

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

**WAI 2575
WAI 2109**

IN THE MATTER of the Treaty of Waitangi Act 1975

AND

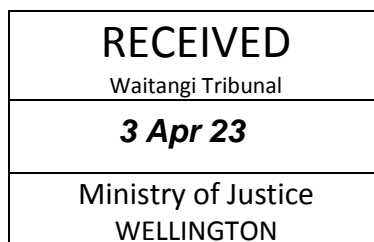
IN THE MATTER of the Health Services and Outcomes Kaupapa Inquiry (Wai 2575)

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 ANDREA KATHLEEN LAMONT

Dated: this 17th of February 2023



Rainey Collins
Solicitors
Level 19,
113-119 The Terrace
Wellington 6140

Counsel: P Johnston

PO Box 689
DX: SP20010
Telephone (04) 473 6850
Facsimile (04) 473 9304

I, **ANDREA KATHLEEN LAMONT**, of Christchurch, say:

1. I whakapapa to Ngati Awa and Ngati Mutunga.
2. My son Tyler is 29 and a half. He has cerebral palsy, hydrocephalus with a VP shunt and uses a wheelchair. He is blind in the right eye and his left eye is vision impaired, although he is able to see a little in that eye. He is on the spectrum for autism.
3. I started losing my hearing in 2019 and then began losing my own vision last year.

OUR JOURNEY

Tyler's experiences

4. Tyler was born at 26 weeks, 3 months premature. He weighed 1300gm. I had manual labour with no medical intervention. Tyler spent three months in neonatal.
5. I believe they used Tyler as a guinea pig. They trialled medications on him, they recorded in his notes that they had asked me and I had said no, but they did it anyway. They also told me he would not live, so I put in a Do Not Resuscitate (DNR) order. But they did resuscitate him. I asked why they resuscitated him and they said they wanted to see what would happen to him. And later they told me he was going to be a vegetable and after that they wanted to turn off his life support again. I told them no.
6. After Tyler was resuscitated, he was put in an old incubator in a corner. He needed a blood transfusion, but was not given that for three days. His blindness, which as a neonatal should have been checked, was not. He didn't get an appointment until six months.
7. I applied to ACC for Tyler many years ago because they had pressured me to put in a DNR order, but then they did resuscitate him, which was when the brain damage started. The ACC claim was declined – they came back and said that I had walked off the street fully dilated, and the hospital didn't have enough time to care for me and give me the injection to stop the birth from happening then. This was not correct. I was on the labour ward for about two hours before I was admitted. I had also gone to the doctor earlier that day and the doctor got me a blood test, told me it was just flu, and to go home and rest.

8. After we left the hospital, we had physiotherapists, occupational therapists and social workers visit our home.
9. The services provided were about what they perceived Tyler needed. When you thought outside of the realm they (e.g. occupational therapists) didn't understand, you wouldn't get anywhere. They perceive what they want with him. We would have to bow down. For example, Tyler got a wound on his bottom and it took three years to get him a hoist. He had to stay in bed and couldn't sit. He spent a year and a half lying down in bed and not sitting, because the occupational therapist wouldn't sign the papers.
10. We've had good times and bad times when it came to the care received. It depends who your key worker is. And you didn't get a lot of choice in that back then. You sometimes got people providing support services who were pretty loopy, some absolute nightmares. I had to get the Police on some of them. You got abuse in your own home.
11. Tyler got lots of tests up to the age of about 14 or 15 and was then treated as an adult. From adulthood, you have to find out what services are available, then you have to advocate for them. The expectation became that now Tyler should be able to make appointments, but that's not his thing, he doesn't know technical terms.

Education and disability supports

12. Tyler attended Conductive Education from two and a half years. It was Government-funded, but not through the Ministry of Health, so when we started going there, we were cut off from other support.
13. For schooling, ORS (Ongoing Resourcing Scheme) Care did not meet Tyler's needs. There were levels – for high needs, you would get \$5,000 a year for a support worker and for very high needs it would be \$15,000. When Tyler was at school, there was another boy who was non-verbal and it was a choice between him and Tyler. It was like a lottery draw.
14. Tyler was in conductive education until three years into high school. He was doing well at conductive high school, he was advanced in every subject, but when he went to mainstream school, they pulled him out of class. They placed him in a

unit with others with similar conditions to paint fairies. They were adults, but they were treated like kids, they'd be all vegetating. The services provided to Tyler have definitely not catered to our taha Maori. Our belief on how you look after babies or anyone is so different. Back then, from when Tyler was a baby there was no taha Maori in the health and disability system. It felt like if you're Maori, they don't give a toss. I reflected back on the care received and in comparison to how others, non-Maori, were treated – we were sort of shunted out. They had the expert care, the on time care, and weren't left alone. At the time, there was just so much stress, people were always in our home, so I didn't really think about it. There is still institutional racism going on today.

