

Whānau Voice 2023 Summary

Whānau Māori with a rare disorder and those who care for them



Background

The whānau we spoke with

Te Aka Whai Ora met with 21 whānau Māori who either have a rare disorder or who care for someone with a rare disorder. The engagements took place in September 2023.

Whānau we met with came from the following locations:

- Tāmaki Makaurau
- Ōtautahi
- Kirikiriroa
- Tūranga-nui-a-Kiwa
- Taitoko
- Tutaenui
- Te Papa-i Oea
- Ahuriri
- Wairarapa
- Te Awa Kairangi
- Ngāruawāhia
- Tauranga

Key themes we heard from whānau

- Whānau want access to Kaupapa Māori health services and health care that values and incorporates te ao Māori
- Whānau face barriers within the health system to be self-determining
- Whānau experience not being seen, heard, and respected within the health system
- Whānau have to fight for access to the services and supports they are entitled to
- Whānau experience a lack of cultural safety and competency in the health system
- Whānau Māori want a te reo Māori kupu to be used rather than the term 'rare disorder'

Positive experiences we heard from whānau

- We heard that allowing time for meaningful whakawhanaungatanga enabled positive and trusting relationships between health professionals and whānau
- When whānau received funding that met their needs, they experienced much needed relief.

Pātai we asked whānau

- What does it mean to you as Māori, to have a rare disorder or care for someone who does?

- What is important to you and your whānau for your hauora and why?
- What is going well for you and your whānau in terms of your hauora and why is it going well?
- What is not going well for you and your whānau in terms of your hauora and what could make things better?
- What is your experience of the health system as Māori?
- How does the health system provide for, or respond to, your cultural needs as Māori?
- If there was one change to the health system that would make the biggest difference for whānau Māori living with a rare disorder, what would that be?

Key themes and insights

Whānau Māori want a te reo Māori alternative to the term 'rare disorder'

Many whānau described a level of discomfort with the use of the term 'rare disorder'. We heard this most profoundly, but not exclusively, from parents of tamariki living with a rare disorder. Whānau want their tamariki to be acknowledged as the taonga they are, not by a term that is medicalised, and deficit based. An official Aotearoa New Zealand definition of rare disorders will provide an opportunity to change the narrative of how whānau and tamariki living with a rare disorder are viewed.

- "No different to any other child, she's a taonga. Our greatest joy our everything."
- "I think there needs to be something specially for our Māori whānau. Something positive. The language is very negative. Because it's medical. The word 'disorder' needs to be put in the rubbish. Because, you know, disordered from whose order?"
- "What I didn't do was let the disease determine my life. I decided the opposite, I would be the orchestrator of my life, not the disease."
- "So, it's just this is the disorder that the guy Williams found. Like what does that mean when you say, 'what's wrong with your son?' 'He's got Williams syndrome' 'What's that?' And you gotta go into the whole, it's like reliving trauma because it's like, 'they develop slow blah blah blah', instead of 'he's [tamariki]'. He loves everyone. Whereas Manaakiao [te reo Māori for William's Syndrome] it sort of prompts positive kōrero, rather than negative. So, I know language is very important to whānau Māori from my own experience."

Whānau experience a lack of cultural safety in the health system

Whānau spoke of experiencing a system with a dominant western clinical view of health, lacking in Māori cultural understanding and responsiveness. Whānau experienced this by interacting with a system which demonstrated little or no cultural understanding of Māori. Whānau spoke of the negative impact a lack of cultural safety has on health outcomes for both people living with a rare disorder and their whānau.

- “But being Māori, we quite often are very expressive with our emotions and let it out, but te ao Pākehā find it hard, and it can be seen as crazy, so the system doesn't allow you to be Māori and that's another barrier. So, it's expecting that you hold on to all of that emotion, you can't howl and express it and let it out.”
- “They've categorised us as Māori's that don't follow up and look after her teeth, this isn't about neglect this is because she has a rare disorder. I've felt that a lot that I am just 'another Māori family'. They judge us right from the beginning. That's not knowing who we are, not knowing [tamariki] history, not wanting to know ... dental needs are about the rare disorder not because she's Māori.”

