



FERNZ

Foundation for Equity and Research New Zealand



Less talking, more action

Views and experiences of Tāngata Whaikaha Māori in
Wairarapa

March 2023

Acknowledgement:

This report is the result of more than a year's planning, kōrero and deep thinking to capture and share the views of Tāngata Whaikaha Māori living in the Wairarapa region during the health and disability sector reforms which began in 2021 and were finalised in 2022. We are exceedingly grateful for everyone who took the time to be interviewed or attend a community hui on this Kaupapa.

This project is Tāngata Whaikaha Māori led and the associated interviews were planned and conducted by Beauche McGregor (Ngāti Kahungunu ki Wairarapa, Rangitane ō Wairarapa) and Marama Tuuta (Ngāti Kahungunu ki Wairarapa), with expert research leadership from Bernadette Ingham (Ngā Wairiki, Ngāti Apa). Notes and initial analysis were also completed by Beauche. Gabrielle Baker (Ngāpuhi, Ngāti Wairupe-Ngāti Kuri) completed the final analysis and led the writing of this report. The report was funded by The Foundation for Equity & Research New Zealand.

Suggested citation:

McGregor, B., Jones, B., Baker, G., and Tuuta, M (2023). *Less talking, more action: Views and Experiences of Tāngata Whaikaha Māori in Wairarapa (Report prepared for Te Aka Whai Ora)*. FERNZ, Wellington.

Published in March 2023 by the Foundation for Equity and Research NZ PO Box 17166 Karori Wellington 6147

ISBN 978-0-473-67473-1

Table of Contents

<i>Executive Summary</i>	4
Recommendations for Te Aka Whai Ora, the Māori Health Authority	5
<i>Introduction</i>	7
About the people we spoke to.....	7
Range of impairment types and services	7
Our approach to analysis.....	8
<i>State of current services</i>	9
The good things.....	9
The bad things	10
Entitlements.....	10
Communication with providers.....	10
Ableism and dehumanising approaches	11
Service availability	11
Service quality	12
Funding and out of pocket expenses.....	12
Service issues connected with Covid-19.....	13
Cultural safety.....	13
<i>The Māori Health Authority / Te Aka Whai Ora</i>	15
Disability should be a top priority	15
Tāngata Whaikaha Māori input is essential	15
Opportunity to adopt a wellness / hauora-based approach	16
There is a need to better understand the needs of Tāngata Whaikaha Māori in Wairarapa.....	16
What should the Māori Health Authority focus on?	17
Improving accessibility	17
Supporting Kaupapa Māori services and Māori workforce	18
Better integration of services.....	19
Mātauranga as a way of supporting Tāngata Whaikaha Māori self-determination	20
<i>Conclusion</i>	21
<i>References</i>	22

Executive Summary

As the health and disability sector was undergoing significant change and adjustment in 2021 and 2022, the Māori Health Director of the then-Wairarapa, Capital Coast & Hutt Valley District Health Boards supported us to gather and reflect on the views of Tāngata Whaikaha Māori¹ in the Wairarapa region. This presented an opportunity to identify both ‘good and bad’ aspects of current services in the region and to capture views of Tāngata Whaikaha Māori about their hopes and ambitions for the health and disability system transformation, which included the establishment of two new agencies (Health NZ and the Māori Health Authority) and what the new agencies should be focusing on from in the first years of operation.

We interviewed 14 participants across the Wairarapa district, which included a mix of Tāngata Whaikaha Māori, whānau members of Tāngata Whaikaha Māori and Māori disability support workers. This group was representative of the diversity of Tāngata Whaikaha Māori, spanning a wide age range, whakapapa throughout the motu, a range of impairment types, and a wide array of services accessed by the people we interviewed.

Current services

While a few participants found positive things to say about the services they regularly access, by and large participants expressed dissatisfaction with the way health and disability services currently operate, including concerns about a lack of information about what supports Tāngata Whaikaha Māori are entitled to, poor communication from providers, and ableism and other forms of discrimination from health and disability support providers. This appears to be associated with the use of a Western medical approach to health and disability, which positions the health professionals (especially medical professionals) as the knowledge holders rather than seeing Tāngata Whaikaha Māori as experts in their own rights.

Participants also raised issues with service availability, including a lack of a suitably trained workforce and the impacts of Covid-19 restrictions, and poor quality services. These concerns about quality extended to a lack of clear complaints procedures by some providers. Some people we spoke to also highlighted the extra expenses that Tāngata Whaikaha Māori have, for example in additional primary health care appointments or co-payments for some disability supports.

