traumainformed care, which includes prevention of trauma, trauma-informed practice approaches in the Oranga Tamariki and health system, and age-appropriate mental health supports to work through the effects of trauma. The effect of trauma on psychological health is likely very high: according to international research, one in four children or young people in care may have post-traumatic stress disorder (PTSD).35 Another international study suggests a prevalence of PTSD for children in foster care that is almost twice that of combat veterans.36 There is uncertainty arising from the data collected in New Zealand, which only records provision of mental health treatment. Among children in care under 10 years old, for example, 27% receive mental health treatment (for all mental health conditions, not just PTSD).37 Under 20% of all current approved caregivers have accessed a trauma-informed learning course funded for all caregivers in the last year.³⁸ We were also told by Oranga Tamariki psychologists that trauma-related treatment is not consistently evaluated for effectiveness. Research also suggests that treatment can be counterproductive or even re-traumatising at worst.39

Unresolved trauma in interaction with an unresponsive system of support can disable children and young people, contribute to avoidance and mistrust of authority, including Oranga Tamariki and the health and education system, and lead to involvement with the youth justice system and life-threatening health crises

Box 6: Intergenerational trauma

Many children and young people are in State care because of unresolved intergenerational trauma. Māori, who make up 67% of those in care, are also at higher risk of trauma. Over 60% of children and young people in care have a parent who has had recent mental health treatment, compared to under 4% of the general population. Around 40% have a parent who has had recent substance use treatment compared to under 2% of those not in care. Methamphetamine use by the mother or other household members is a factor in half of all decisions to take children into care. Data is not collected about the proportion of children and young people in care with parents or family who are care-experienced, but we were told by care providers that this is likely high.

Females are at higher risk of trauma, undiagnosed mental disorders, and sexual abuse, presenting particular risks for intergenerational transmission of trauma. Research suggests females experience PTSD at two to three times the rate that males do, including because of their greater exposure to sexual assault. Among young females in care, there are also higher rates of early sexual initiation and teenage pregnancy, compared to the general population but data is not available on the proportion who are pregnant or parents when they are in care. Pregnancy and birth are a period of higher risk for re-triggering trauma among young parents. Nearly 50% of children and young people in care are females.

International research indicates that resolving parental trauma and actively supporting parent-infant attachment are the most important factors in addressing intergenerational trauma but strategies need to target relationships and the familial, community and societal levels are essential. Kaupapa Māori wrap around providers and Presbyterian Support Family Works programmes are among the primary health services that are supporting critical holistic whānau and community approaches essential to preventing transmission.

in adolescence.⁴⁰ Children who enter care under the age of five years old are six times more likely to be ordered by court to a youth justice residence, presenting with very high levels of health and disability need.⁴¹ Last year, a quarter of young people in care overall received

³⁴ Oranga Tamariki Act 2017, s13 (2).

³⁵. Posttraumatic Stress Disorder in Foster Care | SAFY

³⁶ Study Finds Foster Kids Suffer PTSD | News | The Harvard Crimson (thecrimson.com)

³⁷ Oranga Tamariki data.

³⁸ <u>Trauma Informed Learning & Support for Caregivers</u>, Caregiver Recruitment & Support, Oranga Tamariki, 6 October 2020. Of the Oranga Tamariki Caregivers approved in the 12 months to end March, 18% have attended Trauma Informed Learning programmes.

 ³⁹ (Mis)understanding trauma-informed approaches in mental health, by Angela Sweeney and Danny Taggart,
 13 August 2018. When it's bad to talk | Health & wellbeing | The Guardian

⁴⁰ The trajectory of PTSD among youth in foster care: A survival analysis examining maltreatment experiences prior to entry into care - ScienceDirect

⁴¹ Most children and young people in care do not, however, end up in the corrections system. See also <u>How</u> we fail children who offend and what to do about it: A breakdown across the whole system' by Professor Ian Lambie, Dr Jerome Reil, Judge Andrew Becroft, and Dr Ruth Allen, 2022.

substance use treatment, compared to 1% of the general population.⁴² 22% of young people with Oranga Tamariki involvement reported having attempted suicide in the last year, compared to 5% in the general population.⁴³ Research suggests New Zealand suicide rates are likely to be four times higher for children and young people in care, and that males are at higher risk.⁴⁴

Risks and protective factors associated with care status

"If we are missing connection with parents and whānau - how do we process that? Our physical symptoms could be related to not being with direct whānau." – Māori care-experienced young person

While children and young people in care enter care to protect their overall health and wellbeing, they typically have fewer protective health factors⁴⁵ than children who are not in care. Care placement itself is a major risk factor for health, especially for those with a high rate of placement instability or who change locality:⁴⁶ for children and young people in care, "the system lacks humanity and struggles to keep children and young people safe, let alone helps them recover from the impact of abuse and neglect."⁴⁷In New Zealand, the average number of placements in care is four, and the average number of social workers allocated to a child or young person over their time in care is ten. However, many children and young people do not achieve placement stability, often because of high unmet needs and unsuitable placement types. In addition to traumatising the child, their caregivers, whānau and social workers involved, placement breakdowns can interrupt consistent and holistic promotion of health and wellbeing, including the system of support around the child. Continuity of the primary healthcare relationship is not consistently a feature of placement change policy, especially given limited placement options.

Children and young people in care also have wellbeing needs that are integral to protection of their health. Chief among these is the need for the fundamentals to good childhood development: nurturing connections, good nutrition, and safe environments. Dr Mavis Duncanson observes: "Many young people have difficulty understanding why an offending adult(s) remained at the home while the child was the one taken away. It is of critical importance that children and young people in out-of-home care find a sense of family in a competent, caring, nurturing, stable...placement."⁴⁸Of 2,549 Oranga Tamariki caregivers, 1,570 are family caregivers, and this number is increasing, which increases the connection to family. But although subject to health checks, many family caregivers may be solo caregivers, have their own health and/or disability support needs, low health literacy and can

⁴² Oranga Tamariki data. This high figure also likely reflects those referred to treatment ahead of Family Group Conferences or other court processes and may not be ongoing.

⁴³ <u>Youth19 - A Youth2000 Survey</u>, Youth 2000 Survey

⁴⁴ Health outcomes of children in State care in Aotearoa New Zealand, Duncanson et al (yet to be published). Data were obtained for all 0–17 -year-olds living in NZ on 31 December 2013. In-care status was ascertained at this point. Outcomes of all-cause hospitalisation and all-cause mortality were assessed between 1 January 2014 and 31 December 2018.

⁴⁵ We note that a lack of protective factors and unmet health needs are also drivers that result in children and young people coming into care.

⁴⁶ There is consistent international literature about the specific features of care systems that heighten health risks. Evidence is not gathered about the extent to which health improves for individuals during care, or if health improves. We were told that there were generally more health records for a young person entering a residence if they had a care history, but these health records were not relied upon and depended on the approach and history of individual social workers. Although rare, children may experience further abuse or neglect during the time they are in care, but research is inconclusive on the extent of maltreatment, with most studies suggesting a prevalence of up to 2% (including perpetrators that include other children or abuse during contact with their parents).

⁴⁷Health Needs of Children in State Care, Duncanson. 2016.

⁴⁸<u>Health Needs of Children in State Care. Duncanson</u>, Power point presentation 2016.

experience significant barriers to primary healthcare, especially Māori caregivers (846 of family caregivers are currently Māori⁴⁹). Enabling primary healthcare for whānau is important to children and young people in non-whānau care too: for example, according to one young person, "*when the parents are good, the children are good*" and to another, having a good life meant that his mum would receive counselling.⁵⁰ In some cases, a return to whānau care or greater whānau connection may depend on holistic whānau interventions well beyond the scope of one government agency.

"Connect us to back to Māoritanga, hapū and iwi and cultural mentors. Marae connections give us a sense of belonging and self-discovery." – Māori care-experienced young person

For many Maori children and young people in care, whatapapa, and connection with wider whānau, hapū and iwi is seen by Māori stakeholders as a health and wellbeing need as much as a Treaty obligation, which also supports recovery from intergenerational trauma (see Box 5). This priority is also underpinned by the Oranga Tamariki Act 1989, which states in section 7AA(2)(b) that the chief executive of Oranga Tamariki must ensure that the policies, practices, and services of the department have regard to "mana tamaiti, whakapapa of Māori children and young persons and whanaungatanga responsibilities of their whānau and hapū". As Tupua Urlich explains: "My whakapapa is my identity. It's my people, my place, it's my history and, in the context of my childhood, whakapapa is where I should have been and who I should have been with."51 Recent research shows that rangatahi Māori connected with Oranga Tamariki have a stronger sense of identity and knowledge of their whakapapa⁵² – and 75% had opportunities to learn about their culture. However, data suggests only 13% of Maori are recorded as having connections to key people from their marae, hapū or iwi,⁵³ with only 5% of care plans considering the views of hapū or iwi.⁵⁴ ⁵⁵ We heard that connection to whakapapa is being prioritised, with kairaranga-ā-whānau roles being rolled out for this purpose. Reportedly social worker capacity for travel organisation and supervision requirements continue to be logistical barriers.

"The support was f@#*&-all, start igniting our strengths." – Māori care-experienced young person

Not all children and young people in care have unresolved trauma. Children and young people in care are individuals who have different levels of resilience and supports around them.⁵⁶ An Oranga Tamariki psychologist observed that the level of trauma is also not necessarily directly related to the reasons recorded by Oranga Tamariki for their entry into care. Their overall health and wellbeing is heavily shaped not just by access to primary healthcare services but other protective factors for health and wellbeing. In addition to connections with whānau, hapū and iwi, some protective factors for health referred to in the National Care Standards include support for culture, belonging and identity, education, play, recreation, community activities, and caregiver support. Care-experienced youth attached a priority to the importance of whānau health, caregiver support, adequate housing, and inclusive education, as well as opportunities for mentoring and peer support with other care-experienced people – issues that are addressed in other in-depth assessments.

⁴⁹ Oranga Tamariki caregiver data.

⁵⁰ What Makes a Good Life Follow Up Report. Report of the Office of the Children's Commissioner, 2019. ⁵¹ 'We didn't know what was ahead of us, but we knew it wasn't good' | The Spinoff

⁵² Compared to the children and young people not involved with Oranga Tamariki. Malatest International 2023.

