ABUSE IN CARE ROYAL COMMISSION OF INQUIRY
DISABILITY, DEAF AND MENTAL HEALTH INSTITUTION HEARING

Under	The Inquiries Act 2013
In the matter of	The Royal Commission of Inquiry into Historical Abuse in State Care and in the Care of Faith-based Institutions
Royal Commission:	Judge Coral Shaw (Chair) Paul Gibson Julia Steenson
Counsel:	Mr Simon Mount QC, Ms Kerryn Beaton QC, Ms Ruth Thomas, Ms Lucy Leadbetter, Mr Michael Thomas and Ms Kathy Basire for the Royal Commission Mr Gregor Allan, Ms Sandra Moore and Mr Vaughan Dodd for the Crown
Venue:	Level 2 Abuse in Care Royal Commission of Inquiry 414 Khyber Pass Road AUCKLAND
Date:	19 July 2022

TRANSCRIPT OF PROCEEDINGS

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Hearing opens with waiata Ka Pioioi and karakia by Ngāti Whātua Ōrākei

[10.13 am]

CHAIR: Tēnā koutou katoa kua huihui mai nei ki runga i te kaupapa o te rā nei te kaupapa Ūhia te Māramatanga. Greetings to everybody who's come today for this very, very important day of the hearing. I want to particularly welcome the survivors who are attending, particularly those from the disability communities, from the Deaf communities and those who suffer mental distress. This hearing is all about you and yours, and it has been a privilege for us to sit and listen to that through these last few days. So welcome very much to you, whether you are here in person or whether you are watching on the livestream.

I'm now going to ask Ms Thomas to introduce our next witness. Thank you, Ms Thomas.

MS THOMAS: Thank you, Madam Chair. This morning we are here to welcome our next witness, Lusi Faiva. She is supported here today with Kelly and Umi from the Donald Beasley Institute and her boss and friend John, and Lusi is able to and ready to take the affirmation and then we'll go to her evidence.

CHAIR: Talofa Lusi, welcome, welcome, welcome to the hearing, we're happy that you've been able to come. And we also appreciate that you've got Kelly and Umi and John there in full support of you, so you're well surrounded. Lusi here's the affirmation.

LUSI FAIVA (Affirmed)

QUESTIONING BY MS THOMAS: Good morning, Lusi. Prior to this morning, have you prepared your full statement with support with Kelly and Umi and have you already recorded all of your statement and you'd like to share into your communication device?

A. **[Nods.]**

Q. Would you like to share that with the Commissioners and with the public now?

A. **[Nods.]**

Q. Thank you.

A. "I will open my statement with key words that will recur in themes of my statement: freedom, expression, choice, routine, fear of being forgotten/left, worry, restricted, respect, affection. I am a proud Sāmoan woman. I am an artist, dancer and passionate freedom seeker. I was two years old when I was diagnosed with Cerebral Palsy. There was little support for disabled children and their families when I was little. The doctor instructed my mum for me to go to an institution, he said, it would be better this way. Soon after I was moved to Kimberley Centre (a specialist hospital for the care of people with intellectual disabilities).

I only remember small amount from my years at Kimberley. I was sharing a room with other children there. During the day we sat in the recreational room but there were no activities going on. We hardly interacted with each other. In the shared space there were people of all ages with different disabilities. The institute felt dark and cold.

I did not know how to express myself. There were no tools or strategies offered to me to communicate with people around me so I could express what I wanted to and needed. It was assumed that I did not have the mental capacity to communicate, and it was assumed that I had an intellectual disability. No-one thought to ask me what was going on for me. I was under five at this point but old enough to remember how trapped I felt in myself.

No-one ever talked to me about my Sāmoan heritage either. I felt like people didn't know or care about my Sāmoan culture. Even if they did, there was no recognition, interest or inclusion. There was no respect or effort to recognise me for who I am.

The nurses didn't look after me properly. The only times that the nurses came on to the ward was to give us children our medicine and then they left. Once, I fell and broke my ankle because no-one was watching me. If I had received better care then, my physical health would be better today. I never received any specialised support until I left the institute even though my mum was told that being there would be better for me.

I think that the concept of institutions are not set-up to care and look after the disabled people because it is built on a system that dehumanises disabled people and I think that hasn't changed much for how the current state care works. Care was about medication, change, showering and other very clinical procedures that does not take into account of the very individual needs such as human connection and affection.