Whānau described the importance of their whānau being an integral part of their support and the consequences for their hauora if this is not acknowledged and respected within the health system. Equally, there are examples of the positive impact for whānau Māori when the value of whānau centred care was recognised and implemented.

- “We always had to look a certain way at all times because we were Māori so we always had to dress the part look the part so we wouldn't be judged for being Māori.”
- “Māori or not its just common courtesy to get someone's name right.”
- “As a Māori it's been pretty poor actually. Pretty poor experiences. Back-to-back, I think right from the word go, right from childbirth actually, even giving birth straight through to diagnosis and being mistreated within the hospital system and it is there, the tikanga – there is nothing. There is no value to you as a Māori at all, your choices. As a woman and a Māori, they disregarded [me], the experiences have been pretty poor.”

Whānau want access to kaupapa Māori health services and health care that values and incorporates te ao Māori

Whānau identified the importance of the incorporation of a te ao Māori worldview of hauora, which includes karakia and whānau centred care. In the experiences of whānau a te ao Māori worldview was often unrecognised and undervalued in their health care journey. Whānau spoke of not knowing how the health system provided, if at all, for their cultural needs.

- “If I did know what there is, I might be able to take up on it.... But haven't been offered anything culturally.”
- “Not enough Māori health workers, [taiwi] who didn't understand even requiring a prayer or the cultural capability to look after us. But also, they don't want to.”
- “And so, there's a huge sort of urgency to ignore Māori ways of doing things based on what they [health professionals] might feel is more important. We experience this pretty much every time.”
- “[lack of] Māori services, thought coming back to New Zealand things would be way better. But in South Auckland there was just nothing.”
- “They [hospital kaimahi] didn't give cup of teas, they didn't acknowledge whānau, so they didn't offer me a cup of tea.”

- “I take probably about 20 to 30 pills a day, that’s no way to function it’s no way to live and I feel like that disconnect from my wairua, I've got all these pills on board but I can't explain it to my doctor, I can't explain it to my surgeon.”

Whānau told us that it was important that Māori are greater represented in the health system workforce and in the broader organisational environment encompassing the rare disorders community. This started with a need for greater Māori representation in the health and social service professions that whānau interact with across their rare disorders journey. For one whānau member of a person living with a rare disorder, this was the one change they would make to the health system to make the biggest change for whānau Māori.

- “On the heart ward but there isn’t any kuia or someone that would go around and talk about their experiences.”
- “Now that our local [GP] surgery has been taken over by ... a Māori organisation and now I walk in and there’s Māori nurses, Māori doctors. I honestly just feel so much more comfortable, and they make us feel like we're at home, you know, and it's just a totally different surgery and I love walking in there and them helping [tamariki] has just been amazing.”
- “Knowledge more knowledge and just being connected with other Māori like me.”
- “The day we arrived for the day of [tamariki] surgery the nurse we had was phenomenal, Māori herself with tamariki in kohanga. She made sure that we had everything that we needed she asked us if we needed to have karakia and made sure that there was a space available for us. She ensured that we were able to do it our way before [tamariki] went into surgery which was great because I got to oriori [tamariki] to sleep before the surgeons came so [tamariki] fell asleep in my arms and when [tamariki] woke up after the surgery [tamariki] woke up in their mother's arms. So, she was amazing so only mum could go in after surgery”
- “I would like to see more Māori representation in the hospital...Have someone who can kōrero Māori and can also represent the tikanga of te ao Māori.”

Whānau have to fight for access to the services and supports that are entitled to

Whānau spoke consistently of having to fight for access. Access to information relating to diagnosis, funding entitlements, and access to support avenues within the health system and wider social services. Whānau provided many examples of being given a diagnosis with little, if any, guidance and support from the health system. Whānau spoke of their exhaustion from fighting, pushing, and advocating for themselves and/or their tamariki. Whānau felt health professionals did not understand what whānau needed nor did they provide them with the information about what was available to support them with their needs. Whānau felt exhausted as a result of having to advocate across the system to access mental health support, skills and capability, and access to the right medications.

- “I just kept pushing, pushing, pushing, and then you have to lose the plot and get angry and have a hissy fit before things start happening and you don't want to do that especially for

Māori because we already get a bad rep about stuff like that, so you try and you know respect them as the professionals they are until you can no longer take any more of their nonsense and you know the taniwha has to come out to protect you in a way that you really don't want to."