⁵³ Independent Children's Monitor Report 2023, p45.

⁵⁴ Independent Children's Monitor Report 2023, p45.

⁵⁵ Data may be capturing all iwi and hapū contact as whānau contact. Oranga Tamariki's information system has limited capabilities.

⁵⁶ See <u>Resilience Against Traumatic Stress: Current Developments and Future Directions</u> which suggests there is considerable variation in the way that resilience is understood.

PART D: The Current Response of the Oranga Tamariki System

Systemic Disadvantage

Being in care is "like growing up with a disease" ⁵⁷ – care-experienced young person

The Oranga Tamariki system is struggling to adapt to the changing needs of children and young people in care and is compounding their disadvantages. The fact that the Oranga Tamariki system is fragmented, disconnected, and siloed, and that it is children and young people in care who are falling through the cracks, drove the enactment of the Children's Act 2014 and the Oranga Tamariki Action Plan. Regarding primary health, however, the problem is an order of magnitude greater: there are a myriad of different placement types, and the primary health system is large, broad, complex, and highly devolved (see Box 6). In addition, children and young people spend most of their time in schools, where there is a variable approach to health and provision of primary health services and supports.

There are numerous drivers of system performance, but chief among them is the lack of a common interagency framework that promotes a collaborative approach to the health and wellbeing of children and young people in care. The children's legislation governing Oranga Tamariki itself focuses principally on the powers of the State to protect all children from harm, with the health legislation governing health agencies focussing principally on the protection, promotion, and improvement of health of all New Zealanders. Education officials have noted that the role of the education system is to meet the educational needs of students, including those in care, in a way that is safe. inclusive and promotes wellbeing, which is integral to health promotion. There are gaps in interagency guidance on how to protect,

Box 7: Primary health rights and services

Under the Convention on the Rights of the Child Article 24, New Zealand has recognized the right of the child to the enjoyment of the highest attainable standard of health and to "facilities for the treatment of illness and rehabilitation of health" and committed to "strive to ensure that no child is deprived of his or her right of access to such health care services and to pursue full implementation of this right", including by "ensuring the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care."

The progressive implementation of the right to health has included expansion of primary and community healthcare in New Zealand, which covers a wide range of free or subsidised services delivered in the community. The sector is complex and wide-ranging, covering diagnosis and treatment, health education, counselling, disease prevention and screening. Today, New Zealand children and young people are entitled to many specific primary health services and supports to address primary health needs. Children and young people with disabilities are entitled to primary health services on an equal basis with others, including population and sexual and reproductive health services.

Primary healthcare in New Zealand includes free maternity care from pregnancy to six weeks after birth, and health and wellbeing checks for babies and children aged from six weeks to five years old. Children under fourteen years old are entitled to free consultations within a general practice setting. Children under thirteen are entitled to free prescriptions for medication. Children under eighteen years old are entitled to free immunisations for certain communicable diseases as well free annual oral health checks and dental treatment. Services are delivered through a wide variety of provider types. Across these there is a mix of for-profit and not-for-profit business models and a wide range of philosophies, scale and scope of services, and models of care.

Under the Bill of Rights Act, all New Zealanders have a right to refuse medical treatment and a wide range of rights are set out in the <u>Code of Health and Disability Services Consumer</u> <u>Rights</u> including the right to be free from discrimination, right to services of an appropriate standard, effective communication, and related to informed consent. Please see also Box 2 on the rights of disabled children and young people.

promote and improve the health and wellbeing of children and young people who are in care. The National Care Standards provide the main statutory guidance which help drive the decision-making and behaviour of government agencies meeting the health needs of children and young people in care as a group, but are limited by being minimum standards that do not apply to all placement types or roles and responsibilities for implementation.

⁵⁷ Children in Care. Nicola Atwool, 2010. P 51.

Roles and Accountability

"We are blamed for everything." – Māori social worker

The main guidance that does exist related to the health and wellbeing of children and young people in care is the National Care Standards. By adopting these standards in 2018, the government committed to take reasonable steps to "ensure that support is provided to address the health needs of a child or young person in care or custody." But the responsibility for ensuring that health needs are met belongs to the chief executive of Oranga Tamariki alone. In practice, health standards cannot be meaningfully implemented by one government agency, especially a child protection agency. As one example, the National Care Standards require that all children and young people have or have access to an annual oral health check, which can only be assured and monitored for quality and effectiveness in partnership with the health system (see Box 7). In practice, the lack of clear roles and accountabilities means that there is no system visibility when the needs of this population are not being met. Although required as part of a court order, we heard that it was not uncommon that care plans and support plans for health were not fully implemented: a Māori shared provider said; "Commitments made by judges are not honoured. Caregivers leave court with promises that are not followed up." We heard that often the right services and supports do not exist in the area or other barriers got in the way, and the lack of an interagency process to escalate system failures and resolve these issues was a concern. We also heard that a prevailing lack of accountability undermined trust and confidence in the government among whanau caregivers, who are reportedly scared and hesitant to rock the boat and complain.

"The Oranga Tamariki National Care Standards have improved compliance on health needs. But this varies according to approach of social worker and whether the child has been transient or had multiple social workers." – residence manager

According to the child-friendly version of the National Care Standards, the child's support worker "will help [the child] stay healthy". In practice, this responsibility must also be shared but we heard there is a lack of accountability and collaboration⁵⁸ among the many people that may become involved in the health of a child or young person in care - ranging from the caregiver and school, who have greatest visibility of the child or young person, through to doctors, psychologists, paediatricians, counsellors, oral health therapists and other government-funded supports. A care-experienced young person reports: "You're just passed around – from the school it was always just go see your social worker."59 Despite the critical role of primary healthcare in reducing avoidable hospitalisations and emergency hospital admissions, which are prevalent in this population, there is no obligation to identify a lead primary health provider who is equipped to meet the ongoing needs of the child or young person. The care plan approved in Court may not be developed with a primary health provider or address legal matters essential to primary healthcare, such as the approach to consent for non-routine treatment, health information, and engagement with the full range of primary health services appropriate to the age and identity of the child or young person. Even if the child or young person has a strong relationship with one provider, there are multiple services operating without guidance on what they might have to do together or in collaboration with Oranga Tamariki, to be effective.

⁵⁸ Consistent with initial observations and themes arising from the Descriptive Analysis of Disability Support Service-eligible in out of home specialist placements 2023, which is finding that there is limited healthcare coordination or accountability.

⁵⁹ School-Based Health Services Review Engagement 2023.

Box 8: Oral health unmet need

"I really want to emphasise the importance of oral health - introduce dental hygiene to the family as a whole, provide toothbrushes and toothpaste."

Dental caries is the <u>most prevalent non-communicable childhood disease</u> in New Zealand, with Māori and Pacific populations, those from low socio-economic backgrounds, and those without access to community water fluoridation most affected. Under the National Care Standards, the chief executive of Oranga Tamariki must ensure that the child or young person "has (or has access to) an annual oral health check by a health professional from the age of two years old."

There is no obligation that a child must enrol in services and a risk that children and young people in care are not practicing good oral hygiene, receiving oral health checks or follow up dental treatment. Shared care providers, youth residences, dental practitioners, and care-experienced youth report that teenagers in care or transitioning out of care have poor oral health that can often require major catch-up dental surgery. Some are presenting in youth justice residences and hospital emergency departments or clinics requiring extensive and treatment that costs \$1500-\$4000 under general anaesthetic.

- The gateway assessment does not include an oral health check but checks if the child or young person has had recent engagement with the oral health system and a referral is made if required. Any follow up of referral is currently, in practice, the responsibility of a social worker, given the high mobility of children and young people in care. We do not know how these referrals are followed up.
- All children and young people in New Zealand have the opportunity of regular oral health examinations through the community oral health service until Year 8. The service is delivered through fixed and mobile dental clinics at various locations including schools.
 - If a child in care arrives at school after the start of the year, or changes schools several times in one year, they may not be being offered an examination if contact is not made with the community oral health service.
 - If a child requires treatment that is not in scope of an oral health therapist, notifications for treatment at a dental practice can be through hard copy notices carried by the child, require consent from legal guardians and scheduling and transport to a dental practice.
- From Year 9, teenagers generally are seen by private dental practices who hold a contract for services. Utilisation of publicly funded services for adolescents was at around 70% pre COVID, with lower uptake for Māori and Pacific populations, and has dropped since COVID.
- There is also variability in the numbers and geographical locations of dental practices and almost no wraparound providers offering trauma-informed oral healthcare. These practices are also not necessarily notified that a child or young person is in care and there is no pathway to the most appropriate services for children and young people in care or a pathway from hospital admission back to primary oral health care.
 - There are 6 Māori and 1 Pacific Oral Health provider delivering services to adolescents that is culturally appropriate care but may not necessarily equipped or funded to deliver trauma informed care or the level of care needed for patients with multi-layered health and disability needs (multiple sessions, and sedation if required) – their locations are Auckland, Hamilton, Tauranga, Hastings, Rotorua, and Porirua.
 - There around 10 12 public dentists that are specially trained to work with high need and vulnerable populations – they are employed in hospitals and able to a higher level of care but are mostly only available in urban centres with more provincial/rural hospitals not having access to this subspeciality.
- Recent New Zealand research by <u>France et al (2017)</u> found that the major barriers to accessing dental care for Pacific adolescents were "negative perceptions of dentists; loss of structured support for dental attendance during adolescence; a mismatch between parents' and/or caregivers' guidance and behaviour around oral health care; and uncomfortable, unsupportive and uninformative dental environments."
- Irrespective of oral health service gaps and procedural difficulties, we were told by care-experienced youth, residences, and shared care providers that children and young people in care may have poor oral health and ignore or avoid oral health checks until it is too late.
 - One care and protection residence took a young person to the dentist at age seventeen for a final check due to transition to independence and end of free dental care, after it was discovered that the young person had been avoiding oral health checks to that point. The young person received over \$1000 of dental surgery.
 - Care-experienced young people described the importance of whānau-centric oral health promotion from a young age, including access to basics such as individual toothbrushes and toothpaste. Those associated with youth justice residences said a Māori-led mobile suite of dental services onsite would improve outcomes for this specific placement type.