I can remember doing schooling at Kimberley. I believe there was kind of school scheme. I think I was just five years old when I started. There were two staff members who were a couple. They visited Kimberley every day and they were the only ones who taught us kids. They recognised that I was switched on and started teaching me how to read and write and to express myself, finally, after I was five. It was strange to see words in the beginning. But as the time went on, I could understand what they were teaching me. I was a fast learner. I had a blackboard with chalk that I was able to hold. They taught me how to spell things. They were kind and gave their time to come and play with us. It was the only time we could do other activities like games and drawing. I learned ways to express myself. I remember them dearly.

While I was in the Kimberley Centre, my mum never visited me. The first time she came was when she came to take me home. I didn't know who she was and I felt nervous.

The two staff members who taught me how to express myself kept in touch with Mum and convinced her to take me home. I felt upset to leave Kimberley because I didn't want to leave them. I did not see them for a long time after I left Kimberley, yet they still remain significant people in my life. Their regular interactions with me taught me that I was someone, I was Lusi and I deserved to be loved. I left Kimberley Centre when I was seven years old.

Returning to live with Mum was challenging. She was in an abusive relationship. Living with his family was so confronting and scary. Mum had only been in New Zealand for eight years at this point and she was left alone without moral support for her. It was a tough time for her.

I liked going to school because it gave me a sense of normality. I could switch off from what was going on at home. I was interacting with other children and learning. But this came to a halt when we had to escape from mum's boyfriend eventually. We went to Women's Refuge first. Then while mum was looking for a place to live for us, I was in a hospital.

As I was coming to the terms with my CP, the doctors decided to make me walk through surgeries. I had a surgery to straighten out my legs and ankles, followed by rehabilitation. The doctors didn't explain what they were doing with me. I felt like my body was being manipulated. They were working with my cerebral palsy as if it was disconnected from me and my feelings did not exist.

My mum came to pick me up at the end of the rehabilitation and we took a train to Auckland to stay with my auntie and her family. She had a four-bedroom house with 15 people in it and everyone spoke Sāmoan. I went from not really understanding my Samoan identity, nor hearing my language, to being thrown into this rich but overwhelming space. This transition required a lot of adjustment from me. I was receiving the cultural knowledge I had longed for but my Sāmoan family didn't know about cerebral palsy and therefore didn't know how to care for me.

We only stayed with them for a short while, and we eventually moved to our own place in another suburb. While I was living with my aunty I went to a school for children with cerebral palsy and I stayed in the same school after we moved. They didn't really teach us, though, because the school was focused on recreation and rehabilitation. Also, none of the schools or education I received had good understanding of my culture.

When things were really hard at home with my family I sometimes wished that I hadn't gone home. However, looking back now, I think that if I had stayed in Kimberley for any longer, my life would have been worse. I wouldn't have had the freedom that I later experienced to explore my own life. I wouldn't be the Lusi I am today.

When I was 15, I joined an acting group. It was my first step towards exploring myself and what I wanted to do. Soon after I started to rebel by partying with my friends. After a while of doing that, I decided that I wanted to explore how far I could push my personal boundaries, break free and be reckless by leaving home. It was risky and at times an unsafe way to live but I needed to feel this, explore this, in order to gain some autonomy on who I am and what I wanted to do with my life. This was life-changing. Meeting similar people often broken by their own history and, like me, seeking their own truths. These people became my family during this time, they got me.

Eventually, I had to return home for obvious reasons. I went flatting in a house run by a disability support service. They provided support workers so that I could do things I needed but I didn't really like it there. I felt restricted and I wanted my freedom back. I moved out after a year to a state house where I've lived ever since. I have support workers who come in mornings and nights now. Sometimes I feel scared living on my own because sometimes support workers don't turn up and I get stuck. There was a lady who passed away alone who lived near my area, and sometimes I get scared it might happen to me. I feel like don't have control over this situation. This sense of fear and restriction brings me back to the memory of being in Kimberley.

I joined a dance group for disabled people by disabled people when I was 28. I had no training, but I knew that this was my passion. I feel free when I dance. To be honest, I still struggle with putting myself on the stage because I feel judged. But I put a facade on to be on the stage and I pour my heart into my performance. I express my identity through my dance. I need it to be real, and it can be challenging to get my moves right. Through dance, I have reconnected more strongly with my Sāmoan culture.