- "Eventually we managed to push, push, and push again and I had to get assertive again and I would say, "I need something done and I need it done now." Then I feel bad having to talk about something like that but then I think about [tamariki] and she needs this, and I advocate for her. It's the wait time when you need it you need it now. If you leave things too late you miss the boat, she's already got delayed development she doesn't need delayed services. If I didn't push for everything she would have fallen through the cracks."
- "Like it's hard, you know, cause I'd be bawling my eyes out like 'help me' and nobody [did]. They'll just like, [say] you know, 'it's hard they [tamariki] don't sleep, they don't do this.' And I said, yeah, it's not that, though. Look at [tamariki] like someone needs to do tests or something. Like it's just not right, you know? So, we fought. We fought for a good year and that was the stressful time."

Whānau experience not being seen, heard and respected within the health system

Whānau want to be listened to and treated with respect. Whānau want to contribute to the solutions to meet their health needs. They want to be heard and supported throughout their healthcare journey. Not listening to, or respecting, the knowledge whānau hold in relation to their hauora too often resulted in poor experiences including increased wait times for diagnosis and increased stress placed on whānau. Simply allowing time for meaningful whakawhanaungatanga supported positive and trusting relationships between health professionals and whānau.

- "So, what's important to me for my own hauora is be taken seriously. How I'm to be seen is, you know a strong Māori woman, not a symptom, not a disease. I'd like to be seen as a person. That's really important to me now."
- " Everything is so transactional. Needs to be more about knowing her [tamariki]."
- "I know my body. I know what's right, what's wrong and I'm just gonna continue to hound you until you start hearing it as well [health system/professionals]."
- "Listen to the family no matter high up you are."
- "If they had just listened to me and understand my daughter the process would have been made easier."
- "It wasn't a good experience for my family, I don't think that he [Doctor] liked a Māori woman questioning his judgement."

Whānau face barriers within the health system to be self-determining

Whānau spoke about the barriers they face to access the key resources and tools that they need to be able to exercise their tino rangatiratanga in relation to their hauora. Whānau want to be informed, given the information about services and funding they are entitled to, access to Māori health providers, and trusted to make their own decisions including with funding. Whānau are having to become the specialist of their rare disorder while at the same time not being considered experts on their own hauora. Whānau told us about the challenges they have with flexibility and use of funding they receive for their tamariki living with a rare disorder. These challenges limit whānau to determine how and what is purposeful for the hauora of their tamariki. Supporting whānau to be informed enables whānau to exercise their tino rangatiratanga.

- “Knowing what’s available for you, I feel like a lot of the time you don’t know what you don’t know. If you don’t know what is available to you, you miss out or you’re spending that time to figure out what you’re entitled to. There’s so many steps. Knowing what is available to you. Managing and juggling different services.”
- “We get \$100 [for] a day respite. So that’s not even meeting a living wage for a carer. So that’s why we can’t find carers. So, \$100, so four hours at \$25, that’s not even going to touch the sides in actually being respite, because I’m so exhausted. I need a weekend, you know? But I can’t afford to pay someone that with my budget.”
- “Knowledge is strength. The more I learn the more I can put procedures in place for my whānau, but if I’m just me learning through Facebook or Doctor Google, that’s not right either. I need the knowledge properly.”
- “More acknowledgement that whānau Māori are the experts in their ways of doing things and that needs to be more overtly acknowledged. Otherwise, it’s just not really even being acknowledged at all.”
- “I find the whole funding process confusing. Funding sucks and is not enough. We need to have more control over it. Need to have a bit more openness to how we use it. Assessments every year. Needs changed [for tamariki] but they ignored it.”

Difficulty navigating the health system when living with, or caring for someone living with a rare disorder

Because of the nature of rare disorders, we heard from whānau that navigating the health system themselves, or whilst caring for someone living with a rare disorder, weighed particularly heavily on their shoulders. This often contributed to feelings of isolation and loneliness and feeling lost in the system. Whānau saw it as essential that they receive close support for their whānau in the direct aftermath of their diagnosis, but also guidance for the routinely long periods between specialist appointments, as well as assistance navigating the complex web of support both internal and external to the health system.

