

“Freedom is Acceptance of Who I Am” by Lusi¹



¹ Lusi chose to use her first name in her story and not to name anyone else.

² Image of red lavalava

To start with, can you tell us a little about yourself?

I am a proud Sāmoan woman. I am an artist, dancer and passionate freedom seeker.

Why and when did you move to Kimberley?

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).

Can you tell us a little about what Kimberley was like?

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”.

How did you communicate when you were in Kimberley?

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 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.

Were there any recognition of your cultural heritage inside the Kimberley?

No one ever talked to me about my Samoan heritage either. I felt like people didn't know or care about my Samoan 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. Even I didn't know.

So nobody ever thought of honouring you for who you were or identified you as your own culture?

No no.

Did the nurses know how to take care of you with your cerebral palsy?

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.

How would you describe “institution” in your own words?

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 dehumanise disabled people. And I think that hasn't changed much for how the current State care works. Care was about medication, changing, showering and other very clinical procedure that does not taken into account of the very individual needs such as human connection and affection.

Did you go to school when you were in Kimberley?

I can remember doing schooling at Kimberley. I believe there was kind of school scheme. I think I was just 5 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 5. 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.

Did you have any family visitors?

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.

What made your mum possible to gain you back and when did you move back?

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 7 years old.

How was it like moving back with your mum?

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 8 years at this point and she was left alone without moral support for her. It was a tough time for her.

Wow, so you went from Kimberley to a situation that was also fraught with somethings that were hard as a young girl, really. Were you going to school at this time?

Yes. 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.

What was your hospital stay for?

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.

Where did you go after that?

That must have been scary too. Where did you go after the hospital?

Yeah it was. 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.

How was staying with your Auntie and her family?

She had four bedroom house with 15 people in it and everyone spoke Samoan. 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 Samoan family didn't know about cerebral palsy and therefore didn't know how to care for me.

Did you stay with your Auntie's place for long?

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 auntie 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.

Have you ever compared staying in Kimberley and staying with your family?

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.

Can you tell us about how you explored your freedom?

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.

Sounds very exciting. What happened next?

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.

You are a phenomenal dancer. Can you tell us how you became a dancer, and what it means to you?

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 façade 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 Samoan culture.

If you were to go back in time and meet Lusi in Kimberley, what would she be like?

If I met myself in Kimberley, I believe that 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 Samoan heritage and she had so many strengths.

How would you explain what being in care means for you and how has this changed in your life?

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.

You have gone through so many challenging times, and some of them can be ongoing. Lastly, but not the least, can you share with us what has helped you to navigate your life?

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.