Tell Me About You:

A life story approach to understanding disabled people's experiences in care (1950-1999)

Executive Summary

Whakataukī

He pōkeke Uenuku i tū ai.

Against a dark cloud the rainbow stands out brightly.

A. E. Brougham, A. W. Reed, & Kāretu, T.

This whakataukī can be found in The Raupō Book of Māori proverbs by A.E. Brougham & A.W. Reed, revised by Tīmoti Kāretu. (p. 97)

Kupu Whakaihi / Dedication

This report is dedicated to all of the storytellers who had the courage to share intimate details about their lives, before, during and after being in care. Their resilience, and their continuing resistance is remarkable. It is also dedicated to disabled people across Aotearoa who have never had the opportunity to tell their own stories about their experiences of care.

He Whakamihi / Acknowledgements

Ko te tuku mihi, ko te whakawhetai atu hoki ki ngā huānga o Te Kāhui Arataki. Naia te mihi mutunga kore ki a koutou katoa. Nei ra te whakatauākī ki te whakarāpopoto ō koutou mahi ki tēnei kaupapa,

E kore e taea te whenu kotahi ki te raranga i te whāriki

kia mōhio ai tātou ki ā tātou.

Mā te mahi tahi ō ngā whenu, mā te mahi tahi ō ngā kairaranga,

ka oti tēnei whāriki.

I te otinga me titiro tatou ki nga mea pai ka puta mai.

A tana wa, me titiro hoki ki nga raranga i makere na te mea, he korero ano kei reira.

The tapestry of understanding cannot be woven by one strand alone. Only by the working together of strands and the working together of weavers will such a tapestry be completed. With its completion let us look at the good that comes from it. In time we should also look at those stitches which have been dropped, because they also have a message. Nā Kukupa Tirikatene.

We acknowledge the members of Te Kāhui Arataki who have guided this project.

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Content Warning

This report includes accounts of abuse and violence.

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1. Whakarāpopototanga Mātua/ Executive Summary

1.1 Whakatakinga/Introduction

The Royal Commission of Inquiry (RCOI) was established in February 2018. The purpose of the RCOI was to investigate abuse in State and faith-based care between 1950 and 1999, to acknowledge survivors of abuse and to make sure that abuse in care does not happen in the future. Similar inquiries have been commissioned in other countries as historic abuse in care had happened outside of Aotearoa as well.

1.1.1 The role of the Donald Beasley Institute in the Royal Commission

The Donald Beasley Institute (DBI) has nearly four decades of experience in disability research. Over the decades, DBI has seen the closing of institutions as well as the evolution of the community-based disability service system. DBI has maintained a focus on research that emphasises lived experience, inclusivity and transformative research approaches. As part of this, the DBI conducted research documenting the closure of large institutions, referred to as deinstitutionalisation research. This included the processes of moving disabled people out of institutions, and the impacts and conditions of institutions on disabled people (Milner et al, 2008; Mirfin-Vietch, 2005). In 2017, while campaigning for a Royal Commission of Inquiry, the DBI was commissioned to conduct a literature review about "experiences of disabled children and adults in State Care". The research findings led to the report being titled "Institutions are places of abuse" (Mirfin-Veitch & Conder, 2017), due to the prevalence of abuse in institutions highlighted within the literature.

1.1.2 Intent of "Tell Me About You" project

The *Tell Me About You* project was designed to provide people with learning disabilities and neurodiversity an opportunity to share their experiences from State and faith-based care, and have their voices heard. The RCOI had asked DBI to conduct this work as the variety of official pathways remained inaccessible for many people with learning disabilities and/or neurodiversity. The DBI drew on a long history of inclusive, narrative-based research to craft a research approach that had the potential to engage with people with learning disabilities and neurodiversity to tell their own stories, in their own way.