- “Apart from the medical part of things, when we were first told about [tamariki] diagnosis we got a pamphlet of what [tamariki] disorder was and then it was just a six-monthly check-up with [paediatric] doctor. It's really confronting because it is the worst of the worst and you see the pictures and there was lots of deformities, and it's too overwhelming. This is going to be my life of calling people up and chasing up for things that [tamariki] needed started. I wish there was help with your diagnosis: ‘This is it, what it means, these are services and here is a support person that could wrap around services for you’. Someone to reach out to you, like a pack ‘this is what you might need to help you’ would have been cool.”
- “You don't know what you're entitled to even like WINZ because they won't help you on this unless you know what you're going in for. Which is sad because a lot of people don't know about child disability allowances and all the support they can get through them. And that's something I find hard. Navigating that, navigating not only like the support things, but navigating the ministries, organisations as well is sometimes quite intense, even though you've got all the other stuff you gotta do with your kids, you gotta deal with the ministry organisations on top of and the Ministry of Education it is a quite intense process everywhere.”
- “So, you get a diagnosis and you go away with just the diagnosis. There's no education. You get referred for respite, which you can't use, but it's like, where is that manaaki post diagnosis especially for someone with a rare disorder?”
- “Looking back on our journey, there are some things that could have been done better and lots of it is about language. So, you get a diagnosis and you go away with just the diagnosis. There's no education. You get referred for respite, which you can't use, but it's like, ‘where is that manaaki post diagnosis, especially for someone with a rare disorder?’ Surely, if it's rare, there's not that many of us that need it. But where is that person who is there to awahi you? Because every parent feels this grief. Because it's actually like a death. Because it's the death of your preconceived aspirations. And it's to come with some kind of hope or lived experience. I would like to see an e-learning module. ”
- “You don't know what you don't know. Having to find things yourself, ‘asking can we get this?’ It's very tiring, you don't know what [your child] is entitled to. Eventually got respite care, turns out she was entitled [all along] for respite care. There is a lot of explaining if you want more. It felt like you were taking from [their] personal wallet.”

Many whānau told us that there was a general lack of up to date and reliable information, resources and expertise around rare disorders that left them feeling unsupported. There were many examples of whānau having to use alternative sources to obtain information on their or their whānau rare disorder diagnosis, largely from the internet, in the absence of specific support or specialised knowledge from health professionals.

Whānau described situations of where they have had to become the expert of their rare disorder or whānau caring for someone living with a rare disorder due to the lack of knowledge and support around their conditions provided by the health system. Whānau routinely spoke about

the lack of support that they were given when they were diagnosed with a rare disorder. For example, one māmā explained how it became a trial-and-error process of figuring out for themselves what was best for their tamariki with a rare disorder, whilst give very little information from health professionals.

- “The other thing that's important to me is having access to doctors that understand the disease you know, and having that knowledge at their fingertips, that's important because otherwise that's what helps create that misdiagnosis and people waiting years before they're actually being diagnosed.”
- “The hardest thing was the paediatrician. There, you got the diagnosis, but basically nobody knows what the diagnosis is. So, for us to get help with helping [tamariki], nobody knows actually what is going to help if that makes sense because it's so rare that they're just basically printing a form off the Internet and saying this is what [tamariki] has got, we'll give this a go or we'll give this a go, but we don't actually know what's really going to help [tamariki] in the long run, and I think everybody's struggled with it.”
- “There's no one to help us proceed through to the next step. And I guess we just always sat in the grey area where we just didn't know what was happening and you know the whole situation, we just felt lost.”

At times, whānau feel isolated and lonely

Many whānau, particularly parents of tamariki living with a rare disorder, experience feelings of loneliness and isolation. Whānau spoke of the impact of diagnosis resulting in parents, often māmā leaving careers and paid employment to provide full-time care for their tamariki. We heard of the impact of parents, often pāpā, working long hours and sometimes away from the whānau, to provide financially while māmā provided the full-time care for their tamariki. We were told of the impact and strain this had on relationships within the whānau. This kōrero reiterated the importance of whānau centred care within the health system.

