

Hauora and Tāngata Whaikaha Māori: A report for Te Aka Whai Ora

Advice to Te Aka Whai Ora on responding to the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori: a strategy for the first two years

1 July 2022

Paper prepared by Gabrielle Baker, Dr Paula Toko King (Baker Consulting Ltd), Bernadette Jones and Associate Professor Tristram Ingham (University of Otago & Foundation for Equity & Research NZ).

Acknowledgements

This paper was developed with funding support from the interim Te Aka Whai Ora.

Te Ao Mārama Aotearoa, a Tāngata Whaikaha Māori led group that provides advice to the Ministry of Health and other agencies, provided feedback on a summary of this report and added to our thinking, particularly on Tāngata Whaikaha Māori governance.

Bernadette Jones and Associate Professor Tristram Ingham would also like to acknowledge support from the University of Otago, Department of Medicine, Wellington.

Suggested Citation: Baker, G., King, P.T., Jones, B., Ingham, T. (2022) *Hauora and Tāngata Whaikaha Māori: Advice to Te Aka Whai Ora on meeting the health and wellbeing needs of Tāngata Whaikaha Māori in the first two years of its operations*, Foundation for Equity & Research NZ (FERNZ), Wellington.

Published by: Foundation for Equity & Research New Zealand (FERNZ), July 2022

Table of Contents

Introduction	4
Summary of recommendations	5
Background	8
Te Aka Whai Ora’s objectives & functions compel a focus on Tāngata Whaikaha Māori	8
Six priority areas for action	9
Priority 1: Responding to the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori	11
Start with a national kōrero	12
Priority 2: Supporting the leadership, governance, and collective voice of Tāngata Whaikaha Māori communities	13
Increase Tāngata Whaikaha Māori participation in leadership and governance	13
Support Tāngata Whaikaha Māori communities	14
Priority 3: Ensuring strategy, policy and locality planning meets the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori	15
Provide advice that ensures the visibility of Tāngata Whaikaha Māori	15
Undertaking ethical co-designing	16
Follow through on commitments made	17
Priority 4: Increasing Tāngata Whaikaha access to Kaupapa Māori providers	18
Increase the number and range of disability support services offered by Kaupapa Māori providers	19
Address the underfunding of Māori health providers so they can better meet the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori	20
Improve commissioning and contracting practices for health services	21
Increase capacity and capability funding	22
Priority 5: Addressing workforce issues for Tāngata Whaikaha Māori	23
Sector focused role: Building the workforce	23
Ensure Tāngata Whaikaha Māori are included in all health workforce development activity	24
Attract more Tāngata Whaikaha Māori into the health workforce	25
Support career pathways for Tāngata Whaikaha Māori	26
Support a workforce that meets the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori	26
Te Aka Whai Ora’s role as a good employer	27
Make an explicit commitment to recruit Tāngata Whaikaha Māori at all levels of the organisation	28
Develop human resource policies and processes with Tāngata Whaikaha Māori	28
Support Tāngata Whaikaha Māori staff	28
Priority 6: Data, monitoring, and accountability for Tāngata Whaikaha Māori	30
Improve data collection	30
Develop a monitoring work programme	32
Support governance of Tāngata Whaikaha Māori data, by Tāngata Whaikaha Māori	33
Conclusion and recommendations	34
References	37

Introduction

The establishment of the Te Aka Whai Ora is a significant milestone for the health sector in New Zealand. Te Aka Whai Ora has roots in Māori-led movements of the 1980s and 90s that pushed Te Tiriti o Waitangi as a basis for all government activity, and in the Waitangi Tribunal claims of the 2000s, especially in primary health care, that highlighted breaches of the principles of Te Tiriti o Waitangi in the Ministry of Health's actions and omissions when it came to responding to and being accountable for Māori health.

As Te Aka Whai Ora began its formal role from 1 July 2022, there are high hopes from all Māori that it does things differently from its mainstream predecessors (including the Ministry of Health and district health boards). But, as outlined in this paper, it is critical that Te Aka Whai Ora pay particular attention to how it can meet the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori (the term used in this paper for Māori with lived experience of disability, although we acknowledge there are also other, equally valid, terms preferred by some groups).

This paper canvasses the main issues for Tāngata Whaikaha Māori, within the direct or indirect influence of Te Aka Whai Ora, and identifies six priority areas over the next two years:

1. **National level kōrero with Tāngata Whaikaha Māori.** Responding locally and nationally to the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori.
2. **Leadership, governance and collective voice of Tāngata Whaikaha Māori communities.** Supporting the leadership aspirations of tāngata whaikaha Māori.
3. **Strategy, policy and locality planning:** ensuring all strategies and policies and commissioning meet the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori and are undertaken in genuine partnership.
4. **Mātauranga Māori & Kaupapa Māori Services:** providing access to mātauranga Māori and increasing Tāngata Whaikaha Māori access to Kaupapa Māori services.
5. **Workforce:** Addressing workforce issues for Tāngata Whaikaha Māori (as employees & employers).
6. **Data, monitoring and accountability:** Improving all data and monitoring for Tāngata Whaikaha Māori and increasing accountability.

Across these six priority areas, this paper identifies 20 recommendations for Te Aka Whai Ora to implement over the first two years of its operations – including some areas where mahi should begin immediately.

Summary of recommendations

Recommendations from 1 July 2022 for Te Aka Whai Ora:

Rec #	Recommendation text	Timeframe
1.	Begin national kōrero with Tāngata Whaikaha Māori held in partnership with Tāngata Whaikaha communities. The national kōrero could contribute to hearing the aspirations of Tāngata Whaikaha Māori and understanding how they choose to describe concepts of disability. Additionally, this is a chance to introduce the work of Te Aka Whai Ora.	Immediately
2.	Work with the Ministry of Health, Health NZ and within Ta Aka Whai Ora to support processes that ensure high levels of participation by Tāngata Whaikaha Māori regarding appointments of Board members to other health sector Crown Entities. This could include working with Tāngata Whaikaha networks and community groups to identify nominees for the appointments.	Within first year
3.	Provide support to Tāngata Whaikaha Māori members of Iwi-Māori Partnership Boards, including provision for peer support and networking.	Immediately
4.	Fund Tāngata Whaikaha Māori communities to come together, network, and input into Te Aka Whai Ora mahi in an ongoing way.	Within first year
5.	Ensure that all health sector policy and strategy documents explicitly consider the needs and aspirations of Tāngata Whaikaha Māori.	Immediately
6.	Undertake ethical co-designing with Tāngata Whaikaha Māori across all programmes. In the context of Tāngata Whaikaha Māori this would mean developing ongoing relationship with their communities, transfer of equitable resources and sharing power as appropriate. Te Aka Whai Ora to set up monitoring to ensure equitable inclusion of Tāngata Whaikaha Māori through the co-design process.	Ongoing
7.	Ensure health sector agency performance in implementing health sector strategy and policy is reported on in transparent ways and accessible to Tāngata Whaikaha Māori.	Within first two years
8.	Increase the number and range of disability support services offered by Kaupapa Māori Providers, including establishing a close partnership with Whaikaha: the Ministry of Disabled People to develop a commissioning framework that explicitly includes the voices of Tāngata Whaikaha Māori and embeds the principle of options.	Within first year
9.	Identify opportunities to facilitate commissioning by Tāngata Whaikaha Māori communities directly.	Within first two years
10.	Address the underfunding of Māori health providers to ensure they are adequately funded to meet the needs and aspirations of Tāngata Whaikaha Māori.	Within first year

11.	Improve commissioning and contracting practices for health services to ensure they meet the needs and aspirations of Tāngata Whaikaha Māori.	Immediately
12.	Increase capacity and capability funding to Kaupapa Māori providers, including: <ol style="list-style-type: none"> 1. Having a specific funding category to support Kaupapa Māori providers who offer, or plan to offer, disability support services. This should be significantly larger than 2 percent of the total Māori Provider Development Scheme (MPDS) budget. 2. Having a specific funding category to support Kaupapa Māori provider responsiveness to Tāngata Whaikaha Māori. This is both about securing future capability and about having hauora-based models of care aimed at improving both accessibility of Kaupapa Māori providers for Tāngata Whaikaha Māori and accessibility of websites and other forms of information. 3. Support the further growth of Tāngata Whaikaha Māori community groups. 	Within first year
13.	Workforce: Ensure Tāngata Whaikaha Māori are explicitly included in all health workforce development activity, monitoring and evaluation.	Immediately, and ongoing
14.	Support career pathways for Tāngata Whaikaha Māori directly through: <ul style="list-style-type: none"> • Prioritising Tāngata Whaikaha Māori in health workforce funding. • Practising fair contracting practices so that Kaupapa Māori providers are able to offer sustainable employment opportunities to Tāngata Whaikaha Māori and provide fair pay and other conditions. • Ensuring provider development funding through the MPDS is available to enable Kaupapa Māori providers to be good employers of Tāngata Whaikaha Māori and provide reasonable accommodations including fully accessible workplaces. • Supporting mentorship for Tāngata Whaikaha Māori either through the MPDS or through additional workforce funding. 	Within first year
15.	Collaborate with partners to indirectly support career pathways for Tāngata Whaikaha Māori, including: <ul style="list-style-type: none"> • Working with regulating authorities to ensure appropriate support for Tāngata Whaikaha Māori who are part of the regulated health workforce. • Ensuring co-commissioned health services fully encourage and support Tāngata Whaikaha workforce participation and development. • Partnering with the Health Research Council to support (or funding providing additional funding for) research programmes or awards to help grow the number of Tāngata Whaikaha Māori researchers across the research pipeline. 	Within two years
16.	Build a health workforce that is responsive to Tāngata Whaikaha Māori, including:	Within first year

	<ul style="list-style-type: none"> • Building disability responsiveness in health organisations along with cultural safety. • Investing in a New Zealand Sign Language interpreter workforce with fluency in Te Reo Māori. • Ensuring workforce planning (conducted in collaboration with Health New Zealand) includes/accounts for critical workforce shortages that primarily affect Tāngata Whaikaha Māori and other disabled people. 	
17.	<p>Be a good employer of Tāngata Whaikaha Māori, including:</p> <ul style="list-style-type: none"> • Developing appropriate human resources policies and processes with Tāngata Whaikaha Māori staff and advisors. This is likely to include policies on recruitment, working from home, flexible working hours and equitable remuneration. • Creating a physically accessible environment that works for Tāngata Whaikaha Māori. • Ensuring the safety of Tāngata Whaikaha Māori staff, (including particularly during COVID-19 through appropriate mask policies). • Providing training and development opportunities for Tāngata Whaikaha Māori, e.g. including internships and networking opportunities with Tāngata Whaikaha Māori staff from other organisations. 	Immediately
18.	<p>Build high quality effective health and disability data across the board that is meaningful for Tāngata Whaikaha Māori and relates to Māori understandings of disability. This action is following on from the national kōrero (recommendation 1).</p>	Within first year
19.	<p>Develop a monitoring work programme that prioritises interrogating areas of publicly funded health sector performance that are most likely to impact Tāngata Whaikaha Māori.</p>	Within first year
20.	<p>Engage with the principles of Māori Data Sovereignty in partnership with Tāngata Whaikaha Māori communities.</p>	Within first year

The premise of all these recommendations is that Te Aka Whai Ora is determined to do better than previous health sector structures and they will seek out, and give visibility to, the views and lived experiences of Tāngata Whaikaha Māori. Te Aka Whai Ora will also ensure that the purported benefits of the new health system, including a more joined up health system with less regional variation, are equitably enjoyed by all Māori including Tāngata Whaikaha Māori.