1.2 Aramahi/Methodology

The focus of *Tell Me About You* was centred around four of the specific aims outlined in the RCOI terms of reference. These were:

a) The nature and extent of the abuse that occurred while they were placed in State care or State funded care (10.1).

b) The physical, cultural and emotional landscape within which abuse was experienced, to throw light on the structural, systemic and practical factors they identify as contributing to reported abuse, neglect or exploitation (10.2).

c) The impact of abuse on storytellers, their families, whānau, hapū, iwi and communities, including their understanding of the immediate, long-term and intergenerational impact of living in State care or State funded care (10.3).

d) What storytellers understand of the circumstances that led them to being taken into, or placed into care and the appropriateness of those placements (10.4).

The main research question was "what was your experience of care". This question was asked in this way so that people could talk about the good and bad experiences they had while in care. The two approaches used to guide and instruct the research were Trauma Informed Approach and Individually Responsive Methods (IRM).

Trauma Informed Approach is based on the understanding of how trauma can affect an individual's thoughts and actions. By acknowledging the impact of trauma, the individual is separated from their thought patterns or actions, which encourages practitioners to ask the question "what happened to you?" rather than "what's wrong with you?". The values of the Trauma Informed Approach also contributed to our decision to invite people who had experienced care to participate as storytellers rather than survivors. This use of language allows the person talking about their experiences (storyteller) to be in control of the narrative to address the imbalance of power that can occur in more traditional research.

Individually Responsive Methods (IRM) was a way of including the voices of disabled people whose experiences are difficult to access using traditional research methods. IRM offers people the chance to design and control their research presence by working with a story gatherer to tell their story in a way that is both personally meaningful, and accessible.

Significant attention was paid to informed consent procedures and ensuring the project was a place of safety for storytellers, and story gatherers. Being able to freely choose whether or not to contribute to this research was at the foundation of creating an ethical and safe project. The steps taken were based on Supported Decision Making (SDM) Principles and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), to ensure the autonomy of storytellers was recognised, valued and accounted for. Based on these principles, a protocol was put in place to guide the informed consent process, particularly if storytellers had a learning disability.

1.2.1 Te Kāhui Arataki and Culturally Responsive Research approach

This project was guided by Te Kāhui Arataki, a rōpū with lived experience and expertise on the research kaupapa. The rōpū included Māori advisors and researchers from across Aotearoa to ensure respect and representation of a broad collective of hapū and iwi. Based on their advice, guidance and input, a respectful and holistic approach was agreed and revised throughout the research process. Collecting, curating and imparting whānau hauā me tāngata whaikaha Māori narrative/pūrākau aligned with the sharing of mātauranga Māori through the generations. Ensuring Māori abuse survivors could represent their experiences according to Te Ao Māori, Tikanga Māori and Kaupapa Māori methodologies was intended to inform the RCOI and resonate within the communities to which their stories more rightfully belong. Including Māori storytelling was also intended to guide the response of

the Royal Commission of Inquiry and to inform the development of policy and service and support practice that is more aligned with Te Ao Māori notions of whakamaioro (abuse) and whakarekereke (violence).

1.2.2 The Storytellers

Of the 16 storytellers who participated in "Tell Me About You", 12 were male and four were female. 14 storytellers identified as European New Zealander, one as Sāmoan New Zealander, and one as Māori and European New Zealander. All storytellers were between the ages of 45 and 75, with a median age of 58-years-old. Ten storytellers had learning disabilities, three had autism, and one storyteller had a neurological disability. At least three storytellers had known coexisting disabilities. One storyteller participated as a family member alongside the storyteller who experienced care. One storyteller used institutional records to tell the story of their disabled siblings.

It was expected that the stories shared by storytellers would touch on painful events and memories. The DBI has clear and well-practised protocols for responding to disclosures of abuse which were further refined and ethically approved for the specific purposes of this project (See Appendix B).

The ethical approval for this research enabled the storytellers to choose to use their real name or a pseudonym. In both cases the storytellers chose how they wanted to be identified and how their story was represented in the research.

1.3 Kōrero/Stories

This section includes excerpts of stories within the full report. Refer to the full report for the development of stories, and the stories in their entirety.

