

# Tell Me About You:

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



**DONALD BEASLEY**  
INSTITUTE



# 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 o 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 o ngā whenu, mā te mahi tahi o 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.

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Artwork by Dale Scoles. Report design by Crush Creative.

## **Content Warning**

This report includes accounts of abuse and violence.

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# 1. Ngā kupu whakamārama / Glossary

Below are definitions of key terms used in this report. Some of the terms and definitions were specifically developed and used by the Royal Commission for the purposes of the inquiry into abuse in care. Others were developed or used by the DBI team for the specific purposes of this research.

**Ableism** is a belief system that values certain body and minds according to the socially constructed idea of what is normal, productive and desirable. It is a root concept, also used to understand all of the other 'isms' such as disablism, sexism, classism and racism as it justifies placing one group over another according to certain characteristics.

**Abuse** can include physical, sexual, emotional or psychological, medical, cultural or spiritual and systemic abuse and neglect. It includes lack of care or inappropriate treatment which causes serious harm to the individual.

**Disablism** is an oppression that directly targets and impacts disabled people, such as abuse and violence that is inflicted on disabled people because they are "disabled".

**Intersectionality** is a concept that is used to draw attention to how the interaction of multiple identities within an individual creates compounding effect of marginalisation. It also invites people to be aware and critical about how power dynamic plays within different identity groups to truly transform the power dynamic.

**Learning disability** is an alternative term to describe intellectual disability. It is the term preferred by self-advocates with learning disabilities in Aotearoa New Zealand.

**Neurodiversity/Neurodiverse** refers to the diversity of all people and the diverse ways people interact with and experience the world. Neurodiversity is typically used to describe neurological or developmental conditions such as autism spectrum disorder (ASD) or attention-deficit/hyperactivity disorder (ADHD); learning disability; communication disabilities; specific learning difficulties; traumatic brain injury; and/or foetal alcohol syndrome disorders.

**Personhood or Respect for personhood** means 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.

**Project champions** is a term used to describe service managers, support workers and advocates of potential storytellers who supported the research team to connect and build relationships with potential storytellers.

**State care** means the State assumed responsibility, whether directly or indirectly, for the care of the individual concerned.

For the purpose of this project, 'State care' includes the following settings:

- psychiatric and psychopaedic hospitals or facilities (including all places within these facilities),
- residential or non-residential disability facilities (including all places within these facilities),

- 
- non-residential psychiatric or disability care,
  - residential special schools and regional health schools,
  - Foster care.

**Story gatherer/s** is a term used to describe the role undertaken by the researchers.

**Storyteller/s** is a term used to describe the people who chose to talk about their experiences of care as part of this research.

**Wāhine whaikaha** means Māori disabled women.

**Whānau hauā me tāngata whaikaha Māori** Whānau hauā refers to disabled Māori people.

Whānau hauā acknowledges that experience of disability is collective whānau experience.

Tāngata whaikaha Māori is a more recent term for disabled Māori people, and tāngata whaikaha refers to the determination and ability of Māori disabled people.



## 2. Kupu rāpoto/Acronyms

**AAC** - Augmentative and Alternative Communication

**ADHD** - Attention Deficit Hyperactivity Disorder

**ASD** - Autism Spectrum Disorder

**CSCCI** - Children in State Care Commission of Inquiry

**DBI** - Donald Beasley Institute

**DSS** - Disability Support Services

**IICSA** - Independent Inquiry into Child Sexual Abuse

**IRM** - Individually Responsive Methods

**NCA** - National Children's Agenda

**NEAC** - National Ethics Advisory Committee

**RCIR** - Royal Commission into Institutional Responses to Child Sexual Abuse

**RCOI** - Royal Commission of Inquiry

**TOR** - Terms of Reference

**UK** - United Kingdom

**UNCRPD** - United Nations Convention of the Rights of Persons with Disabilities



## 3. Whakarāpopototanga Mātua/ Executive Summary

### 3.1 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.

#### 3.1.1 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.

#### 3.1.2 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.

### 3.2 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.

### **3.2.1 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).

### **3.2.2 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.

### **3.3 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.

## **3.4 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*.

### **3.4.1 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:<sup>1</sup> 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.

### **3.4.2 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.

<sup>1</sup> 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.



### 3.4.3 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.

### 3.4.4 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.

### 3.4.5 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.

### 3.5 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<sup>2</sup> and disablism<sup>3</sup>. 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.

<sup>2</sup> 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).

<sup>3</sup> 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).

### 3.6 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;<sup>4</sup> 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).

<sup>4</sup> 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.

### **3.7 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.



## 4. He Kupu Whakataki/Introduction

### 4.1 Journey to the Royal Commission of Inquiry

On February 1 2018, the New Zealand government announced their commitment to implementing a long-called-for<sup>5</sup> Royal Commission of Inquiry into historical abuse in State care to acknowledge survivors of abuse in State care, as well as to protect children from future abuse in State care (Martin, 2018).

The Commission was a result of decades of community and political advocacy from those who had experienced abuse in State care such as survivors of the Lake Alice Adolescent Unit in the 1970s and disabled people who had been institutionalised in a variety of settings, as well as their family/whānau and allies (Mirfin-Veitch & Conder, 2017).

Following the announcement, a period of consultation on the draft terms of reference took place. This process resulted in over 400 public submissions. On the basis of these, a report including opinions on the nature of the Royal Commission's terms of reference (TOR) was presented to the government on May 31, 2018. The final TOR were confirmed and released on November 12, 2018, and specified that the Royal Commission would investigate abuse in care for New Zealanders who lived in a range of care settings from 1950 - 2006, while expanding the scope of the investigation to include faith-based care settings. Amendment to the original terms of reference came three years later in July 2021 (Royal Commission of Inquiry Abuse in Care [RCOI], 2022), when the scope of investigation was narrowed to investigate in detail abuse and neglect experiences between 1950 and 1999 only. (RCOI, 2021a).<sup>6, 7</sup>

In recognition of the long and pervasive history of violence and abuse in care experienced by disabled people, in 2020 the Donald Beasley Institute was commissioned by the RCOI to contribute to their work by documenting the care experiences of people with learning disability and neurodiversity. The following report, *Tell Me About You: A life story approach to understanding disabled people's experiences in care (1950-1999)*<sup>8</sup>, is the outcome of this important work.

The report begins by contextualising Aotearoa New Zealand<sup>9</sup>'s RCOI in what has become a global movement to recognise and redress violence and abuse caused in state care settings, before presenting the DBI's role in the RCOI and the intent of this project. The methodology is then presented, outlining the importance and use of a Tiriti o Waitangi and trauma informed approach, Individually Responsive Methods (IRM) and informed consent during the research process. The role of Te Kāhui Arataki and culturally responsive research approaches are discussed before the participants (storytellers) are introduced. The methodology section also

<sup>5</sup> See for example, The Royal Commission of Inquiry into Historical Abuse in State and Faith-Based Care: A Preliminary Review <https://cdn.auckland.ac.nz/assets/auckland/arts/our-research/research-institutes-centres-groups/ppi/ppi-reports/complete%20report%20Winter.pdf>

<sup>6</sup> Despite the reduced time period of the investigation implemented during the 2021 amendment, experiences outside of the period were still considered as a way of informing recommendations.

<sup>7</sup> See Appendix A for detailed timeline of Royal Commission Inquiry into Abuse in Care

<sup>8</sup> Hereafter *Tell Me About You*

<sup>9</sup> Hereafter Aotearoa



provides detail about the engagement process and health and safety considerations. Before the stories are presented, details about how they were developed are provided. An ecological model of disability abuse and violence is then used to analyse the findings from an individual, relational, community and society level, with the different levels then woven together to form a holistic understanding of the stories. A final discussion then shifts the focus from past experiences, to the future direction of the Inquiry, particularly in relation to redress from an ecological model perspective.

## 4.2 International inquiries

Abuse within institutional settings is not a phenomenon isolated to Aotearoa. Inquiries investigating abuse in care, including factors that have contributed to this abuse, have occurred in other countries. A brief summary of some of the most relevant inquiries are detailed here to highlight how abuse in care is globally recognised as having impacted multiple generations of people across the world.

Close to home in Australia, multiple state-based inquiries have been commissioned. One example is the South Australian Children in State Care Commission of Inquiry (CSCCI). The CSCCI was announced in 2004 and inquired into allegations of sexual abuse and deaths as a result of criminal conduct, as well as state handling of allegations between 1930-2004. The final report was released in 2008 (Mullighan, 2008), leading to a public apology. The apology acknowledged both the abuses that took place, as well as the state's failure to meet its obligation to protect children from abusive experiences. 49 of the 54 recommendations contained within the 2008 report were accepted, culminating in the state investing \$190.6 million in initiatives to keep children safe in accordance with the CSCCI's recommendations.

Following the CSCCI and several other state-based inquiries in Australia, a national inquiry was announced in 2012 - the Royal Commission into Institutional Responses to Child Sexual Abuse. The purpose of this Australian Royal Commission was to inquire into "institutional responses to allegations and incidents of child sexual abuse and related matters," as well as identify what could be done better in the current context (Royal Commission into Institutional Responses to Child Sexual Abuse [RCIR], 2017, p. 17). The final report of this comprehensive inquiry (RCIR, 2017) resulted in a national apology and a raft of promises from the Australian Government including: a 'Message to Australia' commemorative book with messages from survivors; a National Redress Scheme providing "counselling and psychological services, monetary payments and, for those who want one, [...] a direct personal response from the institution where the abuse occurred"; a National Office for Child Safety (for prevention and detection of child abuse); higher standards for working with children and a national database; and funding for a national centre of excellence to raise awareness and support helpseeking (Morrison, 2018, p. 3).

Directly relevant to the focus of the current report, in 2019 Australia launched the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, which has the extensive power to inquire into the abuse of disabled people in all settings and contexts, past and present. The inquiry was also charged with exploring and identifying ways



in which governments and institutions can better prevent abuse; protect disabled people from future abuse; and determine the best practices for reporting, investing and responding to abuse (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2021). This explicitly disability-focused inquiry is ongoing (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2020).

Further afield, Germany is also part way through their national Independent Inquiry into Child Sexual Abuse (Unabhängige Kommission zur Aufarbeitung sexuellen Kindesmissbrauchs). Announced in 2015, this inquiry is investigating “sexual violence in institutions, in families, in the social environment, by foreign offenders or in the context of organized sexual exploitation” (Independent Commission for the Study of Child Sexual Abuse, n.d.), from 1949 to the present. Although the inquiry was scheduled to conclude in 2019, it has been granted an extension until the end of 2023. Given the inquiry is ongoing, there are no concrete outcomes or recommendations to report at this time.