Background

The health system, and indeed the government overall, has a history of failing to meet the needs and aspirations of Tāngata Whaikaha Māori. Research commissioned by the Waitangi Tribunal in 2018 reported that between 1840 and the 1990s, the government segregated and removed Tāngata Whaikaha Māori from their whānau, and actively assimilated Tāngata Whaikaha Māori through the suppression of cultural practices. In addition, the government attempted to systematically eliminate disabled people who they considered ‘undesirables’, with policies underpinned by eugenics ideologies. Such government policies led to the establishment of large institutions based on paternalistic and culturally unsafe approaches to the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori, causing immeasurable damage for those lost from their whānau and those abused within government owned and funded institutions.¹ The Waitangi Tribunal research also observed how the government often employed the same strategies of segregation, suppression and paternalism in its broader approach and actions toward Māori, with Tāngata Whaikaha Māori further impacted due to the intersection of disability with colonisation, coloniality, white supremacy and racism.²

To this day, Tāngata Whaikaha Māori continue to experience inequitable health and wellbeing outcomes due to colonisation, coloniality, white supremacy, racism³ and ableism.⁴ The impacts of disability on Māori are wide-ranging. Significant inequities exist for Tāngata Whaikaha Māori compared with Pākehā disabled people from inequitable access to the determinants of health and wellbeing, inequitable access to and through health and disability care, and from the differential quality of health and disability care received.

Te Aka Whai Ora’s objectives & functions compel a focus on Tāngata Whaikaha Māori

The reformed health system, which comes into effect on 1 July 2022, is established under the Pae Ora (Healthy Futures) Act 2022 (the Act). The purpose of the Act is to provide for the public funding and provision of services in order to protect, promote and improve the health of all New Zealanders and achieve equity in health outcomes among New Zealand’s population groups, in particular for Māori, as part of building towards healthy futures for all New Zealanders.⁵ The Act requires the development of a ‘Government Policy Statement’ on Health that sets out the priorities for the publicly funded health sector⁶ and both a ‘Hauora Māori Strategy’⁷ and a ‘Health of Disabled People Strategy’⁸ (amongst others).⁹ At the same time, funding for disability support services, traditionally part of the Ministry of Health’s responsibilities, will be shifted to a newly established departmental agency within the Ministry of Social Development.

¹ King, 2019.

² King, 2019.

³ Cormack et al., 2020; Harris et al., 2019; Reid et al., 2019; Talamaivao et al., 2020.

⁴ King, 2019.

⁵ Pae Ora (Healthy Futures) Act 2022, s3.

⁶ Pae Ora (Healthy Futures) Act 2022, s34.

⁷ Pae Ora (Healthy Futures) Act 2022, s42.

⁸ Pae Ora (Healthy Futures) Act 2022, s44.

⁹ The Pae Ora (Healthy Futures) Act 2022 also requires: a ‘New Zealand Health Strategy’; a ‘Pacific Health Strategy’; a ‘Women’s Health Strategy’; and, a ‘Rural Health Strategy’.

While Te Aka Whai Ora does not have any legislative responsibility for developing the Health of Disabled People Strategy, nor for the contracting of disability support services, it is nevertheless expected to discharge its roles to benefit all Māori including Tāngata Whaikaha Māori, by virtue of its responsibilities in relation to all Māori in general. This includes:

- Ensuring planning and service delivery respond to the aspirations and needs of Tāngata Whaikaha Māori (s18(a)).
- Designing, delivering and arranging services to achieve the best possible health outcomes for Tāngata Whaikaha Māori (s18(b)(ii)).
- Promoting health and preventing, reducing and delaying the onset of ill health for Tāngata Whaikaha Māori, including by collaborating with other agencies (s18(c)).

The Act also sets out a series of functions of Te Aka Whai Ora. Although all of its functions need to be discharged in a way that responds to the needs and aspirations of Tāngata Whaikaha Māori, there are some aspects that warrant particular attention, including:

- Improving service delivery and outcomes for Māori at all levels of the health sector (s19(1)(c)).
- Collaborating with other agencies, organisations and individuals to improve health and wellbeing outcomes for Māori (s19(1)(d)).
- Providing accessible and understandable information to Māori on the performance of the publicly funded health sector (s19(1)(e)).
- Commissioning Kaupapa Māori services and other services developed for Māori in accordance with the New Zealand Health Plan (s19(1)(f)).
- Providing policy and strategy advice to the Minister on matters relevant to hauora Māori (s19(1)(i)).
- Monitoring the delivery of hauora Māori services by Health New Zealand (s19(1)(l)) and monitoring the performance of the publicly funded health sector in relation to hauora Māori, in collaboration with the Ministry of Health and Te Puni Kōkiri (s19(1)(m)).
- Supporting and engaging with Iwi-Māori partnership boards (s19(1)(n)).
- Designing and delivering programmes to improve the capacity and capability of Māori health providers and the Māori health workforce (s19(1)(o) & (p)).
- Undertaking and supporting research relating to health (s19(1)(q)).
- Engaging with Māori in relation to their needs and aspirations for hauora Māori (s20(1)(a)).

Six priority areas for action

This paper has been informed both by a review of Te Aka Whai Ora's roles and functions as set out in legislation as well as evidence gathered through a range of written sources, including:

- An environmental scan and a series of rapid desktop evidence reviews and analyses of available information from government agencies.
- Publicly available reports (such as the Waitangi Tribunal's findings so far in its inquiry into Health Services and Outcomes).
- A review of national and international literature.
- A small number of internal documents provided by the interim Māori Health Authority.

Throughout our environmental scan and evidence reviews, we have identified six priority areas for Te Aka Whai Ora to focus on as it establishes itself to meet the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori. Within these priority areas we have suggested possible actions for Te Aka Whai Ora to undertake in the first two years of its operations. These six priority areas are:

1. **National level kōrero with Tāngata Whaikaha Māori.** Responding locally and nationally to the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori.
2. **Leadership, governance and collective voice of Tāngata Whaikaha Māori communities.** Supporting the leadership aspirations of tāngata whaikaha Māori.
3. **Strategy, policy and locality planning:** ensuring all strategies and policies and commissioning meet the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori and are undertaken in genuine partnership.
4. **Mātauranga Māori & Kaupapa Māori Services:** providing access to mātauranga Māori and increasing Tāngata Whaikaha Māori access to Kaupapa Māori services.
5. **Workforce:** Addressing workforce issues for Tāngata Whaikaha Māori (as employees & employers).
6. **Data, monitoring and accountability:** Improving all data and monitoring for Tāngata Whaikaha Māori and increasing accountability.

Priority 1: National level kōrero with Tāngata Whaikaha Māori. Responding locally and nationally to the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori.

In order to meet the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori, Te Aka Whai Ora has to first understand what these are. Relying on data alone is never a good idea, but it is particularly problematic when considering Tāngata Whaikaha Māori, both because of analyses that tend to treat disabled people as a homogenous group, and a lack of good quality ethnicity and disability data (this is elaborated on in priority area 6).

In 2013, (the last time that Stats NZ specifically reported prevalence disability data), 176,000 Māori compared with 885,000 Pākehā were reported to be living with disability. Māori were also reported to have a higher prevalence of disability (23 percent compared with 15.6 percent for Pākehā), as well as a higher proportion of disability across all the age groups.

For adults, multiple impairment¹⁰ increases with age. Tāngata Whaikaha Māori adults are more likely to have multiple impairments compared with Pākehā disabled adults across all age groups.¹¹

Māori are more likely to experience disability 12-months after an injury than Pākehā (21 percent compared with 13 percent). Predictors of disability for Māori following injury involve: two or more chronic conditions; trouble accessing healthcare services; hospitalisation due to injury; and inadequate household income. Māori hospitalised for injury are 1.8 times more likely to experience disability at 24-months than non-Māori.¹² Tāngata Whaikaha Rangatahi Māori are less likely to feel they are a part of their school or feel safe at their school,¹³ and are more likely to report higher rates of mental health concerns than Pākehā young disabled people. Only 49 percent reported good wellbeing, over half reported symptoms of depression (53 percent), and almost half (45 percent) reported serious thoughts of suicide in the last year.¹⁴

Tāngata Whaikaha Māori have higher proportions of unmet need than Pākehā disabled people. This includes lesser access to health professionals, and lesser access to special equipment. Tāngata Whaikaha Māori compared with Pākehā disabled people have lesser access to disability support services in accordance with need, and face substantial barriers to healthcare such as being able to book an appropriate appointment time, location of services (and related transport options) and direct costs associated with care (such as patient charges for general practice visits or for prescriptions). This particularly impacts Tāngata Whaikaha Māori living in rural areas.¹⁵ One in four Tāngata Whaikaha Māori report having insufficient income to meet their daily needs and experience inequities in accessing health professionals and funding for equipment and care.¹⁶

¹⁰ In this context, impairment refers to “a problem with body function or structure. A person may have a range of barriers and impairments restricting their full and equal participation in society” (King, 2019, p. xiv).

¹¹ Clark et al., 2021; King, 2019.

¹² McCarty et al., 2018.

¹³ Clark et al., 2021.

¹⁴ Roy et al., 2021.

¹⁵ King, 2019.

¹⁶ King, 2019; Stats NZ, 2015.

Considerable inequities between Tāngata Whaikaha Māori and Pākehā disabled people (as well as within Tāngata Whaikaha Māori communities) have occurred due to differential government responses to impairment (depending on the mechanism of impairment). For instance, accidental injury (covered by ACC) versus non-injury-related impairments. In addition to inequitable access to services, there are inequities in the quality of care received, such as the government's use of seclusion on Tāngata Whaikaha Māori. For instance, data from the Ministry of Health for the year 2017 shows that Tāngata Whaikaha Māori under the Intellectual (Compulsory Care and Rehabilitation) Act were, on average, being secluded up to 36 times each. This compares with Ministry of Health figures from 2017 which report that, on average, people in adult inpatient services are secluded twice.¹⁷

Research for the Waitangi Tribunal also reported that when the health and disability system (and its core institutions) were established through the New Zealand Public Health and Disability Act 2000, the responsibility for disability support services was only semi-devolved to district health boards (for people aged over 65 years). The Ministry of Health retained its role in the provision of disability support services for people under 65 years of age. While full devolution to the district health boards was initially discussed in the early 2000s, this did not happen (it is unclear why). There has been no evaluation on the impacts of this policy on Tāngata Whaikaha Māori but these semi-devolved funding arrangements for disability support services are likely to have contributed to the current inequities experienced by Tāngata Whaikaha Māori. This is due to the fact that Māori have a considerably younger age structure than non-Māori and are more likely to have co-morbidities than non-Māori. Māori are also more likely to have co-morbidities at a younger age than non-Māori and are more likely to have multiple co-morbidities than non-Māori.¹⁸

Start with a national kōrero

As Tāngata Whaikaha Māori needs have been invisibilised in most central government engagement with Māori, Te Aka Whai Ora will need to consider how they contribute to meaningful redress for these mistakes to date. While several suggestions are made through this paper, a first step is to begin national kōrero with Tāngata Whaikaha Māori held in partnership with Tāngata Whaikaha Māori communities throughout the motu. In addition to being a chance to introduce the work of Te Aka Whai Ora, the national kōrero could be a step toward contributing to understandings around how Māori choose to identify or describe themselves (or not) in relation to concepts of disability.

