ROYAL COMMISSION OF INQUIRY INTO ABUSE IN CARE

COLLECTIVE STATEMENT OF TĀMAKI MAKAURAU WHĀNAU HAUĀ

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BENNION LAW

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Introduction

1. We are a group of Whānau Hauā, predominantly based in Tāmaki Makaurau, who wish to give our evidence as a collective. This group is supported by Te Roopu Waiora and includes the kōrero of some of its members. Our evidence is focused on our collective experiences as Whānau Hauā, and our wishes for the community for the future.

2. A group of about 30 Whānau Hauā met with Royal Commission kaimahi and lawyers on 29 and 30 September 2022 in Tāmaki Makaurau. A wānanga was held to discuss our collective experiences of:

   a. Our experiences as tamariki hauā;
   b. Our experiences as adults;
   c. The impacts of our experiences;
   d. The barriers Whānau Hauā face to reconnecting with te ao Māori; and
   e. What changes we would like to see in the future for Whānau Hauā.

3. Our collective voices from this wānanga are set out in this statement. We have decided to share as a collective because, as Whānau Hauā, we identify as a collective and share many experiences. Therefore, we have not identified individuals to quote throughout this statement. This statement represents all of our views.

The Kupu "Disability"

4. It is important to begin this statement by setting out our kōrero about the kupu 'disability' and 'disabled'. Instead of these Pākehā descriptors, we use the term Whānau Hauā which includes Māori who have lived experience, our whānau, hapū, iwi and other support people.

5. Prior to colonisation, Māori did not view or speak about Whānau Hauā with the lens of 'disability'. The kupu hauā was used to describe us from a strengths-based perspective and not from a disadvantaged lens:

> *"The first time that the kupu hauā was brought in from a disadvantage point of view is in the English view. They took a positive kupu and made it derogatory. It comes from atua, from Tāwhirimātea, to cleanse you."*
>
> *"This is the impact of colonisation, kupu Pākehā has come and destroyed our kupu."*

6. This reframing of what it means to be Whānau Hauā has separated us from our cultural identity and acted as another barrier to our connection with whānau, hapū and iwi. Because of this, many Whānau Hauā have felt disconnected from the kupu hauā, and have created another to define themselves:

> *"Now part of the community doesn't like hauā, so they invented whaikaha in order to find strength to that of atua, and yet we here are personification of Tāwhirimātea himself, without him we wouldn't be able to breathe. This is a true separation of us from our Māori-ness."*

7. There are many stories in te ao Māori about tūpuna hauā, for example Hape, Kairako and Pūkākī. They are well-respected rangatira, and tohunga. Through these stories, we know that pre-colonisation, Whānau Hauā were not seen as 'disabled'. It is to these stories and these tūpuna that we turn to redefine ourselves from the Pākehā imposed view:

> *"These are the stories that are around in these places, which allow the Whānau Hauā and whaikaha to be inspired by and to aspire to carry on their journey as Māori."*
>
> *"Hape was seen as too old and too feeble. He was club foot. Hape was left behind, but because he was a tohunga, he called upon Tangaroa to provide him with a waka. This was kaiwhare."*
>
> *"He [Kairako] was a young strong tāne who was Takiwā – but he saved his village."*
>
> *"The face of the 20-cent coin is my tupuna from Te Arawa, Pūkākī. They say he was an amazing and remarkable person. He was kāpō."*

Institutionalisation

8. Many of us were removed from our whānau at an early age and taken into Pākehā 'care' institutions based on our 'disabilities'. When we were taken away, we were disconnected from our whānau, hapū and iwi, and from te ao Māori. This removal was not by choice, as many whānau felt like there was no option for them to keep their tamariki hauā at home:

> *"Aunty was taken to an institution, but before that she was pushed around on a pram. They told us that we couldn't do that, and that they*

> *would take her and put her into a home where she would be with similar people. And so she was taken away."*