If I met myself in Kimberley, I believe that this little Lusi would be happy seeing someone like her wanting to play alongside her. That little Lusi at Kimberley wanted to know she was important, loved and deserved of affection, that she was from a rich and vibrant Sāmoan heritage and she had so many strengths.

As an adult, I fell in love with the performance world. The creative space allows me to explore myself through dance. It brings me beautiful moments, movement, interactions, tears, love and laughter.

Being in care was like a slap in my face. There was no freedom of choice in entering care. I was lost in care. There was no acceptance, brief or trust from others that

I needed freedom. Freedom is acceptance of who I am as an individual. There was no voice of freedom in the institution.

Living independently now is a source of freedom, but it has moments of good and bad. Although I am living independently, the support services are not resourced enough to be reliable when I need them urgently, even today. It frustrates me a lot. Care still fundamentally operates under a similar system where I am left without care and support for a long period of time. This reality is a reflection that the system lacks the respect for freedom and even basic human needs."

Q. Thank you, Lusi. Are you okay to carry on?

A. **[Nods.]**

Q. In preparation for your evidence today, the Commissioners have given you four questions which I understand you have already typed in to your communication device. If I read those questions one by one, would you like to respond to those now?

A. Yes.

Q. The first question is what would be the ideal living situation with the right support, what would this look like for you right now, Lusi?

A. Answer 1. It is hard to say. The support I have now is good in terms of the support workers I have, but there is always uncertainty whether they will turn up or not, and not having that security is very hard. Right support for me looks like having consistent support where I don't have to feel worried about how I am going to get out of bed, or I can come home at night when I want to and still be able to get ready to sleep with support.

Q. Thank you. Question 2, would your relationship with your family be different if you did not go to Kimberley?

A. Answer 2. Maybe if I didn't go to Kimberley, I would have known more about my mother's earlier life, which would have given me more idea about who she is. The time I went to Kimberley, my mother was still a new migrant from Sāmoa and she had struggles in settling in this country. At this time, she was in a poignant time in her life and when I was placed in Kimberley, I was at a poignant development phase of my life. When I came home, it felt like we were strangers and it has been really hard to make-up the years we missed out on being with each other.

Q. Thank you. Question 3. Does the government provide you funding for communication supports?

A. Answer 3. Yes, they supported me via the Ministry of Health and this has been good. But funding isn't easy to get because New Zealand is often not aware of new technology. So to get funding for the latest technology that works better for communication is not easy.

Q. Thank you. And question 4, what more can we do to ensure people's needs to communicate are not neglected, what do people providing care and all other members of the public need to know about communicating with people who use communication devices or augmented communication systems?

A. Answer 4. People need to know and understand that people can communicate and through taking time to know the person, people can come to understand how to communicate with the person. There are so many ways to communicate. Through different communication abilities, such as my technology, my eye and my hands, and people need to understand that.

Sometimes people need to have a training and patience to understand that everyone has the ability to communicate. The system of caring inside an institution or in the community is dictated by the routine of the day and it does not necessarily allow uniqueness of individuality to be respected, which means that some people providing care and some other members of the public do not have patience to communicate well.

Q. Thank you, Lusi. Thank you for all of your evidence today and for your answers to those questions. I'm just going to leave you now with the Commissioners who would like to speak with you.

A. **[Nods.]**

CHAIR: Thank you so much, Lusi. Commissioner Steenson is going to thank you formally.

COMMISSIONER STEENSON: Talofa lava Lusi. You're so brave, your statement was so inspiring. So insightful for the Royal Commission to hear and everybody here. Thank you. You've given us such a huge amount of information and what really stuck out to me was how you talked about institutions dehumanising people, and how the clinical procedure is not human care. And I want to acknowledge your resilience, incredible resilience, you're very inspiring. And it's beautiful to know how you connected with your Sāmoan culture through dance, just beautiful. So, on behalf of the Royal Commission, manuia, ngā mihi nui, tēnā koe, thank you.

CHAIR: We will take a break now.

MS THOMAS: Yes, if we take the morning adjournment now until 10.45.

CHAIR: Thank you Lusi.

Adjournment from 10.31 am to 10.57 am