Nearly all participants said that cultural safety was either non-existent, tokenistic or, at best, patchy amongst the services they access, with rare complements being directed at individual staff members who went out of their way to support Tāngata Whaikaha Māori.

The Māori Health Authority

When we first started interviewing participants for this project, the news of a Māori Health Authority being established was fresh, and not everyone knew about it. Regardless, support

¹ Throughout this report we use the term Tāngata Whaikaha Māori¹ to refer to Māori with lived experience of disability, although we acknowledge that Māori use a diverse range of equally valid terms, such as whānau hauā, to describe their own lived experience of disability

for something like a Māori Health Authority was strong from the people we spoke with. There was a strong view that disability should be the very top priority of the Māori Health Authority. This could be demonstrated by listening to the voices of Tāngata Whaikaha Māori directly, rather than having them mediated through providers, non-disabled or non-Māori ‘experts’, or through government agencies.

The hope shared by many participants was that the Māori Health Authority would be able to adopt a holistic approach to health and wellbeing, based on Māori concepts of hauora. Given the feedback on the current services, this was naturally positioned as being in contrast to the Western medical model most of our participants had to contend with in their daily lives. Participants also expressed hope that the Māori Health Authority would take seriously its role to understand the needs and aspirations of Tāngata Whaikaha Māori in Wairarapa, including through the collection and analysis of high quality disability data by ethnicity, and by balancing a national focus with local intelligence and insights.

When asked what the Māori Health Authority should focus on in the immediate future, four main points emerged: improving accessibility, supporting Kaupapa Māori providers and a Māori workforce, integrating services (across all sectors) and supporting the use and growth of mātauranga Māori as it relates to disability.

Recommendations for Te Aka Whai Ora, the Māori Health Authority and Te Whatu Ora (Health NZ)

As the new health entities begin planning for the second year of operations and beyond, there continues to be a need for greater focus and concerted effort to meet the needs and support the aspirations of Tāngata Whaikaha Māori in the Wairarapa region. The people we interviewed were clear: there needs to be less talking amongst officials and more action that leads to better outcomes for Tāngata Whaikaha Māori.

To this end we make four recommendations to Te Aka Whai Ora and Te Whatu Ora (Health NZ) for immediate action

1. Establish mechanisms to ensure Tāngata Whaikaha Māori communities have a say in policy design, service development and how services are monitored. This could begin with a national kōrero on the mahi of the Māori Health Authority, but will need to include locality or regional discussions. From what we heard in interviews, the communities will know best how these conversations could be run, be it a quarterly forum where officials meet with Tāngata Whaikaha Māori over kai, a formal Tāngata Whaikaha Māori community advisory committee run by Tāngata Whaikaha Māori and feeding into Te Aka Whai Ora or something else entirely.
2. Invest in Kaupapa Māori services (both those offered by Māori providers and those run by Māori communities), which must include building the Tāngata Whaikaha Māori workforce and ensuring Kaupapa Māori options for Tāngata Whaikaha Māori seeking disability support services. We note that Te Aka Whai Ora has recently indicated it will invest in mātauranga Māori solutions and this is consistent with what participants thought was needed, though it is important that this also includes opportunity for Tāngata Whaikaha Māori-led projects.

3. Work with Whaikaha: The Ministry of Disabled People, Te Whatu Ora (Health NZ) and the Ministry of Health to demonstrate a commitment to holistic approaches to hauora and wellbeing. This will mean investing in Māori models of health, in cultural safety of providers and health and disability professionals, and in work across sectors that improve the wellbeing, and support the aspirations of, Tāngata Whaikaha Māori.
4. Prioritise Tāngata Whaikaha Māori needs and aspirations when undertaking monitoring of the publicly funded health system. We heard (and have experienced) too many consistent stories of poor performance by health and disability services for them to be one off occurrences. Tāngata Whaikaha Māori have the right to expect the services they access to meet performance expectations, and publicly funded health services and systems must be held accountable if they let Tāngata Whaikaha Māori down.

Introduction

As the health and disability sector was undergoing significant change and adjustment in 2021 and 2022, the then-district health boards in the Wellington region supported us to gather and reflect on the views of Tāngata Whaikaha Māori in the Wairarapa region. This presented an opportunity to identify both good and bad aspects of current services in the region and to capture views of Tāngata Whaikaha Māori about their hopes and ambitions for the Māori Health Authority and what it should be focusing on from in the first years of its operation.