This national kōrero needs to be led by Tāngata Whaikaha Māori. A suggested approach to implement this priority would be to leverage existing sector relationships and disability strategies, e.g. by engaging with TAMA the National Māori Disability Advisory Group to the Ministry of Health and using Whāia Te Ao Mārama the National Disability Action Plan 2018-2022. We also recommend this would be an opportunity to provide synergies with Whaikaha – the Ministry of Disabled People – who could contribute to this kōrero along with Te Aka Whai Ora.

¹⁷ King, 2019.

¹⁸ King, 2019.

Priority 2: Leadership, governance and collective voice of Tāngata Whaikaha Māori communities: Supporting the leadership aspirations.

In order for Te Aka Whai Ora to do its job well and meet its objectives in responding to the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori, it will rely on the leadership and collective voices of Tāngata Whaikaha Māori communities. Indeed, this is a requirement for all of government, and supports the realisation of Tāngata Whaikaha Māori rights as set out in Te Tiriti o Waitangi and international human rights instruments.¹⁹

Increase Tāngata Whaikaha Māori participation in leadership and governance

Increasing Māori participation in leadership and governance roles has been part of the overall goals for Māori health workforce development for decades and aligns with action 3.3 in ‘Whakamaui: Māori Health Action Plan 2020–2025’. It is also a priority within ‘Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan’ to increase the number of Tāngata Whaikaha Māori in leadership roles. However, to date the health and disability sectors have not given specific attention to supporting Tāngata Whaikaha Māori participation in leadership or governance roles. For example, Waitangi Tribunal research noted that reasonable accommodations were not put in place by government organisations to support participation of Tāngata Whaikaha Māori in leadership and governance roles, amounting to exclusion of Tāngata Whaikaha Māori from health and disability sector decision-making. Tāngata Whaikaha Māori membership of boards is currently low (including non-existent on the interim Health New Zealand and Māori Health Authority boards),²⁰ organisations do not ensure Tāngata Whaikaha Māori are part of advisory groups, and participation in the health and disability workforce by Tāngata Whaikaha Māori is not well documented.²¹

While the Act has been criticised for not explicitly requiring Tāngata Whaikaha Māori membership on the Health New Zealand or Te Aka Whai Ora boards, there are still opportunities for Te Aka Whai Ora to support Tāngata Whaikaha Māori in leadership and governance roles in the sector through:

- Te Aka Whai Ora actively including Tāngata Whaikaha Māori career development within its own organisation (outlined in the priority area 5).
- Working with the Ministry of Health and Health New Zealand to support processes around appointment of board members to other health sector Crown Entities (such as Pharmac, the NZ Blood Service, Health Quality and Safety Commission, the Health Research Council of New Zealand) or on health sector committees (such as the Nursing Council) to ensure high levels of participation by Tāngata Whaikaha Māori. This could include working with Tāngata Whaikaha Māori networks and community groups to identify nominees for the appointments.
- Providing support to Tāngata Whaikaha Māori members of Iwi-Māori Partnership Boards. For example, when district health boards were first established, Māori board members were supported by the Ministry of Health with additional training on a range of topics such as Māori health and governance, and an opportunity to come together and meet for peer support and networking. This is something that could be facilitated by Tāngata Whaikaha Māori groups with resourced support from Te Aka Whai Ora.

¹⁹ Including (but not limited to): the Convention on the Rights of Persons with Disabilities; the Convention on the Rights of the Child; the International Covenant on Economic, Social and Cultural Rights; the Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment; and, the Declaration on the Rights of Indigenous Peoples.

²⁰ Ministry of Health, 2021a.

²¹ King, 2019.

Support Tāngata Whaikaha Māori communities

A November 2021 internal paper to the executive leadership team at the Ministry of Health highlighted that as part of the health system reforms there will need to be “mechanisms to include disabled people, including tāngata and whānau whaikaha, in the leadership and governance of the Ministry of Health, Māori Health Authority and Health NZ”.²² That paper argued specifically for what it termed ‘voice mechanisms’, including the use of disability advisory groups with strong Tāngata Whaikaha Māori representation and increased effort to employ and recruit disabled people.

We agree with the use of such mechanisms but consider that this must be appropriately resourced, for example by funding existing Tāngata Whaikaha Māori community groups and supporting the development of new community groups that align with Tāngata Whaikaha Māori aspirations, rather than specific government priorities.

It is recommended, therefore, that Te Aka Whai Ora provide funding for Tāngata Whaikaha Māori communities to come together, network, and input into Māori Health Authority mahi in an ongoing way. This recommendation could be achieved by building on (and increasing) funding previously made available under the Māori Provider Development Scheme (MPDS) to national Māori disability rōpū. However, it is important that this is not just about supporting groups previously covered by this funding stream. It may be that Te Aka Whai Ora needs to support the establishment and operation of a wider range of rōpū who are led by, and work for in the interests of Tāngata Whaikaha Māori, especially where they are underserved by mainstream disability advocacy groups.

²² Ministry of Health, 2021a, p.1.

Priority 3: Strategy, policy and locality planning: ensuring all strategies and policies meet the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori.

Te Aka Whai Ora has a substantial role as a policy and strategy advisor to Ministers of Health. In keeping with Te Tiriti o Waitangi and human-rights based approaches, we argue that this can only be done well if Te Aka Whai Ora is fully aware of the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori and is committed to acting on this knowledge.

In previous sections we have outlined how Te Aka Whai Ora could build its understanding through a national kōrero with Tāngata Whaikaha Māori. To this end we have also proposed support to Tāngata Whaikaha Māori so that they are able to participate in leadership and governance roles within the health sector, as well as providing direct support to Tāngata Whaikaha Māori communities. As we discuss later, this needs to be complemented with high quality data and information.

Combined, these can support Te Aka Whai Ora to give good quality advice that leads to good quality strategy, policy and planning. However, there are some specific areas that Te Aka Whai Ora needs to implement to ensure that strategy, policy and locality planning (and its implementation) meets the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori.

Provide advice that ensures the visibility of Tāngata Whaikaha Māori

Following on from the national kōrero and building on its partnerships with Tāngata Whaikaha Māori communities, Te Aka Whai Ora will need to ensure that key health sector policy and strategy documents explicitly consider the needs and aspirations of Tāngata Whaikaha Māori. Initially this means including actions in the 'Interim New Zealand Health Plan' (and we suggest many of our recommendations could be used in this regard). Over time it will mean ensuring Tāngata Whaikaha input into:

- The Government Policy Statement.
- The New Zealand Health Strategy.
- The Hauora Māori Strategy.
- The Health of Disabled People Strategy.
- The Women's Health Strategy.
- The Rural Health Strategy.

It is also expected that Te Aka Whai Ora will be part of developing strategy and policy that is not legislated for, such as a proposed medicines strategy as outlined by the Pharmac Review Panel.²³ Development of these strategies and policies should follow the same principles of including the voices of Tāngata Whaikaha Māori.

²³ Pharmac Review Panel, 2022.

Undertaking ethical co-designing

Co-design has increasingly been advanced as an innovative way forward in the design of strategies, policies, interventions or services with Indigenous peoples and other social groups that experience health and social inequities. Yet the rapid rise in co-design rhetoric within health and disability contexts in New Zealand and overseas has not led to a growth in the evidence-base around its effectiveness or appropriateness as an applied approach within Indigenous health and wellbeing contexts.²⁴ Further to this, research undertaken in New Zealand has identified the emergence of co-design as a market/commodity, and the parallel presence of colonial, racist, paternalistic, deficit and extractive discourses within the co-design field. These discourses reveal an ostensible disconnect between the rhetoric of co-design and its professed benefits, and how co-design appears to be currently practised in New Zealand.²⁵

Tāngata Whaikaha Māori have been impacted by this indiscriminate use of co-design. For instance, a 2020 implementation evaluation of the 'Mana Whaikaha' system transformation²⁶ reported:

engagement with Māori could have been stronger. Early in the co-design stage, a company was contracted to manage the design process. However, the engagement with Māori was seen to be not enhancing the mana of the co-design partnership because: the company representatives were unknown to participants [and] their approach was to 'take or get something from you'.²⁷

The evaluation also reported that the "legitimacy of the prototype was questioned by Treaty partners Māori as engagement had not been as successful with some Māori, and some Māori thought they had not been represented by those involved in the co-design".²⁸

In response to the potential harms identified in the field of co-design within health and disability contexts in New Zealand (and overseas),²⁹ the concept of "ethical co-designing"³⁰ has been put forward. "Ethical co-designing" is defined as:

an ongoing reflexive, respectful, and reciprocal process of designing which, underpinned by tāngata whenua rights, requires equitable power-sharing with [Tāngata Whaikaha Māori] and whānau throughout, in the determining of, and collective creativity in addressing those issues of importance to them. Ethical co-designing necessitates accountability to [Tāngata Whaikaha Māori] and whānau and supports meaningful transformative outcomes.³¹

²⁴ King, 2021; King et al., 2022.

²⁵ King, 2021.

²⁶ The 'Mana Whaikaha' prototype, based on the Enabling Good Lives vision and principles was introduced in the MidCentral District Health Board region 1 October 2018.

²⁷ Allen + Clarke, 2020, p.18.

²⁸ Allen + Clarke, 2020, p.19.

²⁹ King, 2021; King et al., 2022.

³⁰ King, 2021.

³¹ King, 2021, p.483.

If Te Aka Whai Ora chooses to undertake co-design with Tāngata Whaikaha Māori, it must ensure this is ethical. In the context of Tāngata Whaikaha Māori this would mean having ongoing partnerships with Tāngata Whaikaha Māori communities (which we have outlined in priority 2), the sharing of power and transfer of equitable resources to Tāngata Whaikaha Māori communities and ensuring that Te Aka Whai Ora is accountable to Tāngata Whaikaha Māori communities by following through on all of the commitments made throughout the co-design process.

Follow through on commitments made

Policies and strategies are rendered meaningless if they are not monitored and evaluated over time to ensure all relevant agencies (the Ministry of Health, Health New Zealand and Te Aka Whai Ora) follow through on their commitments. To this end, Te Aka Whai Ora must ensure its performance in implementing health sector strategy and policy is reported on in transparent ways and accessible to Tāngata Whaikaha Māori. In turn, this requires data collection be embedded into strategy and policy development, and any locality plans, and that any indicators selected and/or developed are done so with Tāngata Whaikaha Māori.

It is also important for Tāngata Whaikaha Māori to be able to easily request more information, or have access to full datasets if required, as research has highlighted that government agencies have a tendency to withhold information critically relevant to Tāngata Whaikaha Māori, on the grounds that it is difficult (for government agencies) to access.³²

³² King et al., 2021.

Priority 4: Mātauranga Māori & Access to Kaupapa Māori Services: providing access to mātauranga Māori and increasing Tāngata Whaikaha Māori access to Kaupapa Māori services.

In its modern application, the principle of options requires that the Crown must adequately protect the availability and viability of kaupapa Māori solutions in the social sector as well as so-called mainstream services in such a way that Māori are not disadvantaged by their choice.

In terms of health services, the Crown has a Treaty duty to enable Māori to have available the options of Māori or mainstream providers as they wish, and that either or both of these pathways are ensured equitable protection by the Treaty. Both pathways should be sufficiently supported by the Crown, meaning that each option offers a genuine, well-supported choice for Māori.