"I still have a fear of the dark…"

As I said, that lock up room, oh god I would go crazy in there aye. In the dark room. When I was locked in here it had a brown mattress – not the one it has now. I would be bashing on the walls screaming let me out of here you know. I still have a fear of the dark. I would be bashing on the walls and me hands bleeding and then, all of a sudden, I would hear the key in the lock, the big steel one, like that young fella had before.

"Happy Times" by Rosie

We heard that Seaview was going to close and I was a bit sad about it. I enjoyed being at Pounamu and would have been happy to stay there. When I lived with mum I had contact with other people, but when I lived at Seaview there were friends around all the time. I had good relationships there. In the end, I spent 6 years at Seaview – from 1994 – 2000. I liked being in there. [I had] happy times up at Seaview.

"One thing that I know Stand up for your rights" by Graham P

We sang songs at Seacliff but I didn't like that because it made me bored and the songs were sad. I moved to Cherry Farm from Seacliff. I can't remember how old I was. When I got there, my arms were shaking. It was scary and frightening. The tablets for my turns made me

all better. They made me feel calm and tired out. I didn't like it there. They locked me up and I don't like that. I don't know why they locked me up. It was cold and made me sad.

"I don't know how I got there..." by Rawiri

I don't remember why I was put into seclusion. In the seclusion room there was a small bed with a mattress on it. There was a small square window that other people could look through. A lady came and checked on me sometimes. Once I got angry in seclusion and threw the sheets around the room. Another time when I went to seclusion, two staff members got hold of me and twisted my arm and broke it.

"I don't get locked up here" by Graeme

Then I was at Cherry Farm. I remember when I went, but I don't remember how old I was or why I went there. I remember feeling angry when I got there, because I didn't want to leave home. I was there for a long time. It was hard to be away from home. I missed all my family. Sometimes Mum and Dad and my sister would visit. My sister gave me a ring once.

"When I Was Small" David's poem

I did the wrong thing.
They took me away to Templeton.
I didn't know what Templeton was.
When I arrived I looked around the place and eventually...
I found a garden beside Beech Villa. I love gardening.

"I was only 9 years old" by Jabert

I ran away from Templeton again and this time I ran to the Speedway and a man gave me money to catch the bus. I then went to the pub in the Christchurch square. I just wanted to get out of Templeton. It was time for me to move.

I stayed in Beech Villa a bit longer until we had a big meeting with all the residents. They told us we were all going to get out of Templeton because it was going to shut down.

"Two Brothers in State Care" by Sarah

After Ricky's death, Sarah tried, again, to find information about her oldest brother Paul's fate. It made no sense to her that a little boy who had been entrusted to the State could have just disappeared into thin air. She had a strong feeling he probably had died in care and tried to find some comfort in imagining Paul and Ricky were together. The only information she had on Paul was from when he was aged 10…

"Freedom is Acceptance of Who I Am" by Lusi

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 take into account of the very individual needs such as human connection and affection.

"The Psychiatric Hospital" by Jen

The turns went around in a circle; if you couldn't think of anything, or were too anxious to do it, there would be trouble, because opting out was not an option. And if you DID do it, you could also be in trouble, because of the incident / issue that you conveyed….. e.g. if it was something that turned out to irritate or upset someone else in the group. The whole group (patients and staff would often gang up on one patient who had "said or done the wrong thing,"...

"She said things about my parents which were not good" by Janet

My foster mother sometimes made fun of my birth father, and said I should go and live with him. She said things about my parents which were not good and made me scared of them. When my mother came to see me I hid behind the couch because I thought she was going to hurt me. My foster mother said I had been hurt at my mother's house when I was there, and had been playing with matches. I don't know if this was true.

"I longed to be a firefighter" by Tim

I remember getting the strap for some reason. I can't think why. It might have been spelling, might have been something to do with lack of learning. Was I being naughty? Was I being cheeky? I don't know. I think the teacher would send me off to the headmaster and I come in here! (smacking sound. Jesus that bloody strap was pure leather! And before the head master strapped me I could see the previous marks on it that had been widely used on the other boys for whatever reasons.