About the people we spoke to

From late 2021 to late 2022, we interviewed 14 Māori participants based in the Wairarapa district. Interviews took between 30 and 90 minutes and were all conducted by Tāngata Whaikaha Māori, who also live in Wairarapa. Participants were recruited through the networks of our interviewers, using a snowball method.

All participants had experiences in accessing health care and disability supports and of the 14:

- 5 participants were Tāngata Whaikaha Māori
- 5 participants were parents, grandparents or siblings in a caring role of Tāngata Whaikaha Māori
- 2 participants were partners of Tāngata Whaikaha Māori
- 2 participants were Māori disability support workers.

Most participants (11) were living in Masterton, with two living in Greytown and Martinborough and one participant living in Carterton.

Most participants identified as female (13; 1 male) and participants ranged in age between 28 and 72 years old. While participants had whakapapa across the motu, they predominantly identified their Iwi as Ngāti Kahungunu ki Wairarapa (9) and Rangitane ō Wairarapa (6).²

Range of impairment types and services

We asked participants about the types of impairments they or the people they care for have, and what services they access.³ Our interviews related to Tāngata Whaikaha Māori with a range of impairment types. The most common types were:

- Physical disabilities including mobility issues (8)
- Developmental disorders, including ASD (3)
- Cognitive issues (2)
- Hearing impairment (2)
- Low- or no- vision (2)

There were also single participants who identified issues including chronic pain, cerebral palsy, arthritis and mental health issues.

² Participants were able to select multiple Iwi

³ Māori disability support workers were not asked these questions

While the length of time Tāngata Whaikaha Māori had experienced the impairments varied, some indicated that the impairment had been since birth (4), from an injury (2) or the result of a stroke (2).

There was a wide range of services accessed by participants in relation to disability or their impairment(s), including:

- Equipment, like wheelchairs and hearing aids (5)
- Care givers and community support workers (4)
- Hospital services, like occupational therapy and physiotherapy (4)
- Community based programmes like King Street Artworks and Riding for the Disabled (3)
- Primary health care (3)
- Support from NGOs, such as the Stroke Foundation (1) or Royal New Zealand Foundation for the Blind (1)
- Respite care (1)

Several participants talked about whānau support (3) and one talked about accessing lotteries funding for expensive disability supports, such as vehicles.

Our approach to analysis

After each interview, short notes were made by the person conducting the interview often using verbatim quotes to highlight a point. Interviews were then listened to and analysed by a second person with some parts of the interviews transcribed to support analysis.

Our analysis was completed using a Kaupapa Māori approach⁴ that centred the views and expertise of Tāngata Whaikaha Māori.⁵ We drew on the principles of Te Tiriti o Waitangi as articulated by the Waitangi Tribunal in its 2019 Hauora report⁶ and found this useful in making sense of the themes from the interviews. Lastly we reviewed the Pae Ora (Healthy Futures) Act 2022 and recent government documents develop recommendations for Te Aka Whai Ora.⁷

⁴ Curtis E. (2016)

⁵ Ingham et al (2022)

⁶ Waitangi Tribunal (2019)

⁷ Te Whatu Ora and Te Aka Whai Ora (2022)

State of current services

When asked about the range of disability related services⁸ accessed by Tāngata Whaikaha Māori in the Wairarapa there was a mix of responses.

The good things

There are no difficulties whatsoever. (Koromiko)⁹

Four participants were positive about current services, especially about those offered through either Masterton Hospital or Starship Hospital (in relation to tamariki).

They were awesome. (Kauri, in relation to Starship Hospital)

The nurses on the children's wards are awesome, they look after the patients and their whānau really well, other than that not much really. (Kahikatea)

When I was in hospital after my stroke, I was treated with the utmost respect from all of the medical professionals at the hospital. (Matai)

Outside of this, where participants were positive about services it primarily related to especially good caregivers (5) or Māori staff (2).