Waitangi Tribunal's 'Hauora' Report (2019)³³

Under the Act Te Aka Whai Ora has the functions of commissioning “kaupapa Māori services and other services developed for Māori in accordance with the New Zealand Health Plan”³⁴ and designing and delivering “programmes for the purpose of improving the capability and capacity of Māori health providers”.³⁵

Although Te Aka Whai Ora's primary functions relate to 'Māori health providers', Kaupapa Māori disability support providers remain an interest to Te Aka Whai Ora for several reasons:

- Tāngata Whaikaha Māori reasonably expect that Te Aka Whai Ora has an interest in all services that relate to hauora and wellbeing. Māori concepts of hauora and Kaupapa Māori models of care are broader than a narrow definition of 'health services', and for many Tāngata Whaikaha Māori support to achieve 'hauora' extends to much of what the Crown defines as 'disability support services'. Te Aka Whai Ora's interests therefore are linked to its broader objectives of responding to the aspirations and needs of whānau, hapū, iwi and Māori in general and the provisions of the Act that refer to Te Aka Whai Ora engaging on the aspirations and needs for hauora Māori.³⁶
- Most Māori disability support service providers also offer health services (and therefore are Māori health providers).
- The MPDS which Te Aka Whai Ora will be responsible for from 1 July 2022, has always been open to both Māori health and Māori disability providers.

There are around 240 Māori health and disability providers in New Zealand,³⁷ about 40 fewer than in the previous national count in 2017.³⁸ Since the 1990s, considerable issues for Māori health providers have been identified in the academic literature, commissioned reports, and

³³ Waitangi Tribunal, 2019, p.35.

³⁴ Pae Ora (Health Futures) Act 2022, s19(1)(f).

³⁵ Pae Ora (Healthy Futures) Act 2022, s19(1)(o).

³⁶ Pae Ora (Healthy Futures) Act 2022 s20(1)(a)(i).

³⁷ Ministry of Health, 2021b.

³⁸ In this context, the definition of a 'Māori health and disability provider' is one that is Māori owned and Māori governed and has contracts to deliver publicly funded health and/or disability services.

government publications but little attention has been paid to Kaupapa Māori disability support services. Information released by the Ministry of Health under the Official Information Act 1982 showed that in 2019 there were only 33 Māori providers (3.4 percent) offering disability support services out of a large sector of 980 disability providers (96.6 percent are therefore non-Māori providers). For the 2017/18 year, Māori providers received only 3.9 percent out of the total DSS expenditure.³⁹

In Stage One of the Waitangi Tribunal’s ‘Kaupapa Inquiry into Health Services and Outcomes’ (the Kaupapa Inquiry), the underfunding of Māori health providers was in the spotlight, along with issues around Crown contracting practices and (in)adequacy of capacity and capability funding.⁴⁰ In Stage Two of the Waitangi Tribunal’s Kaupapa Inquiry, which began in March 2022, claimants are also raising questions of the extent to which the Crown has ensured that resourcing of Māori health and disability providers has been proportionate to the scale of health inequities and unmet needs of Tāngata Whaikaha Māori.

Increase the number and range of disability support services offered by Kaupapa Māori providers

Despite there being only 33 Māori disability support providers in New Zealand, neither ‘Whakamaui: Māori Health Action Plan 2020–2025’ nor ‘Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan’ have priority areas or actions to increase the number of Kaupapa Māori disability providers, or the range of disability support services offered by Kaupapa Māori providers. Similarly, the ‘New Zealand Disability Strategy’ and its associated action plan lack a focus on creating *options* for Tāngata Whaikaha Māori to access disability support from Māori providers. This further contributes to the invisibilisation of Tāngata Whaikaha health and wellbeing needs and aspirations within the health and disability sectors.

To meet the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori, Te Aka Whai Ora should begin by ensuring its role as lead commissioner of Kaupapa Māori services, focusing on expanding and developing provision of services targeted at Māori communities,⁴¹ is discharged in a way that explicitly targets Tāngata Whaikaha Māori. The second step for Te Aka Whai Ora is to establish a partnership with the new disability agency (referred to as the ‘Ministry for Disabled People’ while it is being established, although its actual name is likely to change). This is aligned with work the interim Māori Health Authority and interim Health New Zealand have developed as a Draft ‘Co-commissioning Framework’. An April 2022 draft of this framework notes “health commissioners will need to establish the appropriate systems for co-commissioning with other agencies. In some cases, health will take the lead, but in other cases it will need to devolve its funding responsibilities to other agencies and play a minor role in achieving joint outcomes”.⁴²

A shared set of priorities for this partnership must be developed that includes:

- Establishing a commissioning framework for disability support services that complements ‘Enabling Good Lives’ and that explicitly includes the voices of Tāngata Whaikaha Māori in its

³⁹ King, 2019.

⁴⁰ Waitangi Tribunal, 2019.

⁴¹ Interim Health New Zealand and Māori Health Authority, 2022.

⁴² Interim Health New Zealand and Māori Health Authority, 2022, p.13.

design, along with Māori concepts of hauora and Māori models of care. This could be an opportunity to use ethical co-designing approaches.

- Identifying opportunities for Te Aka Whai Ora to facilitate commissioning by Tāngata Whaikaha Māori communities directly.
- Embedding the principle of *options* in all work associated with commissioning to ensure that wherever possible Kaupapa Māori providers are supported to expand their current service offerings or enter the provision of new disability support services. This could include providing seed funding to help establish new services or recruit and train new staff. This also helps to increase the likelihood that Tāngata Whaikaha Māori with individualised funding arrangements can access disability support services from Māori providers.
- Ensuring Tāngata Whaikaha Māori are part of decision-making at all stages of disability support commissioning for national, regional, and local disability support contracts.

Address the underfunding of Māori health providers so they can better meet the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori

Māori health providers have argued for over two decades that they have been underfunded in primary healthcare. Specifically, Māori health providers have argued that:

1. Māori health providers are not funded sufficiently to meet the needs of a predominantly Māori population, and
2. Māori health providers are not funded to deliver their services using Kaupapa Māori models, which include approaches that are focused on whole-of-whānau support and care.

In 2019, the Waitangi Tribunal found the way the Crown funded Māori health providers in primary healthcare was a breach of the principles of Te Tiriti o Waitangi and that “the funding arrangements for primary health care have hampered – and at times outright undermined – the ability of the primary health care sector to improve inequitable Māori health outcomes”.⁴³

Subsequently, the Waitangi Tribunal claimants⁴⁴ commissioned Sapere to quantify the impacts of the underfunding in primary health care. Sapere found that primary health care funding requires up to an additional \$1 billion per annum to support provision of comprehensive services that encompass aspects of providing care to a Māori population, supporting Māori providers, and expressing Māori principles in line with Te Tiriti o Waitangi.⁴⁵

While identifying that Māori age and morbidity patterns (including disability) are not adequately accounted for in the primary health care funding formula, Sapere was only able to calculate the impact based on age alone. This calculation identified a total funding gap of \$40,462 per year for a sample Māori general practice. Logically, the figure would be even higher if disability rates were able to be included in the calculations.

Te Aka Whai Ora and Health New Zealand already have work underway to improve primary health care funding. It is essential that this is done in a way that makes it explicit that meeting

⁴³ Waitangi Tribunal, 2019, p.117.

⁴⁴ Claimants under Wai 1315 (Taitimu Maipi, Hakopa Paul, Lady Tureiti Moxon and Janice Kuka) and Wai 2687 (Henare Mason and Simon Royal).

⁴⁵ Love et al., 2021.

the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori is core business for primary health care.

One way to demonstrate Tāngata Whaikaha Māori as a priority population group is to have a 'disability adjustor' in the primary health care funding formula (the same way as age, ethnicity and deprivation are – to varying extents – incorporated in the way primary health care is funded today). While, for reasons covered elsewhere, the data on Māori disability is not robust enough to form the basis of an 'adjustor', interim steps are:

- Involving Tāngata Whaikaha Māori in primary health care funding design and decision-making.
- Prioritising actions to improve Māori disability data (as outlined in priority area 6).
- Ensuring primary health care funding changes support Māori health providers to be able to offer and extend their holistic primary health care services (including those offered by non-general practice providers) to Tāngata Whaikaha Māori.

Improve commissioning and contracting practices for health services

Māori providers have shared frustrations with government contracting practices in a range of forums, including the Waitangi Tribunal. These frustrations are also documented in research examining public health contracts that found examples of racism experienced by Māori providers compared to non-Māori providers. The research has highlighted that Māori providers had shorter lengths of contracts, higher intensity of monitoring, greater compliance costs, and higher frequency of audits compared to their non-Māori counterparts.⁴⁶ More recently there has been criticism that the language used in contracts acts counter to rangatiratanga by using empty language and rhetoric (for example, discourses relating to Te Tiriti o Waitangi), reshaping Māori health priorities in line with government priorities, and using a deficit lens when talking about health inequities.⁴⁷

A central question, therefore, for Te Aka Whai Ora and Health New Zealand is how will contracting for Māori providers be improved in a way that demonstrates a commitment to Te Tiriti o Waitangi and Tāngata Whaikaha Māori?

This is not as simple as adopting outcomes-based contracting alone. A rights-based approach requires the inclusion of Tāngata Whaikaha Māori in the processes of contracting and priority setting (adopting, for example, ethical-co-designing). For Te Aka Whai Ora and Health New Zealand it is also about ensuring that the people managing the contracts have the skills to manage contracts in a culturally safe and disability responsive way.

Having considered an April 2022 draft of the 'Co-commissioning Framework',⁴⁸ we have identified specific steps Te Aka Whai Ora can take now (in addition to the steps outlined in priority area 5 relating to workforce development):

⁴⁶ Came, 2017.

⁴⁷ Eggleton et al., 2021.

⁴⁸ Interim Health New Zealand and Māori Health Authority, 2022.

- Ensure commissioning is based on an assessment of the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori. While this should include an analysis of Māori disability data where possible, it needs to be complemented with the views of Tāngata Whaikaha Māori.
- Demonstrate understanding of intersectionality.⁴⁹ In the draft 'Co-commissioning Framework', intersectionality is framed by the interim Health New Zealand and interim Māori Health Authority as a type of population group in and of itself,⁵⁰ rather than a combination of impacts. When looked at as a single phenomenon in this way, it obscures the fact that root causes of the inequities faced by Tāngata Whaikaha Māori are racism and ableism.
- Explicitly encourage Kaupapa Māori providers to develop and design services with Tāngata Whaikaha Māori to meet their health and wellbeing needs. This involves examining services that address root causes of inequities and services that support health and wellbeing, including mātauranga and rongoā Māori, home-based supports, public health and clinical services.
- Ensure the intended outcomes of commissioned services include improved hauora outcomes for Tāngata Whaikaha Māori, and that performance monitoring and accountability explicitly reviews achievement (or not) of these outcomes.

Increase capacity and capability funding

The MPDS was established in 1997 to support the capacity and capability of Māori providers. Critically, the funding available through the MPDS has, until Budget 22, remained static (around \$8.9 million per annum). Although Māori owned and governed disability support providers have been eligible to access MPDS funding, it is impossible to know what proportion of the MPDS was spent specifically on supporting disability support services, since most eligible providers are also health service providers. Until recently there was also \$200,000 per year set aside for national disability organisations (those who provide services in multiple district health board areas) which equated to just over 2 percent of the MPDS budget.⁵¹

Announcements from Budget 22 indicate that the MPDS will receive an extra \$30 million over the next four years for “securing future capability and shifting into new models of care”.⁵² This new funding must contribute to Māori providers being better able to meet the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori, both as service providers and as employers. We recommend that Te Aka Whai Ora take three main approaches to improving the MPDS in this regard:

- Establishing a specific funding category to support Kaupapa Māori providers who offer, or plan to offer, disability support services. This should be significantly larger than 2 percent of the total MPDS budget
- Supporting the further growth of Tāngata Whaikaha Māori community groups (outlined in priority 2).
- Establishing a specific funding category to support Kaupapa Māori provider responsiveness to Tāngata Whaikaha Māori. This is both about securing future capability and about having hauora-based models of care and will likely encompass improving both accessibility of Kaupapa Māori providers for Tāngata Whaikaha Māori and accessibility of websites and other forms of information.