"It all comes back to Oranga Tamariki to finance, even when it should be free." – Oranga Tamariki health and education adviser

Multiple internal and external stakeholders also claimed certain services also often "stood back" if they knew that Oranga Tamariki was involved, due to a belief that Oranga Tamariki had other means of addressing health needs. This trend may be worsening in an environment of resource pressures.⁶⁰ Under regulation 35(1)(g) of the National Care Standards, the chief executive of Oranga Tamariki must "ensure that a child or young person is supported to access other services (for example, private health services or therapeutic services) if existing publicly funded services to address their needs are not available in a timely manner." Private services can increase timeliness but be disconnected from the public system and ineffective, harmful, and stigmatising at worst. The cost can be prohibitive, creating a perception among kaimahi that private providers may be driving up prices when they know that Oranga Tamariki is paying. There were also major market gaps, which had contributed to the expansion of an internal health capability within Oranga Tamariki, including employment of over 40 in-house psychologists operating outside the public health system. In some regions, there are no psychologists available inside or outside Oranga Tamariki, with competition across government to secure staff. Many psychologists are reportedly now in private practice, often working at rates for ACC that are not able to be matched by the Oranga Tamariki system.

Health crises absorb system capacity...

"After that, I didn't have any stable placements, home was wherever it was. I'd go to school one day, the next thing you know I'm going to a different town, different people, and a totally different sort of environment, without any sort of notice. I went to nine different schools in the 12 years I was in the state's care." – Tupua Urlich⁶¹

Despite the introduction of the National Care Standards, the health needs of children and young people in care are still often not being addressed until it is too late. We heard from Oranga Tamariki kaimahi that health needs often tended to be first identified because of the impact of the child's behaviour at school rather than by a primary health provider. By the time the government focusses on health, health-related problems are often reaching a crisis point, with Oranga Tamariki generally leaping over primary healthcare services, and into a conflict with other agencies about specialist referrals. This process can be time-consuming and challenging due to different service offerings and uncertainty about whether needs meet very high eligibility criteria for different kinds of interventions. In the absence of a system response, the child or young person is at high risk of a placement breakdown and exclusion from school, which further undermines the stabilisation of their health and wellbeing (see Box 9). If an unplanned placement change occurs or is categorised as temporary, health interventions can be delayed or denied – a potentially discriminatory practice that is prohibited in other countries.⁶² According to a regional health and education adviser, a child was denied a health intervention because of a plan to return the child to the care of their mother in two years' time. Children and young people can transition out of care without their needs being addressed (see Box 10).

⁶⁰ Oranga Tamariki health and education advisers and kaimahi.

⁶¹ We didn't know what was ahead of us, but we knew it wasn't good by Izzy Joy Te Aho White. Media Article. The SpinOff, May 3, 2023.

⁶² <u>Promoting the health and well-being of looked after children</u>, p7. Statutory guidance for local authorities, clinical commissioning groups and NHS England.

Box 9: Young people leaving care placements without health plans

A significant minority of children and young people in care experience placement instability, or three placement breakdowns in a year. The underlying health and disability needs contributing to placement instability are specific to the individual and can be complex and masked by trauma symptoms, but the presentation is the same distress and externalising behaviour that impacts on others. The proportion of young people experiencing placement instability is not currently monitored and reported in New Zealand, but the phenomenon is a common feature of care systems. In England, the proportion who have had three placement breakdowns in one year is monitored to reduce the incidence and is currently 11%

Once they reach the age of fourteen, some young people are leaving placements without plans in place. Up to 20% of the population may not be receiving ongoing health support although they remain in the custody of Oranga Tamariki, and they may not be enrolling in the transitions service. Of 4638 in care as at December 31, 2022, 432 returned home, 112 were in independent living, and 84 youth justice residences, and a further 671 in an unspecified placement type, in addition to family and foster care and care provider placements. There is a significant decline in numbers of young people in the custody of Oranga Tamariki after the age of 14 years old generally.

Social workers spend much of their time dealing with the fall-out of these health crises, mired in interagency compliance obligations and supervising a child or young person when the rest of the system does not have a response. Leaving aside limitations of capacity, social workers also conveyed different views about the extent of their role in primary health. Some said they saw addressing primary health needs, such as oral health, as more appropriate to the role of the caregiver. Children and young people in care say they heavily rely on the skills and support of their caregivers, but caregivers told us they were uncertain about their role and decision-making on health; recent caregiver surveys suggest they also often have limited access to up to date or essential health information about the child or young person. Caregivers do not receive training in primary health, including in areas which are regulated by other countries, such as skills in first aid, including mental health first aid, or administration of medication. Caregivers also said they were hesitant about overstepping their role, especially given the complexities around consent and risk of suddenly displacing the child. A Maori caregiver said a GP had prescribed drugs without safeguards to a young person who had attempted suicide four times earlier that year but had not felt able to intervene.

International research suggests late identification of needs is a feature of care systems, which struggle to match the impact of a nurturing parent who has cared for a child consistently since birth: "generally, caregivers and social workers do not understand or appreciate the full extent of the child's health needs and lack the medical expertise to sufficiently advocate for their children."63 Many Maori and Pacific caregivers also face additional barriers to accessing primary health services, including racial discrimination and judgemental practice: "You're trying to talk to them [health care provider] so that they can understand what's going on, but it's like 'yeah, yeah, yeah' ... you don't even listen ... 'we are the nurse, we know what we're doing. You don't know anything' because that's how I feel when they do that." (Pacific caregiver).⁶⁴ In addition, Māori and Pacific caregivers can frequently be solo caregivers or have multiple caregiving responsibilities and a lack of time and transport, especially those living in rural areas or who are poor.65 Those caring for a disabled child or young person may need to manage an illcoordinated array of support professionals - one caregiver said her disabled child was supported by ten support workers, including two speech and language therapists required by different government agencies.

⁶³ <u>Accessing Health Care as a Foster Child</u>, by Claire O'Donnell. 24 J. Health Care Law & Policy Journal 157 (2021). P 162.

 ⁶⁴ See Ethnic differences in the uptake of child healthcare services in Aotearoa, by Terryann Clark, Kabir
 Dasgupta, Sonia Lewycka, Gail Pacheco & Alexander Plum. New Zealand Work Research Institute, 2023.
 ⁶⁵ See Ethnic differences in the uptake of child healthcare services in Aotearoa, by Terryann Clark, Kabir
 Dasgupta, Sonia Lewycka, Gail Pacheco & Alexander Plum. New Zealand Work Research Institute, 2023. This
 ⁶⁵ see Compute Services and Compute Services in Aotearoa, by Terryann Clark, Kabir
 Dasgupta, Sonia Lewycka, Gail Pacheco & Alexander Plum. New Zealand Work Research Institute, 2023. This
 research used Growing Up in New Zealand data and indicates ethnic disparities related to access to primary
 and community health services, including immunisations, oral health, and maternity, and examines ethnically
 motivated discrimination and other barriers. Caregivers who were sole caregivers or had multiple caregiver
 responsibilities faced greater barriers.

We were also told that education needs, rather than health needs, tended to dominate attention - about 80% of the time, Oranga Tamariki health and education advisers were reportedly focussed on education, compared to 20% on health, and the shared care service specification⁶⁶ prioritises education but not health. Caregivers are not systematically required to have training in primary health such as first aid or management of medication. A paediatrician told us there were often significant opportunities to improve the health of this population through nutrition, hygiene, sleep, and routines, which could be addressed in a range of ways including through a primary health relationship. Speculation about the reasons for the greater system focus on education has included that education is mandatory, with a system response triggered if a child is not attending school or requires support to remain at school and a ripple effect on adults. For example, a social worker described supervising a child's lunchbreak on an ongoing basis at school because of a funding shortfall in the education system. Health stakeholders make the point that health and education are mutually reinforcing both in childhood and youth and across the lifespan - children with better health are better placed to engage in learning, while adults with better education have better health.

Box 10: Youth justice and primary health

Young people involved in ramraids, car thefts and street fights have renewed public debate on youth crime and how to address it, but there is less attention on their health and its relationship to youth offending behaviour. Of 4638 in care as at December 31, 2022, 84 were placed in youth justice residences. Over 40% of young people in youth justice residences have care and protection histories and many arrive with very high unmet health needs and are disabled – in other words, they are likely to be young people who have not had their needs addressed when they were in care or transitioning out of care.

Data is being collected to enable an up to date understanding of the health needs of young people in custody in youth justice settings. A <u>review of literature</u> undertaken in the New Zealand by The Werry Centre concluded that "prevalence rates of mental health issues of between 40% and 60% highlight that mental health and alcohol and other drug issues cannot be ignored in the youth offending population". Youth justice residence placement presents a significant opportunity to identify and address high presenting primary health needs. <u>Gluckman</u> concludes that "youth interventions work best where all aspects of functioning are addressed."

But time in a residence is also limited and defined by court orders. As a result, we heard that there is often insufficient time to deliver suitable health interventions, with limited ways to transition ongoing primary or other health support back into the community. Security crises and immediate concerns can also complicate or restrict efforts to evolve to a trauma-informed model of care and deliver health interventions. Mobile dental buses are now providing oral health care in some residences, but this is complicated by resourcing issues. The wide range of other services required by young people in youth justice may not be mobile or tailored to meet the multi-layered health and disability support needs of this population.

In certain other countries, there are <u>specific standards for children in the youth justice system</u>, including assessments of risk and need, due to the complexity of care. New Zealand's Children's Commissioner is a designated National Preventative Mechanism under the Optional Protocol of the Convention against Torture and is providing <u>reporting</u> on compliance under this treaty. This includes a finding that the custodial environment should be a place of trauma informed rehabilitation. However, restriction of access to primary health can also lead to cruel, inhumane or degrading treatment.