I can see that the caregivers care for my moko and that is a weight off my shoulders knowing that my moko is in safe hands. (Kōwhai)

This was mirrored by one Māori Disability Support Workers who participated in the interviews, who emphasised that supporting Tāngata Whaikaha Māori was a highlight of their mahi:

I do it in mainstream services as well, but especially for our Māori ones, wherever they are, I make them feel extra special. Extra in that they feel loved, and that there is a difference and I make a difference in their daily lives. I think that is what I like doing. (Mānuka)

One participant accessed individualised funding through Manawanui and was positive about the way this allowed them to have a greater say over the services they received and who they received them from:

You don't have anyone above you or below you, you're on an even keel and you get to let your staff know, so you employ them, and you get to let your staff know what you want. And I absolutely love it. (Horopito)

⁸ This term is used instead of "disability support services" as participants tended to identify a wider range of services than those only offered by disability support service providers, for example it included supports provided through Masterton Hospital and GP services in some instances.

⁹ Quotes are taken directly from our interviews. Participants have been assigned Māori plant names as pseudonyms to ensure anonymity.

The bad things

The only way that that could be fixed is just to scrap the whole thing and don't hire anyone that used to work there. (Karaka)

Despite some positive feedback on current disability related services, participants mostly identified problems with access to services, service quality, workforce, discriminatory approaches, a lack of flexibility, and funding.

Less talking, more action. (Harakeke)

Issues with communication were most commonly raised by participants (10). Cultural safety was also raised, but will be addressed in its own section of this report.

Entitlements

Amongst the most common communications concerns raised in interviews, participants felt that information about disability support entitlements is not widely shared, nor well understood amongst Tāngata Whaikaha Māori (5).

Our people are shy about asking for help, they prefer to struggle on on their own until somebody says "this lot should be helping", but if that lot haven't been asked, then they don't know. (Akeake)

In some cases it was seen as an issue with government agencies not advertising what is available, and in other instances it was seen as providers actively withholding information from Tāngata Whaikaha Māori.

Apparently there is a funding amount that he is eligible for and the lady on the phone from [Triton Hearing] said it was \$1000 every six years but she wouldn't tell us how much we have used of that or when it rolls over. (Kawakawa)

The lack of information extended to Ministry of Social Development supports, in particular those from Work and Income:

We were always made feel like we had to ask for things that we needed, it was always awkward. Noone openly told us what we were eligible for especially from WINZ, we found more out from whānau. (Kauri)

Communication with providers

Three participants raised issues in communicating with service providers, and two additional participants raised issues in communicating with management.

These issues included finding it difficult to reach health providers to get advice, arrange services or change appointments.

It is very hard to get a hold of the occupational therapist so better communication is needed. (Matai)

Communication issues are exacerbated where providers have offices or call centres outside of the Wairarapa.

We used to have an office that we used to deal and it was awesome because they knew us. They knew our names, they knew where we lived, and they knew what we needed. Then all of a sudden it was sold off to the biggest buyer and all the coordinators got moved up to Auckland. So, we're in little old Masterton, they don't even know where we are. (Karaka)

There were also concerns raised about providers not being pro-active in communicating with Tāngata Whaikaha Māori. For one participant the consequence of this was that they had gone through all of their funding without warning.

I got into a situation where I had actually gone through all my funding through manawanui... And yes we are responsible for our own funding.. but my phone had broken down and I couldn't get into the portal and see what's there. I feel as a client [they] could have actually given me a call and said 'actually you're a few weeks into going into no funding if you don't slow down'. Nobody told me that til the last minute. (Horopito)

Ableism and dehumanising approaches

Several participants shared examples of health and disability services treating them in ways that were ableist, racist (5) or adopted a paternalistic Western Medical approach (2).

I know my body I know what I want and I know what my body needs. Sometimes feel that they over ride, they try and shut you down. (Karaka)

Two participants gave examples of interactions with professionals that left them feeling 'othered'.

I hate going to the doctors because it would turn into a spectacle show. (Kauri)

There were also instances described as racist by participants, including when accessing entitlements:

Well, they didn't say to my face that I would abuse the disabled car park. They didn't say it. But I got the racism out of it and the prejudice... and it was never approved. (Ratā)

Service availability

The caregiving agency are really bad with their organising. (Matai)

Four participants highlighted limited service availability as an issue for Tāngata Whaikaha Māori in Wairarapa, especially when it comes to care and support workers. This was seen both as a workforce shortage issue and an issue with providers managing their staff well.

Some participants, however, thought part of the issue was not knowing what was available in the first place. This issue was connected with the lack of communication about what services Tāngata Whaikaha Māori are entitled to. One participant commented specifically that the reliance on putting information on the internet does not work for many people in Wairarapa.