In Canada, the Canadian Law Commission was called on to prepare a report outlining “the means for addressing the harm caused by physical and sexual abuse of children in institutions operated, funded or sponsored by government” (Law Commission of Canada, 2000). As the inquiry has played out, the inequitable impact of abuse on indigenous children have become very apparent (Facing History & Ourselves, n.d.). The Law Commission’s report was released in 2000 and in 2011, the Government of Canada released their report of response, more than a decade later. The Government of Canada outlined a range of measures that had either been implemented, or committed to, during the period since the inquiry’s findings had been released. These included: an initiative promoting healthy child development and early childhood development (“National Children’s Agenda [NCA]” and “Early Childhood Development agreement”); a family violence initiative; research initiatives into abuse prevention; a national strategy on community safety; a crime prevention initiative; screening of people working with children; protections for victims in the criminal justice process; and signing international agreements such as “the UN Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children”, to supplement the United Nations Convention Against Transnational Organized Crime, in December 2000” (Department of Justice, 2011).

Similarly, in the European context the Swedish Commission to Inquire into Child Abuse and Neglect in Institutions and Foster Homes was launched in 2006 and ended in 2011. This inquiry investigated the experiences of abuse and neglect of children between 1922 and 2003 (Ministry of Social Affairs, 2010; Wright et al., 2020). The recommendations generated through the Swedish inquiry led to a specific inquiry into appropriate redress for past abuse, the issuing of a public apology, the establishment of a financial redress scheme, and the development of new regulations and advice concerning the responsibilities and duties of the social services (Lundström et al., 2021, p. 7).

In the United Kingdom (UK), the Independent Inquiry into Child Sexual Abuse (IICSA) was launched in 2014 to investigate the sexual abuse and exploitation of children in state and non-state institutions in England and Wales. The inquiry also had the power to investigate failings of the state relating to the protection of children, and to identify what is needed to



better protect children going forward (IICSA, n.d.). The UK IICSA has encountered difficulties throughout, including at a leadership level,<sup>10</sup> and while the inquiry has recently concluded it is difficult to access specific findings, recommendations and actions related to this investigation.

Finally, the Scottish Child Abuse Inquiry, established in 2015, had the purpose of investigating the nature and extent of abuse experienced by children in care in Scotland; as well as the extent of failings by the institutions who were legally obligated to protect the children (Scotland Government, 2021). This inquiry resulted in a public apology and the implementation of new legislation through the Redress for Survivors (Historical Child Abuse in Care) (Scotland) Act 2021 and law changes to remove barriers to justice for child abuse survivors (Scotland Government, 2021). The government of Scotland also opened a redress scheme for survivors who experienced child abuse prior to December 2004, as well as an initiative named Future Pathways to provide person-centred support to survivors (Scotland Government, n.d.).

From this brief summary of international inquiries it is clear that the Royal Commission of Inquiry into Abuse in Care in Aotearoa mirrors those occurring overseas. The focus of our abuse in care inquiry is similar to many other past or current investigations. Unique to our inquiry into abuse in care is that it is underpinned by, and responsive to, Te Tiriti o Waitangi which sets out a relationship between two societies of mana, and that it recognises the deep and multifaceted abuse experienced by tāngata whenua.

### **4.3 The role of the Donald Beasley Institute in the Royal Commission**

The Donald Beasley Institute (DBI) has been involved in disability research in Aotearoa since 1984. Over nearly four decades, DBI researchers have witnessed both the closure of institutions, and the evolution of the community-based disability service system during this time. Prioritising research based on lived experience, and inclusive and transformative research approaches,<sup>11</sup> the DBI has remained committed to research that ensures the human rights of people with learning disabilities and other disabled people are upheld.

In the 1990s and 2000s, the DBI documented the closure of large-scale institutions – commonly referred to as deinstitutionalisation research - with the aim of providing research evidence that could inform best-practice disability supports and services in the community. Deinstitutionalisation research typically focuses on the process of moving disabled people out of institutions (Sobsey, 1994), and, on disabled people’s lives in their new community-based services and settings (Kim et al., 2001). Research tells us that the deinstitutionalisation movement gained momentum for three main reasons: the appalling conditions in institutions (Blatt & Kaplan, 1974); the idea that disabled people should have life experiences like non-disabled people in their particular culture and society (Nirje, 1985; Wolfensberger, 1972); and the development of a community-based service system (Ericsson & Mansell, 1996).

<sup>10</sup> See Wright, K. (2017). Remaking collective knowledge: An analysis of the complex and multiple effects of inquiries into historical institutional child abuse. *Child Abuse & Neglect*, 74, 10-22. <https://doi.org/10.1016/j.chiabu.2017.08.028>

<sup>11</sup> Examples of the DBI’s research can be found at [www.donaldbeasley.org.nz](http://www.donaldbeasley.org.nz).



Unfortunately, deinstitutionalisation research has not always sought to capture the lived experiences of people while still in, or soon after they leave institutional care. This is one reason why abuse in care has been able to go unchallenged for such a long period of time (Mirfin-Veitch, 2019). So, while research designed to explore the closure of institutions such as Templeton (Mirfin-Veitch, 2005; Grant, 2007) and Kimberley has been conducted (Milner et al., 2008), this research did not typically include an intentional focus on identifying and understanding abuse in the lives of those who resided in these settings. Despite this omission, experiences of overt and covert abuse, loss of relationship, and material poverty of disabled people who have lived in institutions are present within this earlier research (O'Brien et al., 1999), as well as in other oral history projects and biographical accounts (Hunter, 1997; McRae, 2014; People First New Zealand, 2010; Martin, 2014; Smyth, 2004; Spectrum Care Trust Board, 2004; Connections Education and Development Centre, 2005).

During the campaign for the Royal Commission of Inquiry in 2017, the DBI was commissioned by the Human Rights Commission to conduct a literature review about “experiences of disabled children and adults in State Care”. As the title “Institutions are places of abuse” (Mirfin-Veitch & Conder, 2017) indicated, the pervasive nature of abuse in segregated and institutional environments was clearly evident within and across a diverse array of publications. Institutions are places of abuse highlighted that people with learning disabilities, when given the opportunity, shared experiences of abuse in State care. However, because such accounts are often not widely accessed, abuse experienced by disabled people can remain invisible. This invisibility is particularly pronounced for people with learning disabilities or people who are neurodiverse who have been subjected to State care, who did not, or do not, always have the opportunity to communicate their experiences.

#### **4.4 Intent of “Tell Me About You” project**

The *Tell Me About You* project was intentionally designed and conducted to bring the care experiences of people with learning disability and people who identify as neurodiverse into the light. Despite the Royal Commission developing a range of approaches and pathways for State care survivors, including opportunities for disabled survivors to provide their personal accounts of abuse in care, it was recognised that these pathways remained inaccessible to some people with learning disabilities or neurodiversity. To address this situation, the Royal Commission asked the DBI to develop a research proposal with the potential to capture the stories of people with learning disabilities and people who identify as neurodiverse, who had lived in State care but who could not, or did not want to share their experiences via the existing mechanisms offered by the Royal Commission.

The purpose of the research project was to create an opportunity for individuals with a learning disability or neurodiversity who were placed in State or State-funded care, to “speak for themselves.” There had been earlier attempts. The Henwood report on the Confidential Listening and Assistance Service (CLAS), specifically highlighted that people with learning disability did not find their way to this mechanism for people who self-identified as experiencing abuse in State care (Henwood, 2015). Because they did not access CLAS, the



opportunity for people with learning disability to be visible within discussions about redress and to receive restitution was, for the most part, lost. CLAS followed an earlier Confidential Forum for former In-Patients of Psychiatric Hospitals (2004-2007) which hoped to hear from disabled survivors but few came forward (Department of Internal Affairs, 2007). As the least represented group of people to come forward to give evidence to the Royal Commission of Inquiry into Abuse in Care, the current project was designed to offer an alternative, research-based approach for engaging with these two particular groups of people who were frequently subjected to abuse in State care. The DBI drew on a long history of inclusive, narrative-based research to craft a research approach that had the potential to engage people with learning disabilities and people with neurodiversity in a way that would enable them to tell their own stories, in their own way.



## 5. Aramahi/Methodology

Four of the specific aims (10.1 - 10.4) contained within the Royal Commission terms of reference were the focus of *Tell Me About You*. 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).

This methodology section details the approach used to enact the life story approach implemented by the DBI research team to answer these questions.

Fundamentally, the research was underpinned by the principal study question: ‘what was your experience of care?’. This question was deliberately phrased in a way that would enable people to talk about all elements of their care experience, including positive memories and experiences. Most critically, and as indicated earlier, when engaging with people who wanted to talk about their care experiences we did not hold an expectation that people would talk about abuse, either explicitly or implicitly. One reason for this was our awareness that not all adverse experiences are immediately recognised as abusive by those who experienced them. This is often the case for people with learning disabilities who have had limited opportunities to share and reflect on life experiences. The second reason was that some people may be ambivalent or have mixed-feelings about their care experiences and that there must be space for them to share positive memories of people and places. The third reason was linked to trauma-informed thinking and approach, which highlight the importance of a focus shift from ‘what’s wrong with you?’ to ‘what happened to you?’ (Center for Health Care Strategies, 2021).

Te Tiriti o Waitangi was the foundation of this research. Te Tiriti was given expression through Māori governance of the project, and by commitment to kaupapa Māori research methodologies and tikanga. This guiding framework for the research is detailed here to demonstrate our commitment to creating a culturally safe and responsive research project.

## 5.1 Te Kāhui Arataki and Kaupapa Māori research approach

The project was guided by Te Kāhui Arataki, a rōpū with lived experience and expertise on the research kaupapa. Given this was a national project, the rōpū was inclusive of Māori advisors and researchers from across Aotearoa to ensure respect and representation is accorded to 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. At the centre of this was an overt recognition of the whakapapa and lineage of both story gatherers and storytellers. Consideration of hapū and iwi differences and the demand for their expertise by many guided DBI on how to effectively facilitate and maximise the hui we had with Te Kāhui Arataki, our Māori advisory group.

Historically, Māori often experienced harsher treatment within State care due to the impacts of colonisation and systemic racism. Understandably, the māmae (hurt) that exists in the community remains raw and acute. Therefore, Te Kāhui Arataki was critical to the research, particularly in ensuring the project was carried out in a way that acknowledged and held space for this māmae.

Collecting, curating and imparting whānau hauā me tāngata whaikaha Māori narrative/pūrākau aligned with the sharing of mātauranga Māori through the generations.

Relationships with local Kaupapa Māori service providers were sought to access potential Māori storytellers and further ensure all voices were heard. Providing a medium through which Māori abuse survivors could represent their experiences according to Te Ao Māori, Tikanga Māori and Kaupapa Māori methodologies was intended to inform the Royal Commission of Inquiry and resonate within the communities within which their stories more rightfully belong, 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 whakamaio (abuse) and whakarekerekere (violence).