- “Sometimes it can be really lonely because it's a rare disorder...It kinda feels like a grief process. You're handed a pamphlet and you're off. People don't understand exactly what you're going through.”
- “Really hard like on our marriage cause you know [pāpā] has to work and do what he needs to do to support us. No, I think like it just puts so much pressure on your family.”
- “You feel isolated and sometimes we just want to give up.”
- “It's changed our lives completely. I've gone from someone that was really, confident, you know, working hard. Making a living, and we really were very social people. Like our lives were completely different.”
- “Financially we are reliant on husband who is working [overseas], which has taken a huge toll on our relationship. Not an easy choice for him to return. He's home five days every fortnight. But this has been our daughter's whole life.”
- “I couldn't work because I couldn't put baby into care for more than a day. All financial commitments were put on my husband so I could care for my daughter.”

Whānau identified opportunities of how the health system could better serve Māori living with a rare disorder

Whānau identified opportunities to improve experiences, including: a centralised service for rare disorders in Aotearoa, e-learning modules, and other learning opportunities for whānau to ensure whānau are aware of support networks, research, and funding entitlements.

- “We need a place that we can go to that addresses the rare disorder. Need a place that can show that manaaki.”
- “A New Zealand Rare Disorders Centre of Excellence.”
- “Some people involved in any way with rare disorders whānau is that they be trained to support that whānau. Also training for carers as well. It's hard when whānau have no free training services to help and grow the whānau as well.”
- “Some sort of centralised but New Zealand specific resource for the health providers to support them to support us [the whānau] with pathways and some links to international expertise.”
- “E-learning module provided at time of diagnosis with all the information whānau need; including entitlements and support groups.”
- “I'd love a one stop shop with stuff about what support is available or what things might be useful for your particular disorder or disability.”
- “She was born for something, if we can change things now for those people who can't do this, there has to be a centre, it just has to happen.”

Whānau want health professionals to have greater understanding of te ao Māori, greater representation of Māori health professionals, and whānau centred practices embedded in te ao Māori. Many whānau believed these solutions would make a positive impact on their, and others, journeys across the health system.

- “Once the professionals knew about the diagnosis, there could be a way that would bring in tikanga in support the way your being told or a nice way to tell whānau. Bring hope to the whānau in uncertain situations, a way that we could bring in tikanga Māori.”
- “I would like to see more Māori representation in the hospital. I would like to see more Māori in the hospital. Have someone who can kōrero Māori and can also represent the tikanga of te o Māori. Or even just the space a big enough space for all of our whānau to be there, for the surgeons to be able to tell all of us at the same time so we could all feel that together.”
- “Well, if I just turned the hospital into a marae then we would all be there. . . we could all stay, they would have all the tohunga and other experts that we need that will just be all there. It's totally inclusive. It's all about kotahitanga, whanaunatanga, about looking after each other, no matter who it is, at the right time or when they need it. You are always connected. You are never alone. It's all of those things. You can go outside. You can have a rahui and shut the doors. Always open. You come and go whenever. If we had a Children's

Hospital in [in the South Island] that could have happened, but there's only one in the country. Everyone could be there all the time."

- "Seeing Māori representation and having that space for whānau is really important and the key things I would like to see."
- "I think my biggest thing is understanding who we are as a culture to give us the best support. That's understanding that every rare disorder is different, it's understanding that it's not only about the person with the rare disorder but the whole family. That's one of the biggest things as having the group of knowing what you can get, knowing where you can go, knowing what supports are out there. That is huge. Half of the time we are fighting 24/7 just to get anywhere with the information we do have."

We heard repeatedly of the benefit having a navigator or connector would provide to whānau across their journey. Whānau believed having a person to support, awahi and guide them combined with improved coordination of care would greatly improve the experience of the health system for whānau Māori living with a rare disorder.

- "If I had someone supporting me at the journey it wouldn't have been so isolating and lonely journey. If you had someone to come and wrap around you then I would have to only deal with emotional needs."
- "Create heaps of funding available to have Māori paediatricians, psychologists. You know what is it, Teach NZ for Māori teachers? We need Māori paediatricians and psychologists."