I think we need a directory for anyone who has [a disability] ... and not everybody has a laptop and if they're my age not everyone wants a laptop. (Akeake)

Service quality

Having two different agencies in my home was just hoha. (Karakā)

Four participants shared stories of poor service quality. In some instances, the quality issues were system level – such as being overwhelmed by services and service duplication. In other instances it was about concerns with the way particular providers delivered services.

There has been numerous occasions that my moko has left in bed unable to connect anybody which is a health and safety concern because the phone has been out of reach, and they have not organised a caregiver to go in when one of the normal ones are away. Sometimes, they ring me, and I must go and do their job, this is so frustrating (Kōwhai)

Of particular concern, one participant highlighted the lack of quality mechanisms included a lack of clear process for follow-up on complaints.

I made two formal complaints, no three, in the last six months and I only got a text message from a number that I couldn't even reply to apologizing one of those complaints. I've never had an email to follow up to what has happened to my complaints. (Karakā)

Funding and out of pocket expenses

Several participants highlighted issues with funding and costs including high user charges or co-payments (4), a lack of flexibility in what is or is not funded by government agencies or providers (3) and problematic funding model (1).

These issues were often intertwined, for example a lack of flexibility in the funding model meant that providers were not able to offer services that better met the needs of Tāngata Whaikaha Māori, even if they were likely to be more beneficial in the long run. At least participant felt this was getting in the way of a quality and cost effective service:

If something costs you \$60 to have someone give you a shower and the way that they're tryin to give you a shower or the days don't quite work then sort it out so it does work for you and it still costs \$60. (Akeake)

For others it was simply the case that costs of accessing unfunded or only partially funded disability supports that too high.

My partner's hearing aid at the moment, one of them, is \$2,100. That's a lot of money. (Kawakawa)

Service issues connected with Covid-19

Everything worked well until Covid. (Harakeke)

Although there were no specific questions about Covid-19 asked in the interviews, three participants highlighted that Covid-19 and its associated response disrupted services in negative ways.

For one participant, Covid-19 restrictions were seen as an excuse to cut day programmes and other service seen as non-essential by providers. This was seen as also a cost-cutting measure on the part of providers.

They used Covid as an excuse. (Kūmarahou)

Cultural safety

Participants were asked about the cultural safety of the services they had received and whether they met their cultural needs as Tāngata Whaikaha Māori.

They all failed us. (Kahikatea)

They haven't supported me, even with kapa haka. (Harakeke)

Five participants said that there was no sign cultural safety in the services they used or knew about. The number was higher if you include the number of participants who raised concerns about the lack of Māori staff (6).

You know what, it is a very pākehā-fied place. I haven't seen a Māori person work at [that office], there is no Māori staff... it's just so Pākehā. (Kawakawa)

The main suggestion from participants was that services need to upskill urgently, as do their staff.

They need to go and learn mātauranga Māori and tikanga and don't be tokenistic with the treaty principles. (Kahikatea)

Five participants said that cultural safety was, in their experience, patchy or seen in one or two of the services they accessed.

Starship was the only place that were culturally aware offering moral, cultural and spiritual support, they made you feel included and not out of place. (Kauri)

Sometimes this was about the way individual practitioners worked with Tāngata Whaikaha Māori.

My support worker is good they do as I ask around taking their shoes off or alternatives to that, like wearing blue booties over their shoes when showering. (Matai)

No one spoke highly of the cultural safety of services, though those participants working as care givers identified that cultural safety at its core is about working in ways that are effective for the person in front of you:

They come from different backgrounds, have different needs and different challenges and you have to approach them different. (Mānuka)

The Māori Health Authority / Te Aka Whai Ora

Is this legit happening? Wow! (Kawakawa)

Views on the Māori Health Authority were sought from all participants. As some of our interviews were carried out at the end of 2021 and start of 2022, not all participants knew about the health system changes and so found it hard to answer any questions.

Disability should be a top priority

Those who were able to answer questions about the Māori Health Authority were clear that disability needs to be top of the new agency's priority list (7):

We should be equal or even be held a little bit higher than others because we have been neglected. (Kahikatea)

It is a critical area and it is like it was forgotten about... so I'm saying this belongs at the top. (Mānuka)

There was, however, some awareness that it issues relevant to Tāngata Whaikaha Māori may be de-prioritised (though, even here participants indicated it would and should still be high on the priority list).