9. This removal had a huge impact on our whānau. We would only see each other in the holidays, we no longer learnt te reo Māori from our whānau, and the ability of our whānau to care for us was reduced:

> *"My grandmother was very upset, and she died about 18 months later."*
>
> *"We were able to live as a village before, we were able to navigate and negotiate how we raise ourselves and how everyone is included. But now, when our aunty would come back to visit, she would be teased by her nieces and nephews because we didn't understand that she had cerebral palsy. She couldn't talk for herself, but her mind was sharp. If she had stayed in our marae and with the whānau, we would have been richer. We could have learnt how to live together as a people. We can be the eyes for those without and they can live in ways we cannot. The removal has highly impacted us."*

10. These institutions were not kind to us tamariki. Many of us experienced multiple forms of abuse while in these institutions, often because we were Māori:

> *"We got hit for speaking Māori, slapped across the face, made to go without meals. Māori kids were the only ones who got treated this way."*
>
> *"I don't like using the word care because I think that system doesn't care and nor do I hope it cares."*

11. Cultural abuse was a common factor in our experiences in these Pākehā disability institutions:

> *"The worst thing I think, I know abuse, all that, I know it's wrong, but the worst thing that happened was my culture was taken away from me."*
>
> *"[we] lost [our] way of being Māori at Pākehā school."*

12. These institutions were emotionally damaging for us. We were separated from our culture and forced to view ourselves in a light inconsistent with te ao Māori. The ongoing impacts of this are evident:

> *“I was put in an institution as a 15-year-old, and I lived there for 25 years. I am a product of a system that didn’t really do me any good except maybe made me more cynical about the world.”*

13. Not all our experiences in these institutions were negative. Many of us became involved in extracurricular activities such as Blind sports, and have had opportunities to travel the world through these. However, we had to be in these institutions to access these experiences:

> *“[We were] allowed to tour the world playing blind athletics, if you weren’t at the foundation, you wouldn’t have done it.”*

Connection to Te Ao Māori

14. As part of our connection to te ao Māori, we are first and foremost Māori:

> *"We came into this world Māori. Whatever happens to us we will always be Māori."*

15. Colonisation has impacted our connection to te ao Māori in many ways. Few of us can speak te reo Māori, and those of us who can have had to learn later in life.

> *“Institutionalisation becomes modern colonisation.”*

> *“The only thing I regret is I never learnt my reo, I went to hospital [when I broke my back] so I didn’t get to go to school. I’ve tried to pick reo up in the last 5 years, through Te Roopu Waiora. It’s a big part of my life.”*

16. Colonisation put huge pressure on Whānau Hauā to move with the changing world, to leave te ao Māori behind in order to live well in this new Aotearoa. It also taught us to be individuals, which has a significant impact on us as a collective:

> *“Because of the changing world, families were separated. The ideology was “leave your culture and language behind”. Some agreed and some disagreed. Some said “leave our world behind, educate the tamariki in the new language”*

> *"We are tribal people – co-dependency and interdependency is how we thrive. We can't do that when you take children and stick them in institutions. We never used to abuse our children. We do now."*

17. Our disconnect from te ao Māori has caused Whānau Hauā a lot of mamae. Our whānau, hapū and iwi connections have been damaged, and for many Whānau Hauā this has led to adverse outcomes, including involvement with the criminal justice system, gangs and drugs:

> *"My mum and sister are Deaf and I am in a wheelchair so we're all disabled. My mum is Deaf, she went to Kelston. I was an interpreter for her from 5 years to 15 years old when I broke my neck. I lost the ability to sign. My older sister was affected by Government organisations racism and turned to the dark side. She turned to the easy way of drugs and gangs, it is hard to pull her back, and this has had a big impact on our whānau. We never had the ability to become Māori, we didn't know how to be. [It's] Dysfunctional, I draw that back to not knowing who we are in tikanga."*
>
> *"P has had a huge impact on my family. It destroys whānau and destroyed mine a bit."*