These days

15. Tyler is now in a residential care facility. The support he receives is still under Enabling Good Lives but now that he's in a facility, he no longer gets as much funding. If you complain, you're punished by the supports not being sent in. We get the same issues as previously, before Enabling Good Lives came in – we ask and they say no. Now it is such a struggle to get anything really.
16. When Enabling Good Lives started, we were all in the same room, parents and providers, so we got the same idea of how things roll. Now, we are back to separate groups – no one knows what anyone else knows. I think it changed because people were starting to struggle, especially newer people who couldn't manage the paperwork and employing people. So they introduced service providers back in. These providers have different information, different to what we were trained for, so we are battling against the system.

My experiences

17. I started losing my hearing in 2019 and then began losing my own vision last year, due to a thyroid issue. The hospital picked up that I had had liver issues since 2019, but my GP didn't get on top of it. It was only last year when I went into surgery for something else (a cyst) that I found out.
18. I think the issues have arisen due to the stress of not having money and having a child with disability. I have been overexerting myself to keep up.

19. I've got three departments I'm going to (ENT, Thyroid, and Eyes), and not one of them is talking to the other.
20. For the first six weeks when I lost my sight, I basically couldn't see anything. My quality of life now is not good. Every day things are really limited now.
21. I received assistance as Tyler's carer to get hearing aids, but my condition is not bad enough to get help through health and disability services. I don't receive any supports; I still do my own cleaning and mow my own lawns. I have not really received information about support I might be eligible for.

Kapo Maori Aotearoa

22. Kapo Maori is whanau inclusive. You make friends, they become part of your whanau, it is extended. You can go to a KMA conference and you don't have to explain who you are – you are just welcomed. KMA would fill us in with what was happening around the country, who does what, so you were kept informed all the time. If something good happened, you'd hear about it too. It was nice to hear some positive things have happened in people's lives.

REMEDIES

23. The basic thing is about listening to us. I've done a lot of Ministry meetings, and you give feedback, they take notes, but then those are not followed through on. That's really frustrating. People in the disability space have been working on what the system should look like for 30 to 40 years, but they are not being listened too – it is just a cycle that is going to continue.
24. For example, with the new Ministry of Disability, I believe it is going to be the same process. It's the same crowd of people working with the Ministry. They are going to forget about our children – they often don't have children themselves, they don't know the struggles. They've all been to university, had a good education, and received good services. Our children have not had that. They are not catering to all needs. There are also no parents of children with disabilities involved with the new Ministry, as far as I am aware. Enabling Good Lives was meant to make things better, but lots of people had to go into care, as the system was broken. Having control meant you didn't have to jump through hoops, but

lots of people struggled with the system, so support agencies were re-introduced. But that means you are back to the old system.

25. We were lucky when we started out, we had a good coach. It was an initiative in Christchurch for about three years, but it doesn't happen anymore. Now, the navigators don't come in and help you. Parents are exhausted and if support workers don't turn up, it's on you. From 2001 to 2006 or so, parents used to be invited to conferences. You didn't have to pay to go. Now you have to pay out of your child's funding. Lots don't have excess to do that. Funding will pay for a support person to go to training, e.g. CPR, but you cannot use it for yourself as a parent.
26. We need a one stop shop with everyone on the same page with no different tiers and different systems and changing rules. People have been screaming for that for 30 years. For example:
 - (a) If you look on the Ministry of Health website, it says we are here to help but not what you are entitled to. They should have it all on one website, or at least pathways to support.
 - (b) There are Ministry meetings, service meetings, and parents meetings – these should be all together so everyone is on the same page.
 - (c) Funding is not the same over New Zealand. There are the Ministry guidelines, but then a service provider has their own ones. We adhere to the Ministry stuff, but then funding goes to a business, and they may not adhere to those regulations, so it gets very complicated. I tried to get my benefit renewed, and it took two weeks to get hold of them. You ring up, they tell the branch to ring you. It is the same with disabilities – you ask, then wait for reply, then it is up to the timing on their behalf, and by the time you have the okay, sometimes your funding has run out – that's happened to us. With all the excuses, you run out of steam after a while. We have to follow the guidelines and the rules, but when the people above don't, it knocks you back.