⁴⁹ For an explanation of intersectionality in relation to Tāngata Whaikaha Māori, refer to Jones et al., (2021).

⁵⁰ For example, Figure 1 of the draft 'Co-commissioning Framework' states equity will be achieved in part through being able to “recognise service design for priority populations: Pacifica, disabled people, rural and *intersectionality*” (Interim Health New Zealand and Māori Health Authority, 2022, p.4, emphasis in italics added).

⁵¹ Awhimai Consultancy, 2019.

⁵² The Treasury, 2022, p.12.

Priority 5: Workforce: Addressing workforce issues for Tāngata Whaikaha Māori (as employee & employer).

From 1 July 2022, Te Aka Whai Ora has obligations in relation to the health workforce, including:

- Its sector focused role, as set out in the Act, to “design and deliver programmes for the purpose of improving the capability and capacity ... the Māori health workforce”⁵³ and “collaborate with relevant entities for the purpose of improving the capability and capacity of the health workforce in relation to hauora Māori”.⁵⁴
- Its obligations as a good employer, including the Human Rights Act 1993 and the Health and Safety at Work Act 2015.

Sector focused role: Building the workforce

While supporting Tāngata Whaikaha Māori in the health workforce was a priority set out in ‘Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan’,⁵⁵ there is very little data available that shows the size of the Tāngata Whaikaha Māori health workforce or how it has changed over time. This is also in spite of ‘employment and economic security’ being an outcome area of the ‘New Zealand Disability Strategy’.⁵⁶ ‘He Korowai Oranga: Māori Health Strategy’ also highlights the need to:⁵⁷

- Increase the number of Māori in the health and disability workforce.
- Expand the skill base of Māori in the workforce.
- Enable equitable access for Māori to training opportunities.

Neither of these two high level documents, or their associated commitments, have been responded to in an intersectional way. Māori health workforce data still does not include disability and the disability employment and economic security data from the Office for Disability Issues is seldom presented by ethnicity.

The limited information⁵⁸ that is available relating to Tāngata Whaikaha Māori in the workforce include:

- District health boards do not usually record disability information for their staff. When asked about this (under the Official Information Act 1982), one district health board declined to provide information on ethnicity and disability status of staff on the basis they did not hold that information. A further 12 district health boards provided a partial

⁵³ Pae Ora (Healthy Futures) Act s19(1)(o).

⁵⁴ Pae Ora (Healthy Futures) Act s19(1)(p).

⁵⁵ This broad priority area included actions such as increasing Tāngata Whaikaha Māori representation on governance boards, contracting Tāngata Whaikaha Māori as consultants, involving Tāngata Whaikaha Māori in developing policies and procedures, and supporting Tāngata Whaikaha to undertake leadership and disability support training (Ministry of Health, 2018).

⁵⁶ This outcome area includes actions on improving transition to employment, increased employment of disabled people, identifying better alternatives to removal of the wage exemption process (which in some situations enabled employers to pay disabled employees below the minimum wage), increasing employer confidence in employing disabled people, and working with private sector partners to progress employment of disabled people (Office for Disability Issues, 2016).

⁵⁷ Ministry of Health, 2016.

⁵⁸ Priority area 6 outlines why the current information is limited for Tāngata Whaikaha Māori.

response, usually only providing staff information broken down by ethnicity. In the rare cases where Tāngata Whaikaha Māori workforce numbers were provided, these were very low, with one district health board identifying one Tāngata Whaikaha Māori employee in the context of an organisation that employs around 1000 people.⁵⁹

- Like district health boards, Health Crown Entities have not been able to provide disability and ethnicity data consistently. In their most recent annual reports neither the Health Quality & Safety Commission nor Pharmac provided any staff disability data. Whilst they did provide ethnicity data (showing 19 percent and 3 percent of their staff, respectively, identify as Māori), the number of Tāngata Whaikaha Māori in the agencies is not provided.
- The Ministry of Health has reported in internal documents that 4.6 percent of its staff identify as having a disability.⁶⁰ No figures are provided on the number of Tāngata Whaikaha Māori in the organisation.

What we do know however, is that Tāngata Whaikaha Māori have been invisibilised in health workforce development activity and that the health system has not been doing its part in building and supporting a Tāngata Whaikaha Māori workforce – despite strategic documents stating this is a priority. If these two things had been taken seriously, then we would know more, for example, how the Tāngata Whaikaha Māori workforce has increased over time. This has implications for the extent to which the rights of Tāngata Whaikaha Māori have been realised, the extent to which Māori health and disability policy have been implemented and reinforces the urgent need for Te Aka Whai Ora to focus on workforce issues from 1 July 2022.

Ensure Tāngata Whaikaha Māori are included in all health workforce development activity

In the most recent Māori Health Action Plan, ‘Whakamaua: Māori Health Action Plan 2020–2025’⁶¹ Māori health workforce is identified as a key enabler for improved health outcomes and equity for Māori on the basis that a Māori health workforce matched to its community’s needs can make a significant contribution to addressing racism in the health system by providing culturally safe and disability responsive care. Specific workforce actions in ‘Whakamaua: Māori Health Action Plan 2020–2025 are:⁶²

- Action 3.1: Expand existing Māori health workforce initiatives aimed at encouraging Māori to enter health careers.
- Action 3.2: Support the development of a Māori primary health workforce.
- Action 3.3: Support district health boards and the Māori health sector to attract, retain, develop and utilise their Māori health workforce effectively, including in leadership and management.
- Action 3.4: Develop a strategic framework and plan to guide the development of the Māori health and disability workforce over the next 10 years.

⁵⁹ King, 2019.

⁶⁰ Ministry of Health. 2021a, p.4.

⁶¹ The action plan is described as a “living document with the ability to evolve in collaboration with stakeholders to ensure it meets existing and emerging needs and is well placed to achieve better health outcomes for Māori” (Ministry of Health, 2020, p.21).

⁶² Ministry of Health, 2020, p.38.

All four actions appear to be within the core functions of Te Aka Whai Ora. Thus, it is within Te Aka Whai Ora's direct control to ensure they are each implemented in a way that explicitly includes Tāngata Whaikaha Māori in planning, designing of interventions and investments, and that monitoring, and accountability mechanisms allow progress for the Tāngata Whaikaha Māori workforce to be tracked over time.

Attract more Tāngata Whaikaha Māori into the health workforce

In recently commissioned reports, Te Aka Whai Ora has also been encouraged to support educational interventions to increase Māori access to health professional training within the tertiary sector, for example Māori secondary schools programmes, bridging or foundation programmes, equity admission processes at universities and Māori academic and pastoral support programmes.⁶³

Attracting Tāngata Whaikaha Māori to the health workforce may require different or additional steps including:

- Funding Tāngata Whaikaha Māori-led research into, and assessment of the specific barriers for Tāngata Whaikaha Māori entering, the health workforce.
- Ensuring the 'Hauora Māori Scholarships' programme meets the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori. This could include specific awards for Tāngata Whaikaha Māori. What the right level of funding would be is outside the scope of this paper, but a first step might be to set aside a 'quota' of undergraduate and post graduate awards for Tāngata Whaikaha Māori. As an example, if five additional post-graduate awards were specifically targeted to Tāngata Whaikaha Māori, based on the funding levels from the 2022 'Hauora Māori Scholarships', it would cost Te Aka Whai Ora an extra \$11,000. An extra ten under-graduate awards specifically targeted to Tāngata Whaikaha Māori would cost an additional \$17,000. Providing a specific 'Tāngata Whaikaha Excellence' award would cost \$1,000 (all of this being achieved for under \$30,000 per year).⁶⁴
- Considering the training and development required to take on a range of non-clinical health sector roles. This includes a Kaiawhina workforce as well as those in health sector policy, research, planning and governance roles (as with an increased awareness of the need to involve Tāngata Whaikaha Māori at all levels of the health workforce comes the need to have people with experience and training across a range of disciplines).
- Supporting Tāngata Whaikaha Māori to build mātauranga and cultural knowledge to play a role in rongoā Māori services.
- Designing or modifying existing bridging or foundation programmes specifically to support Tāngata Whaikaha Māori to enter into university and other tertiary education programmes.
- Working with training providers to support equity admission processes and pastoral and peer support specifically targeted to Tāngata Whaikaha Māori.

⁶³ Curtis et al., 2022.

⁶⁴ Refer to Ministry of Health (2021c) for further information on the 'Hauora Māori Scholarships'.

Support career pathways for Tāngata Whaikaha Māori

Once qualified or ready for employment, it is important to ensure Tāngata Whaikaha Māori are able to work with employers that provide enough support to allow them to thrive.

Te Aka Whai Ora's roles in this are both direct (especially in relation to its lead commissioner roles) and indirect (through co-commissioning or broader sector leadership).

Direct roles include:

- Prioritising Tāngata Whaikaha Māori in health workforce funding. The new workforce funding announced in Budget 22 (\$39 million across four years) must include specific programmes to support the ongoing professional development of Tāngata Whaikaha Māori in the health workforce. This includes professional development that supports Tāngata Whaikaha Māori into leadership and management roles across the health sector.
- Practising fair contracting practices so that Kaupapa Māori Providers are able to offer sustainable employment opportunities to Tāngata Whaikaha Māori and provide fair pay and other conditions (for instance, leave provisions).
- Ensuring provider development funding through the MPDS is available to enable Kaupapa Māori providers to be good employers of Tāngata Whaikaha Māori and provide reasonable accommodations including fully accessible workplaces.
- Supporting mentorship for Tāngata Whaikaha Māori either through the MPDS or through additional workforce funding.

Indirect roles (for example, through collaboration with partner agencies) include:

- Working with regulating authorities (as set out in the Health Practitioner Competency Assurance Act 2003) to ensure appropriate support for Tāngata Whaikaha Māori who are part of the regulated health workforce. This includes ensuring entry and 'fit to practice' criteria support, rather than unreasonably restricting or limiting, Tāngata Whaikaha health professionals.
- Requiring co-commissioned health services to fully encourage and support Tāngata Whaikaha workforce participation and development. This would include ensuring organisations are culturally safe and disability responsive. This could be worked into the 'Co-commissioning Framework' of Te Aka Whai Ora and Health New Zealand.
- Partnering with the Health Research Council to support (by funding within current funding streams or providing additional funding for) research programmes or awards to help grow the number of Tāngata Whaikaha Māori researchers across the research pipeline from community and under-graduate support to post-graduate and emerging researcher support to large research studies, projects and programmes led by Tāngata Whaikaha Māori.