For example, if Māori storytellers chose to take part in the research, they were able to choose to work alongside a Kairangahau Māori story gatherer when exploring pūrākau (see for example, Ingham, et al., 2022), Māori imagery and other indigenous platforms of cultural expression. Rapport building, including phone calls and visits would take place prior to all writing pairs working together, consistent with the kaupapa Māori research principle, kanohi ki te kanohi (face-to-face). At the storyteller's request karakia timatanga (beginning blessing) and a mihimihi (greeting process) could take place before the interview and karakia mūtunga (closing blessing) at the end of the interview. For meetings at the storyteller's home, storytellers could determine what kawa (Māori protocols) to follow to ensure they remained in control without imposing expectations. Like all storytellers, Māori storytellers were able to have support people during the meetings and were informed of their right to do so. Finally, the project had the capability for Māori storytellers to have the option to kōrero all or part of their life-story in te reo Māori, with appropriate translations provided to support this preference.



These aspects were readily available to all storytellers and members from Te Kāhui Arataki which supported recruitment efforts, despite this only one Māori storyteller participated in the project. Although aware of the opportunity to engage with a Māori story gatherer, this person made an informed decision to work with two story gatherers who did not identify as Māori. This was due to the rapport they had built when learning about the research, and potentially because the storyteller was disconnected from his whakapapa. A further issue confronted by both members of Te Kāhui Arataki and the research team was a communicated mistrust of the research given its link with the Royal Commission. Understandably, long-term colonisation and racism which were correctly perceived as underpinning abuse in care, meant that whānau hauā me tāngata whaikaha Māori were reluctant to contribute to the inquiry and/or Royal Commission as an instrument of the State. At a broad level, Māori have endured many inquiries and Royal Commissions related to land loss over many decades, most of which have not led to demonstrated positive outcomes. Furthermore, some whānau hauā me tāngata whaikaha Māori felt directly let-down by early contacts with and processes undertaken by the Royal Commission in relation to the Commission's engagement with Māori including whānau hauā who had experienced tukino (abuse) in care.

Another reason for the limited participation by Māori storytellers was the guilt or whakamā felt by whānau if they had given into real or perceived pressure to place their children into care. The RCOI itself had the effect of triggering past trauma for some whānau. Therefore, parental guilt and a fear that their children were yet again going to be “used” for research created barriers to our recruitment efforts. Given the time constraints of the project, the team recognises that some of these barriers could have been overcome with the luxury of time to build authentic partnerships of trust with whānau hauā me tāngata whaikaha. The team acknowledges the lack of representation of Māori storytellers in this project, and accepts this as a serious limitation of the research.

## 5.2 Trauma Informed Approach

A trauma informed approach also guided the way story gatherers interacted with storytellers. The trauma informed approach is based on the understanding of the impacts of trauma on individuals, including how trauma can influence an individual's thoughts and actions (Wilson et al., 2013). By acknowledging the impact of trauma, the individual is separated from their thought patterns or actions, which serves to encourage practitioners to ask the question “what happened to you?” rather than “what's wrong with you?” (Center for Substance Abuse Treatment, 2014).

The five core values of trauma-informed care are (1) safety, (2) trustworthiness, (3) choice, (4) collaboration, and (5) empowerment (Fallot & Harris, 2008). An important aspect of trauma informed care is that the individual takes ownership of their story (Center for Substance Abuse Treatment, 2014; Wilson et al., 2013). When applied in the context of research, this approach to care shifts the relationship dynamic between the researchers and participants from a hierarchical relationship to a collaborative partnership, mirroring inclusive research approaches used in research with people with learning disabilities.



This understanding of trauma and the core values of trauma informed care influenced the design of the current research, alongside carefully considered culturally and individually responsive recruitment, data collection, and analysis methods. These values also contributed to our decision to invite people who had experienced care to participate as storytellers rather than survivors. Although we deeply respect the kaupapa of the term survivor and support its use in relation to the Royal Commission, we were aware that some of the people who would eventually choose to take part in the research would tell stories of abuse in care but not necessarily identify specific actions toward them or others as abusive, nor refer to themselves as survivors. Storyteller is a term the DBI has used in previous inclusive, narrative-based research with people with learning disability on sensitive topics (Mirfin-Veitch et al., 2021). It conveys that the person talking about their experiences (storyteller) is in control of the narrative and is an attempt to address the imbalance of power that can occur in more traditional researcher-participant representations in research. This research aimed to offer an alternative research-based approach for people with learning disability or neurodiversity to tell their story and for the Royal Commission to have the opportunity to ‘hear from’ people who had, to date, not been heard. A key focus of this research was that people be in control of how their stories were told, therefore necessitating a narrative-based research approach.

In order to indicate the primacy of the storytellers’ narrative within the production of the care stories, researchers are referred to as story gatherers - the people who simply use their skills to assist storytellers to tell their stories in their own way(s). More information about the production of each story is provided later in this report.

### **5.3 Individually Responsive Methods (IRM)**

To further enhance storyteller choice and control over how they told their stories, the research team used an Individually Responsive Methods approach. Individually Responsive Methods (IRM) was developed by researchers from the DBI as a way of including the voices of disabled people whose experiences and subjectivities are difficult to access using conventional research methods (Milner & Frawley, 2019). IRM differs from most conventional research, which typically only offers the people taking part one predetermined way to participate. Instead, 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. IRM is aligned with the trauma informed values of safety, trustworthiness, choice, collaboration, and empowerment, and most importantly, requires story gatherers to build relationships of trust with storytellers. Identifying and making decisions about the way a storyteller might want to first communicate and then present their lived experience compels story gatherers to develop an authentic and holistic understanding of that person.



In the context of *Tell Me About You*, storytellers chose to draw on one or more of the following range of data collection methods including:

- Kaupapa Māori methods including pūrākau (Ingham et al., 2022).<sup>12</sup>
- Semi-structured interviews/ 'Just sitting and talking': Loosely structured interviews about the 'different faces' of care, experiences and nature of abuse and the paths to recovery.
- Walking Methods/ 'Walking and talking': Storyteller's orientating their writing partner to their life by taking them to places that were important and telling them why as they walked.
- Personal Archives/ 'Sharing things that say who you are and what you have experienced': Storytellers selecting and sharing personal archives such as photos, film, music or text that helped them to talk about their experiences of care and abuse.
- Art-based ethnography/ 'Finding creative ways to tell a story': Using art or poetry as a way of thinking and talking about abuse and relationships.
- Telling their story with the help of trusted whānau, friends or advocates, or having them tell their story (as they knew it) for them.
- Telling their story via email or other online technology.

The kaupapa of the project was that the storytellers were the experts when it came to (re) presenting their own experiences of care, including abusive experiences. Taking an IRM approach opened space for storytellers to reflect, interrogate, refine and control the way they were present in the research. IRM was particularly important for this project as it respected, and was responsive to, the diverse communication styles and strategies of each storyteller. In summary, the dual focus on the development of relationship and the methodological flexibility of story gathering method meant that the voices of an often silent or silenced group of storytellers were able to emerge.

## 5.4 Informed consent

Before this storytelling could occur, 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 during the initial informed consent process and throughout the process were based on Supported Decision Making (SDM) Principles and the United Nations Convention on the Rights of Persons with Disabilities (Bigby, & Douglas, 2020; United Nations, 2006), to ensure the autonomy of storytellers was recognised, valued and accounted for. Based on these principles, a protocol was implemented to guide the informed consent process, particularly if storytellers had a learning disability. The protocol is described in greater detail below.

<sup>12</sup> Although not taken up in this research, all DBI projects utilising IRMs include Kaupapa Māori methodologies as part of the suite of methods offered, for example Storytellers could use pūrākau as a way of expressing or telling the story of significant life events or of communicating the Storyteller's feelings. For examples of Kaupapa Māori methodologies within IRM visit [https://www.donaldbeasley.org.nz/assets/projects/Mean-As/PDF-Stories/DB\\_MeanAs\\_Kotepurakautipa.pdf](https://www.donaldbeasley.org.nz/assets/projects/Mean-As/PDF-Stories/DB_MeanAs_Kotepurakautipa.pdf) and [https://www.donaldbeasley.org.nz/assets/projects/Mean-As/PDF-Stories/DB\\_MeanAs\\_lamagoodman.pdf](https://www.donaldbeasley.org.nz/assets/projects/Mean-As/PDF-Stories/DB_MeanAs_lamagoodman.pdf)



The National Ethics Advisory Committee (NEAC) Standards<sup>13</sup> require that disabled people must be presumed competent to participate in research, and also that their informed consent must be gained in order for them to do so. Although most of the people who expressed an interest in the study could clearly communicate their informed consent, several potential storytellers who communicated interest in taking part in the project had difficulty making their intent clear. Aligning with the principles of accessible information and Supported Decision Making, informed consent was broken down to three fundamental components: 1) what the project was about; 2) what each individual would be asked to do as a storyteller; and 3) what was going to happen to their stories at the end of the project. It was often difficult for people to communicate their understanding of and agreement to this last component of the consent process. Often people in this group had things (they wanted) to say, but unfortunately we were not always able to (formally) listen. This was due to the ethical standards that currently govern the research involvement of people who are unable to demonstrate informed consent in Aotearoa.

In order to respond to this challenge and to at least attempt to ensure that people with complex disability were able to claim their (rightful) place in the project, ethical approval was sought which enabled us to talk to their family, whānau or close supporters of those with more complex communication and other needs. Approval was given on the basis that they did not act as a proxy for the disabled person's own voice, but as tellers of the person's story from their own perspective as family, whānau or close supporters. Unfortunately, this strategy did not enable us to include everyone; several people identified by the project champions as having important care experiences to "tell" did not have family, whānau or close supporters who could share the experiences of State care from their perspective. Ultimately three families and close supporters were approached but were hesitant about sharing their experiences and chose not to participate.

Despite the efforts of the research team and champions of the research there are a group of people whose stories were not gathered and therefore do not form part of this report. We heard about some of their experiences in the recruitment process to gauge eligibility for the research. While they were eligible and their stories relevant, it was not possible for these to be heard and included in the report. Despite this we acknowledge that significant parts of their lives were lost to institutions and their stories remain untold and invisible.

## **5.5 Engaging with Storytellers in the Tell Me About You project**

Between 2021 and 2022, sixteen people, including people with a learning disability, people who identify as neurodiverse, and family members of people with a learning disability and/or neurodiversity chose to become storytellers. Initial engagement occurred via project champions working in mainstream and kaupapa Māori disability support services or via allies, advocates and close supporters of interested individuals. A small number of neurodiverse

<sup>13</sup> NEAC Standards: 5. Disability Research <https://neac.health.govt.nz/national-ethical-standards/part-two/5-disability-research/>



storytellers learned about the project directly from members of the research team as a result of longstanding relationships and their desire to share their story with the Royal Commission in a different way.