I'd like to see it at number 1, but i think it will be number 3 to be quite honest. (Horopito)

Tāngata Whaikaha Māori input is essential

I think disability needs to be take into consideration and they need to allow us to have our voices heard. (Karaka)

Half the participants we spoke to emphasised the need to have Tāngata Whaikaha Māori input into the work of the Māori Health Authority (7). This was usually viewed as an opportunity to right the wrongs of previous health agencies by ensuring Tāngata Whaikaha Māori were heard directly by the agency, not moderated through providers.

We aren't given a voice, for years and years we haven't had a voice anyway really, hence why I think the health system is ... I think it is fully derailed. (Horopito)

The roles of whānau and caregivers were also acknowledged as important, as a way of supporting the voices of Tāngata Whaikaha Māori.

I hope that you learn to speak to the families, learn to speak to whoever the disabled person is and you learn to speak to the caregivers because those people are the ones who know what they want, know what they need. (Akeake)

When asked how to best ensure Tāngata Whaikaha Māori input, some suggestions focused on the need to find ways to have face to face kōrero with Tāngata Whaikaha Māori communities.

For me it has to be a kanohi ki te kanohi around the table discussion. (Rata)

Others suggested the use of local advisory groups, supported by the Māori Health Authority.

Maybe they could pay for the kai or the venue or getting us all there to meet... three or four times a year... just to focus on the positive things and the changes within our tāngata whaikaha community. (Rimu)

There were also strong suggestions that the Māori Health Authority board needs to include Tāngata Whaikaha Māori, perhaps as a requirement in the Pae Ora (Healthy Futures) Act 2022.

They should have a representative with disability on their board (Koromiko)

Opportunity to adopt a wellness / hauora-based approach

Several participants indicated that the Māori Health Authority represented an opportunity to adopt a holistic approach to wellness and wellbeing (5). This included adopting Māori models of hauora.

There is a lot to be said about colonisation. It's been done to us and that should be for the NZ health authority to clean up. The Māori Health Authority should look at Māori models. (Rimu)

From their Iwi to their spiritual to their daily to their appointments to everything. You have to cover all bases... your health, your mental wellbeing, your physical wellbeing, everything. (Kūmarahou)

Participants also shared views that the creation of the Māori Health Authority was a chance for a fundamental overhaul, with the associated view that this meant a change in key staff and a willingness to do things radically different.

I hope it is a name change and a whole overhaul of people. I mean, what is a name change going to do if the same people are just going to be on it safe it is not going to fix it. Just start anew because it hasn't for as long as I can remember it hasn't worked. (Horopito)

Participants also so wide scope to improve the connection of health and disability services with social services, council services and even the private sector.

[There should be a] lot more joint work Not just the medical stuff. It involves carpenters, it involves teachers, they need a bigger circle, they need engineers, they need people with practical experience because they're all working out of a book. (Akeake)

There is a need to better understand the needs of Tāngata Whaikaha Māori in Wairarapa

Four participants highlighted the need for the Māori Health Authority to get a better understanding of disability related issues (2) and what is happening locally in Wairarapa compared to the rest of the country (2). There were also strong views expressed that the

Māori Health Authority should be pushing for better quality disability data, disaggregated by ethnicity, so that we know what is happening for Tāngata Whaikaha Māori.

There were concerns shared that Tāngata Whaikaha Māori were often ignored or seen as a homogenous group based on those who qualify for disability support services, which further served to invisibilise the particular and varied needs and aspirations of Tāngata Whaikaha Māori.

I would like to see them step up and treat us like equals and remember that all disabilities are not seen, some are hidden don't put us all in the same category. (Kahikatea)

Other participants raised that the best approach for the Māori Health Authority is to start locally and support communities to respond to their own needs at marae and hapū level.

We should consult with more locally wise people instead of just going to Wellington. The best people for the jobs here are our own people from our own area. (Mānukau)

Several participants highlighted that other conditions or needs, which are not necessarily seen as disability related, are amplified by the ableist approach of current health services or leave Tāngata Whaikaha Māori missing out on services. The Māori Health Authority was seen as having potential to reduce and address these issues by using its influence with other agencies (such as the Ministry of Health or Health New Zealand / Te Whatu Ora). Areas raised include mental health, support for Covid-19 and women's health.

Why can't you have a hysterectomy and this not be one thing you need to worry about? (Akeake)

What should the Māori Health Authority focus on?