"It might be all houses there now" by Allan and Nathan

N: If I didn't want to do anything at school, the teachers would write a note and go get someone. They were pretty angry and they came to get us. If it was not the hot seat, they used to send me back to the villas.

A: Some villa staff were helpful but some weren't so helpful. When I was being teased or bullied and I got upset and complained they would think I was overreacting.

"Father and Son" by Michael and Trevor

Poor Michael. The threats and things, it can cut such a deep groove in people. My friend, I mentioned her before, she said to me that these boys were threatened. And you can imagine, they all had intellectual disabilities for a start and it wouldn't be hard. The brothers would know what to say. So they become beliefs and they take them on as beliefs and they stay there. I know Michael has a memory like an elephant.

1.4 Kitenga/Analysis of the Findings

An ecological model of disability violence and abuse (Sobsey, 1994; Hollomotz, 2013; Fitzsimons, 2009 provides a framework for exploring and understanding the interrelatedness of factors that both impact on disabled people, and create environments where violence and abuse is able to occur. The ecological model explores these factors at the individual and relationship/relational (microsystem levels, the community level (exosystem and the societal

level (macrosystem; Hollomotz, 2009) to understand why abuse occurs, what responses are needed to address it, and how to prevent violence and abuse from continuing to impact disabled people. In the following section, the four ecological levels inherent to the model are explained and illustrated by using the data gathered (in the form of stories) in *Tell Me About You*.

1.4.1 Individual level

When the collective body of stories were analysed at the individual level, four sub-themes were identified that speak to this conceptualisation. Storytellers were not inherently vulnerable and did not inherently lack capacity, but while in care they universally experienced a:

- Lack of agency: Storytellers talked explicitly and implicitly about repeated restrictions and assaults on their individuality and personal agency while in care settings, often by highlighting what was important to their sense of wellbeing now.

- Lack of rights, will and preferences: Almost all storytellers indicated that they were not seen as rights-holders and, relatedly, were assumed to lack the capacity to express their will and preference.

- Cultural alienation and loss of identity.

- Lack of recognition of personhood:[1] the personhood of storytellers was regularly challenged by medical practitioners and other staff in the care settings. Storytellers were infantilised and devalued through the use of labels and language.

1.4.2 Relational level

Echoing the assumptions and presumptions that storytellers experienced at the individual level, analysis at the relational level found similar patterns. Three sub themes were identified at the relational level highlighting experiences of:

- Others holding power over (disabled people); Storytellers experienced physical, emotional/psychological abuse and neglect, particularly in the form of forced seclusion and sexual abuse at the hands of people they came in to contact with 'because' of their disability and their perceived need for 'care' by professionals.

- Others made decisions about their lives, including dictating the rules of relationship(s): Storytellers went unconsulted and remained voiceless in decisions that directly affected them.

- Lack of opportunity to form, manage, or mediate equal and respectful social, familial, peer and intimate relationships: Storytellers experienced limited connection with family members, and in some cases family relationships were prevented.

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[1] Respect for an individual's essence of being, freedom to make choices and have autonomy, freedom to love and be loved, to belong and to relate with others.

1.4.3 Community level

Analysis at the community level illustrated the positioning of storytellers outside of their communities, the impacts of which were identified in the following four sub themes:

- Lack of access to housing/employment/education: Storytellers were prevented from access within the community because of their disabilities.

- Understood as non/unproductive community members: Being labelled or perceived as 'non-productive' members of the community (in the neoliberal sense of productivity) meant that their place and rights within the community were continuously under threat.

- Understood as recipient of services and supports and 'in servitude' to State: many of the storytellers were assigned the role of 'recipient of services and supports' through being placed in care. This sometimes meant they were placed in different institutions, one after another, without choice or control.