Project champions from disability services were invited to meet with story gatherers, where the purpose and the process of the project was explained. As anticipated, this was a critical step in reaching potential storytellers, who were supported by formal disability support services providers. Building trusted relationships with project champions enabled us to identify and reach out to potential storytellers, particularly people with learning disabilities whose participation was mediated by disability support services. At the end of the meeting, project champions were given an Easy Read version (in English or Te Reo Māori) of the Participant Information Sheet and Participant Interest Form to share the project with potential storytellers. This approach gave potential storytellers with learning disabilities an opportunity to learn about the project in a 'safe way'. This allowed them to consider their participation in the project without any sense of obligation to the research team.

In keeping with the IRM approach, storytellers were also assisted by project champions or the project lead to choose the story gatherer they wanted to work with. Practically, there were some restrictions to their choices due to some geographical limitations. However, storytellers' choices were upheld to the greatest extent possible. Early meetings were focused on building rapport and exploring the supports and accommodations the storytellers needed to tell their story. When sufficient rapport had been built, story gatherers asked for the storyteller's fully informed consent to participate.<sup>14</sup>

In addition to challenges relating to informed consent, COVID-19 also had an impact on recruitment efforts. During the recruitment phase (September 2021 to February 2022), COVID-19 response alert levels changed multiple times. This meant that disability services - particularly kaupapa Māori disability services - were under pressure and not accepting outside visitors. This also restricted the process of building rapport with project champions - many of whom were engaging with potential storytellers living in long-term residential services, and who also needed to feel safe with the story gatherer's presence. If project champions felt unsafe or unsure about the engagement with the research or the researchers, this had the potential to limit the story gatherer's ability to build a relationship with both the project champion and the storyteller. As a result, the original aim of gathering stories from 20 storytellers was not achieved within the timeframe. With freedom of movement, increased time, and the absence of COVID-19 restrictions, there is no doubt the original sample target of 20 storytellers would have been met.

As this project was a research project, all Storytellers were offered koha in the form of a \$100 voucher of their choice to acknowledge their contribution to knowledge creation.

<sup>14</sup> The storytellers were able to take as much time as needed to understand what they were consenting to. Story gatherers read out the consent form to them, and asked questions about their understanding. Where clarification of their understanding was needed, their caregivers who knew them better went over the information with them and addressed any questions. The consent form was given in Easy Read format. Our full informed consent framework is available upon request.



## 5.6 Demographics

Of the 16 storytellers who participated in “*Tell Me About You*”, 12 identified as male and four identified as female. Fourteen 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 were autistic, and one storyteller had a neurological disability. In addition, at least three storytellers also had known co-existing learning disability and physical disability, learning disability and neurodiversity, or learning disability and psychosocial disability. One storyteller shared his perspective as a family member alongside the disabled person who had experienced State care. A final storyteller shared institution records to tell the (system’s) story of her disabled siblings who did not use spoken words to communicate.

The care contexts included eleven storytellers who had lived in State-run institutions, four who had attended faith-based schools, and one who had lived in foster care. Nine Storytellers had lived in multiple care settings, including faith-based schools and psychiatric institutions. Currently, five storytellers live independently, with three supported by support workers. Nine storytellers now live in residential homes run by Disability Support Services (DSS).<sup>15</sup>

## 5.7 Health and safety of storytellers and story gatherers

It was expected that some of 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 Participant Information Sheet and Informed Consent process were explicit about the research focus and possible conversational themes, and potential storytellers were encouraged to reflect about the pro’s and con’s of their participation. This was often done alongside their project champion or close supporter.

Allowing sufficient time for trust to develop, and the use of IRM, provided storytellers with the ability to control the way they told their story (including determining when and where to meet and which conversational methods were adopted or adapted). These individually responsive research design elements were intended to enhance feelings of personal safety and allow storytellers to control what they disclosed. Storytellers were also encouraged to contact their story gatherers at any time during the project. At each stage of the interview, story gatherers reminded storytellers that the interview could be paused or stopped if it became difficult for the storyteller or when navigating sensitive issues. Significant effort went into ensuring each research encounter ended on a positive and affirming note. As a minimum, storytellers who were judged to have been particularly emotionally affected during a research encounter were contacted the day after the interview as a way of checking the person’s emotional wellbeing, and determining if any further support was needed. For some story tellers there was ongoing contact over several months as the storytelling raised new memories and the

<sup>15</sup> One family member told the story of two siblings who were not directly involved in the research themselves.



stories were crafted into an appropriate form for the final publication. Despite taking direction from the storyteller in such situations, further and ongoing liaison with the close supporters about support needs also occurred, with the particular storyteller's knowledge and approval. When required, storytellers were given information about and the contact details of a range of relationship, counselling, sexual abuse and violence recovery services and other support groups in their community. In some instances storytellers and/or their supporters expressed some confusion about the difference between the research and the investigation being undertaken simultaneously by Royal Commission staff. The DBI researchers managed these situations when they arose by giving individuals more time and detailed information.

Co-creation of stories and privacy of storyteller information are central to Kaupapa Māori and IRM methodologies, which also have a focus on relationship building. Approaches were used to ensure storytellers felt comfortable when making decisions about how they wanted their stories gathered and how they wanted to craft their stories. Each storyteller met with their story gatherer at least three or four times, but sometimes more, to tell their stories.<sup>16, 17</sup>

One key consideration for storytellers was the option to, and associated risk of using their own names. These risks were clearly stated in the Participant Information Sheet and covered again during the Informed Consent process. However, in keeping with the DBI's stance that informed consent is an ongoing process throughout research, the storyteller's initial consent to story gathering was revisited as the research progressed. At each interview, story gatherers began by confirming the storyteller's informed consent, and seeking permission from each storyteller to make an audio recording and take notes of the conversations they shared together. All of the recordings were turned into verbatim transcripts by DBI's own "in-house" transcribers. The transcripts were then used as a guide to help craft the story. In many of the stories, the questions asked by story gatherers were simply removed and the stories were the exact words spoken by the storytellers with little or no alteration. This was an incredibly powerful process for storytellers who were often perceived by others (and in some cases themselves as having few words and little to share. Hearing their own words spoken back to them was often an emotional but validating experience, and a privilege for story gatherers to be part of. The details of each story's development are shared at the end of this methodology section.

When the story was drafted, storytellers and story gatherers met again to review the story. In most cases it took a few more meetings to edit and add more details to the transcript, to the point that the storytellers were happy with their story. Storytellers who wanted to be identified were again alerted to the potential risks of self-identification. Once storytellers were happy with their story, and had decided on whether to disclose their name or not, they then gave final permission for story gatherers to publicly release their story in this report. For some, the

<sup>16</sup> In addition, the DBI team collaborated with the RCOI Disability Engagement Team, and storytellers could access the support measures offered via the Wellbeing Framework to disabled survivors of abuse, including a Personal Advocate sourced via the Personal Advocacy Safeguarding Adults Trust. This support was not utilised.

<sup>17</sup> For story gatherers, peer debrief sessions were always readily available from other research team members. If and when more support was needed they were able to access appropriate professional supervision, or cultural healing practices such as mirimiri.



detail they chose to leave out of their story indicated deeper māmae they were not prepared to share at this time or spoke to a deeper storyline that merged at times with guilt about their role in abusive situations. For others, they may simply have felt the research was not the platform to share any more openly than they did.

Storytellers who chose to remain anonymous directed how their narrative was de-identified during the writing process, following the process employed by O'Shea (2016). Assisting storytellers to change narrative details was intended to provide them with a continuing sense of ownership over how their story was re-presented.<sup>18</sup>

## 5.8 Development of the stories

To showcase the uniqueness of each story's development, and the importance of relationship to this project, a description of how each storyteller and story gatherer worked together is shared below. Following these descriptions, their stories are shared in full, in the same order. As already noted, the delicate balance between creating space for storytellers to freely share their experiences of care and avoiding risk to the natural justice of others is acknowledged in this research. For this reason, in discussion with the storytellers, efforts have been made to de-identify any information that may carry risk to another person's privacy or access to natural justice, or that which could damage important relationships.

As noted above, some storytellers have chosen to use their real name while others decided to use pseudonyms to protect their identity. These individual choices are indicated at the end of each story development description.

We acknowledge the bravery of each storyteller for sharing their authentic self and stories with us regardless of whether or not they used their real name(s).

### **A**<sup>19</sup>

A was introduced to the research team by a disability service provider. He lived in Hokitika on the West Coast, and talked about his experiences of care in Seaview Hospital. A was very clear about the purpose of the research, and assertively gave his informed consent. A worked with Brigit, a fellow West Coaster, to tell his story. Because of the long distance between them, A and Brigit had two blocks of several days together to develop A's story. A was a wonderful storyteller, with incredible memories of all phases of his life, delivered in rich detail. A was an active person, so walking and talking was the obvious IRM to use when piecing together the story of his time in care. A and Brigit spent a lot of time during one of their sessions on site at Seaview Hospital, and A got to revisit, for the first time, the villas that he had lived in, and other spaces he occupied as a 'patient' at Seaview. His recollections were vivid and insightful, and he was very clear about the parts of Seaview that he was happy to revisit, and those areas that were emotionally off-limits. A and Brigit signalled the

<sup>18</sup> Before the analysis process began, the stories were read by a researcher to ensure the risk to natural justice was minimised. The purpose of the project is to create a space where storytellers could tell stories that are true to them, and in a format of their choosing. This meant there was a delicate balance between honouring this purpose and making sure any risk(s) to natural justice were reduced.

<sup>19</sup> This pseudonym has been chosen for no specific reason other than that it is the first letter of the alphabet.



end of storytelling sessions with tea and cake in a local cafe, with the conversation turning to local news and their shared West Coast history.

This storyteller chose not to use his name or to name other people in his story.

### **Rosie**

Rosie also lived in Hokitika, but was not a life-long West Coaster. Rosie was introduced to the research team by a disability service provider, and she took the opportunity to tell quite a different story about her time in Seaview Hospital. Rosie also told her story to Brigit, over several sessions. She was happy to sit and talk about her life, sometimes using photos to show Brigit people and places that were important to her. Unlike all the other storytellers, Rosie was positive about her time in care, but would still rather live in the community as she does now. Rosie's story is instructive as it tells of a particular time in one institution's history, and highlights that some disabled people in care were treated differently to others.

Rosie chose to use her real first name in her story.

### **Graham P**

Graham was introduced to the research team through a local disability support service provider. He chose to work with Eden. From the beginning he communicated very clearly that he was keen to tell his story. He also articulated clearly when he wanted to stop talking about some of the memories from the institution but repeatedly mentioned that "you welcome back anytime, if you can" indicating that he was happy to talk to Eden. This was very reassuring and a demonstration of assent and that he knew it was his choice and that he had control over his participation.