...and are driven by earlier system failures

"Assessments are inaccurate and far too late...if you can get one at all. There is a tendency to blame the parents rather than take a closer look." – non-Māori shared care provider

⁶⁶ <u>Shared-Care-Service-Specification-August-2022.pdf</u> (orangatamariki.govt.nz)

The major implementation mechanism for the National Care Standards on health is the production of a needs assessment - 'the gateway assessment' - to help address system weaknesses and identify needs early. We were told this approach tended to bypass primary health, but was an improvement on having no health engagement at all, and different views about who should lead the assessment, and how to tailor the process to this population.⁶⁷ For example, some wanted greater access to cognitive assessments to help early identification of global development delay, foetal alcohol syndrome disorder.⁶⁸ autism spectrum disorder, attention deficit hyperactivity disorder, and learning and communication disorders, which were all perceived as prevalent in the population.⁶⁹ Some felt assessments were being "skewed to the supports available" with diagnoses "totally unavailable under the age of five years old". Care status makes diagnosis more challenging, and impairment can be exacerbated or even caused by untreated primary health conditions and primary health barriers experienced by the child. Whether or not gateway assessments are accurate, we know that around 25% of the 5000 in care have not had one - and that the 600 in youth justice custody do not access them. We also heard that assessments could be delayed by months or even years or be out of date. 70

Māori shared care providers we spoke to had concerns about the framework of the gateway assessment: they said assessing the health and wellbeing of Māori children should be Māori-led, kaupapa-based, and take place within a whānau framework. One shared care provider said that a process based on individual needs promoted a focus on deficits of tamariki and rangatahi Māori. A Māori shared care and primary health provider said devolution to Māori was essential to address unacceptable delays. Furthermore, a Māori health provider cited assessments in general as "a prime example of the system not working...assessments are scheduled at times and on days that are not suited to the working family of for the families that need transport assistance or rely on public transport to get them to appointments. If they miss more than two appointments, they are released from the wait list and tamariki need to be referred again." More generally, international research indicates that assessments, however these are produced, are only as useful as their follow up and integration into a collaborative and coordinated approach to ongoing

⁶⁷ Recommended practice in the US and the UK appears to include an initial screen upon entry to care and a full health assessment completed within thirty days. New South Wales, in Australia, recommends the assessment process starts within thirty days (Georgetown University Child Development Center).
⁶⁸ Foetal alcohol spectrum disorder in Aotearoa, New Zealand: Estimates of prevalence and indications of inequity. FASD prevalence in the general population is estimated to be 1.7% (95% confidence interval [CI] 1.0%; 2.7%) in the 2012/2013 year. For Māori, the prevalence was significantly higher than for Pasifika and Asian populations. In the 2018/2019 year, FASD prevalence was 1.3% (95% CI 0.9%; 1.9%). For Māori, the prevalence was significantly higher than for Pasifika and Asian populations. The sensitivity analysis estimated the prevalence of FASD in the 2018/2019 year to range between 1.1% and 3.9% and for Māori, from 1.7% to 6.3%.

⁶⁹ International research suggests that these conditions are prevalent in children and young people in care. ⁷⁰ The Diagnostic and Statistical Manual of Medical Disorders (Fifth Edition) or DSM-5 is a US classification system that was updated in 2013. Christopher Pearson suggests that mental health diagnoses in children are "complicated by the additional factor of continuing mental and physical development" and which rely on "subjective elements" including "the ability of the parent to provide an accurate history of the child's behaviour, the behaviour of the child in the room at the time, and the bias of the assessor," in his 2017 article The diagnostic validity of mental health diagnoses in children.

primary healthcare.⁷¹ Some countries also have an age-based approach, with guidance on primary health content required.⁷²

Invisibility in the public health system

"We need access to primary healthcare, but organisations have too many patients. Waiting lists and eligibility criteria can exclude us." – Māori care-experienced young woman

Unlike refugees or veterans for which the State also has a positive obligation, children and young people in care are not identifiable in the health system or entitled to a specific approach to their primary healthcare. The main safety net is that each child or young person in care must be enrolled with a Primary Health Organisation (PHO), with children and young people in care accessing GPs on the same basis as any other New Zealander. According to care providers we spoke to, this obligation had helped them to prioritise PHO enrolment - 93% of males and 95% of females in care are enrolled with a PHO, comparable to the general population.⁷³ But enrolment only means that a child has visited the PHO in the last two years and tells us little about the quality and effectiveness of engagement, or even whether the child still lives in the PHO area. No data is available on the State's obligation to provide an annual health check.

Children and young people in care are, however, likely disproportionately impacted by current professional shortages because of their high levels of mobility. We heard from kaimahi that some children and young people in care are ending up at the bottom of waitlists when they move, and experiencing significant delays and different doctors at the same practice. Some are unable to enrol in a preferred practice,⁷⁴ and may be accessing consultations through emergency and after-hours services. A shared care provider said children and young people in care do not necessarily have "a tailored service or long-term GP." According to the 'What Makes a Good Life' Follow Up report of the Children's Commissioner, 31% of children and young people in care did not feel they could go to the doctor when they needed to (compared to 16% of those not in care). Over 20% of children and young people are living independently, have returned home or are in unspecified placement types that are not managed by care providers or are not family or foster placements with Oranga Tamariki caregivers responsible for their day-to-day needs.

We know children and young people in care face arguably more barriers to primary healthcare than any other group in New Zealand due to their age and maturity, ethnicity, and disability, including intellectual and neurological disabilities.⁷⁵ But they also face barriers specific to their care status which is invisible in the health system. In particular, the health

⁷¹According to Kools et al, "priorities for clinical practice including care coordination and interdisciplinary collaboration; maintenance of adequate and up to date health records; vigorous follow up and health-target advocacy." Foster Child Health and Development: Implications for Primary Care, 2003. In England, providers of health services designate a doctor and nurse for children and young people in care. These named professionals coordinate the provision of services for individual children and provide advice and expertise for fellow professionals. The concept of a medical home was first trialled in the US in the 1960s among paediatricians who cared for children with chronic health conditions and continues to be a feature of foster care systems in certain States in the US.

⁷² See UK Statutory Guidance - <u>Promoting the health and well-being of looked-after children - update note</u> added to start in August 2022, Annex A.

⁷³ Compared to 95% of males and 95% of females in the general population.

⁷⁴ GP Crisis a pressing human rights issue. June 24, 2022, Stuff.

⁷⁵ Children and young people in general face barriers to primary healthcare, which are greater for Māori and Pacific children, as noted in New Zealand research by Dr Mona Jeffries using Growing up in New Zealand data: <u>Prevalence and Consequences of Barriers to seeing a GP for children</u>. In addition, there is a high prevalence of disabilities. Specific to care status, children and young people in care are often in the care of strangers who may be temporary or not know the child and may have present to GPs with little to no health information, due to their high levels of mobility.

system is not notified systematically that a child or young person is in care, care status is not identifiable in the health system and there is no health strategy, policy, professional development or consistent clinical governance to guide and support primary health providers.⁷⁶ A GP told us that even if they are informed by an accompanying caregiver that a child or young person is in care, this had no bearing on their primary healthcare. A lead primary health provider is not designated or consulted when a child or young person enters care and health providers do not have access to guidance on what care status might mean for the health of the child or their primary healthcare if consulted. New Zealand's refugee health handbook⁷⁷ offers some insights into information that health providers can access on refugees. Many primary health providers will have limited exposure to children and young people in care, who number less than 5000 in a population of over five million.

Another barrier specific to care status is unreliability of health information, which impacts effectiveness (See Box 12). Primary health providers may not know about the child's family, level of trauma, physical or sexual abuse, or disability:^{78 79} "health information may not follow the child through various living situations and they may receive incorrect doses, too many medications and other inappropriate treatment as a result."⁸⁰ Health records are often siloed and inaccessible, disproportionately impacting children and young people in care, because they frequently change location and can rely on caregivers and social workers who also change. Young people in care consistently report having to 'repeat their story,' but many are young and most have communication difficulties. An accompanying adult might not know the child well or know little about the child's health or health history. Caregivers don't have a right to access health information and there is no systematic primary health check upon entering care.⁸¹ Caregivers told us health information could be limited, out of date and even withheld on privacy grounds related to adults involved, undermining the safety of the child and family. A lack of information-sharing and different legal status and consents can particularly complicate immunisations (see Box 11).⁸²

⁷⁸ A social worker described spending three days carrying out case note research to discover that a young person had been diagnosed with an impairment when they were four years old but had not been told or supported. Another picked up a child was not receiving medication because it "had dropped off their records," with another intervening to prevent repetition of an invasive assessment because records had been lost.
⁷⁹ The reasons can relate to the kind of service, how data is managed through to whether and how information about the child is shared with the health system and the high mobility of children and young people in care, which means that records may need to be transferred across multiple services and localities. Health information difficulties are common in care systems, with different methods to address this barrier to primary health care including heath passports and health homes and designated doctors and nurses.

⁷⁶ The most recent resource is a <u>Paediatric Policy on the Health of Children in Out of Home Care by the Royal</u> <u>Australasian College of Physicians</u>, 2007.

⁷⁷ <u>Refugee Health Care: A handbook for health professionals (moh.govt.nz).</u> See also <u>Refugee and Migrant</u> <u>Health</u>, which is an Otago University paper for health professionals on the health needs of refugees and migrants, ranging from information about the group and differences among them, through to how they should prepare and communicate, common health issues, including mental health issues and conditions, special health and disability needs, and resource people and providers as well as publicly available <u>Te Whatu Ora</u> <u>information services</u> specification for refugee and migrant health and <u>local services</u>.

⁸⁰ Advocates say overmedication of children in foster care still a problem - Indiana Capital Chronicle.

⁸¹ Caregiver surveys show that being informed about the child and their story is critical to caregiver satisfaction, but health is not explored in caregiver surveys. See <u>2019 FCA Caregiver Survey Report</u> and <u>501 FCA Caregi</u>

Box 11: Immunisations and consent

'I had anxiety, and the team came into my house for immunisations. It was the best.' – Māori care-experienced young woman

Children and young people in care are generally identified as a group highly likely to miss immunisations. Youth justice and care and protection health services in residences check the immunisation status of all those coming into care and immunise as appropriate, but there is no equivalent check-up upon entry into family care. Children and young people in care are not identifiable on the National Immunisations Register as a priority population and there is no legal requirement to enrol them. Immunisation officials report difficulty finding children and young people in care, given their high mobility. There is no data about how many in this population have opted off the National Immunisations Register or declined immunisations.