18. Much of the disconnection of Whānau Hauā from te ao Māori can be traced back to the enactment of the Tohunga Suppression Act 1907. Because we were prevented from practicing our traditional methods of healing, rongoa and supporting Whānau Hauā, a large amount of that mātauranga was lost:

> *"I had it pretty easy when I was younger, but I have seen the impacts of tohunga suppression, because my whanau didn't know what to do when I broke my back."*

19. The Act, alongside other colonial institutions and instruments such as Blind schools, separated Whānau Hauā, disconnecting tamariki hauā and turi from our whānau, hapū and iwi. By removing our ability to support Whānau Hauā with our own traditional methods and forcing whānau to send our tamariki away for much of their early lives, our whānau, hapū and iwi were disconnected. Knowledge was lost, and to this day we struggle to regain this mātauranga so we are able to support our Whānau Hauā within our communities:

> *“I see it as the Tohunga Suppression Act still impacting until today, it’s why we have all these issues; certain areas of our lives have been suppressed. The health system is designed to be individualistic, which is detrimental to Māori. How does that work for us when we make decisions as a whānau?”*

> *“Those tohunga were able to make sure we could live together as one people. And now this is how it was. All of us raised in villages know this, even if we were forced to leave, we return to the village, and our people don’t know what to do with us. These are the cultural impacts, and when will that change?”*

20. The forced disconnection has impacted not only Whānau Hauā, but all of Māoridom. Few marae are accessible to whānau waka turu, kāpō Māori and there is a scarcity of trilingual interpreters. Our whānau, hapū and iwi often do not know what we need, and this is painful for them and for us:

> *“They invited all Whānau Hauā to Tāmaki Makaurau for a hui. Whānau became whakamā, because so many whānau hauā came, with so many conditions and impairments. People were whakamā because there was no education around that for our whānau back then. We learn from our whānau, from our past generations, and everything that it means to be Māori was taken away from us, from those taken to institutions and from the whānau, because when we came back they didn’t know how to manaaki, how to look after us, how to awhi their Whānau Hauā. That is cultural abuse.”*

21. Despite the extreme impacts of colonisation, our whānau, hapū and iwi have made strides in relearning how to support Whānau Hauā. That might look like a shift in roles on the marae, more accessibility for hui and wānanga, or keeping tamariki hauā within the whānau instead of sending them to institutions.

> *“I wanted to stay in the back as ringawera, but my dad asked “can you dig a hole for hangi, dry a dish? No. So then you can go in there, listen and learn from your uncles.” It was about finding a use and a purpose for me within the marae. Now who do my people look to as māngai? Me.”*

> *“We can show our Māori that we have a voice, that we can live amongst our people. We don’t need to hide in the institutions, we can find our strength within our number first and then they can take us back.”*
>
> *“My whānau treated us all the same, there wasn’t this idea of identifying as disabled, which is something I straddle in this world as an adult, I have to identify to get resources, to have a voice etc. There was not this separation in my whānau.”*

Pākehā Organisations

22. Many of us work in or are associated with Pākehā disability organisations out of necessity as Māori organisations do not have the appropriate resourcing or coverage. Institutions that are tasked with working with the disability community, such as the Blind Foundation, are, in our experience, not working with the community as they should be:

> *“Their job is to provide services and initiatives for kāpō, but it seems driven by profit rather than people. Feels like they’re neglecting the kāpō and not promoting them the way they should. Feels like negligence.”*
>
> *“It’s dangerous, anything to do with Māori in there, it’s not there.”*

23. When we do get appointed to governance positions, we are frequently unsupported by management and our voices are often ignored:

> *“Some people help me, but the people at the top pulling the strings aren’t doing their jobs.”*

24. A large number of those in positions of power in these organisations are Pākehā and able bodied themselves. They are making decisions on policy, practice and funding *for* the disabled community, but without lived experience:

> *“…an abled person tries to find solutions for a person like me, I don’t like that, they don’t know shit, they are just observers. They put it up as policy but half the time they don’t consult with membership, they lose the community consultation.”*
>
> *“…abled people assume what you need but never ask you. Who has the impairment, them or us? They don’t listen, they won’t go out and find out, they’ll just find their own solutions and dictate it to you.”*

> *"Policies need to change and the people they are employing need to be upskilled properly. They are not helping us, they are disabling us. We are living this life, they're just watching and observing. If you are the service provider, then provide the service. Don't provide things that are inaccessible."*

25. Because these organisations employ very few Whānau Hauā, and often do not listen to their advice, there are major hurdles to Whānau Hauā accessing their resources:

> *"They say "jump on the email" but a lot of my peers don't have luxury of having WIFI and can't even see it. They say we need to be technically inclined, but then we can't get funding for that or even to know how to get funding. And then, if you do have internet access, you still have to know how to fill out the form."*

Government Organisations

26. The Pākehā healthcare and social services systems are not designed to work for Māori. They are centred in an individualistic perspective, which works to divide whānau, hapū and iwi connections:

> *"The Pākehā system is all about individuality. How does that work for people like us? We work as a whānau."*
>
> *"I always wanted to be Māori but it's really impossible to be Māori in a system where you've got to project yourself in the most negative way so that you can be recognized and deserving of any kind of support."*

27. The structure of at home care is not fit for purpose for Whānau Haua. If we want our whānau to be funded to take care of us, we have to define them as carers and they become our employees. We also have to define ourselves to Government agencies as 'high and complex needs". This is a mana-diminishing process, for both ourselves and our whānau.

> *"It's a diminishing process – I am the main income earner, a career professional, I have mana and pride, my husband has mana and pride about his role."*

28. The system requires us to see ourselves as individuals, not as part of our collective. Our whānau work as collectives, but we have to define ourselves within specific parameters that the Government sets out, in a highly individualised way. This creates a disconnect between us and our whānau:

> *“The system calls my husband my fulltime carer, and he only qualifies for carer support. This has caused a lot of fighting in our home. It caused a lot of mamae because he does not identify as my carer, he is my husband.”*

29. We want our whānau to be resourced to support us, but on our terms and not as our employees. We should be able to choose who cares for us, as we know who is right for us:

> *“I just want to be resourced appropriately, and to manage my whānau appropriately. That should be our right, to decide who comes into our whare.”*

30. Government information is often inaccessible for Whānau Hauā. Many of us don’t have the skills or access to the technology needed to engage with Government services. Very few Government websites provide information in accessible formats, and rarely, if ever, are these provided in te reo Māori:

> *“The policies (MSD for example) and government agencies are inaccessible towards us. They say they are trying to get up with technology but not everyone can do technology.”*

31. There is a lot of racism within Government organisations, and this makes it very difficult for Whānau Hauā to engage with and access the support we need from these organisations:

> *“ACC, MOH, there is lots of racism. If you have a Pākehā and a Māori in the same institution, the Pākehā gets everything a lot faster than we do, and we have to jump through hoops and justify why we need what we need.”*
>
> *“…they never want to listen so now our turi whanau suffer.”*

32. We are frequently treated differently by Government agencies and service providers. They don’t understand whānau dynamics, make judgements about

us and our needs based on the colour of our skin, and often don't even know how to spell our names:

> *"ACC were the funder of services, and the service providers would come into our home and think I had more than enough help because I had a wife, a pregnant daughter next door, and a 3-year-old tamariki. Pākehās with nothing will get the 24/7 care. My Pākehā brother, because he doesn't have whānau around, he gets all the help. The CPI providers didn't tell me what I was eligible for. The provider would look at me and see brown person. My colour was my disability, not the actual disability I was carrying."*