Throughout reading his story to him, Eden paused frequently to check in with Graham and he confirmed that each part was true to his view of his life. As Eden got to the end of the story, it talked about how things are now, and for Graham, things are much better. There was a complete change of tone, energy, and presence in Graham. He was so happy, beaming "this is my story". It was a magical moment, difficult to describe. Listening back to the audio was lovely, an example of what this work is able to do with the people involved. To have lived that life and to have a moment of full circle. Eden would have liked to capture his reaction at the end. How happy he was to be seen, heard and acknowledged. Eden said to Graham, "you've been through a lot, but there is a happy ending" and he beamed, smiling ear to ear, and said "yep."

Graham chose to use his real first name in his story.

### **Rawiri**

Rawiri was introduced to Brigit and Umi through a disability support service. They met with him twice to establish rapport and relationship before the story gathering process began. Rawiri is Māori and he had the option of working with Kelly, our Kairangahau Māori researcher. However, because he had already established a relationship with Brigit and Umi he chose to continue working with them, with Kelly in support if needed. His supporters



also joined the meetings to make sure he felt comfortable. He preferred short meetings, so we met for short but frequent periods of time at his home over a few months. Rawiri gave Brigit and Umi insights into his life before and during care through his recollections of the music and fashions he liked, and through other experiences he shared with Brigit and Umi. Although he sometimes struggled to remember what exactly happened in his life, he had a good memory about Brigit and Umi's lives and asked follow up questions from the previous visits. Before the story gathering process began, his close supporters were concerned that telling his story might cause him some distress but the story gathering process went smoothly. However, on their last official visit to sign the story off, he found it very emotional to listen to his own story in its entirety. The dark feelings that were a feature of his life were stirred by hearing himself tell his own story. Brigit and Umi made sure Rawiri had the support and time he needed to process his feelings. His response to his own story was a stark reminder of the māmae that he felt for the part of his life that had been stolen by institutional care.

He chose to use a pseudonym for himself, and for other people he talked about in his story.

### **Graeme**

Graeme learned about the research from his disability service provider, and was very clear about his intent to take part in the research. Graeme knew Brigit a little bit before expressing his interest in taking part in the research, so he was comfortable with her being his story gatherer. Talking is difficult for Graeme but he loves to be listened to. So for him, just sitting, talking, and being listened to over a cup of coffee was the way he wanted to tell his story. Over several sessions, the story of Graeme's time in care emerged. It is told almost entirely in his own powerful words. At the end of the story gathering process, when he heard his story spoken back to him Graeme became emotional. He asked Brigit to read his story out to one of his close supporters. The story moved her to tears as she had never heard a detailed account of Graeme's experiences of care, and how he felt about those experiences before, despite having supported him for a long time.

Graeme chose to use his real first name in his story. He chose not to refer to anyone else by name.

### **Jabert**

Jabert was eager from the beginning to tell his story and contribute towards this research. He was very organised and having discussed the research with his primary caregivers, had already signed the consent form by the time Kelly called him to discuss the next steps. Kelly conducted three interviews and once she had written the first draft of the story she met with him again at his house to go over his story. Jabert listened well and was clear and articulate about which parts he didn't want to include, which parts needed to be corrected and which parts needed to stay in his story. He preferred to keep the stories of hierarchy, bullying, neglect, isolation in a small corner of his memory to give greater space and preference to the memories that sit well with the life he lives now. That includes the community of staff



and residents at Templeton – the friendships that formed at Templeton over the years from children to mature adults. The length of knowing and supporting each other was the might that got them all through their years of institutional care. Jabert’s storytelling saw Kelly and him revisit Templeton Centre. This walk and talk around the old Templeton site enabled him to be an expert; sharing his knowledge with the current owner of the land that Templeton occupied. He was also intrigued with the photos Kelly and a photographer had taken during the walk and was thrilled to have a copy of all of them for his room.

Jabert chose to use his real name in his story, but other people’s names have been changed.

### **David**

David had seen Kelly come in and out of his house to meet with Jabert when she was checking Jabert’s story. He was curious about why Kelly was there and was eager to tell her about his stories at Templeton. David was a social person, keen to show Kelly things that he enjoyed doing, such as his games on his ipad, the model sets he had made and generally talk to Kelly about what he had done that day.

David told his story at his house, often in the recreational room with his primary caregiver in attendance. David brought photos to these sessions showing Kelly school photos from his time at Campbell Park. He often laughed and had a great sense of humour and in this humour David seemed able to speak more frankly about the times of being misheard, misunderstood and mistrusted. He has been in his current residential house for over 23 years. The people he shares the residential house with, including staff, are his whānau and closest friends. When asked about why he went into care David responded with, “because I did wrong” or, “I didn’t do the right thing.” There is a deep sadness around this answer; David believes he deserves to be in care.

David chose to use his real name in his story.

### **Sarah**

Sarah, the sister of two older brothers who lived in different institutions in different regions of Aotearoa, spent a decade trying to find out what happened to them before she found them both as older adults. Sarah and Hilary corresponded via email during the pandemic before meeting in person. This story was mainly compiled after several intense days of reading through and discussing the files that Sarah had managed to obtain.

All names used in this story are pseudonyms.

### **Lusi**

Kelly and Umi already knew Lusi prior to the project, and when Lusi was asked whether she would be interested in telling her story, she agreed. Lusi also chose to work with both Kelly and Umi as her story gatherers. Lusi does not have learning disability or neurodiversity, but she was considered to have a learning disability during her time in Kimberley institution. She recognised that taking part in this project was a safe way to share her story. Lusi mainly uses an ipad as her communication device. During the story gathering process, she used the chat function on Zoom for spoken/written communication.



She expresses herself dynamically through non-verbal communication such as her facial expression, body language and her laughter. Due to COVID-19 restrictions, over eight months Lusi and the two story gatherers met via Zoom to listen to and develop Lusi's story. The principles of talanoa, which is a Samoan, Tongan and Fijian word to describe talking and sharing ideas, guided the story crafting process by emphasising the feelings and conversations beyond words. As chosen by Lusi, and in keeping with the values of talanoa, the final story is presented in a conversational style.

Lusi chose to use her real name in her story.

## **Jen**

Hilary and Jen first met at an event in the early 2000s where Jen was speaking on the topic of autism. Jen was diagnosed with autism as an adult, which explained much about her life experiences; she was puzzled by, and felt different to, other people. Since her diagnosis, Jen has been involved in providing practical information for other autistic adults.

Due to COVID-19 restrictions and personal preferences, the discussion between Hilary and Jen was conducted mainly, and has been preserved, as an email conversation. Hilary suggested some questions to prompt Jen which she referred to and responded to in correspondence during late 2021 and early 2022. Two chapters from the first edition of Jen's popular autobiography *Congratulations! It's Asperger's Syndrome* have been made available via the Donald Beasley Institute website in conjunction with her story for this project. The chapters add significant insight into Jen's experience of State care. In her story, Jen also suggests what needs to change so that young people with autism can find the information and support they need.

Jen chose to use her real first name in her story.

## **Janet**

Janet and Hilary have been friends for about a decade. Janet is originally from Aotearoa New Zealand but currently lives in Australia where she is completing a law degree. Janet was placed in foster care as a baby until she left when she was teenager. She was diagnosed with autism as an adult. Janet's story was compiled over several months from conversations by email, Zoom, Facebook messenger and finally in person.

Janet chose to use her real first name in her story.

## **Tim**

Tim's story was recorded by Hilary over four Wednesday morning sessions at his home in late 2021. For most of the time his regular support worker was present, and he occasionally added comments. Tim is an animated and colourful storyteller and he talked about his childhood and family life in Fiji and his adult life in Wellington, as well as school days at Marylands. Tim has written two short memoirs: *The Lost Boy* (about his abuse at Marylands) and *The Kingfisher* (about family life in Fiji).<sup>20</sup>

<sup>20</sup> You can access these stories from the DBI website:



He provided evidence for the Marylands hearing of the Royal Commission about his own experience of sexual abuse by a fellow student that has caused him a lot of anguish, anger and questions in the decades since. Because of COVID-19 the 2021 hearing was postponed until February 2022 and then went online. Tim had hoped to be there in person but instead he and Hilary watched the live stream of the stories and evidence from his home. It was an intense experience for him hearing about the extent of abuse and recognising names and places from his Marylands days.

Gathering and telling Tim's story and getting the initial transcripts into an agreed shorter format took several meetings over several months of relationship and trust building. Tim also showed Hilary photos and artefacts. The process also involved coffee and cake, as well as chats with his parents. Both he and his support worker caught COVID-19 which delayed visits to finalise his story.

Tim chose to use his real name in his story and changed some names in the story to pseudonyms. Real names are used for Brothers at Marylands whose names are already in the public domain due to them having been convicted of abuse of students at Marylands.

### **Allan and Nathan**

This story is about two old friends, whose life paths crossed time and time again throughout their lives in different care settings. They now live in the same community. Allan and Nathan wanted to reflect on their stories together. Umi knew these two friends before the project began, and when they were approached to participate, they were keen to work with her to develop their story. They have monthly dinners at Allan's house with their close supporter, so Umi joined these dinners over three months to gather their stories. On one occasion Allan and Nathan, together with their close supporter, also came to the DBI office for a story gathering meeting. Indicating his informed consent was slightly tricky for Nathan, but with support from his close supporter and using supported decision making strategies, informed consent was finally obtained. The contrast between their time in care and their life now is very vivid. Allan would sometimes talk for Nathan, and Nathan was happy for him to do so. Similar stories were repeated over the story gathering process, which highlighted important and memorable moments in their lives. At the end of each meeting, Nathan would say, "I enjoyed this." Both Allan and Nathan were pleased with the story they crafted together, which reflects where they are at in their lives currently.

Allan and Nathan both chose to use their real first names in their story.

### **Michael and Trevor**

Trevor was introduced to Eden to share his experiences as a father whose son had spent time in a faith-based school specifically for boys with learning disabilities. Trevor believed that Michael had been abused at a faith-based school. Trevor expressed that it would be too upsetting for Michael to talk about his experiences so Trevor would share on Michael's behalf. Trevor and Eden spent a good amount of time getting to know each other and building rapport. There was a lengthy discussion around the nature of Michael's consent,



as the story was to be from Trevor's perspective, but the discussion would still be centred around Michael's experiences.

After the first two sessions, Michael decided to join Trevor and Eden. Eden checked with Michael to see if he understood the purpose of the meeting and to see if he was comfortable. Once he had confirmed, and consented to the interview being recorded, the interview proceeded. The interview took the form of a casual conversation and Eden carefully moved away from the topics that Michael had signalled he was uncomfortable with. Eden made sure to finish up the meeting on a positive note.