In New Zealand data suggests that around 63% of children and young people in care in New Zealand are fully immunised at the milestone age – which is the age of eligibility to receive an immunisation on the National Immunisations Schedule - which covers over twenty different immunisations. This appears to be lower than the general population, but also likely to reflect a lower rate of immunisations over the COVID-19 pandemic. But 85% are fully vaccinated against measles, mumps, and rubella, which compares favourably with the general population.

Currently there are varying approaches to consent depending on the legal status and age and maturity of the child - children and young people in care can consent to a COVID-19 vaccine from the age of 12, but not to other immunisations. A lack of enrolment and dedicated support and planning for consent with the child and family was identified by Oranga Tamariki kaimahi, health officials and caregivers as likely contributing to immunisation difficulties and delays for a minority of children and young people in care.

Decision-making delays can be contrary to the best interests of the child and can contribute to higher rates of avoidable hospitalisations. For those that move location, caregivers report a lack of up-to-date information on immunisations and the child or young person may drop off the National Immunisation Register for a period. For a certain minority, legal guardians may not receive the necessary support and can be unresponsive, leading to court processes to resolve issues after they have emerged, rather than before immunisations are scheduled.

Box 12: Medication and misdiagnosis

"Chuck them in the depression folder, or anxiety folder, and put them on meds that all the bro's are on too. A quick fix". – Care-experienced youth

As result of research and public awareness raising, the US has enacted laws due to concerns about overmedication of children and young people in foster care. <u>US research</u> has revealed that children and young people in care can be misdiagnosed and over-medicated. Children in foster care in the US are prescribed psychotropic medications at a rate three times that of other Medicaid-enrolled children in the US and they have higher rates of polypharmacy. Psychotropic medications are any drug capable of affecting the mind, emotions, and behaviour. Once psychotropic medications are prescribed, children in care are likely to be kept on them longer than children who are not in care.

US research suggests that factors that may contribute to overtreatment with psychotropic medications include caregiver demand for medication to manage disruptive behaviours and lack of understanding of trauma symptoms, lack of paediatric mental health supports, and misdiagnosis of trauma symptoms as other mental health conditions. Psychotropic medications may not address the underlying trauma and attachment issues at the root of the challenging behaviours of children and young people in care. The same study concludes psychotropic medications should be prescribed only after a mental health evaluation and trauma assessment by a child mental health expert and only for a specific mental health diagnosis. The medication should be appropriate to the diagnosis, initiated at the lowest appropriate dose, and increased slowly while monitoring for efficacy and adverse effects. Polypharmacy should be avoided whenever possible.

There are no equivalent research or guidelines in New Zealand with respect to children or young people in care with data on medication unreliable and inaccessible. However, over the past five years, there has been a 50% increase in prescriptions for anti-depressants among children and adolescents in the general population. In 2021, a New Zealand study found that the benefits of antidepressants for children and adolescents are usually modest, and the drawbacks can be major, including increases in suicidal thinking in some users.

Fear, avoidance, and re-traumatisation in care

"I went to the doctor for the first time in ten years last week. I had some fear. I couldn't get an appointment for a week. I was worried how much it was going to cost and whether it would be invasive. The lady was really nice. She was telling me about all these things I didn't even know. It was a bit invasive, but it was ok." – Māori care-experienced young person

The National Care Standards include an obligation to support the recovery of children and voung people in care from trauma, but not expressly to build trust in the health system and protect them from re-traumatisation. The most basic primary health need of children and young people in care is for health professionals to do no harm.⁸³ Professor Bruce Arroll of the University of Auckland states: "trauma can be a potentially major component of the patient's context; therefore, it is "relative malpractice to miss it." ⁸⁴ Despite the often-best efforts of health professionals, primary healthcare itself can also be unpleasant and create feelings of fear for children⁸⁵ and at worst be traumatic for them, especially dental treatments⁸⁶ and immunisations.⁸⁷ Children and young people in care are at greater risk, because of high rates of trauma, histories of abuse and mistrust of authority, as well as mental health conditions, including anxiety disorders, and greater hospitalisation, emergency admission and exposure to invasive procedures associated with care status. In this context, the obligation in the National Care Standards to provide an annual check with a health professional was described by a shared care provider as problematic and stigmatising, and inconsistent with an holistic approach to health and wellbeing, especially if the contact was casual and not trauma-informed and occurring within the context of a trusted and ongoing primary health relationship.

"Iwi service providers are great - you are connected and are entitled to care." – Māori care-experienced young person

Trauma-informed primary healthcare services can help prevent re-traumatisation and are few but growing, led by Māori and Pacific and youth specific wrap-around health providers.⁸⁸

⁸³ The avoidance or minimisation of harm or non-maleficence often cited in health ethics relies on context and access to essential information.

⁸⁴ https://www.nzdoctor.co.nz/sites/default/files/2021-06/HTT_Trauma-informed-care

⁸⁵ "Frequently, episodes of care such as preventive clinic visits, acute care, medical procedures, and hospitalization can be emotionally threatening and psychologically traumatizing for paediatric patients...Throughout a child's life, approximately 15% to 20% will encounter some form of relatively severe trauma." Lerwick, J. <u>Minimising paediatric healthcare-related anxiety and trauma</u>. World Journal of Clinical Paediatrics, 2006 May 8; 5 (2): 143.

⁸⁶ "Fear and anxiety toward dental issues and going to the dentist affects a considerable proportion of children and adolescents [1], with a huge negative impact on their future behaviours." Fernandes, S.C.; Loureiro, A.; Lopes, L.B.; Esteves, F.; Arriaga, P. <u>Children's Attitudes and Behaviours about Oral Health and Dental Practices.</u> <u>Healthcare 2021</u>, 9, 416.

⁸⁷ "In one study, 63% of children (aged 6–17) reported a fear of needles, and significant relations between a fear of needles and the female sex, as well as increasing perceived pain intensity during immunizations...In the adult population the fear of needles is estimated to be 22%. Needle phobia, an anxiety disorder affecting 3.5% - 10% of the general population has a median onset of 5.5 years. The literature shows that needle phobia decreases with age...Of 18-year-old adolescents expressing dental anxiety, 11% have reported being needle phobic." Orenius, Saila, Mikola, and Ristolainen. Fear of Injections and Needle Phobia Among Children and Adolescents: An Overview of Psychological, Behavioural, and Contextual Factors. Sage Open Nursing, 2018. Published on-line March 2018.

⁸⁸ Health system reforms aim to promote more effective and holistic primary health services for all New Zealanders. Currently, most General Practices are private businesses which are publicly funded to address primary health needs within a fifteen-minute service window. There is no system-wide approach to

The National Care Standards provide that each child or young person has "access to a health practitioner with the same knowledge and experience of cultural values and practices." New Zealand research shows that young people connected with Oranga Tamariki are more likely than those not connected with Oranga Tamariki to utilise these kinds of services, and that they prefer these services, which tend to be trauma-informed. Wrap-around Māori health providers explained they were better placed to understand the holistic needs of children and young people in care, and their whānau, and support their recovery from trauma over their lives, rather than just for the duration of a care placement. A care-experienced youth agreed, preferring iwi services even if not located in the same area. A non-Māori shared care provider commented on the model of care of iwi services: "a shining light is Awarua Whānau Services – free but also accessible, open after work hours (until 7pm) - a non-judgemental, strong, relationship-based service." We heard that often preferred services were swamped by demand, could struggle with sustainability, and may not reach children and young people in care.

Children and young people in care are still, however, likely to have to engage across New Zealand's primary health system due to their high needs and wide variety of services required. There is an ongoing shortage of Māori (and Pacific) health professionals across the health system in relevant services - only 7% of nurses are Māori and this reduces to 2% of pharmacists and 1% of optometrists.⁸⁹ Trauma-informed approaches are more common in mental health and addiction services, but research shows that even most of these do not carry out trauma screening,⁹⁰ and mental health treatment provided to a child or young person in care may not be monitored for quality and effectiveness. There is no credentialling of trauma-informed health services, which could help promote referral. In the case of GPs and other primary health professionals, professional development is self-funded; incentives may not exist. Trauma-informed services are relational, and often require additional time and capacity, as well as skills. Certain GP practices have chosen to move in this direction and present opportunities for system learning about what works and what is needed.

"We need to educate everyone about trauma and the physical and mental impacts of trauma... Trauma therapy should be available to everyone." – Māori care-experienced young person

Engagement with the primary health system does not present the only opportunity for retraumatisation of children and young people in care. Care-experienced young people told us that they could be re-traumatised through their relationships with caregivers, teachers, social workers through to the courts and local police, when people playing important roles in their lives failed to understand their trauma symptoms or respond effectively. There is significant work across the Oranga Tamariki system to promote a trauma-informed approach to service delivery, but we were told that in the absence of system leadership there was a risk of government agencies being siloed, ineffective or inconsistent. We heard conflicting reports about progress of trauma-informed approaches in youth justice residences, where young people in care have high rates of trauma and may have to engage with a wide range of staff

credentialling and funding of trauma-informed care – few GPs are trained in this approach and professional development is self-supported. Trauma-informed care is relational and often requires additional time to support trauma-screening and build a trusting relationship.

⁸⁹ health workforce 7053 31 july19.pdf

⁹⁰ "A systematic [New Zealand] review explored the presence of trauma screening within adult mental health services. Nine studies revealed that only 28% abuse and neglect identified by researchers was documented in client files. A study conducted in the UK found only 18% of mental health staff screened men for a history of sexual abuse half the time or more, with one-third reporting they never asked. Likewise, an Australian study found only 23% of staff agreed with the statement "I routinely ask patients about childhood trauma, including sexual abuse"...The timing of screening matters. A [1998 NZ] study identified significantly higher rates of disclosure when people were asked on admission to an inpatient service (47% disclosing childhood sexual abuse, compared with 6% when asked later)." <u>Trauma-Informed Care by Anna Elders</u>. p38, New Zealand Doctor 17 March 2021.

and other professionals from within the Oranga Tamariki system.^{91 92}There is currently no system-wide approach to trauma-informed workforce development, and we were told existing training was not necessarily jointly designed or monitored for quality and effectiveness and could face implementation difficulties and that better access to information about trauma-informed primary health services could help.