In addition to seeking general views on the Māori Health Authority and its potential to support Tāngata Whaikaha Māori, we asked participants what the Māori Health Authority could focus on in the immediate future.

Improving accessibility

Participants highlighted the barriers to accessing a wide range of health, disability, and community services. Many of these participants felt the Māori Health Authority could support improvements to make services more accessible (9). This included removing cost barriers to health care (4).

Free health care would be good. (Akeake)

It's like just about 50 bucks just go go and see a doctor. [The local Māori provider] is like \$18 bucks but he can't get into [the provider] cos it is overloaded (Kawakwa)

Non-financial barriers were also raised, including the inaccessibility of forms to access health care services.

When you go into a health provider and you're filling out forms and things like that it can be hard, so make it more simplistic – so that it is readable, that everyone can understand it. (Horopito)

Participants also emphasised that there needed to be a focus on lifting the quality of disability support services so that they were better able to meet the needs of Tāngata Whaikaha Māori. For example, one participant highlighted that provider's insisting care and support workers are entry level positions, not requiring experience, particular skills, or qualifications both diminishes the value of such essential workers but also potentially puts Tāngata Whaikaha Māori at risk of harms.

I think there needs to be a standard as to where these people who are working with our kaumatua, our most vulnerable disabled people, you know, there needs to be a higher standard than, no experience needed. They should at least give some form of qualifications otherwise what's going to happen to our vulnerable people if a whole new lot come in and they've got no experience, what's going to happen? (Karaka)

Physical accessibility and the built environment were also raised by several participants, along with a view that the health system (and Māori Health Authority) have a role to play to advocate for change.

There is a need for better access when it comes to getting around and our own communities like access into shops better entrances into shops and footpaths because wheelchair users find it hard getting around. (Matai)

Lastly, several participants talked about the Māori Health Authority supporting individualised approaches to services so that Tāngata Whaikaha Māori can receive services in culturally safe ways that work for them.

[Rules should only be applied] if it 'works' ... it might not fit everybody. (Akeake)

Supporting Kaupapa Māori services and Māori workforce

I would dearly love to see something here set up in Masterton, I see a huge need for our Māori people and our disabled people to come together to have their own place that they can call their own. (Mānuka)

By Māori-For Māori Services

We asked participants their views of by Māori-for Māori services. Most of the people we spoke with gave unequivocal support for Māori services (8), both because it was seen as empowering for Māori overall and because it was seen as a way of addressing the ableism, racism and other discriminatory approaches so many participants had seen from services.

It's empowering... Māori know how to work effectively with other Māori because they have a shared understanding of the disparities that Māori face. (Rimu)

I feel more comfortable talking to a Māori because they are relatable and they are less likely to talk down to us instead they will treat like we're on the same level. (Kauri)

Three participants did not support a focus on by Māori-for Māori. This was not a criticism of Kaupapa Māori services per se, but a view that either it should be by Māori-for everyone (1) or that the lack of Māori staff would make it impossible to be truly by Māori-for Māori (2).

There aren't enough Māori people qualified in the health services. (Koromiko)

Participants saw an important role for the Māori Health Authority in building both Kapapapa Māori services (by providers or by communities themselves) and in building the capacity and capability of the Māori workforce in the health and disability sectors (6).

I would be better if a Māori support person who knows the system were available or at least offered to sit in the appointments. (Kauri)

I feel like there is not a balance. Predominantly you go into a health care provider or any organisation and there is not a Māori person who works there and I'm not making assumptions but as far as I know none of them understand it, none of them understand tikanga. (Horopito)

Some participants also talked of the need to increase the number of Tāngata Whaikaha Māori working in the health and disability systems, for example wanting:

...a team of likeminded people who share our experiences they are the people that I will listen to because they understand what we are going through. (Kahikatea)

Better integration of services

A system that works for all areas... just wellbeing in general cos that's what life is, ahe. (Kūmarahou)

In keeping with the views that the Māori Health Authority should adopt a holistic approach in meeting the needs and aspirations of Tāngata Whaikaha Māori, several participants thought the Māori Health Authority should focus on better integration of services (6). This included a

sense that there should be greater access to wraparound services from a range of government sectors, all with a wellness focus.