Once the story was complete, Eden met with Michael and Trevor once more to check for accuracy. At each pause, Michael and Trevor would reminisce about their shared memories. By the end, they both approved the story as their perspectives and signed a consent form so that their sign-off was clear. Trevor, Michael and Eden had extensive discussions about what names to use, and by the end of their time together Trevor and Michael had both decided to use their real names. They left very happy and thankful for their experience and support in sharing their stories, especially given the evolution from a father's story, to a story of a father and son.

## 6. Kōrero/Stories

The following section presents sixteen stories. Te Kahui Arataki and the research team view the stories as precious taonga (gifts). While storytellers have told these stories in the context of and to make a contribution to the current inquiry into abuse in care, they will now be in the public domain forever. We ask that they are respected every time they are read or drawn on for any purpose now and in the future.

### **"I still have a fear of the dark..."<sup>21</sup>**

I was born in Wellington, North Island in 1951. And last July, I was 70.

Me Pa and Mother were old, old before they died sort of thing. We lived in by the beach [down] by Greymouth. We moved there [when] I was four or something years old. We went to [our local] primary school. From Primer 1 to Standard 4. And two years in the Greymouth High School, on High Street.

I had a lot of brothers and sisters – 5 boys and 5 girls, a big family. Ten kids and Pa and Mother. I was in the middle sort of. One of my sisters' [went to] Seaview psych ward when she was 15. Another sister died years ago. I've got two older sisters. Oh! And I have got a younger sister too that I just remembered. [One brother] is about 80 something, [two] brothers are younger than me. [And another brother] he died too, a while ago.

We lived [close to] Cousins, Uncles, Aunties there was heaps of us in [our] family.

Pa worked in a coal mine, just past Greymouth. Yeah he was a real muscle man sort of thing, with a big Banjo shovel. He had those callouses on his hands. I still remember it all, it's still there. He was good to me and I was his best son sort of thing. Yeah, he was good to me.

Mum - she was a bit, ah, retarded when she was born and [one of me older sister's was] born retarded just like my mother was. She was born like it. And a younger sister, she was born deaf and dumb, couldn't talk. She drowned when we were young. We all missed her. I had a couple of my sisters that were retarded, born retarded sort of thing.

[Primary] school was hard for me I couldn't figure maths, numbers and that. But my best subject was that thing I did before [when I was filling out your forms]. Painting and writing. That was my best subject. My spelling sometimes goes wonky on me. It took me longer to learn things. I was a bit sort of slow. As I said the mathematics and that was too confusing. Some teachers were mean and some teachers were kind. Two of my sisters didn't go to school, but my other brothers and sisters were alright.

It was hard for me mother. My dad had to, ah, teach [my mum] how to cook. I can't remember how they met, as I say, my memory's not as good as it was.

When I was at high school, I wouldn't speak to anyone or anything or any people's. I was what do you call it, I was sort of wouldn't even speak to people's or anything aye. I don't really know why but I was a bit worried people would tease me. I wasn't close to my younger

<sup>21</sup> This storyteller chose not to use his name or to name other people in his story.



brothers because they would pick on me. Yeah tease and that and they would tease poor [sister] too. My older brothers and sisters were alright I suppose. Even though [my sister] was older than me I felt like I had to look after her a bit, sort of my other sister before she drowned too. Drowned as I said, I was 10 I think and she was 5 when she died.

During the week I worked with horses, father would wake me up early and he would fix brekkie for me and I used to work with horses, what do you call it? A stable hand or stable boy. I was only 14 or something years old then. Twice a day it was. At the racecourse in Greymouth. I biked over on a push bike over to Greymouth. I can't think now how come I did that thing [the stable hand job].

I went there in the early hours [of the] morning about 6 or 7 o'clock or whatever it was to um, train the horses. They were trotting horses - you know the horses in the sulky thing. I remember I crashed the bloody thing and boomed me head aye. And I had that concussion thing. Twice I fell off the horse and hit the tarseal road and out to it. I fed the horses, the old bran, molasses, hay and chaff and all that. It was good. A sulky, yeah. Bridle and the hobbles on the legs. My boss was - yeah, he was alright as a boss. [I worked for him] right up until I was 15 or 16 years old. And the money I would get paid from the job I would give to me mum and dad to pay for all the food for the kids and that. Sometimes I got to buy some trousers or jeans, sometimes.

Um, [then] I worked with the carpenter people. Ah yeah, just a what do you call them? A carpenter's labourer. Yeah, I liked that job. I was slow, slow, slow as hell you know and they sacked me because I was too slow and all that. Ah, [I was] 18 I think. Oh, I sort of got all emotional about all the different jobs I had. From one job to the other and I couldn't stay long on one job, [I had] a nervous breakdown.

I remember the last job I had, making concrete pipes and products that's right and that was too hard for me, hard work with the bloody concrete. A big round spinney thing, and shovel concrete and gravel.

[I found it hard to learn quickly and I lost jobs because of it]. Yeah, and for one part of it there I was on the unemployment benefit for years and years. I knew people from the pubs. I would go to the pub as a 15-year old and I overdid it a bit, the booze, the alcohol. I got really crook off it aye, and not long after I had a nervous breakdown thing. I over did the alcohol and, in the morning, I would get the normal hangover. I overdid it too much.

When I was on the unemployment benefit [for a] couple of years we used to go down the Greymouth river white baiting [with a] scoop net. My father had a motorcar then. And then not long after I went up Seaview. I was only 18 when I went to Seaview psych villa, [an] 18-year old! I hit the booze too much, the alcohol. I got all unwell. I must've been really bad aye? I was in there permanently sort of. I remember my Pa taking me to Seaview. My sister was already there.

I'd get paid staff pay working up at the gardens at Seaview and all that. I first went there, they had me doing the occupational therapy thing and I made leather belts and all them things.



I was really good at that too, leather work you know. I [also] worked on the laundry truck. Where they had them big laundry bags full of washing. I was even in the painting gang too for one part of it. The billiards and that, I was in a painting gang thing they called it.

Yeah and on Friday after pay day. Friday, was a pay day thing on the staff pay. Me and another patient from [my villa] would walk down to town. They would let us go there by ourselves, to the hotel and in them days there were no pills so I used to drink alcohol then and I didn't get caught with it.

My father got me to bring my sister home for the weekend sometimes, and in them days [there was] a railway road services bus thing. I would take me and my sister home for the weekend sort of thing. And then on Mondays I'd come back with her.

See over there? That's the villa where they had the ladies. The men were in [another one]. There must have been about 20 or something people there. In the ladies one [there was] a great big full-sized snooker table. We had one of them in each villa, a pool table and the nurse fella's taught me how to play. All the other villas they had pool tables in them. In the other villa's they had small pool tables like the one they got just in that room over there.

Those two [villas] - they were both alright. They had a kitchen, big main kitchen and they would bring the meals around in it and they had beautiful meals too, [everyone sat together for meals]. At night time, at sunset, in the skies, the sun would go into the sea and at nights there used to be a beautiful sunset from the window.

I had my own single room thing. I would get up out of bed when I liked, I didn't have much. Just a bed and a bedside table and a locker thing for some of my clothes yeah. I brought [my clothes] from my house from where my father and me mother [used to] live.

Sometimes the old lady that lived next door or below me – the old pension ladies would fiddle round with my washing that I put on the line. Yeah, I did [my own washing]. Yes, all them years I was up there, even though the washing machines them days were oh old, old things. Ringer things. If you put jeans in there then, boom the thing would plop out of the side and nearly get you.

Then I got moved to [villa name], they were mean to poor old [me] in them days. They were mean to me then. [The] nurses in [villa name]. I'd hear it in the lock, big steel key, they'd lock me in there. The male staff, seven of them would grab me and chuck me in there and ever since them days I have had the pain around me back.

If you broke windows or fight any other patients, [you would get put] in the lock-up, no bloody bullshit them days aye, they were really mean to me then. When peoples or someone upset poor [me], yeah I used to go crazy. There always used to be this young fella in [my villa], [he must have been] 18 and I was 21 or something. He used to punch, you know fighting me, he was too strong for me I couldn't handle him aye, yeah no. [I would be] angry if someone upset me or something upset me, I would boom – punch windows. I was getting that good at it, I didn't even cut my hands. [I hit the] veranda window and I didn't even cut my knuckle.



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. Men would rush in there, hold me on the floor, give me a needle in the backside thing to calm me down a bit and then they would lock it all again, big steel key. I would lie on the floor in there, the lock up room in [villa name]. I don't know how many hours they would leave me in there and, ever since then, I have had a fear of the dark at night you know [I still] I have a bedside lamp going beside me bed while I'm in bed.

And that place [over there] with the fence around. That was so we wouldn't escape or whatever yeah, that was that place where they built an ICU intensive care unit and the lock up rooms had the grey leathery beds in there yeah.

Most of the people in there were brain damaged. You know, epilepsy peoples and one patient there a thin, thin man, a boy I mean and he, he lost the will to live and he wouldn't eat or anything aye and the nurses there would shove food in his mouth trying to force him to eat because he wouldn't. Cause he was what do you call it? Lost the will to live or what else. [Person's name] he would have those epileptic seizures and bash into the pool table his old head and the glass door window things he would crash through them and he had all stitches on his face and everywhere.

[Today] was the first time I've had a look around Seaview [since I moved to the community] and shows people's you know. Some of the villas are gone. That big steel key made me remember things. I'm not upset – I'm ok with that, cause the psych hospitals, the national government closed them all down didn't they? I think half of Hokitika peoples worked at the psych villa[s].

I lived with [a friend] after we first left Seaview psych hospital. When she got old and crook, her legs packed up on her, her knees [I looked after her]. I felt more relaxed and that, sort of, once I settled into [that] place with her. That was the first house that me and [friend] went to after this place closed cause, me and [friend] were the best people to go out in the community thing. I've been to heaps of different houses before here. Yeah, me and my friend. Yeah and she died, oh it would be coming up one or two years now. And when I come here [to the cemetery], I used to cry remembering about [my friend], and my sister, dead both of them, and sometimes I have a cry you know. I should have brought some flowers up.

[But] I'm getting on alright with those other four people at the [new] house. And I've got a little key in me locker door thing, a little key to lock all me money and wallet in there, things like that.

I do a lot of walking. Yesterday morning I went for a walk down to the river because you got to keep them knees going.

## **"Happy times" by Rosie** <sup>22</sup>

I was born in the Bay of Islands hospital, on the 6th of November 1957. I grew up in Kaikohe, Northland.

My Dad was a carpenter and my Mum was a housewife. My father passed away in 1975, and in 1994, my mother passed away too. That was a sad time for me.