"People don't understand the health reforms. We are so used to being told to stay in our lanes. We need to collaborate and do things differently." - Māori nurse

The National Care Standards are silent on the role of the education system in the health of children and young people in care. Schools are where most children and young people in care spend most of their time and where health and wellbeing issues are sometimes being identified are acute: school leaders, teachers and school-based health services are relevant levers for health promotion for this age group. Research indicates that school-based health services are highly valued by children and young people in care, but only available to those who are attending school.⁹³⁹⁴ Leaving school to access services can be disruptive, stigmatising, and difficult for whanau, disproportionately impacting on Maori and Pacific children in whanau care. Different schools and education professionals can have variable skills and involvement in health⁹⁵, and GPs do not work in schools.⁹⁶ School nurses attempt to straddle the divide, but may not be told that a child or young person is in care or know the child's GP; these services are also only available at Decile 1 – 5 schools. Other services based out of schools, such as counsellors, the immunisation service or the community oral health scheme do not generally coordinate or deliver an integrated approach, and there is, in general, a variable long-term commitment to primary health in school leadership.⁹⁷ When children and young people do not attend school, or are excluded, they may miss out.

Need for independent primary health support

"Oranga Tamariki is under pressure – this leads to dictating too much, telling whānau what to do, when and how. The process is not whānau-led, there is a mismatch of timeframes." – Māori shared care and health provider

Under r35(1)(e) of the National Care Standards, the chief executive of Oranga Tamariki must take reasonable steps to ensure that health information is provided to the child or young person "on relevant health matters (for example, physical development and growth, healthy relationships, and positive attitudes to sexual health, psychological, and emotional health), including how health services can be accessed." For those in family or foster care, children and young people in care are often placed with caregivers who are elderly, or a different gender, or have low health literacy and may not know how to talk about all aspects of health. Care-experienced youth want much greater support for them and their caregivers to address primary health needs at home and to feel safe to access services. For children and young people in care, this starts with someone to talk to about "whether my menstrual cramps are

⁹¹ <u>Oranga Tamariki putting children in care with young offenders when options run out</u>. Katie Doyle, Stuff. August 5, 2022.

⁹² Youth Offending: Is it About Justice or Health, Sue Buckley, The Nathaniel Centre.

⁹³ Improving Youth Health/ Cross cutting themes (waitematadhb.govt.nz)

⁹⁴ Data suggest that around 30% of children and young people in care attend Decile 6-10 schools.

⁹⁵ <u>O is for Awesome: National Survey of New Zealand School-Based Wellbeing and Mental Health Interventions</u> by Thabrew, Biro, and Kumar explores how government-identified responsibilities for wellbeing and mental

health in schools are implemented. The research concludes that a lack of staff time, confidence and knowledge is a major barrier and that there is limited use of evidence-based interventions (i.e., those with research evidence of efficacy and/or effectiveness). This is despite the availability of multiple evidence-based interventions for the prevention and treatment of common mental health issues in schools (O'Reilly et al., 2018).

⁹⁶ Oranga Tamariki has developed and funded SWIS and YWIS services to help meet some of the gap.

⁹⁷ Nurses slam school health review - NZ Herald

normal', "helping my grandfather learn about giving the right dosage of Panadol" and "getting us all toothbrushes". Sexual and reproductive health and rights were consistently raised as challenging access and realise (see Box 13). One caregiver social worker described an aunty being uncomfortable 'talking about the birds and the bees' with a young man, which in turn was raised as an issue for a care-experienced young women supported by a solo father. A regional disability adviser observed: "Young people and children in care are often among strangers and already have communication difficulties – they don't know or can't communicate their needs." This communication challenge is identified consistently in international literature as specific to those in care.

"We need to feel safe to receive services. I was too scared to go to the doctor, scared of the wrath of 'OT'" – Māori care-experienced young woman

Box 13: Sexual and reproductive health unmet needs

Children and young people in care told us that trauma-informed sexual and reproductive health information and support was an area of unmet need, especially for those living in rural areas or who lived with a caregiver that was not the same sex, gender, or sexual orientation. Early sexual initiation and teen pregnancy are more common among young people in care. More than <u>a third</u> of young people with any Oranga Tamariki involvement reported having had sex – statistically significantly higher than those who had never been involved.

- Early parenthood for care-experienced young people is not necessarily a poor outcome if they are provided with consistent and adequate support. However, pregnancy and birth can trigger both trauma and poor mental health- and care-experienced youth reported highly mixed experiences of support at this time, depending on their regional location.
- Research highlights the importance of maternal mental health during and after pregnancy even mild to moderate stress during pregnancy can lead to neurodevelopmental, emotional, and cognitive changes that place a child at risk of later disadvantages such as learning difficulties, mental health issues, school failure, poor relationships, and antisocial behaviour.
- Practical support is suggested from maternity products, such as a breastfeeding pillow mentioned by one care-experienced youth, through to menstrual products. New Zealand research shows that young people with care involvement were close to three times as likely to have experienced period poverty, and close to four times as likely to have missed school due to period poverty (compared to those with no care involvement).
- Disabled young people also need access to sexual and reproductive health that is response and inclusive of their disability support needs. Often disabled young people are infantalised and are not given information, support and access to services. These rights are explicitly identified in the Convention on the Rights of Persons with Disabilities, because of pervasive barriers. Mt Cargill Trust, which provides intellectual disability care, provides dedicated support, but this approach is not assured outside of a residential settings.

For children and young people in care, how health support is delivered is as important as addressing the unmet need. They want more structure around their relationship with Oranga Tamariki on health: "*There is a massive trust barrier… a fear that children will be ripped away, which may prevent whānau caregivers from raising issues.*" Another describes lifelong mistrust arising from mishandling of information: "*My issue with counsellors is when I was younger, I was being abused and I went to school and spoke with the counsellor, told him that I was being abused, he notified the caregiver, so I went home to another hiding. So even as an adult, I have a problem talking to counsellors.*"⁹⁸ They are concerned about a bigger role for Oranga Tamariki in addressing unmet primary health needs: "*Someone from Oranga Tamariki feels like its people 'scoping out' the situation*", and they are wary of government accountability processes that drive compliance, which might be "*too prescriptive and put pressure on whānau.*" They told us they wanted confidential relationships with health providers who know their history and understand them, are non-judgmental and allow them and their whānau and caregivers to go at their own pace. International research also shows that supports need to be tailored to the specific needs of individual children, taking into

⁹⁸ <u>'We didn't know what was ahead of us, but we knew it wasn't good' | The Spinoff</u>

account their age, culture, gender, disability and rainbow needs, making a one size fits all approach unlikely to succeed.

Removing the stigma

"I get my hyper vigilance from trauma, and a great eye for the opportunity" – Māori former ward of the State and shared care provider

In the end the most important provision is missing from legislation and policy governing the Oranga Tamariki system - that every child or young person is supported to make healthy choices while they are in care and to develop trust in the health system and life-long healthseeking behaviours. Rather than a green light for tailored care in the health system, they can experience disadvantage and stigmatisation, including from having to repeat their story, being misunderstood and labelled with diagnoses in ways that they don't like. Privacy about care status may be in the best interests of the individual in many cases, but also presents risks - invisibility in the system prevents identification or understanding of the health rights and needs of the group as a whole, and access to appropriate supports and potential benefits for individuals (see Box 14), including contact with their peers, mentors and leaders. The Oranga Tamariki system status quo can inadvertently reinforce stigma while also inhibiting support from the wider New Zealand community and make invisible the unique resilience and strengths of this group of young New Zealanders growing up in the custody of the State.

Box 14: Health and wellbeing promotion

New Zealand identifies certain small vulnerable populations and provides publicly available and accessible information for them and their healthcare providers to help promote health and wellbeing. In the case of refugees, for example, this group is identifiable in the health system, which also produces relevant information about refugee health and a range of dedicated supports, including a refugee health care handbook since 2001. Internationally, countries have different ways of identifying and targeting children and young people in care, and their caregivers, to promote health and wellbeing, which are relevant to their different health systems. Australia, for example has a Foster Care Health Card, which enables access to prescriptions, bulkbilled GP appointments and reduced out of hospital medical expenses, as well as a range of other deals and discounts varying across different States.

The <u>United Kingdom</u> has a foster carer ID and promotes a wide range of public and private perks and benefits for caregivers and their birth and foster children including discounts, deals and cashback from high street retailers, a Max card, a Blue Light card, West End shows, a "recommend us" bonus of around NZD\$3000, access to networks and a helpline, on-line libraries, home insurance and the Duke of Edinburgh scheme. The <u>United States</u> provides that children and young people in foster are generally eligible for their Medicaid system, including behavioural health and trauma services, and many States provide a "health home" for foster children, with different States having foster carer IDs that promote access to benefits and networks.

PART E: Focus Areas

Government processes and platforms to build on

Across government, there are already significant initiatives underway which will help meet the primary health needs of children and young people in care. These include priority areas under the Child and Youth Wellbeing Strategy, actions under the Oranga Tamariki Action Plan, the transformation within the health system including reviews of Well-Child Tamariki Ora programme and School-Based Health Services, as well as the Oranga Tamariki Future Direction Work Programme, and work to revamp digital enablers at Oranga Tamariki, including its case management system.⁹⁹

In 2019, Oranga Tamariki introduced a fundamental shift in its practice approach. The approach is framed by te Tiriti o Waitangi and is inherently relational, inclusive, and restorative. It draws on Te Ao Māori principles of oranga but recognises that what this means will be different for all whānau and within whānau. It views oranga as a relationship between whānau and their cultural, natural, physical, and social environments, and as holistic and fluid, with states of oranga changing over a lifetime.

The current Oranga Tamariki assessment framework, Tuituia, was adapted from a framework developed in the United Kingdom. Work is currently underway to replace Tuituia with an oranga framed assessment process. This requires social workers to work with whānau to facilitate and develop understandings of their oranga aspirations and support needs, and to respond to these support needs. Oranga framed assessments and the associated changes to models of practice are significant and will take two to three years to embed.