33. The way we have been treated by Government agencies has led to many of us taking up action against them, particularly ACC. We have had to go to court just to be treated equally and have access to the services and resources that we need:

> *"My wife had to work 3 jobs to pay our mortgage, that's the impacts of not allowing me to get access to resources. But Pākehā or more white whānau got treated better, much more support. They told me I needed to push, because they were getting a different level."*
>
> *"I took ACC to court, I had lost my eye, and they said I had 7.5% vision in artificial eye. The Judge said no, that's not good. I fought for 12 years against ACC."*

34. For some of us, our experiences with service providers have been consistently negative. For some of us, we continue to be abused and oppressed by these organisations and service providers:

> *"The blind foundation has locked out our kāpō whānau. We have caregivers abusing whānau waka turu. What happens in the confides of those houses is not known."*

35. We are unable to trust service providers to accurately record what we have told them, particularly the needs assessors. The reports and decisions of the needs assessors can have huge impacts on our access to and quality of care:

> *"The trick for me is, I record anything I say to those assessors, so that nothing can be refuted. They can't change anything because I've written*

> *it all out. They go back and write their own reports about how they interpret what I've said and next thing, our hours are getting cut and you're left on your own."*

Whānau Hauā Representation

36. Some of us have had experience working in and with Government organisations, including in advisory, consulting and employment capacities. Even though we may have had a seat at the table, we have consistently felt that our voices are not heard in these spaces, particularly given that we are often the only Whānau Hauā present:

> *"We have a tension sitting in the newly established Ministry, but the ability to raise a Māori voice in that is an issue, as there are only one or two representatives."*

37. The fact that we are here today is a rare opportunity and it is critical that these voices are heard:

> *"We are really relying on this process as one of the mechanisms for our voices to be heard."*

Looking to the Future

38. In envisaging what the future looks like for Whānau Hauā, it is not enough to simply tweak a few aspects of these institutions and organisations. We need substantive, structural and systemic changes in order for Whānau Hauā to have a bright future:

> *"We have to be prepared to undo stuff so we can rebuild again…The foundations that we are working with are always going to be lacking."*
>
> *"If we keep doing what was always done or build on wrong assumptions, then we will just get the same same but slightly different, it's just lipstick on a pig. The same issues remain but dressed up differently and got a Māori name on it. Similar to Oranga Tamariki, sticking a Māori name on it doesn't make it different."*

39. We do not feel that the institutional care system is the way forward. It has caused irreversible harm and is systematically not fit for purpose. It cannot be

tinkered with, it must be overhauled and a new, whānau / community-focused approach be taken:

> *"Why do we need care? Why are we taking people out of their homes and communities, where they can be kept safe? Why do we need care in the first place?"*
>
> *"Māori are the most disadvantaged and then above that is Pākehā with disabilities. You really need to tear the system down and rebuild it. If we are the most disadvantaged, it should be by Māori for Māori."*

40. Some of us have worked in this space for decades. We have seen very little progress. Government agencies come to us and ask for solutions, but they never actually listen to us. When we do offer solutions and suggestions, we often come out of this process feeling humiliated, demeaned and abused. And when we are actually listened to, we are not credited for our ideas, they are simply taken:

> *"The stats from back then [1970's] are still the same now. If they haven't changed and they keep putting resources and solutions in, something's not working."*
>
> *"They say "you're the community, give us the solutions" and we give them solutions. In some way this is abuse, because every time we come up with a solution there is a built-in compromise. We don't tell them everything because we know that they don't understand it, or we tell them and they try to understand in their framework. All of the solutions get filtered through their framework."*
>
> *"We have to demean ourselves to explain what we're trying to get through to them."*
>
> *"Ideas generated from community and taken to government organizations are taken and not attributed back to where they came from. They could be developed as social enterprises. It feels very extractive."*

41. We would like to see the home care system redesigned. Needs assessors are not currently fit for purpose, and many of them have caused us harm in the course of their assessment. Self-assessments would be more appropriate, as

currently these needs assessments do not reflect our needs and the needs of our whānau:

> *"Self-needs assessment would be better for me! The needs assessment in [location], I had to spell my name out to her. She couldn't spell my iwi. So many assumptions were made, so many comments about how flash my wheelchair was, how lucky I was. I want them to get out of the way, I could do a better job than that person. I could do my own needs assessment. It didn't capture the essence of my whānau and what's important to us."*
>
> *"Even if they funded me the same amount tomorrow, their process is so mana diminishing. Why would I need somebody to write my story, they're the ones holding the pen and writing it in their words."*
>
> *"I don't know how they can define how to do a needs assessment on individuals. They just come in with a template. A template for discrimination against culture and colour. They need to change their policy. There are people who shouldn't be in these jobs. I already know how to help myself. I would rather do the job myself."*

42. Data access and quality is a substantial issue for us. The Government has no comprehensive, accurate records of Whānau Hauā around the motu. They also are seemingly unaware of the inequity of access to resources and support for Whānau Hauā. Whaikaha - the Ministry of Disabled People should do a stocktake of all packages given to Whānau Hauā, and consider the variables of location, ethnicity and age:

> *"I would put money on the fact that there is an inequitable resource allocation, purely based on ethnicity. We need this hard data to show it in order to reverse it."*

43. This resourcing issue is only increasing the equity gap for Whānau Hauā. We are the most disadvantaged, and layers of poverty and racism are intermingling with additional resourcing barriers to create even more negative outcomes for us:

> *"Many whānau will never be able to close that gap for themselves. We need better solutions. It might be that you must have different services*

> *and approaches for Māori. It might just be that we have a separate pathway for Māori."*

44. The Government should take a step back from trying to fix things for Whānau Hauā. They have no place in the development of solutions, as they actually create problems. The power imbalance is ever-present and creates barriers to effective solutions. They must resource us appropriately, so we are able to make change for ourselves. We have tried to work with them, but it is evident that that process is more harmful than helpful for Whānau Hauā:

> *"The first thing the Crown has to accept, is that they have no place in the solution. They have nothing to offer except a cheque book. It is our chequebook, other than that, they have nothing to offer. That has been proven over centuries. I don't want to wait until my great-grandchildren to see nothing has changed."*
>
> *"There will be mistakes, and disagreements, but the structure and core of te ao Māori, has the answers. The Crown is wanting to control it."*
>
> *"When you invite whaikaha Māori to share and talk about "partnership", it assumes there is a level playing field but there's not. It's lowkey tokenism."*

45. Enabling Good Lives ("EGL") is an example of a great concept created by Māori, for Māori that was pulled away by the Government and repackaged. Without Whānau Ora, it wouldn't exist at all. Now there is only one Māori principle of EGL, out of seven. It should return to the original vision of the concept, not what it has become.

> *"I think that the system tries to operationalize how people could have a good life."*
>
> *"They should have just kept it as whānau ora and treated us as whānau."*

46. If we had the choice, we would want a whānau-led system, not a disability system. We want to be able to define ourselves and determine our own outcomes, within the whānau collective structure:

> *"I wouldn't be in a disability system, I would be in a whānau system, give us the resource and I will be accountable, but get out of my way. The only option I am left with, is to be a high and complex needs woman. That is what the system tells me I must be to be resourced, but that is not how I see myself."*

47. Overarchingly, we want options. We want to choose our own care, our own destiny. We should be resourced, funded and supported to make our own decisions and design our own care and support structures.

Collective statement

This statement represents the views of the Whānau Hauā in attendance at the Royal Commission hui held at Papatūānuku Kōkiri Marae in Māngere, Tāmaki Makaurau, on Thursday 29 and Friday 30 September 2022.

This statement was drafted by Bennion Law as members of the Commission's Legal Assistance Panel. The purpose of this statement is to provide evidence to the Royal Commission in a format that can be made public.