- Understood as non-citizens: Storytellers were deprived of citizenship by being placed in an institution and prevented from leaving, restricted in who visited and when they visited, expected to undertake unpaid or low paid work, and had limited access to life experiences and education and training that could support their ambitions to determine their own future.

1.4.4 The Societal level

Analysis at the societal level revealed an ableist system, built on privilege that was not afforded to disabled people who were excluded from society and treated inequitably. Four sub themes were identified highlighting:

- Laws and policies that deny personhood rights: policies relating to support for disabled people in the era of institutionalisation were developed in response to a system which valued segregation and neglect.

- Education, employment and health models that segregate and 'specialise': Storytellers described being segregated from their families; taken away from home to institutions that were 'special' services.

- Limited access to legal and social protections: Storytellers had little effective control over the way they were treated, no clear pathway(s) to justice or for seeking accountability for violence and abuse.

- 'Outsiders' in Society: Societal attitudes of the time meant that when support or treatment was sought, the seeker was placed out of sight, in institutions at the margins of their communities.

1.4.5 Weaving the four levels together

The relationship between each ecological level created the reality and circumstances that storytellers shared. For example, the lack of choice about where to live at the community level was at the core of each storyteller's story. This reality was a result of interplay between all of the other three levels. Their families were often not well supported or resourced at the community level which may be indicative of beliefs held by professionals that storytellers

were better off being placed within care. These professionals often exerted their power over storytellers at the relational level by making independent 'clinical' decisions about their need for care. This decision was often underpinned by the assumption of incapability and the lack of respect for will and preference of storytellers at the individual level. These assumptions and beliefs were supported by ableism and disablism at the social/systems level, through policies that segregated disabled people 'out of' society.

1.5 Kōrerorero/Discussion

Using the ecological model of understanding to analyse the collective body of stories, it was revealed that systemic abuse within care had a pervasive impact on the experiences of storytellers. Systemic abuse refers "not only to the direct physical abuse" but "violence inherent in a system" (Žižek, 2008, p.1–8). This was demonstrated both by the wider social system that placed disabled people into segregated environments and the systems within care settings where order was prioritised over individuals' needs, will and preferences (Goodley & Runswick-Cole, 2011; Minshull, 2004). All stories of abuse and violence stemmed from systems that granted power to professionals to make decisions about where a storyteller lived and how they would be cared for.

These two interrelated social and care systems were (and are) underpinned by both ableism[2] and disablism[3]. Abuse of disabled people in care, including (most of) the storytellers in this research can be considered as blatant disablism; they were abused because they were part of a system that created the opportunity for abuse to occur, and they were in that system because they were disabled.

It is important to acknowledge that ableism and disablism were not an inherent part of society in Aotearoa. Prior to colonisation, it is known that whānau hauā me tāngata whaikaha Māori existed as part of "whānau or acknowledged as having particular gifts or contributions that added to the lives of wider collective" (Ingham, et al., 2022, p. 2). The institutionalisation and segregation of whānau hauā me tāngata whaikaha Māori was and remains the enduring and negative legacy of colonisation.

The influence of the false science of eugenics in the early 20th century created fears about disability and reproduction (Chapple, 1903) which were expressed in legislation and policies which segregated and surveilled disabled people. Institutionalisation was the main response for the rest of the century (Aitken, et al, 1953; Sullivan & Stace, 2020). The intersection of colonisation and eugenics meant that Māori were disproportionately affected.

[2] A belief system that values certain body and minds according to the socially constructed idea of what is normal, productive and desirable (Lewis, 2020, as cited in Wieseler, 2020).

[3] Oppression that directly targets and impacts disabled people, as it is a prejudice that considers disabled people's body and mind as 'deviant' from the norm, therefore, in need of intervention to adapt to the order of the society (Nieminen, 2022; Goodley & Runswick-Cole, 2011).