This report comes at a time of significant change in the health system as the government works to deliver the Pae Ora reforms, with the intent of:

- meeting the complex demands of a growing population.
- address the persistent inequalities experienced by Māori.
- ensure greater access, experience, and outcomes for those traditionally not well served by the system Māori, Pacific and disabled people.
- utilise modern technology and develop new and innovative ways of working.
- focus on keeping people, their whānau and their communities well and out of hospitals – not just caring for them when they get sick.

They will also create a more locally responsive system, using Localities and Iwi-Māori Partnership Boards that will enable local priority identification and planning. These are significant long-term changes, but they will create a system that can be more responsive to the Oranga Tamariki population, including whanau and families and those on the edges of the care system.

Health agencies are committed to improving health and wellbeing outcomes for these children and young people and have a comprehensive range of work underway to make change to support these children and young people to have better, healthier lives. These are set out below and discussed in more detail in Annex 3.

- a. Pae Ora health reforms
- b. Oranga Tamariki Action Plan

⁹⁹ Request to include but not clear whether this information is able to be shared publicly.

- c. Kahu Taurima
- d. School-Based Health Services
- e. FASD and neurodiversity
- f. Mental wellbeing

Lifting the health and wellbeing of this small population in the care of the State is an important litmus test of the health reforms. We consider that it is critical to support system collaboration on the reforms and to remain connected at the national, regional, and local levels as the health reforms are implemented and to report to joint Ministers regularly on how this is unfolding.

The focus areas

We identify the follow five focus areas for system attention and note that this work will need to consider the particular needs of Māori, Pacific and disabled children and young people and those in different placement types including those in placement instability.

- 1. Ensure **accountability arrangements** for health and wellbeing for the Oranga Tamariki system are fit-for-purpose, including reviewing the definition of health and wellbeing, with a focus on health promotion and prevention, and supporting the child or young person and whānau to live healthy lives while involved with Oranga Tamariki, and to develop trust in the health system and life-long health-seeking behaviours.
- 2. Improve **provision of whānau-centric health and wellbeing supports** for these children, young people and whānau, with a focus ensuring these are culturally appropriate, holistic and trauma informed and to support healthcare continuity and coordination.
- Identify opportunities to enable and expand independent health support for children, young people and whānau - including information on consent, information sharing, entitlements, wellbeing advice and options for local health provision to promote engagement, trust, and confidence in the system. As part of this, advice could be provided on complaints processes.
- 4. Explore potential improvements to **data and information sharing** between the health system to improve the ability of Oranga Tamariki and the health system to understand the health and wellbeing of children and young people in care and ensure children and young people are having their needs met, in a way that respects their privacy.
- 5. Review the system approach to **trauma-informed care** with the intent of improving system capability, safety and appropriate trauma-informed supports for children and young people in care, and those who work with them. Te Aorerekura (family violence and sexual violence) capability frameworks for specialist and generalist workforces could be investigated, given children's agencies are part of Te Puna Aonui.

The gateway review will pick up issues raised in this report related to the assessment process, including the question of a need for improved integration with disability and related assessments and supports to prevent unmet needs, as this relates to secondary or specialist services. Agencies will report back to the Social Wellbeing Board within three months with a roadmap of how focus areas will be addressed, including the agencies responsible and initial timeframes, as well as other work to address specific primary healthcare issues raised in this assessment.

ANNEX 1: Lower South Equity Insight

"Māori solutions are not national or even regional. What might work in Invercargill might not work well in Dunedin." – Iwi partner

This insight has been prepared in consultation with some Oranga Tamariki partners and staff that live and work in Otago and Southland to provide an insight into the challenges and opportunities for addressing primary health needs of Māori in a specific region, including to help identify any regional differences or disparities for tamariki and rangatahi Māori.

Age	-1-1	2-5	6-9	10-13	14-16	17
Māori (137)	6	35	31	42	17	6
Non-Māori (147)	8	20	26	36	48	9

Custody of the CE as at 31 December 2023 - Lower South Region

There are 137 Māori in care in the Lower South region. The Maori population of the former Southern District Health Board is estimated at 34,630, much smaller than most other regions, but expected to grow to 62,060 by 2038.100 The rate of Māori entering care appears to be potentially much higher than in regions with higher Māori populations. Māori make up the majority of children and young people in care in every age group, consistent with national patterns. However, there is a much greater disparity compared to national patterns between Māori and non-Māori in care aged 14-16 years old, where Maori numbers halve to 17 from 42 compared to 48 of non-Māori, whose numbers instead increase by 80%.

Living in the Lower South

Maori groups and people emphasised that the primary health needs of Maori were different in their area and required local solutions. Most saw a pervasive bias that was specific to living as Māori in this location, where Māori needs were less understood. One non-Māori shared care provider said they sometimes help mitigate racial discrimination experienced by Māori whānau when accessing healthcare in Southland, by accompanying Maori to health appointments. A Māori mother had been turned away from Invercargill's Emergency Department four times raising concerns about her child's behaviour and was advised the problem was behavioural. The provider had supported the caregiver to see a GP, and the process eventually identified a brain tumour. Māori were often not recognised as Māori by the government system and could be categorised as non-Māori if they did not have a Māori name. One care-experienced youth with a Māori name reported not being treated as Māori because she "looked Irish." A major

obstacle to health and wellbeing was the lack of support for a child's whakapapa. Iwi recording was not mandatory, and sometimes inaccurate - one iwi was given predominance when that might not be appropriate to the complexity of the whakapapa of the child. Whakapapa was foundational to identity and health history: how could the child understand themselves without understanding their parents? Whānau, iwi and hapū connections also needed to be authentic.

In general, professional shortages were acutely impacting services throughout the region, but especially Southland and rural areas. GPs generally had closed books in Invercargill and other locations, and dental services were often delivered through mobile clinics out of Dunedin. A major increase in organised crime and meth in Southland was driving complex health needs and there was a lag in supports and services. Professional shortages meant significant delays and low likelihood of seeing the same doctor twice in Dunedin, and in Invercargill, there was no choice: GPs would not accept a person that was already enrolled at another GP. These dynamics likely disproportionately impact Māori.

Trauma-informed whānau framework

The fundamental Māori health need was healing intergenerational family trauma and ensuring support provided to children was whānau-based and trauma-informed. There was interest in more devolution to iwi to lead government processes and place more Māori in the care of Māori shared care providers. Government generally functioned in silos and Oranga Tamariki was "trapped in crisis mode", which led to "dictating too much, telling

¹⁰⁰ Demography | Southern Health | He hauora, he kuru pounamu

whanau what to do, when and how". There was a mismatch of timeframes: Oranga Tamariki needed to go at the pace of whānau, which was much slower than the pace of Oranga Tamariki. There were positive approaches to collaboration, supported by Oranga Tamariki, Police and health providers. The greatest system gap in Southland was a framework to addressing the needs of each whānau holistically, which would go at the pace of whānau: "you can't deal with a child's primary healthcare needs in isolation. We need a local runaka-led whānau-centred, whole of government, community-engaged framework based around all needs of individual whānau".

Unmet health needs

Health system data shows that generally Māori children and young people in Southland have health disparities. Needs are reportedly becoming higher over time including those associated with a perceived prevalence of intellectual and neurodevelopmental disabilities. We heard there was a gap in cognitive assessment in the area, with females much less likely to be identified for assessment and diagnosed accurately. A backlog of 19 cognitive assessments had recently been completed by Oranga Tamariki, half of which identified intellectual impairment found in only 1% of the population. We were told that assessments have been seriously delayed, prohibitively expensive and skewed to the supports available.

Māori groups on the other hand called for health assessment processes to be holistic, Kaupapa-based and Māori-led for Māori in care, including to address delay. A delay could have pronounced and unintended impacts on children and young people. For Māori groups, there was an even higher risk of perceived unreliability of assessments given lower cultural competence, especially for Māori children and young people who only spoke Te Reo and been educated in Kura Kaupapa within a different framework of development. There was support for this shift within Oranga Tamariki.

Māori groups said trauma manifested in selfdestructive and self-harming behaviour, including early sexual initiation and harmful sexual behaviour. An unmet need on entry into the local residence was sexual and reproductive health – a full time occupational therapist was employed to meet this need but not funded by the government (more information available in Box 13). A Māori careexperienced young woman described a lack of quality maternity care and a teenage pregnancy unit at school to offer wrap-around support: "It was just my GP and my friends." There are reportedly almost no school-based health services or Youth One Stop Shops. Family Planning had some limited capacity, which was not tailored to the needs of young people in care.

A Māori shared care provider called for transition support to begin at a younger age. Given the sudden drop in numbers of Māori in care in this region aged 14 - 17, it is not clear that all care-experienced youth under 17 are receiving transition support who need it. This assessment was not able to identify the reasons for the disparity. Social workers consulted interpreted the disparity to adolescents with a history of placement instability who were rejecting care arrangements and re-locating often in an unplanned way and without any ongoing supports, but these individuals should generally still remain identifiable.

Opportunity for Change

Māori are starting to provide tailored, traumainformed kaupapa-based primary healthcare which was highly regarded but swamped. In Dunedin, this was a full wrap-around service for all Māori in care across GP, nurse, oral health, mental health, well child, immunisations, and pharmacy. We heard, however, that some caregivers did not understand health needs of Maori children and young people and stuck to their own providers. Young people choose their own provider at the Mt Cargill Trust residence, preferring a GP associated with the residence who specialised in their needs and had a relationship over time with them. Absent a strong primary care relationship, the requirement to have an annual check had little impact.

ANNEX 2: Health Data

The Independent Children's Monitor has identified that Oranga Tamariki is currently restricted in its capacity to self-monitor due to lack of data. Under the National Care Standards, there is a requirement to maintain a record of the health history of children and young people in care. The purpose of doing so, and the roles and responsibilities to achieve the purpose, or data measures to monitor the Standards, are not set out in the Regulations. In practice, there is not an accurate or comprehensive record of the health of children and young people in care as individuals or as a group.