Support a workforce that meets the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori

A critical driver for the health sector reforms has been the inequities created by a health system that does not meet the needs and aspirations of Māori. This is especially true for Tāngata Whaikaha Māori, for whom the impact of culturally unsafe or racist health services is amplified by services not being responsive to disability nor being fully accessible. For instance, the most recent Omicron wave and overall COVID-19 experiences to date have also highlighted that for

Tāngata Whaikaha Māori and disabled people who receive home care supports, there are some critical workforce shortages – made worse by carers needing to isolate with COVID-19 or other illnesses.⁶⁵

In 2014, the ‘Committee on the Rights of Persons with Disabilities’ (CRPD) released their report, ‘Concluding observations on the initial report of New Zealand’, highlighting under Article 21 of the Convention on the Rights of Persons with Disabilities, their concerns that “it is still the case that Māori people with disabilities find it more difficult to access information in their own language. Māori people who are deaf find accessing information in New Zealand Sign Language even more difficult, owing to the lack of interpreters from Māori into New Zealand Sign Language”,⁶⁶ recommending “greater efforts be made to enable Māori and Pacific people with disabilities, and especially those who are deaf and deaf-blind, to access information”.⁶⁷ Yet, there has been a consistent lack of national progress in the capacity development of New Zealand Sign Language (NZSL) interpreters who have fluency in Te Reo Māori. For instance, there are approximately 110 registered NZSL interpreters nationwide, and only two registered trilingual NZSL interpreters.⁶⁸

In light of this, we recommend that Te Aka Whai Ora:

- Ensures cultural safety across the health sector is paired with disability responsiveness in health organisations.
- Invests in building a NZSL interpreter workforce with fluency in Te Reo Māori, including funding training and supporting employment once qualified as interpreters.
- Ensures workforce planning (conducted in collaboration with Health NZ) includes / accounts for critical workforce shortages that primarily affect Tāngata Whaikaha Māori and other disabled people.

Māori Health Authority’s role as a good employer

As a new organisation, Te Aka Whai Ora has the opportunity to demonstrate a strong commitment to being an employer of choice for Tāngata Whaikaha Māori. Although this section draws on reviews of government agency diversity and inclusion policies, advice that is provided to agencies,⁶⁹ and review of national and international literature, it is important to note that there is very little in the way of an evidence base for what organisations can do to attract, retain and support Tāngata Whaikaha Māori. This section is therefore based on our assessment of what would add to other guidance Te Aka Whai Ora would have received from the Public Services Commission.⁷⁰

⁶⁵ Baker & King, 2022.

⁶⁶ Committee on the Rights of Persons with Disabilities, 2014, para. 43.

⁶⁷ Committee on the Rights of Persons with Disabilities, 2014, para. 44.

⁶⁸ Wai 2143, #1.1.1(a).

⁶⁹ For instance, refer to Human Rights Commission (2015).

⁷⁰ We have assumed this will include guidance such as ‘Te Aratohu Mawhiti mō te Papa Pounamu’ which sets out focus areas for diversity and inclusion and social inclusion in 2020-21 (Public Service Commission, 2021).

Make an explicit commitment to recruit Tāngata Whaikaha Māori at all levels of the organisation

It is important that Te Aka Whai Ora signal to Māori, and to the other organisations it works with, that it aims to provide a culturally safe and disability responsive environment within which Tāngata Whaikaha Māori are supported to work. This needs to be carefully worded as it is important that the commitment avoids jargon or infers the job has already been done (for example, statements such as “we are anti-ableist”), and is backed up by actions that are followed through whereby Te Aka Whai Ora demonstrates accountability to Tāngata Whaikaha Māori employees.

It is also important that this commitment is championed by organisational leaders, including the Chief Executive and that progress on this commitment is reported publicly (as part of general transparency to Tāngata Whaikaha Māori and the public as well as signalling to other organisations in the health sector what the norms should be in terms of being a good employer).

Develop human resource policies and processes with Tāngata Whaikaha Māori

Te Aka Whai Ora will need to match its high-level commitment with human resource policies and processes that support recruitment, attract Tāngata Whaikaha Māori to Te Aka Whai Ora as an employer of choice, and enable Te Aka Whai Ora to retain its Tāngata Whaikaha Māori staff. It is crucial that these are developed with Tāngata Whaikaha Māori staff and advisors. Important policies to consider include:

- Recruitment policies and processes including; how jobs are sized; the specific skills included in job descriptions (and whether they create unnecessary barriers such as requirements for post-graduate study); shortlisting processes (and ways of ensuring that Tāngata Whaikaha Māori do not experience discrimination in short-listing processes due to bias); and, use of recruitment companies that can demonstrate they are cultural safe and disability responsive.
- Policies relating to flexibility in terms of working from home, flexible working hours and the option for job-sharing or part-time work.
- Remuneration policies that ensure pay equity by gender, ethnicity and disability is in place, for example through regular pay equity reviews.

Support Tāngata Whaikaha Māori staff

Retaining Tāngata Whaikaha Māori staff will also require the culture of Te Aka Whai Ora reflect its values. This requires basics like ensuring manager and organisational leaders have clear expectations on them to provide reasonable accommodations as required by Tāngata Whaikaha Māori and to work in ways that are culturally safe and responsive to disabled people. There will be other specific supports required, but again it is important that Te Aka Whai Ora work with Tāngata Whaikaha Māori staff and advisors to decide what these supports are. Three areas we suggest exploring are:

- Creating the right workplace environment. This is about the physical environment (both its accessibility and its safety for disabled people, particularly during COVID-19, for example with appropriate mask policies) and about the culture of the organisation (which links back to human resources policies providing working from home options and flexible work hours).
- Providing training and development opportunities for Tāngata Whaikaha Māori staff, including making reasonable accommodations to enable the opportunities to be taken up.
- Funding networking opportunities with Tāngata Whaikaha Māori staff internally and supporting networking with Tāngata Whaikaha Māori from other organisations.

Priority 6: Data, monitoring and accountability: Improving all data and monitoring for Tāngata Whaikaha Māori and increasing accountability.

For Tāngata Whaikaha Māori, the impact of disability can be pervasive yet often invisible.^{71,72} As canvassed in many of the earlier sections of this paper, there are significant gaps regarding meaningful disability data and information for Tāngata Whaikaha Māori arising from the exclusion of Te Ao Māori from Western-centric concepts of ‘disability’, ‘impairment’, and ‘illness’, and recognition and acknowledgement of the political, social, cultural, economic and environmental contexts within which Tāngata Whaikaha Māori live.⁷³

As the existing body of disability data in New Zealand is primarily shaped without the specific perspectives of Tāngata Whaikaha Māori, the national level kōrero, outlined under priority area 1, between Te Aka Whai Ora and Tāngata Whaikaha Māori is a vital step in ensuring the data collected and analysed by relevant agencies is responsive to the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori.

Beyond this first step, Te Aka Whai Ora has three interconnected roles to act upon as a priority. These are:

- Improving data collection, in order to capture meaningful Māori disability data – which both allows Te Aka Whai Ora to monitor its own progress on actions to achieve health equity, and ensures it can undertake public monitoring and reporting of timely high quality ethnicity data, and other data and information responsive to the epistemological aspirations (mātauranga Māori)⁷⁴ of Tāngata Whaikaha Māori, disseminated via accessible modes and formats (including translation into Te Reo Māori, NZSL, Braille, Easy-Read) to ensure informed decision-making by Tāngata Whaikaha Māori communities.⁷⁵ It will also support the monitoring and reporting of other parts of the publicly funded health system for all Tāngata Whaikaha Māori (including those in the care and protection and youth justice residences, and prisons across New Zealand).
- Developing a monitoring work programme that responds to the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori.
- Resourcing governance of Tāngata Whaikaha Māori data by Tāngata Whaikaha Māori communities,⁷⁶ guided by principles of Māori Data Sovereignty.⁷⁷

Improve data collection

Waitangi Tribunal research has found that government definitions of disability across policy, implementation and monitoring are inconsistent with the ‘New Zealand Disability Strategy’ placing emphasis on a disabling society, but the Ministry of Health and Stats NZ primarily defining disability based upon reduced functionality secondary to impairment(s). In addition,

⁷¹ Jones et al., 2021; King, 2019.

⁷² Cormack & McLeod, 2010; Reid et al., 2016; Cleary, 2021.

⁷³ Hickey & Wilson, 2017; Jones et al., 2021; King, 2019.

⁷⁴ Jones et al., 2021.

⁷⁵ Pae Ora (Healthy Futures) Act 2022, s19(1)(e), (l) and (m).

⁷⁶ Jones et al., 2021.

⁷⁷ Te Mana Raraunga, 2018.

current data collection and monitoring for identifying and addressing inequities in services and outcomes for Tāngata Whaikaha Māori is not effective. Though the Ministry of Health collects routine disability support services data (via the SOCRATES database),⁷⁸ the usefulness of this data regarding addressing health and wellbeing for Tāngata Whaikaha Māori is limited to the level of examining trends in service utilisation (and only for those who have access to disability support services).⁷⁹

The Waitangi Tribunal research also demonstrated that the government does not collect adequate data to monitor its own performance for Tāngata Whaikaha Māori. There are large knowledge gaps where the government does not collect data, or where it does collect data, it does not interrogate the data that it has. When it came to contracted health and disability support services, district health boards did not have the accountability mechanisms in place to ensure that the services they purchased were effective for Tāngata Whaikaha Māori. Nor were they required by the Ministry of Health to have these accountability mechanisms in place.⁸⁰

Particularly concerning, considering the youthful demographic of the Māori population, are the significant gaps in data collection and monitoring for inequities in access to services and outcomes for young Tāngata Whaikaha Māori including the Ministry for Children's care and protection and youth justice residences (where Māori are significantly over-represented). In addition, there are significant gaps in the data collection and monitoring for inequities in services and outcomes for both Māori and Tāngata Whaikaha Māori imprisoned by the state. This is especially concerning as Māori compared with Pākehā are significantly over-represented in both the men's and women's prisons in New Zealand.⁸¹

Due to the long gap between disability surveys (the most recent was in 2013, the next disability survey for New Zealand will not be conducted until 2023), Stats NZ added the 'Washington Group Short Set on Functioning' (WG-SS) to a number of its regular surveys (for instance, Census 2018 and the New Zealand Health Survey in 2018/19).⁸² However, the WG-SS questions are not designed to measure the prevalence of disability. Rather, they are used as a categorical variable regarding impairment (for example, by ethnic group or gender) to allow for comparison of outcomes by different population sub-groups. The WG-SS questions have not been designed or validated for Indigenous peoples, and thus may not be useful mechanism for the provision of meaningful data and information for Tāngata Whaikaha Māori, and many other social groups (for instance, Pacific peoples, children and young people, people with lived experience of neurodiversity or mental health conditions). WG-SS questions only relate to five impairment types (vision, hearing, mobility, cognition, self-care), and the questions pertaining to each type are likely to undercount Tāngata Whaikaha Māori. For instance, the question relating to cognition only asks if a person has difficulty remembering or concentrating.⁸³

Recently, Stats NZ and the Office for Disability Issues publicly released data Tāngata Whaikaha Māori data that is based on linking the WG-SS to the regular surveys.⁸⁴ Unfortunately the data

⁷⁸ SOCRATES is a national database used by 15 Needs Assessment and Service Coordination (NASC) organisations across New Zealand, NASC organisations assess the disability needs and allocate services for people eligible for Ministry of Health funded disability support services. For further information, refer to King (2019).

⁷⁹ King, 2019.

⁸⁰ King, 2019.

⁸¹ King, 2019.

⁸² Murray et al., 2022.

⁸³ Washington Group on Disability Statistics, 2020.