I come from a really big family. There's five sisters and two brothers. There's eight of us. I'm the youngest. I am a twin – I have a twin brother Bill. I am close to my brother. Sometimes he and his wife sneak down to Hoki to see me. I write letters to keep in touch with my family. I am a good letter writer.

When I was five I went to Kaikohe East Primary School. It was a little school. I liked school, I had friends, and I found the work easy. I liked sport. I played netball. I wasn't that good at it but I liked it. High school was good too - I loved going swimming.

When I was nineteen I left school to look after my mum. Well I tried to get a job in Kaikohe but it was hard because they already had someone employed at the supermarket, and it was a smallish place so not many jobs around.

Anyway, I looked after my mum because half of my sisters were married and got kids of their own and because I was the last one at home I got to look after Mum. Mum and I were quite close. She was grateful that I was helping her.

She was very, very sick at the end. [Her] friend come over and she asked me if she could ring the doctor, which she did and my mum went to the Bay of Islands hospital and they could do nothing for her. She died in hospital. It was hard on me.

I was still living in Northland when my mum passed away and I didn't feel that there was much for me in Kaikohe. After Mum's funeral I spent a month in Rotorua. I spent time with my sister in Rotorua, and then I rang my sister who lived in Hokitika, and I said to her "I made my decision and I'm coming".

It was a big shift down to Hoki!

My family thought it would be a good idea for me to live at Seaview. One of my sisters' worked there. Going from living with my mum in our own house in the community to living in Seaview was a big change. I was thirty-nine years old when I moved in!

I was a bit nervous for a start. I was most nervous about meeting people. There was a lot of people around. It was a bit nerve-wracking meeting staff too. I had never had staff. But I'm a people person so I introduced myself and everyone got to know me pretty well.

In my first months there I lived in House 6 with three other people; me, another woman, and two guys - we got on pretty good. One of them, a guy named Ewan, became my boyfriend!

He was older than me and it was good to have a boyfriend because my mother would not let me have one. No she wouldn't let me, I was not allowed me to have a boyfriend. Sometimes I felt like walking away because of it.

<sup>22</sup> Rosie chose to use her real first name in her story.



When I lived in the house, I had nicknames for all the guys over at the hostel - at Pounamu. I had nicknames for the staff too. And they had a nickname for me – Hairy McLeary!

When I was in the house I sometimes cooked for myself and sometimes I went over to the hostel for meals.

I had my fortieth birthday at Pounamu soon after I moved into Seaview. Pounamu was the old nurses home. There might have been 16-20 people that lived in the hostel, but at the start I lived in the house over the road.

When Ewan passed away I had to move into Pounamu. I had my own room and my own things. I liked the staff there – they were a bit cheeky but so was I. I was a ratbag.

We had lots of adventures. Holidays in Christchurch all together - we used to do holiday swaps with Templeton hospital. It was fun because they have even got a hot swimming pool at Templeton. We had one at Seaview too, right outside Pounamu but it was open air and freezing cold! We also went to Nelson and stayed at the Tahuna Camp. We went out around town and went to Nature Land, which was a small zoo. We got on really well as a group. I have lots of photos of those times.

When I was at Seaview we used to have the Christmas party at the community hall. Grog involved, everyone was there. Everyone turned up at my 40th. I had that at Pounamu. There was no dancing but I had fizzy and two cakes.

I was friends with children that belonged to some of the staff. They were like my family too. I would take them off by the hand and find some goodies somewhere. They are all grown up with kids of their own now. I love kids.

We'd go around all of the villas and to the canteen. And I used to go to OT [occupational therapy]. The bus would pick us up to go back for lunch, then in the afternoon we'd go back to the OT again. Mostly I did knitting. My niece had a little baby girl and I knitted her a baby jersey and the lady put a brown teddy bear on there for me.

I met Phillip at Seaview and I picked up with him. He lived in Pounamu as well. It was love at first sight! He was, he was a good looking guy and fun-loving. We were together for a short time, and then out-of-the-blue his family found him and took him back to the North Island. I never saw him again but I used to write to him. He stopped writing back because he passed away.

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.



We had a choice about who we got to live with, and I moved out with friends, and over the years I have lived in three different houses. I found it was great to be in the community and I didn't look back.

One of the best things in my life was Andrew. We were introduced by someone else, and it was love at first sight for both of us. I was the older woman! I taught him how to cook. We went for drives in the weekend with friends of ours. Sometimes we even went to Christchurch.

We lived in the same house with two of our friends.

One day Andrew went to visit his grandad and didn't come home. I was wondering where he was because he didn't come home for tea. Andrew and his grandad were both shot by a neighbour. Andrew was just in the wrong place at the wrong time. I was in shock and couldn't sleep. I felt very, very upset for a long time. This year it is 10 years since Andrew died. I haven't had a boyfriend since Andrew – I don't want to ever have another boyfriend. Never.

I am settled in this house. I like living with the other four women here. I knew them in Seaview. I get to see my family. I had my 64th birthday with my sister and nieces in Invercargill. We went to Queenstown and went on the Earnslaw. I hadn't done that before. I sometimes call my sister that lives in Hokitika on my cell phone.

I've lived out here for ten years. I love it out here.

It's beautiful. This was a good place for me to get over losing Andrew.

If I could stay out here or move into Hoki I would stay here but I go into Hoki most days. I go for drives, I go to the activity centre every morning, and I go to sunset point, but I like getting home.

I liked Seaview and I was sad when I heard it was closing down. But I like living out in the community more. I've got more choice living here than I did at Seaview.

## **“One thing that I know Stand up for your rights” by Graham P <sup>23</sup>**

My name is Graham P. I was born in Alexandra. Growing up, I lived at home with my Mum and Dad, and my brother and two sisters.

When I was a little boy, I got bowled over by a train in Alexandra. I was trying to chase a kid off the railway track and the train came and bowled me over. I was scared.

I almost drowned in Alexandra. I was at the river with my Mum and Dad. The water went up to my neck. It was deep and I went under. Mum and Dad helped me get out. I was scared. I didn't want to go back in after that.

I went to Dunedin after the train bowled me over. I went to Sarah Cohen School. I remember wearing a black helmet to protect my head from getting hurt because I had turns [seizures]. I spent some time at the IHC Workshop when I left school and then I moved into an IHC house.

I lived in Seacliff too. **I was there right, I said to them I don't like being locked up.** But they did lock me up a lot and for long times. I had to take tablets so I didn't have turns. I had a friend at Seacliff. Her name is Josie. We used to play Snakes and Ladders together. I was good at Snakes and Ladders and would win. I don't play it anymore but I would like to. 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 was falling off the chair. Someone helped me up. She was nice to me. I would have turns and fall onto the floor. The staff didn't help me.

I missed my family. It made me feel sad a bit. **I used to dream about my Mum and Dad a lot.** Mum and Dad are up in Heaven and I was sad about that. I liked them. I treated the staff like family. They didn't treat me like family. Made me sad a bit. No one would comfort me when I was sad.

**Some staff bossed me around and I don't like that.** Some staff were nice to me, like Ivan, he drove a yellow truck. During the day, I would watch TV and listen to music. I liked listening to music. I had a friend there too, his name was Robert. I miss him.

We recorded a Cherry Farm C.D, I sang on it, everyone did. I liked it a wee bit. The Cherry Farm songs were good. I rode a three-wheeler bike there. I went everywhere on it. There were lots of kids there, people around my age. I was in a Villa with nine other people. I had my own room but I didn't like it. There was just a bed in it. I was happy to get away from Cherry Farm all together. **I was in there, but I was sad there. Don't talk about it. Let's stop talking about it.**

<sup>23</sup> Graham P chose to use his real first name in his story.



When I left Cherry Farm, I didn't get to choose where I went. I was put into a house. I was scared. It was a strange place. The people weren't nice. Shoved me in the corner. I used to walk everywhere. I used to walk around the block there but now I can't. It's not nice. I don't remember what happened. I don't remember how I stopped walking. **I wish I could get that back again. So hard. Really hard. It will be good when I get back on my feet again, won't it?**

They put me in hospital too. I wanted to get out. The people were nice but I wanted out. I wanted to go for walks and listen to my music but I couldn't do that there.

**I don't want to talk about it no more. Time to move on.**

**I like it here. I like to be in a big house. Saved my life it did.** I like it here because it's handy to the shops. Seacliff and Cherry Farm were far away. I live close to everything now. I like to be part of things. Part of the community. People take me for walks but I would like to go more. I feel bad when I can't go. I wish I could go by myself but it's hard. It's so hard.

I like my room here, it's comfortable. I have things in my room, I have a T.V set. I have more control and can be myself, look after myself. I do my dusting. It makes me happy. I can relax in my room. I don't get shoved. If I fall and can't get up, people help me. Things are better now. It's all gone away.

A good life is going and looking around shops, getting coffee. **I'll tell you a good thing right, if I'm on a radio show, you might hear my voice everywhere.** I was on a radio show and I can still be on it. There's a song I like. "I'll be home for Christmas, you can count on me". It makes me a bit happy.

**One thing that I know, stand up for your rights.**

**You get together with someone and stand up.**

**That means rights.**

**That means rights.**

## **"I don't know how I got there..." by Rawiri <sup>24</sup>**

I'm 62, but 24 on the inside.

At the moment I live in a house out in the country. We have a big garden, and lots of animals. But I grew up in Dunedin.

We lived in Columba Ave, in the Corstorphine area. There was a dairy on the corner. When I drive around there now I remember some of the houses that my friends used to live in. And we saw Mum's house but I don't think it was really there. It was different! When I go to see mum now it is at the Andersons Bay Cemetery. It says her name on the grave.

Mostly it was just Mum and I in the house at Columba Avenue. Sometimes my brother was there too. I think he was younger than me.

Mum worked at the Gregg's factory, down by the University. She used to bring jellies. Raro sachets of juice. The powder stuff. She used to bring coffee and instant puddings too.

I don't remember too much about my father. He didn't really live with us but he brought us some pāua once to mum's house. I didn't like seafood though. He never visited me in Cherry Farm. After I came out of Cherry Farm, we met with each other a few times but not for a long time now. Probably 10 years. I haven't seen my brother for a long time either, but I remember his wife's name, and my nephew and niece's names too. My father, he's Māori, they're both Māori – my father and my brother. I think I am too. I might be half cast, part Māori?

I can't remember what Primary School I went to, but I think I went to Logan Park for High School. I remember some lady there, but not much else. Oh, I had lots of friends. Sandra. She was the longest. Then there were [a lot of others].

For a while I got into a bit of trouble. Yeah, we used to walk around and get in a car and go and visit people. We had lots of drives and lots of beer. And spirits. I used to have rum and coke. I like my rum and coke. They were good days.