The current approach to data collection for this cohort and in New Zealand more generally drives a narrow focus on needs rather than the promotion of holistic health and wellbeing. Data normally gathered and presented emphasises sickness/poor outcome data, leading to a focus on higher level interventions, which are important, but not sufficient – this approach means that there is less information about health prevention and promotion which is critical in the long term and to health and wellbeing outcomes.

Health data at the national and regional level are essential to the monitoring of population health to allow effective targeting and identify disparities. Accordingly, the New Zealand health system has many datasets that are organised by demographical splits (cohorts), including data related to children and young people. Examples include the National Minimum Dataset (hospital discharge information), National Maternity Collection, Mortality Collection, NZ (New Zealand) Cancer Registry, National Immunisation Register and primary care enrolment data.

The New Zealand health system holds certain data of direct relevance to understanding the health of children and young people in care, but children and young people in care are not visible currently in the health system because identifying data is not shared by Oranga Tamariki. There are no systematic data sharing arrangements and data is largely siloed. Furthermore, each health system dataset has different data governance structures and access rules that have been established within the bounds of what the data can be used for and based on the consenting arrangements that are in place. This has two impacts:

- Legal obligations for the use and access to health data are straightforward and the clinician's obligations are clear but the interplay between the obligations of health workers and Oranga Tamariki on access to health data held by the health system is not clear. Oranga Tamariki has not been able to access health data from the health system at the level of the child or young person without the legal right to do so, which can also depend on the legal obligations that underpin the use of the particular health dataset.
- In 2023, high level general practice enrolment data and immunisation data have been made available by the health system for the first time. The data is in a nationally standardised form in terms of collection, curations, and reporting. Most other primary healthcare service data, however, is only available either in a batch form or related to contract reporting with providers and not able to be accessed without further work on permissions.

Health data are also collected by Oranga Tamariki in its information management system (CYRAS), but much of this data is not reliable, relevant, or accessible at the national level. Oranga Tamariki data does not generally include, for example, engagement with primary health services or compliance with health checks required by the National Care Standards. CYRAS also does not currently have structured data fields or a dedicated zone to record individual primary health information. Regional data cannot be disaggregated, including to identify disparities for Māori and other groups.

The Oranga Tamariki gateway assessment dataset may contain significant health data, but most of this data is not accessible either. Data is not generally available on the health needs identified due to the variability of data entry practice and approach to the assessment process by different practitioners in different regions. In addition, gateway assessment data tends to be a point in time dataset so, even if accessible, this dataset would not be reliable for providing accurate overall information on population health.

There is no mechanism to collect qualitative health data systematically. The health system carries out health and disability consumer surveys for the general population but children and young people in care are not identifiable within these surveys. Oranga Tamariki does not survey children and young people about their health and disability consumer experience. Surveys of caregivers, however, have identified general consumer issues related to caregivers lacking sufficient information and training in dealing with health and disability needs.

ANNEX 3: Health Sector Commitment to Children and Young People in Care

Oranga Tamariki Action Plan

In addition to the system changes, health agencies are progressing work programmes specifically focussed on this population. Most notably, the Oranga Tamariki Action Plan sets out a range of collaborative actions to deliver better outcomes for children, young people and their families involved with Oranga Tamariki, some of which align to the findings in this report, including:

- Oranga Tamariki, the Ministry of Health, and the Ministry of Education committed to reporting to the Ministers of Health, Education, and Children by December 2022 on the scope and approach for a review of gateway, and to gain Ministerial decisions on the scope of a review by mid-2023. This is an opportunity to identify opportunities to ensure gateway assessment process is meeting the health and wellbeing needs of these children in a timely and culturally appropriate way.
- Develop locally tailored resources to support social workers and carers supporting children and young people to arrange access to health and oral care services, fulfil health entitlements, and enrol with health care providers. This is an opportunity to develop tailored and responsive resources and information to improve social worker capability and confidence in addressing health and wellbeing issues, and support engagement with appropriate care.
- Children and young people in care and youth justice have their health needs assessed, planned for, and met through an integrated service model by agencies working together to provide holistic and tailored care. The Integrated Service Model work is an opportunity to develop new ways of delivering health supports and services that are holistic and culturally responsive. The model will be informed by this Oranga Tamariki in-depth needs assessment.
- Establish a cross-agency data and insights group between the Manatū Hauora and Oranga Tamariki to inform immediate and ongoing priorities and actions. This is an opportunity to take a strategic approach to improving data, and addressing issues that impact on the quality of data available.

As part of the Action Plan, health agencies are also supporting Oranga Tamariki with other needs assessments, including the recently published Mental Health and Wellbeing Needs Assessment and the cross-agency response outlining actions underway or planned to improve mental wellbeing services and support. This plan outlines nineteen actions to ensure that children and young people with the greatest needs get the help they need to support their mental wellbeing.

Kahu Taurima

In addition to the Action Plan, there is the Kahu Taurima programme which is the joint Te Aka Whai Ora and Te Whatu Ora approach to maternity and early years (pre-conception to five years old, or the 'First 2000 days of life') for all whānau in Aotearoa New Zealand.

To support the transformation, the Kahu Taurima team will commission new, integrated, interprofessional, culturally tailored maternity and early years' service delivery models. These service delivery models will contribute to achieving consistency in national service

delivery while enabling local tailoring to support whānau aspirations and goals. This will include working with whānau, communities, Hauora Māori Partners, and service providers across the motu.

School Based Health Services enhancements programme

Funding was received in Budget 19 to expand School Based Health Services to decile five schools (complete) and enhance SBHS. The SBHS enhancements programme started in late 2019 and is ongoing. The enhancements programme aims to ensure that SBHS are effective and efficient in improving outcomes for young people and achieving equity. The enhancements programme:

- reflects Te Tiriti o Waitangi (Te Tiriti) principles recommended in the 2019 Hauora report for the health system.
- ensures the needs and concerns of young people are central to the measures and indicators and addressed by the service.
- links to the <u>Child and Youth Wellbeing Strategy</u> and other relevant government agency strategies.

The enhancements programme has a focus on populations currently not well served by the system, including:

- rangatahi Māori
- Pacific young people
- rainbow young people
- young people in care
- young people with disability.

The enhancements programme is built on Te Ūkaipō, our Vision and Values Framework (Te Ūkaipō). Te Ūkaipō is an expression of te ao Māori values and principles, Te Tiriti o Waitangi principles, He Korowai Oranga (Māori Health Strategy) and Whakamaua; Māori Health Action Plan (Whakamaua).

This work programme is also working in partnership with Māngai Whakatipu, our youth advisory group, which was formally established in July 2022 to focus on quality improvement and enhancement activities of SBHS. Māngai Whakatipu includes members of our population groups for the enhancements programme. Our partnership with young people through Māngai Whakatipu means they can be involved in all stages of design, equal with adults. It also means they can educate and inspire others to act, learn and demonstrate leadership skills, model positive behaviours for peers, and contribute to positive development of young people and their communities. Te Whatu Ora is working other partners, including the youth health sector, and the Ministry of Education for the enhancements programme.

The voice of young people is key to the mahi. Advice from our early engagement with young people identified four priorities:

- a supportive culture around accessing SBHS so services are accessible without barriers.
- all rangatahi youth in Aotearoa NZ, no matter what education they are receiving, or their background have access to all health services.
- the environment which rangatahi receive SBHS should be safe and comforting.
- a system that caters to all and is not a "One-Size doesn't Fit All" approach.

Together with our partners, Te Whatu Ora developed a work programme to progress the following enhancements to SBHS:

• SBHS model of care

- Evaluation and quality improvement
- workforce development and support, including addressing an identified need for training in trauma-informed care, and working with gender and orientation diversity (i.e rainbow populations)
- improved linkages with other services and sectors, especially the education sector to support integrated care for young people.

FASD and neurodiversity

Ongoing work continues around the assessment and response to Foetal Alcohol Spectrum Disorder and other neurodiversity. Te Whatu Ora is working closely with Whaikaha to identify ongoing improvements to screening, assessment, and behavioural supports. Over time, this is likely to see an expansion of neurodevelopmental screening as well as enhanced access to behavioural supports.

Mental wellbeing

In 2021 the Government published *Kia Manawanui – long-term pathway to mental wellbeing*, which is our ten-year strategy and action plan to work towards the vision of 'Pae ora healthy futures: An equitable and thriving Aotearoa in which mental wellbeing is promoted and protected'. Manatū Hauora's implementation of *Kia Manawanui* for the Oranga Tamariki-involved population is interconnected with the Oranga Tamariki Action Plan and our leadership of the Child and Youth Wellbeing Strategy's focus on supporting mental wellbeing (this focus was added in 2022 so is still in development).

Work to support child and youth mental wellbeing led by the health sector includes:

- Support for primary mental wellbeing through educational settings and communities (the Mana Ake programme delivered in primary schools; School-Based Health Services delivered in intermediate [Ross/John pls confirm] and high schools and activity centres, offering both physical and mental health support; mental wellbeing support in tertiary education institutes; and the Access and Choice youth, Māori and Pacific streams) and expansion of youth-focussed of telehealth and digital supports
- Enhancement of youth forensic services responsible for young people with combined mental health needs and offending behaviours
- The addition of youth as a priority population in the Strategy to Prevent and Minimise Gambling Harm 2022/23 to 2024/25
- Expansion of specialist child and adolescent mental health and addiction services, plus workforce development support for these services

Government has also committed to a number of actions as part of our response to the 2022 assessment of the mental wellbeing needs of the Oranga Tamariki-involved population. This includes a focus on healthcare, including mental, healthcare in residences; development of an integrated service model across the health and Oranga Tamariki systems; workforce development around mental wellbeing; and research and analysis of the mental wellbeing needs of the Oranga Tamariki involved population.

Manatū Hauora has two key priorities for child and youth mental wellbeing policy in 2023 and ongoing. Firstly, we want to drive interagency work towards mental wellbeing – for example through our leadership of the recently-added priority of the Child and Youth Wellbeing Strategy, 'supporting child and youth mental wellbeing.' Secondly, we want to gain a better understanding of the continuum of mental health and addiction care that is available to young people, with a focus on specialist mental health and addiction services: what they deliver, how well it works, and how well these services are integrated into the health and social systems broadly.