

**IN THE WAITANGI TRIBUNAL
HEALTH SERVICES AND OUTCOMES KAUPAPA INQUIRY**

**WAI 2575
WAI 2109**

IN THE MATTER of the Treaty of Waitangi Act 1975

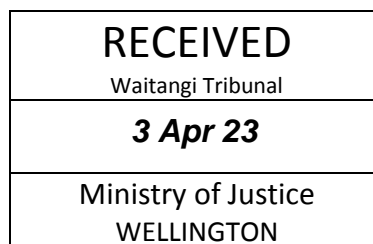
AND

IN THE MATTER of the Health Services and Outcomes Kaupapa Inquiry

AND

IN THE MATTER of a claim by Maaka Tauranga Tibble for himself and on behalf of all Kapo Maori (Maori blind, vision impaired and deaf blind persons) and their whanau and Kapo Maori Aotearoa/New Zealand Incorporated (Wai 2109)

SUMMARY OF BRIEF OF EVIDENCE OF NATASHA JOY SWANN



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MAY IT PLEASE THE TRIBUNAL

I, **NATASHA JOY SWANN**, of Hamilton, say:

1. I am an Executive Member of Te Kahui Tumuaki of Kapo Maori Aotearoa (KMA). I am also the co-leader of Nga Roopuu O Manaaki Taangata Kotahitanga (MTK). The name of our roopuu reflects our vision 'People helping people however possible, acknowledging that impairments don't define who we are and uniting the Kapo community together as one whanau'. Our purpose is to work with KMA to ensure a young voice is heard by sharing our ideas and opinions to help improve services and to work with KMA to make the world more accessible for all those living with a disability, nga Tangata whaikaha o Aoteraroa.
2. I was born with a rare syndrome called Klippel-Trenaunay-Weber Syndrome. Due to the rarity of my syndrome it is unknown why I have vision loss. I was told from a young age that my vision will deteriorate as I get older until I am fully blind.
3. I have been to many schools across the motu. It was very hard to adjust and get used to being in the school because I never knew how long I would be there before I had to move again. Adding my disability into the equation made it even harder for me to navigate the school and make friends. Living with my brother, he got me a push bike, but I had so much equipment, it got to the point where I had to get up early and walk 45-50 minutes. My teachers always singled me out and treated me differently. I was always put at the front of the class in front of the board by myself to help me "see" the board, well that didn't help. As a result of my poor schooling I fell behind in class a lot and never actually graduated.

EXPERIENCES RECEIVING HEALTH AND DISABILITY SERVICES

4. The services I have used to date are from CCS Disability Action, Blind and Low Vision and KMA. Throughout High School I was granted special equipment like laptops and cameras funded from BLVNZ. The main thing I received from CCS is a mobility card for parking due to my lack of mobility.
5. When I was younger we used to have events organised by CCS and the Blind Foundation, like Olympics for disabled people and blind camps. There were just

fun things with other disabled people and it was like a community. But when you become a teenager you age out of everything and they don't do them.

6. Moving around the motu a lot throughout my life has affected the accessibility of the services I have received. From living on a farm to living in the city, the travel time to services has differed. I have not received subsidised transport to date. However I recently received a free bus 'Accessibility Concession' card for bus services in the Hamilton region which is paid by the Council.
7. The health and disability services I received as a child did not meet my needs. My education failed as result of disability services not providing the adequate resources and supports I needed to complete my education. With moving around the motu, you have to register with the new CCS and Blind Foundation. When you leave a school the equipment gets returned so when you get to the new school you have to apply for the new equipment and then it's too late. Each time I moved I did not receive my appropriate equipment I needed to help me with my schooling until half way through the school year. I should have been given my school equipment from day one. Just because I have an impairment doesn't mean I need to wait half a year to have the equipment. As a result I did not receive my literacy and numeracy credits or my NZQA certificate and now struggle to fill out forms and documents such as medical forms and beneficiary documentation.
8. My experiences dealing with health care services have been both positive and negative. My negative experiences would be when people speak to me slow like I am "dumb" or in general just putting me down telling me "I cannot do things because of my disability". For me I use that to push me to do things that people would otherwise tell me not to do. I really dislike being told "you're blind you can't do that", that to me is like saying "oh I'm blind so I shouldn't live on my own or cook on the stove top". Also people wouldn't talk to me, they would talk to my guardian at the time which would frustrate me too. They should talk to the patient. Going through services with CCS I was initially talked to slowly due to incorrect files saying I was intellectually disabled. But whether I am or not, talk to me like a normal person. People in general need more education about talking to people with a disability.