1.6 Titiro whakamuri, kōkiri whakamua - Recommendations for redress

One of the key aims of *Tell Me About You* was to contribute to the conversation about redress, including the implementation of actions to ensure that the injustices experienced in care by a significant number of New Zealanders will never be repeated. It has already been asserted that effective redress must be:

● founded on Te Tiriti o Waitangi;

● trauma-informed and achieve justice for all individuals who experienced abuse and neglect in care settings;

● inclusive of systemic transformation to prevent abuse and neglect within care settings (RCOI, 2021b).

Many of the storytellers had a difficult time contemplating their right to redress, hence their recommendations are few. In addition to the recommendations for redress identified in He Purapura Ora, he Māra Tipu: From Redress to Puretumu Torowhānui (RCOI, 2021b), the system of redress needs to be implemented in a timely way, be transparent and accessible to all. Using findings framed by the ecological model it could also respond in the following way across all levels of the systems of violence and abuse.

From an ecological model perspective, the following recommendations were also made:

Individual level: Redress must respond to individuality; be inclusive; be based on trauma-informed approach; challenge ableism and disablism; respond to intersectionality; include broader forms of abuse;[4] be ongoing; and redress payments should not be considered as taxable income.

Relational level: The development of any redress scheme must be done so in full compliance with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and in particular Article 12 of UNCRPD - Equal Recognition Before the Law. For example, redress schemes must provide equitable access, consider diverse needs and identities, and consider barriers that may discourage or prevent disabled people from engaging with redress.

Community level: Historically, justice has been seen to be served by the closure of disability institutions (deinstitutionalisation). Following their closure, institutions are typically repurposed or abandoned and left in derelict states. However, this can act to erase the abuses and violence that had occurred there, and from the collective conscience. On the other hand, Sites of Conscience provide society with a way of remembering the injustices that occurred and to prevent further occurrences (Steele, 2022).

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[4] Such as neglect, loss of family and ongoing relationships, restraint and seclusion, failure to provide adequate education, emotional abuse due to ableist treatment and language, lack of privacy, loss of culture and cultural abuse, and financial abuse (RCOI, 2021b, p 85).

Systems level: In order to cement the legal rights and personhood of disabled people, particularly people with learning disability and neurodiversity, relevant legislation needs to be reformed to adhere to Article 12 of UNCRPD - Equal recognition before the law. In order to redress segregation, the exclusion of disabled people in all social systems - education, health, housing, justice and invisibility in Aotearoa's historical record to name a few - must be addressed.

On the basis of the evidence to date and the findings of *Tell Me About You*, the aforementioned recommendations remain relevant and appropriate. They are informed by survivors, and their allies, and should be adopted in full. All of the four ecological levels of redress are interlinked with each other, and often one level of redress cannot take place without the other levels of redress also being achieved.

1.7 Kupu Whakamutunga/Conclusion

Using an ecological analysis approach, the stories and collective findings outlined in *Tell Me About You* tell us about the nature (bullying, emotional/psychological abuse, physical abuse, sexual abuse, medication abuse, cultural abuse, neglect) and extent (pervasive and violent) of the blatant and covert abuse experienced by disabled people in care settings. They also detail the physical, cultural and emotional landscape(s) within which abuse was experienced, including being relationally and culturally impoverished, and largely deprived of systems that either prevented abuse, or provided a pathway to complain. It was revealed that segregation was a direct result of both disablism and ableism, and the impact of abuse was clearly articulated by family and whānau who describe their enduring guilt. Even to this day, storytellers have little knowledge of the circumstances that led them to being taken into care.

Even so, the *Tell Me About You* project only captured the stories of a small number of disabled people - we know there are many more disabled people in Aotearoa who will never get the opportunity to share theirs. The DBI research team acknowledges the bravery it took for every single storyteller to share their story and recognise that for some storytellers, participating in this project forced them to relive the māmāe (pain) and whakamā (shame) they felt while in care. We are deeply grateful for their contributions. Justice for the storytellers, and the many others who without question shared similar experiences will only be achieved if redress is underpinned by Te Tiriti o Waitangi, and occurs swiftly and in a way that is inclusive of and accessible to all.

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