⁸⁴ Figure NZ, & Stats NZ, 2022; Office for Disability Issues, 2022.

is framed as relating to “disability status”. For reasons already outlined, this is potentially misleading.

Other government work around disability data and information is currently underway, such as the Patient Profile and National Health Index project (PPNHI),⁸⁵ but while these purport to provide access to a much broader range of data about disabled people, significant problems remain. In the case of the PPNHI, Tāngata Whaikaha Māori are likely to be invisibilised again through underreporting (from both a disability and ethnicity perspective) in national datasets including the National Health Index (the database the PPNHI utilises).

The impact of poor data and information quality is that the government is not able to fund, plan and design services to meet the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori based on real time data and insights. There are also considerable issues around accessibility and public availability of data and information. For instance, in addition to finding that the government did not collect adequate data for the equitable rollout of the COVID-19 vaccine for Māori and Tāngata Whaikaha Māori, thus breaching the ‘Treaty principles’ of *active protection* and *equity*, the Waitangi Tribunal 2021 report ‘Haumarū’ also found that the government did not provide accessible information for Tāngata Whaikaha Māori.⁸⁶

Issues like these, limiting the collection and access to meaningful Māori disability data, are a driving force behind our recommendation for a national kōrero with Tāngata Whaikaha a Māori, as outlined in priority area 1. We also note a Health Research Council funded Kaupapa Māori mixed-methods research project entitled, ‘Te Ao Mārama – Disability perspectives of tāngata whaikaha Māori’ (led by Bernadette Jones and Associate Professor Tristram Ingham at the University of Otago (Te Whanganui-a-Tara)) is underway and aims to develop culturally appropriate approaches to measuring disability for Māori.⁸⁷ Amongst other things, this research project will contribute to an increased understanding on Māori views of disability.

Develop a monitoring work programme

As part of its monitoring functions, it is assumed that Te Aka Whai Ora will be developing a monitoring work programme. In light of what has been observed throughout this paper, it is important that consideration is given to interrogating areas of publicly funded health sector performance most likely to impact Tāngata Whaikaha Māori, and that Te Aka Whai Ora involves Tāngata Whaikaha Māori in identifying these priority areas.

In line with evidence provided to the Waitangi Tribunal in March 2022 on Fetal Alcohol Spectrum Disorder (FASD) in New Zealand and the implications for health and wellbeing of Māori,⁸⁸ the publicly funded prison health service would be an area worth giving particular attention, noting that young Māori reported to be overrepresented in FASD statistics⁸⁹ in addition to the trajectory that Māori with lived experience of FASD face regarding

⁸⁵ Ministry of Health, 2021a.

⁸⁶ Waitangi Tribunal, 2021.

⁸⁷ The research commenced in 2019 and is of 48-months duration.

⁸⁸ Disability Rights Commissioner & Children’s Commissioner, 2021.

⁸⁹ Crawford et al., 2020.

overrepresentation in the justice system, and places of incarceration.⁹⁰ It is important that the health and wellbeing outcomes of Tāngata Whaikaha Māori in places of incarceration are monitored, in terms of: access to publicly funded health and disability support services; the quality of health and disability care received, and; health and wellbeing outcomes.⁹¹

Support governance of Tāngata Whaikaha Māori data, by Tāngata Whaikaha Māori

Māori Data Sovereignty refers to the fundamental rights and interests of Māori relating to the “collection, ownership, and application of Māori data (digital or digitisable information or knowledge that is about or from Māori people, language, culture, resources or environments)”.⁹² The affirmation of Māori Data Sovereignty⁹³ by Te Mana Raraunga/Māori Data Sovereignty Network, is underpinned by tāngata whenua rights articulated in Te Tiriti o Waitangi and supported by the United Nations Declaration on the Rights of Indigenous Peoples.⁹⁴

Māori scholars highlight that, “as an approach to data, Māori Data Sovereignty requires a fundamental rethinking of how data should be collected, cared for, used, stored, shared, or restricted”.⁹⁵ Te Mana Raraunga has described six principles of Māori Data Sovereignty to guide approaches to the collection, management, and use of data. These principles are: Rangatiratanga (Authority); Whakapapa (Relationships); Whanaungatanga (Obligations); Kotahitanga (Collective benefit); Manaakitanga (Reciprocity); and, Kaitiakitanga (Guardianship).⁹⁶

The principles of Māori Data Sovereignty can be engaged with by Te Aka Whai Ora in partnership with Tāngata Whaikaha Māori communities as a meaningful starting point. This will support Te Aka Whai Ora to examine, reflect upon, and address its current approaches to data and information for Tāngata Whaikaha Māori across all its policies, processes, practices, and arrangements at every level.

Application of Māori Data Sovereignty principles supports a Māori Health Authority approach to data that recognises and acknowledges data obligations for Māori under international human rights instruments⁹⁷ and improves data justice⁹⁸ for Tāngata Whaikaha Māori through minimising the likelihood of data harms (including the harms of undercounting Tāngata Whaikaha Māori), monitoring for data harms, redressing data harms that have occurred, and preventing further data harms.

⁹⁰ Disability Rights Commissioner & Children’s Commissioner, 2021.

⁹¹ King, 2019.

⁹² Kukutai & Cormack, 2019, p.204.

⁹³ Kukutai & Taylor, 2016; Kukutai & Cormack, 2019.

⁹⁴ Te Mana Raraunga, 2018.

⁹⁵ Cormack & Kukutai, 2022, p.133.

⁹⁶ Te Mana Raraunga, 2018.

⁹⁷ Cormack & Kukutai, 2022.

⁹⁸ Cormack & King, 2022; Cormack & Kukutai, 2022.

Conclusion and recommendations

The establishment of Te Aka Whai Ora presents significant opportunities for the government to do better for Māori. But, as argued in this paper, this opportunity will be lost if it is not also used as an opportunity to shine a light on Tāngata Whaikaha Māori, solidify Tāngata Whaikaha Māori leadership, governance and community input, and invest in services that meaningfully impact on the health and wellbeing needs and aspirations of Tāngata Whaikaha Māori.

Across six priority areas this paper makes 20 recommendations for Te Aka Whai Ora to implement in its first two years. The below table summaries these recommendations and indicates a rough guidance around timeframe. The first of these, a national kōrero with Tāngata Whaikaha Māori, should happen immediately and others, such as introducing new funding categories in the ‘Hauora Māori Scholarships’ and providing support to Tāngata Whaikaha Māori members of Iwi-Māori Partnership Boards are ‘low hanging fruit’ which could be implemented easily.

Recommendations from 1 July 2022 for Te Aka Whai Ora:

Rec #	Recommendation text	Timeframe
1.	Begin national kōrero with Tāngata Whaikaha Māori held in partnership with Tāngata Whaikaha communities. The national kōrero could contribute to hearing the aspirations of Tāngata Whaikaha Māori and understanding how they choose to describe concepts of disability. Additionally, this is a chance to introduce the work of Te Aka Whai Ora.	Immediately
2.	Work with the Ministry of Health, Health NZ and within Ta Aka Whai Ora to support processes that ensure high levels of participation by Tāngata Whaikaha Māori regarding appointments of Board members to other health sector Crown Entities. This could include working with Tāngata Whaikaha networks and community groups to identify nominees for the appointments.	Within first year
3.	Provide support to Tāngata Whaikaha Māori members of Iwi-Māori Partnership Boards, including provision for peer support and networking.	Immediately
4.	Fund Tāngata Whaikaha Māori communities to come together, network, and input into Te Aka Whai Ora mahi in an ongoing way.	Within first year
5.	Ensure that all health sector policy and strategy documents explicitly consider the needs and aspirations of Tāngata Whaikaha Māori.	Immediately
6.	Undertake ethical co-designing with Tāngata Whaikaha Māori across all programmes. In the context of Tāngata Whaikaha Māori this would mean developing ongoing relationship with their communities, transfer of equitable resources and sharing power as appropriate. Te Aka Whai Ora to set up monitoring to ensure equitable inclusion of Tāngata Whaikaha Māori through the co-design process.	Ongoing

7.	Ensure health sector agency performance in implementing health sector strategy and policy is reported on in transparent ways and accessible to Tāngata Whaikaha Māori.	Within first two years
8.	Increase the number and range of disability support services offered by Kaupapa Māori Providers , including establishing a close partnership with the Ministry for Disabled People to develop a commissioning framework that explicitly includes the voices of Tāngata Whaikaha Māori and embeds the principle of options.	Within first year
9.	Identify opportunities to facilitate commissioning by Tāngata Whaikaha Māori communities directly.	Within first two years
10.	Address the underfunding of Māori health providers to ensure they are adequately funded to meet the needs and aspirations of Tāngata Whaikaha Māori.	Within first year
11.	Improve commissioning and contracting practices for health services to ensure they meet the needs and aspirations of Tāngata Whaikaha Māori.	Immediately
12.	Increase capacity and capability funding to Kaupapa Māori providers , including: <ul style="list-style-type: none"> 4. Having a specific funding category to support Kaupapa Māori providers who offer, or plan to offer, disability support services. This should be significantly larger than 2 percent of the total Māori Provider Development Scheme (MPDS) budget. 5. Having a specific funding category to support Kaupapa Māori provider responsiveness to Tāngata Whaikaha Māori. This is both about securing future capability and about having hauora-based models of care aimed at improving both accessibility of Kaupapa Māori providers for Tāngata Whaikaha Māori and accessibility of websites and other forms of information. 6. Support the further growth of Tāngata Whaikaha Māori community groups. 	Within first year
13.	Workforce: Ensure Tāngata Whaikaha Māori are explicitly included in all health workforce development activity, monitoring and evaluation.	Immediately, and ongoing
14.	Support career pathways for Tāngata Whaikaha Māori directly through: <ul style="list-style-type: none"> • Prioritising Tāngata Whaikaha Māori in health workforce funding. • Practising fair contracting practices so that Kaupapa Māori providers are able to offer sustainable employment opportunities to Tāngata Whaikaha Māori and provide fair pay and other conditions. • Ensuring provider development funding through the MPDS is available to enable Kaupapa Māori providers to be good employers of Tāngata Whaikaha Māori and provide reasonable accommodations including fully accessible workplaces. • Supporting mentorship for Tāngata Whaikaha Māori either through the MPDS or through additional workforce funding. 	Within first year
15.	Collaborate with partners to indirectly support career pathways for Tāngata Whaikaha Māori, including:	Within two years

	<ul style="list-style-type: none"> Working with regulating authorities to ensure appropriate support for Tāngata Whaikaha Māori who are part of the regulated health workforce. Ensuring co-commissioned health services fully encourage and support Tāngata Whaikaha workforce participation and development. Partnering with the Health Research Council to support (or funding providing additional funding for) research programmes or awards to help grow the number of Tāngata Whaikaha Māori researchers across the research pipeline. 	
16.	<p>Build a health workforce that is responsive to Tāngata Whaikaha Māori, including:</p> <ul style="list-style-type: none"> Building disability responsiveness in health organisations along with cultural safety. Investing in a New Zealand Sign Language interpreter workforce with fluency in Te Reo Māori. Ensuring workforce planning (conducted in collaboration with Health New Zealand) includes/accounts for critical workforce shortages that primarily affect Tāngata Whaikaha Māori and other disabled people. 	Within first year
17.	<p>Be a good employer of Tāngata Whaikaha Māori, including:</p> <ul style="list-style-type: none"> Developing appropriate human resources policies and processes with Tāngata Whaikaha Māori staff and advisors. This is likely to include policies on recruitment, working from home, flexible working hours and equitable remuneration. Creating a physically accessible environment that works for Tāngata Whaikaha Māori. Ensuring the safety of Tāngata Whaikaha Māori staff, (including particularly during COVID-19 through appropriate mask policies). Providing training and development opportunities for Tāngata Whaikaha Māori, including internships and networking opportunities with Tāngata Whaikaha Māori staff from other organisations. 	Immediately
18.	<p>Build high quality effective health and disability data across the board that is meaningful for Tāngata Whaikaha Māori and relates to Māori understandings of disability. This action is following on from the national kōrero (recommendation 1).</p>	Within first year
19.	<p>Develop a monitoring work programme that prioritises interrogating areas of publicly funded health sector performance that are most likely to impact Tāngata Whaikaha Māori.</p>	Within first year
20.	<p>Engage with the principles of Māori Data Sovereignty in partnership with Tāngata Whaikaha Māori communities.</p>	Within first year