9. I find out about services through word of mouth and whanau. My GP also refers me to services if need be for my health like dental care specialist as I cannot just rock on up to any old dentist due to my syndrome.
10. Due to the rarity of my syndrome my health care services find it difficult to navigate me in the right direction and provide adequate health services. The barriers I have experienced have varied in difficulty. For me catching a bus is a big barrier as I cannot read the number on the front of the bus, so I have to stop every bus to ask their number. I have come across some very angry bus drivers who have called me a "nuisance" for stopping them, then proceeded to speed away. The lack of doctors is a barrier for me. Waiting for specialist appointments is a big barrier as it can be months after a referral my GP has sent the hospital before I receive an appointment.
11. When I first lived in Taupo I was a young teenager. I got my first job and that was pamphlet delivery and that was horrendous. I only lasted a couple of months. Having a disability adds the extra burden when having to do a simple job. I didn't have a choice, having a disability you have to figure out your own way of how to do it, you can't ride a bike because you might crash into something and it's just an extra burden to add onto the disability already and what you have to do to earn your own pocket money and have your own job.
12. I have received Maori health and disability services from KMA who have gone 'above and beyond' to support me when needed. I do not know of any Maori health and disability services, the only one I know of or registered with is KMA.
13. Due to the lack of literacy skills I have, I have not formally written a complaint to a health or disability service provider. I would have to get help from whanau. While I have wanted to write a complaint in the past, I cannot remember who it would have been to or what it would have been about because I block a lot of those experiences out of my mind. However I have verbally given a complaint about a health and disability service before. It was back in the day with CCS with one of my coordinators and the fact that they were a family relation so there was a conflict of interest. I should have been referred to someone else. And she just wouldn't turn up for appointments. She would say we're going here and I would get a phone call later with excuse after excuse. She was using her family relationship not to provide me services. I think she lost her job in the end.

14. I am also in the process of complaining about a doctor that verbally abused me recently in front of the reception full of patients. I've been acting on behalf of my mum and stepdad. Their benefit was getting cut off because they needed a reapplication and a medical certificate to say they still need to be on the benefit. The benefit got cut off on the 5th of January but the doctor's office was closed until the 17th of January so I went there that morning. You are supposed to line up because it's on a first in first served basis, but I couldn't wait in line. My mum is unwell so I had to organise someone to watch her and they could only watch her for an hour and I also needed someone to drive me around so I couldn't just come back later. So I rocked up to the doctor's office and explained my situation. The receptionist took the forms and gave them to the doctor and he filled them in but they hadn't been backdated. The receptionist told me to wait for the doctor to come out in between appointments. I was waiting there for 30 minutes with my stepdad and when he came out the doctor said to my stepdad "there's nothing wrong with you". My stepdad is special needs and can barely talk, he doesn't have much cognitive function. The doctor said "you aren't getting anything from me, you're joking, it's a joke and you can go now". He then walked off when I was talking to him and said "what do you Maori's all want from me". The receptionist apologised on his behalf. Just because someone is Maori, don't treat people like that. He knows I'm disabled too because I have my cane. While I didn't book an appointment, I think under the circumstances I could have been given priority as I couldn't come back.
15. We have had other negative experiences with this same doctor. A month ago my mum went in and the doctor said that there is nothing wrong with her and she isn't going to have a heart attack, and then a couple of weeks later she had a heart attack. I had to get all her doctor stuff to get the benefit, they didn't care that she was in hospital, they just wanted it. The doctor also is supposed to give each patient 15 minute time slots, but in the past has only given my whanau 5 minutes each. As a free doctor patients shouldn't be treated like that. I feel like the doctor is abusing his power and also the fact that he is free.

MTK REPORT

16. Attached and marked 'A' is a report written by MTK with our lived experiences in which we presented to the Hon. Carmel Sepuloni (Minister of Disability issues)

in April 2021. Although this report was not prepared for the Waitangi Tribunal, it contains information relevant to health and disability.

RECOMMENDATIONS

17. Being Tangata Whaikaha we get asked for our opinions but they don't appear to take our advice. We often have the experience of not being listened to.
18. I would like the Crown to let Tangata Whaikaha have their say and actually listen to and act upon what we have to say and offer.
19. I would like to see more funding and resources for Maori based health organisations and disability organisations like KMA so that Tangata Whaikaha have more support. I also think there should be education for Tangata Whaikaha so they know about their rights and how to go about a complaint if they face a negative health and disability experience. Disabled people need to know there are people you can talk to and go to with a complaint.
20. I would also like to see the public health system be educated on how to approach Maori and disabled Maori. Being Maori you already have a disadvantage and then you add on the disability and we are disadvantaged twice over. I think the general public health systems should talk to disabled people as people, including the double disadvantaged within the health system.
21. I would also like to see more fun events organised by low vision organisations for teenagers and adults. It would really improve the mental health of Kapo Maori as events are an important way to socialise and share stories and it would help towards MTK's vision of uniting the Kapo community together as one whanau.

Dated this 18 day of February 2022



Natasha Joy Swann