Even though the Maori Authority is dealing with health, there is no reason that they can't have avenues to other sectors, such as housing, such as kai, such as counselling, you know hinengaro stuff. They need to be able to refer and pull in those other sectors when needed and they all need to work together to help our people because our people really do have a myriad of issues all in one person. (Karaka)

Participants were in general keen to see better relationship between the Māori Health Authority and a full range of non-health sector services to improve quality of life and reduce barriers to accessing health and disability support. These included better connections with Work and Income (3), transportation (2), recreation and play (2), housing, budgeting and motivation support.

Two participants highlighted the need for the Māori Health Authority to use their influence to advocate for changes across other health and disability sector organisations such as Whaikaha- Ministry of Disabled People, Ministry of Health and Te Whatu Ora to ensure services are more effective for Tāngata Whaikaha Māori.

Mātauranga as a way of supporting Tāngata Whaikaha Māori self-determination

Bring back rongoā! (Kahikatea)

Although several participants raised the importance of Māori knowledge, tikanga and world views, two participants were explicit that the Māori Health Authority should focus on mātauranga Māori as a way to support Tāngata Whaikaha Māori. This conversation encompassed both the use of rongoā Māori and the need for the specific mātauranga of Tāngata Whaikaha Māori (for example when it comes to Māori understandings of disability).

That's something that I would like to see in the Māori Health Authority, that they have schools of rongoā... cos one way doesn't fit everyone and it could be that rongoā is better than pills for some people. (Akeake)

Conclusion

As the Māori Health Authority (Te Aka Whai Ora) and its partner agency (Te Whatu Ora, Health NZ) begin planning for future operations, the results of this project suggest continued need for a concerted effort to meet the needs and support the aspirations of Tāngata Whaikaha Māori in the Wairarapa region. The people we interviewed were clear: there needs to be less talking amongst officials and more action that leads to better outcomes for Tāngata Whaikaha Māori.

To this end we make four recommendations to Te Aka Whai Ora and Te Whatu Ora for immediate action:

1. Establish mechanisms to ensure Tāngata Whaikaha Māori communities have a say in policy design, service development and how services are monitored. This could begin with a national kōrero on the mahi of the Māori Health Authority, but will need to include locality or regional discussions. From what we heard in interviews, the communities will know best how these conversations could be run, be it a quarterly forum where officials meet with Tāngata Whaikaha Māori over kai, a formal Tāngata Whaikaha Māori community advisory committee run by Tāngata Whaikaha Māori and feeding into Te Aka Whai Ora or something else entirely.
2. Invest in Kaupapa Māori services (both those offered by Māori providers and those run by Māori communities), which must include building the Tāngata Whaikaha Māori workforce and ensuring Kaupapa Māori options for Tāngata Whaikaha Māori seeking disability support services. We note that Te Aka Whai Ora has recently indicated it will invest in mātauranga Māori solutions and this is consistent with what participants thought was needed, though it is important that this also includes opportunity for Tāngata Whaikaha Māori-led projects.
3. Work with Whaikaha: The Ministry of Disabled People, Te Whatu Ora (Health NZ) and the Ministry of Health to demonstrate a commitment to holistic approaches to hauora and wellbeing. This will mean investing in Māori models of health, in cultural safety of providers and health and disability professionals, and in work across sectors that improve the wellbeing, and support the aspirations of, Tāngata Whaikaha Māori.
4. Prioritise Tāngata Whaikaha Māori needs and aspirations when undertaking monitoring of the publicly funded health system. We heard (and have experienced) too many consistent stories of poor performance by health and disability services for them to be one off occurrences. Tāngata Whaikaha Māori have the right to expect the services they access to meet performance expectations, and publicly funded health services and systems must be held accountable if they let Tāngata Whaikaha Māori down.

References

Curtis E. (2016) Indigenous Positioning in Health Research: The importance of Kaupapa Māori theory-informed practice. *AlterNative: An International Journal of Indigenous Peoples*. 2016;12(4):396-410.

Ingham, T. R., Jones, B., Perry, M., King, P. T., Baker, G., Hickey, H., ... Nikora, L. W. (2022). The multidimensional impacts of inequities for tāngata whaikaha Māori (indigenous Māori with lived experience of disability) in Aotearoa, New Zealand. *International Journal of Environmental Research & Public Health*, 19, 13558.

Te Whatu Ora and Te Aka Whai Ora (2022) *Te Pae Tata*. New Zealand Government. Wellington.

Waitangi Tribunal. (2019). *Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry – pre publication version*. Legislation Direct, Lower Hutt.

