

**IN THE WAITANGI TRIBUNAL**

**WAI 2575  
WAI 2624**

**UNDER**

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 David Ratu (Wai 2624)

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**SUMMARY OF BRIEF OF EVIDENCE OF DEB COLE  
DATED 11 OCTOBER 2021**

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**RECEIVED**

Waitangi Tribunal

**11 Oct 2021**

Ministry of Justice  
WELLINGTON

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## MAY IT PLEASE THE TRIBUNAL

*He marama nō mamaru, he kongakonga nō Ngatokimatawhaorua  
He puehu nō Pūwhere, he tambara nō Motatau  
He iti pioke nō Rangaunu, he tukau nō nga pukepuke rau  
Koia rā ngā pou tūpuna ko Kabutiānui, ko Hineāmaru  
Nō wāi abau? Nō Ngāti Kabu, nō Ngāti Hine  
Ko Deb Cole abau*

1. I am the second eldest of 8 wāhine toa, mother of 5 and nana of 20 not including my nieces, nephews and their children who are mine as well.
2. I became the full-time carer for four of my mokopuna when they were eight-months, two-years, four-years and six-years. That was in 2005. I refer to my mokopuna as ‘T’, ‘J’, ‘H’ and ‘P’ throughout my brief.
3. Two of my mokopuna have been diagnosed with fetal alcohol spectrum disorder (FASD), ‘H’ and ‘P’.
4. My full brief of evidence discusses my haerenga with my mokopuna and how their experiences with FASD have affected them, our whānau and myself. I also discuss the issues with the government approach to FASD and my vision for the future for tamariki affected by FASD.
5. In this summary I have included the brief critical observations that I have made. My full brief is over thirty pages so this only provides a small insight.

### **The critical information**

6. FASD severely affected the life of my two mokopuna:
  - a. My mokopuna ‘H’ is now 19. She has severe behavioural issues and violent outbursts that started at a young age and

still lasts to this day. She was not diagnosed with FASD until it was ordered by a youth judge at 14 years old. She began disappearing at around age 13 and was sent to youth jail at 14 years old for committing grievous bodily harm. Today she is living in a motel as she is unable to live at any whānau homes due to her outbursts. It is her fifth place in the past 10 months and she is continually on the verge of being trespassed and being homeless; and

b. My mokopuna 'P' is now nearly seventeen. He was only diagnosed because I pushed him for a test after he started having run ins with the police. He also had a lot of behavioural issues and has been unable to stay in school and finds it hard to be in employment. He has been out of school and work mostly for three years now and is I believe slightly illiterate. He was getting into a lot of trouble with police at a younger age but has straightened himself out. However, he has been kicked out of home and is on a youth benefit.

7. FASD is permanent and people with FASD will require assistance from minimal to residential for their lifetime which means:

- a. They should not be subject to Government changes and policies but should have security for all their life;
- b. They should not be subject to changing definitions of what benefit they may be eligible for; and
- c. They should not be seen as 'disabled' but given all assistance to be valuable, contributing members of society.

8. Whānau supporting/raising a person with FASD require support: financial, respite, education and health.

9. Whānau supporting/raising a person with FASD need to have their knowledge and support affirmed and acknowledged by

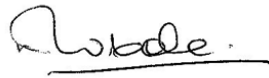
Services as contributing to the overall health and welfare of those in their care.

10. The pressure on married couples who have children with FASD is intense. Whānau often reach out, knowing something is wrong. They are told that there is nothing wrong, that it is a behavioural or mental health issue that is up to their parents to fix.
11. A lack of recognition of FASD and its associated problems means:
  - a. Service providers use measuring tools and guidelines designed for 'normal' neuro-typical children. This is like trying to fit a round peg into a square hole, leaves children misdiagnosed and whānau disenfranchised from society increasing their isolation;
  - b. Services provide short-term intervention e.g., 20-weeks mentoring, 6-weeks counselling, medication, with the misguided understanding that the problem will be fixed: FASD is a permanent, lifelong disability, it cannot be "fixed", it must be supported and accommodated. When that happens, the person with FASD can thrive and grow to their potential; and
  - c. Whānau employment – I had to give up my well-paid job to care for my mokopuna. That drop in income had adverse impacts on our household and contributed to my isolation and eventual break-down.
12. I went through a lot of problems with my whānau and my marriage due to the strains of caring for my mokopuna:
  - a. My marriage of 32 years ended in divorce;
  - b. I was left with the children;

- c. I had to sell our whanau home of 25 years which meant that the safe place for my children and mokopuna to come and stay, was gone; and
  - d. I had to go renting and went into financial hardship because I was living on my credit cards.
13. I became the full-time caregiver for my mokopuna affected by FASD. This meant:
- a. These mokopuna lost their 'nana' and gained me as an 'old, grumpy mum';
  - b. My other mokopuna lost their nana because I had so little time and energy to spend with them;
  - c. What energy I had was spent on these children not myself or my children or other mokopuna;
  - d. I felt isolated from 'normal' adult company and conversation;
  - e. For a while my alcohol consumption was elevated;
  - f. I had a nervous/exhaustion collapse and was ordered to seek psychiatric help;
  - g. I received no respite care/breaks from caregiving; and
  - h. Paid privately for therapy session for years for H, my mokopuna.
14. My experiences dealing with Education, Social Services, Police, Youth Aid, High Court, Rangatahi Court was traumatic and exhausting:
- a. Endlessly telling the same story;
  - b. Having these services sift through our whānau history over and over again;
  - c. Endless recommendations from different groups to attend parenting courses – which I did but they were not helpful; and

- d. Being told the extreme behaviour exhibited by H did not meet thresholds of risk thus being denied urgent support and intervention.
15. Lack of awareness and education in every sphere of society makes for: desperation, hopelessness, powerlessness, frustration, anger and depression.
16. There is a lack of awareness and education across all service providers:
- a. Service providers rely on out-dated systems of assessment and analysis resulting in misdiagnosis;
  - b. Paradigms of thinking, assessing, and responding create a 'one size fits all' mentality resulting in mistreatment; and
  - c. FASD persons and whānau knowledge is discounted and diminished.
17. Whānau led approaches are the way forward because:
- a. They have worked with and can identify the issues;
  - b. They have worked with and can identify some of the solutions; and
  - c. The 'one size fits all' approach of Government has shown this approach not only doesn't work but is systemically racist and victimises further those who are the 'victims'.
18. My dream for those with FASD is a marae type residential setting with housing and several small studio spaces available. FASD children are referred there, especially if they can whakapapa back to where these marae are based and enter a programme. It should be noted that most people with FASD will need supported living for the rest of their lives, so it is what can we do as a community that is important.

**DATED** at Auckland this 11<sup>th</sup> day of October 2021.

A handwritten signature in black ink, appearing to read "Deb Cole", is written above a horizontal line.

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**Deb Cole**

To: The Registrar, Waitangi Tribunal and Crown Law Office, and those on the notification list for the Wai 2575 Health Services and Outcomes Kaupapa Inquiry.