Whānau talked about the difference it makes when they have better access to funding

- "...descale the amount of processes that enables parents to do what they want to enable their lives. I think any process, if you just set the general goal for your child, or for whoever, and that sometimes you could get to a boiling point and you just need access to some funds to maybe pop out to the zoo or to do something that's spontaneous but aligns with that person's goal. I think if you can descale any of the paperwork that they can give you the funds quickly, I think that's really good."
- "Respite funding to a wage that is to an amount that we could actually employ carers that wanna do caring. And a connector post diagnosis for that grief."
- "I'd like all the paediatricians to know if you get someone with rare disorder, Māori or non-Māori, they need some education on, 'what are you entitled to?' Because it's kind of like not gatekeeping, but you don't know what you don't know. And they're not really forthcoming. So I was lucky that I work in disability and people were like, "you can get this and do this and do that. These are your rights."

Positive experiences of the health system

While whānau living with a rare disorder detailed some significant challenges and barriers in the health system, whānau also spoke of the positive impact some of the most simple interactions

and gestures health professionals demonstrated. These are learning opportunities for the health system to build on to improve whānau Māori experiences of the health system.

Whānau provided examples of being respected and heard by health professionals. This occurred through health professionals valuing whakawhanaungatanga and ensuring adequate time was provided for this, their interactions with Māori health professionals, and connections with other whānau living with rare disorders. We heard that allowing time for meaningful whakawhanaungatanga enabled positive and trusting relationships between health professionals and whānau. Whānau spoke of the positive impact on their health journey through the building of good quality relationships with doctors and care teams.

- “Cardiologist and surgeon are warm, ngakau, respectful, they walk you through things, they draw diagrams they treat people how you would like to be treated. Taking the time to be present with me and the whānau, they have a gift that makes you feel like you're being heard. They communicate in a way that they don't leave you feeling unclear. Allowing us to do karakia before surgery, impacts are huge it builds trust, make us feel at ease. The team are angels that work at a high calibre.”
- “They [health care team] walked in and introduced themselves to our family. They would also say [pāpā] introduce us to your family. If a doctor walked in they would walk in and know our names. He [pāpā] would say ‘who are you what do you want’ when they just walked in without introducing themselves and asking about us [his whānau].”
- “They contacted me because I ticked Māori on one of the forms or something. She just talked to me about different options, which I thought was amazing, just to have that. So, when I get things like this like amazing, it's like ohh yay someone else that can help in different ways you know.”
- “I've got lovely doctors ... my specialist is a lovely joker and good friend. Your stay in hospital is always made better if you have good nursing staff and good doctor. Someone who is passionate about their jobs. There are so many doctors who are basically overworked and underpaid, and it shows in their presentation, and I go, no, no, no, don't fob me off I want more than five minutes of your time. I try not to dwell on the bad, I try to focus on the good.”
- “For me it means a lot of cultural understanding in that arena as well and that they make that effort culturally to make sure that that's being respected, which it was, and that we had that time with her with our whānau to come together and that we have enough time for karakia because that means a lot. And respect I guess.”
- “..and there was another one [nurse] who came in after, she was the theatre nurse who was non Māori but she was very nice and very clear, she gave me nanny vibes ... very obviously loved her job and loved caring for people and she understood how we would be feeling with our baby going into surgery so she was very compassionate so she was more person to person rather than culturally the first nurse knew what we needed culturally.”

When whānau received funding that met their needs, they experienced much needed relief

- “Respite funding has helped. Being able to get things for myself, going to get a massage, me and my partner going to Queenstown, having time for ourselves. Time going away to enjoy and to fill our cup. Slowly started to get time back to myself and learning to manage my life easier. Makes a difference to your flow of life.”
- “Funding has made a huge difference. Can fly my mum here to look after [tamariki] so that I can go to noho marae and mum can look after her.”
- “I have really been impressed, with Enabling Good Lives. But I'm really hopeful and really enthusiastic about where the funding is shifting. So [redacted] is quite slow to shift but we have more individualised funding. The way I see it as sort of trusting whānau to be able to make those decisions themselves, and for me personally, in the past few years I haven't had to fight as hard to be trusted with making good decisions. In the past we had to really fight to get any kind of funding so we're quite familiar with how difficult it used to be. . . so seeing this shift is really nice”.
- “EIF [Enhanced Individualised Funding] funding from Ministry of Health. Always for respite for me or my daughter. I can get a carer for me to have a break.”