References

- Allen + Clarke. 2020. Implementation evaluation of Mana Whaikaha system transformation. <https://www.manawhaikaha.co.nz/about-us/evaluation/implementation-evaluation/>
- AwhiMai Consultancy. 2019. Māori Provider Development and Hauora Māori Scholarship Review. Wellington: Ministry of Health.
- Baker, G., & King, P. 2022. Inquiry into the Support of Disabled People and Whānau During Omicron. Human Rights Commission, T. Ingham, editor. Wellington: Human Rights Commission.
- Came, H., Doole, C., McKenna, B., & McCreanor, T. 2017. Institutional racism in public health contracting: findings of a nationwide survey from New Zealand. *Social Science and Medicine*. 199: 132–139.
- Clark, T., Sutcliffe, K., Greaves, L., Roy, R., DaRocha, M., & Fleming, T. 2021. A Youth19 Brief: Rangatahi Māori with a disability or chronic condition. Auckland, New Zealand: The Youth19 Research Group, Victoria University of Wellington and the University of Auckland.
- Cleary, L. 2021. Using ethnicity data in health statistics. Wellington: Ministry of Health.
- Committee on the Rights of Persons with Disabilities. 2014. Concluding observations on the initial report of New Zealand, CRPD/C/NZL/CO/1. <https://www.ohchr.org/en/countries/new-zealand>
- Cormack, D., & McLeod, M. 2010. Improving and Maintaining Quality in Ethnicity Data Collection: Issues for the Health and Disability Sector. Wellington: Te Rōpū Rangahau Hauora a Eru Pōmare.
- Cormack, D., Harris, R., & Stanley, J. 2020. Māori experiences of multiple forms of discrimination: Findings from Te Kupenga 2013. *Kōtuitui: New Zealand Journal of Social Sciences Online*, 15(1), 106–122.
- Cormack, D., & King, P. 2022. Beyond the “abyssal line”: knowledge, power, and justice in a datafied world. In M. Walter, T. Kukutai, A.A. Gonzales, R. Henry (Eds.), *The Oxford Handbook of Indigenous Sociology*, doi: 10.1093/oxfordhb/9780197528778.013.35
- Crawford, A., Te Hāpuku Te Nahu, L., Peterson, E.R., McGinn, V., Robertshaw, K., & Tippett, L. 2020. Cognitive and social/emotional influences on adaptive functioning in children with FASD: clinical and cultural considerations, *Child Neuropsychology*, 26:8, 1112–1144.
- Curtis, E., Loring, B., Harris, R., McLeod, M., Mills, C., Scott, N., & Reid, P. 2022. Māori Health Priorities – A report commissioned by the interim Māori Health Authority (iMHA) to inform development of the interim New Zealand Health Plan (iNZHP). Wellington: Interim Māori Health Authority.
- Disability Rights Commissioner & Children’s Commissioner. 2021. Report of the Disability Rights Commissioner and Children’s Commissioner to the Prime Minister – Fetal Alcohol Spectrum Disorder: A Call to Action. Wellington: Human Rights Commission, Office of the Children’s Commissioner.

- Eggleton, K., Anderson, A., & Harwood, M. (2021). The whitewashing of contracts: Unpacking the discourse within Māori health provider contracts in Aotearoa/New Zealand. *Health & Social Care in the community*. <https://doi.org/10.1111/hsc.13691>
- Figure NZ, & Stats NZ. (2022). Aotearoa Disability Figures [Internet]. <https://disability.figure.nz>
- Harris, R.B., Cormack, D.M., & Stanley, J. 2019. Experience of racism and associations with unmet need and healthcare satisfaction: The 2011/12 adult New Zealand health survey. *Australian and New Zealand Journal of Public Health*, 43(1), 75–80.
- Hickey, H., & Wilson, D.L. 2017. Whānau hauā: Reframing disability from an Indigenous perspective. *MAI Journal*, 6(1), 82–94.
- Human Rights Commission. 2015. Reasonable Accommodation Guide focussing on persons with disabilities. Wellington: Human Rights Commission.
- Interim Health New Zealand and Māori Health Authority. 2022. Joint Board Sub Committee paper (3 April 2022): Co-commissioning Framework. Wellington: Interim Health New Zealand and Māori Health Authority.
- Jones, B., King, P., Baker, G., & Ingham, T. 2021. COVID-19, Intersectionality, and Health Equity for Indigenous Peoples with Lived Experience of Disability. *American Indian Culture and Research Journal* 2021, 44(2), 71–87.
- King, P.T. 2019. Māori with lived experience of disability: Part I, Wai 2575, #B22.
- King, P.T. 2021. Oranga Mokopuna: Ethical co-designing for the Pluriverse [PhD thesis]. Wellington: University of Otago.
- King, P., Baker, G., Jones, B., & Ingham T. 2021. The Official Information Act, Māori with Lived Experience of Disability, and New Zealand Disability Data: A case study. *Policy Quarterly*, 17(1): 72–78.
- King, P.T., Cormack, D., Edwards, R., Harris, R., & Paine, S-J. (2022). Co-design for Indigenous and other children and young people from priority social groups: a systematic review. *SSM – Population Health*, 18(101077). doi:10.1016/j.ssmph.2022.101077.
- Kukutai, T., & Cormack, D. 2019. Mana motuhake ā-raraunga: Datafication and social science research in Aotearoa. *Kōtuitui: New Zealand Journal of Social Sciences Online*, 14(2), 201–208.
- Kukutai, T., & Taylor, J. 2016. Indigenous data sovereignty: Toward an agenda. Canberra, Australia: ANU press. Ministry of Health. (2015).
- Cormack, D., & Kukutai, T. (2022). Indigenous Peoples, Data, and the Coloniality of Surveillance. In A. Hepp, J. Jarke & L. Kramp (Eds.), *New Perspectives in Critical Data Studies* (pp. 121–141). Cham: Palgrave Macmillan.
- Love, T., Moore, D., Milkop, A., Woon, L., Young, M., & Comendantet, C. 2021. Methodology for Estimating the Underfunding of Māori Primary Health Care. <https://srgexpert.com/wp-content/uploads/2021/08/Methodology-for-Estimating-the-Underfunding-of-Maori-Primary-Health-Care.pdf>
- McCarty, G., Wyeth, E.H., Harcombe, H., Davie, G., & Derrett, S. 2018. Māori Injury and Disability Information Sheet. Dunedin: Ngāi Tahu Māori Health Research.

- https://blogs.otago.ac.nz/ipru/files/2018/11/Māori-injury-and-disability-poster_FINAL.pdf.
- Ministry of Health. 2016. Te Ara Tuarua – Pathway 2: Māori participation in the health and disability sector [Internet]. <https://www.health.govt.nz/our-work/populations/maori-health/he-korowai-oranga/pathways-action/te-ara-tuarua-pathway-2-maori-participation-health-and-disability-sector>
- Ministry of Health. 2018. Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan. Wellington: Ministry of Health.
- Ministry of Health. 2020. Whakamaua: Māori Health Action Plan 2020–2025. Wellington: Ministry of Health.
- Ministry of Health. 2021a. ELT Memorandum – Achieving Equitable Health Outcomes for Disabled People in the Reformed Health System. Wellington: Ministry of Health.
- Ministry of Health. 2021b. Funding to Māori Health Providers 2015/16 to 2019/20. https://www.health.govt.nz/system/files/documents/publications/maori_provider_funding_report_v3.pdf
- Ministry of Health. 2021c. Scholarship categories [Internet]. <https://www.health.govt.nz/our-work/populations/maori-health/hauora-maori-scholarships-2022/scholarship-categories>
- Murray, S., Eden-Mann, P., Figure NZ, & Stats NZ. 2022. An introduction to disability data in Aotearoa [Internet]. <https://disability.figure.nz/intro>
- Office for Disability Issues. 2016. Outcome 2 - Employment and economic security [Internet]. <https://www.odi.govt.nz/nz-disability-strategy/employment-and-economic-security/#accordion-1051-heading>
- Office for Disability Issues. 2022. Tāngata whaikaha Māori data [Internet]. <https://www.odi.govt.nz/guidance-and-resources/tangata-whaikaha-maori-data/>
- Pae Ora (Healthy Futures) Act 2022.
- Pharmac Review Panel. 2022. Pharmac Review: Final report. Wellington: Ministry of Health.
- Public Service Commission. 2021. Te Aratohu Mawhiti mō te Papa Pounamu – Papa Pounamu Quick Guide [Internet]. <https://www.publicservice.govt.nz/our-work/diversity-and-inclusion/papa-pounamu-driving-diversity-and-inclusion-across-the-public-service/papa-pounamu-quick-guide/>
- Reid, G., Bycroft, C., & Gleisner, F. 2016. Comparison of ethnicity information in administrative data and the census. Wellington: Stats NZ.
- Reid, P., Cormack, D., & Paine, S.J. 2019. Colonial histories, racism and health – The experience of Māori and Indigenous peoples. *Public Health*, 172, 119–124.
- Roy, R., Greaves, L. M., Peiris-John, R., Clark, T., Fenaughty, J., Sutcliffe, K., Barnett, D., Hawthorne, V., Tiatia-Seath, J., & Fleming, T. 2021. Negotiating multiple identities: Intersecting identities among Māori, Pacific, Rainbow and Disabled young people. Auckland, New Zealand: The Youth19 Research Group, The University of Auckland and Victoria University of Wellington.

- Stats NZ. 2015. He hauā Māori: Findings from the 2013 Disability Survey. Wellington: Stats NZ.
- Talamaivao, N., Harris, R., Cormack, D., Paine, S-J., & King, P. 2020. Racism and health in Aotearoa New Zealand: A systematic review of quantitative studies. *The New Zealand Medical Journal*, 133(1521), 55–68.
- Te Mana Raraunga. 2018. Māori data sovereignty principles [Internet]. <https://www.temanararaunga.maori.nz/tutohinga>
- The Treasury. 2022. The Estimates of Appropriations 2022/23 – Health Sector B.5, Vol.5. Wai 2143, #1.1.1(a).
- Waitangi Tribunal. 2019. Hauora, WAI 2575 Stage One Report. Wellington: Waitangi Tribunal.
- Waitangi Tribunal. 2021. Haumarū – The COVID-19 Priority Report, WAI 2575. Wellington: Waitangi Tribunal.
- Washington Group on Disability Statistics. 2020. Washington Group Short Set on Functioning (WG-SS) [Internet]. https://www.washingtongroup-disability.com/fileadmin/uploads/wg/Documents/Questions/Washington_Group_Questionnaire__1_-_WG_Short_Set_on_Functioning.pdf