Got in lots of trouble. Got locked in the prison, the one opposite the train station. [It was] an orangey/red brick building. It was horrible and so run down in there. Burglary. Broke someone's window with a hammer. And one of Mum's windows. I had to break my own window once to get in because the key wasn't under the rock by the door outside. I always kept a key under the rock. So, I broke the window and climbed in. But I was lucky I didn't get cut from the glass.

One time mum went away on holiday and we had lots of crates of beer. I think we left a mess.

I was happy with lots of alcohol. And drugs and Marijuana. In the 80's. Used to have marijuana. Hash oil. You used to get the box of hash about that long and that thick. You used to cut a bit off and put it on the .... Not the fireplace. You know, element, the ones that you light up? So you'd move it and sniff it. That was nice. We used to take datura. Friends cooked it up and we drank it and got really high.

<sup>24</sup> He chose to use a pseudonym for himself, and for other people he talked about in his story.



I was on an invalid's benefit. I used to go on this invalid's benefit. I don't know how much I got. Hmm, a bit of money. In the Exchange there was a building there. I don't know if it's in the same area? Umm, it was a place in the Exchange that I used to go to [I think]. Yeah, we got forms and things. Hmm, see I can't remember any of that part. Someone must have taken me there.

My friends [had] a Ford Galaxy. Left hand drive. It had mag wheels. And it had pinky red inside it. It was a nice car. I put money in to pay for it. I did try to sit [my licence] but it didn't work out. I couldn't drive. I asked to but they said "no - you have to have a licence". Once though, a friend and me we were out driving. He was in the driver's side and I asked if I could steer it. And I steered it from Logan Park down to the shop at the bottom.

I was in Cherry Farm, sort of at the side. I think I was about 28 years old [when I went there]. I don't know how I got there. I feel like I was born in Cherry Farm. Did you find out how I got there?

I used to have a swastika on my arm. It's covered up now. When I got [to Cherry Farm], I went to sleep in a room and when I woke up and all of a sudden there were tattoos on me. That one was there when I was at Cherry Farm. Yeah it was really scary. They used to put me in lockdown seclusion. It was horrible. My worst memory was seclusion.

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 had to have a sling for that. But finally someone came and opened the seclusion door in the end. I had to take a blue pill while I was in Cherry Farm to calm me down. All my life I've had medication but um these people at Cherry farm weren't very nice to me. There were two seclusion rooms in my ward. Yeah, everybody would have hated [getting locked up], I should've felt for them more.

I remember some other things about Cherry Farm. One stage in the end, they got the canteen set up. They had drinks and stuff. And smokes that were 25 cents each. And there was a hall and church, and a swimming pool? I think it's still there. I can't remember how long I lived there.

Mum visited me sometimes. And one time she bought me lots of presents. I had a friend who used to come to see me on his motorbike too. Sometimes I would get to go home. Yeah I used to get the mini bus. So they must have dropped me off. Mainly overnight, or maybe a few days, or the weekend. Yeah, I'd get picked up in a car or a bus.

When I left Cherry Farm I went to Wakari Hospital. They had seclusion there too. The staff were a bit hard to get along with and the patients sort of, patients [were] quite, quiet. Some of them were quite tough. [There was a staff person there] who was really tough, oh he actually hit me one day - I might of told ya - I was at Wakari Hospital 9A and he hit me in the back of the head. Oh, he's ah sort of got upset, I did something wrong. He also worked at Cherry Farm.



And then I moved into the community. I had some jobs. Yeah. Sherwood - the place that used to do all the wood and stuff. Is it still open? Yeah, I used to work at St Leonard's at this lady's house. There was a wee farm in there. She had dogs and cats and goats and sheep. We did fencing. You know, you dig holes really deep.

I liked heavy metal. I liked Led Zeppelin, Pat Benatar. I had about 12 of the albums. I used to hire videos from video stores. But now they've closed down. I actually have about 110 records. [I love] Purple Rain. It makes me cry. Not all the time but sometimes. Quite a lot. [The song My Name is] Luca does too. And "Yesterday". I grew up listening to that song.

At the moment I live out in the country. I [can] grow my hair, I don't think I've had it this long, I think this is the longest I have ever had it.

I can have black nail polish, eyeliner and black hair dye.

I've got a tattoo of a tiger now.



## **“I don’t get locked up here” by Graeme** <sup>25</sup>

When I was a little kid I lived in Glen Road with Mum and Dad, my big sister, and my two brothers. My sister wore glasses, and she looked after me. We got on well.

I have lost all my family now. I am sad about that. I loved Mum and Dad and all my family.

Mum stayed at home and done the housework and cooking. She was a housewife. We got on well. Dad used to work on the railways. I think he was a train driver but I never got to ride on the train. Sometimes my Grandad would come around for a cup of coffee and morning tea.

I went to Tahuna Primary School. It was ok for me. I had friends but it is hard to remember their names. Sometimes my brothers and other kids bullied me. I was sad a lot. I liked playing football and rugby with the other boys at school. I remember one teacher. His name was Mr Watson. He used to tell me all about school. I liked him.

I liked the learning. I learned to read and write, but I don’t remember how to any more.

I never went to High school.

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.

Sometimes I would get angry and yell out and put holes in the walls. I find it a wee bit hard to talk about [being at Cherry Farm]. And I don’t like thinking about it. I don’t like Cherry Farm.

I lived in Villa 2 with three other people – all men.

The staff were no good to me at Cherry Farm. They used to give me a needle in the arse.

They would stab it into me. And give me lots of pills. I hadn’t done anything. I was scared of them. [They would] just knock me around because I used to play up and that. They used to ah, hit me.

I got locked up in Cherry Farm. The room was empty. Only floor boards and a big door. I was in that, room for a long time. Sometimes I used to hurt people too - I don’t know why I done that.

During the day I used to work in ah, Morris house, Morris house workshop. I used to make huts and that. Play Huts. We used to sell them. I enjoyed [making them]. Sometimes I got some money.

I started drawing at Cherry Farm because I got bored. I still do artwork. I go to community art studio every week now. I did look forward to going to Church on Sunday [at Cherry Farm]. God is important to me.

<sup>25</sup> Graeme chose to use his real first name in his story. He chose not to refer to anyone else by name.



When I got to leave Cherry Farm, I was happy. I was very, I was, I was very happy to see um mum and my sister. Sometimes I got to go home for the holidays, and for my birthday. I was always happy to go home, and I was upset when I had to go back to Cherry Farm. I had a few friends there. I remember them but I can't remember their names. I lived there for a long time didn't I? It's good that I don't live there anymore.

I've got no family now, only this family. I like it here. I don't get locked up here. I wouldn't want to go back to Cherry Farm.

## **"I was only 9 years old" by Jabert** <sup>26</sup>

Tuatapere, Southland. I was born there. 28th July 1959. I was two months premature.

I was the last baby in our family to be born. I have three brothers. All my three sisters have died but my three brothers are still alive.

When I was two years old I went to a Cerebral Palsy Unit and I began to walk at four and a half years old. I attended this unit for three years and then I left.

I was only five years old.

I then shifted to Christchurch and I remember going to the cerebral palsy school in a taxi. We were in a house on a farm not far from the pub. We had animals. We'd feed them with hay and they'd always come up to me when they'd see me. More hay, hay, hay. I loved feeding the animals.

My father was a hard worker and he died in 1967. I came home from school one day and my brother told me he had passed away and he led me into my parent's room where dad was lying.

I was only 8 years old.

In 1968, I went to Templeton for a short-term stay. My mum found it difficult to manage me so I went to stay at Templeton for short stays and then eventually these stays got longer.

I was only 9 years old.

I've been to the Timaru IHC workshop and I have stayed in some other homes over the holidays. In 1969, I stayed with Mrs Miles for support with my cerebral palsy.

A nurse at Southland Hospital wanted to adopt me to be her son. And Mum said, "no". My brother said, "no", Dad said, "no" and I said, "yes". I wanted to be adopted. She wanted to marry a man and then have her own child and that child was me. All the brothers in my family said, "no you can't take my brother away". But my sisters they said to my Mum, "let the nurse have him - have our brother!"

I was only 10 years old.

At Templeton you had to make your bed and then change the sheets a couple of days later. Then I would go down the hallway to the staffroom. I would get the key off the night staff, unlock the big boys bathroom. The boys bathroom had a bath and showers. My bathroom just had showers.

I was in my 20's.

I'd look after boys who have seizures and that. Make sure they're ok.

The boys did bully others but not me. They didn't bash me. I'd stick up for myself. I had another another friend who stuck up for himself too. The staff would tell 'em off a couple of days later. Those boys were silly buggars. Just some people got pushed around. And I had to stick up for some of the people and not get pushed around.

<sup>26</sup> Jabert chose to use his real name in his story, but other people's names have been changed to pseudonym.



I remember one guy he climbed up the tree. He couldn't get down so my friend climbed up to get him down. And one time a staff member put my friend in the laundry bag and he couldn't get out. So I had to get him out. No worries for me to help him.

He was a good boy ol' T. He knows what is going on. I look after T cos I don't like people hitting him. Staff were hitting sometimes, and I like ol' T. Don't know why they did that must have been mean. Not all staff were mean just some of them. I really liked S at Templeton. She was my main caregiver, she knitted me a jersey and was kind to me. I bought the wool.

Every Thursday I went to Hornby on the bus. I'd have a look around there – sometimes I went with other residents no staff just us.

Some of my friends at Templeton would go home here and there but I didn't much. I would go and see my brother who was in Rolleston Prison. I used to bike around Templeton. I also used to go to the Chapel every Sunday. I was in the choir group before I started working in the store. Yes, then I moved from the choir back to work Monday, Tuesday, Wednesday, Thursday and half day Thursday.

Sometimes at lunchtime, the staff would have a game of basketball. And I said I'd look after the office phone. I took messages, wrote them down. Then L would come back and have a look at the messages and he would ring them all back.

I was in my 30's.

When the nurses went on strike at Templeton I volunteered to help look after other residents. I would go and help in Maple Villa. I was trusted. I had to let the staff know what time I leave and then what time I return. If you play up you go into level one and you go to another villa until the staff came back and get you. In Briar Villa, you couldn't just go out. The staff had to go down and get all the stuff for you. I would go in the van too and get the food from the villas for the pigs and all that kind of stuff. And I loved to go out by myself. I'd walk down the roads, don't know where I'm going just getting out and about around Templeton.

I used to swim in the pool. One day at swimming, one of the girls - staff didn't see her. She sunk under the water and died. I saw her and I had to take my wallet and my bus pass out of my pocket.

I left my shoes on and jumped into the water.

I carried her over to the steps of the pool and the staff took her from there. She had to go away - back to the villa, Kowhai, and they put her in the spare room until the police come, and a coffin.

Yeah, too late to save her. She was already dead. The staff didn't see her. Later the staff said, thank you.

Mum went into a rest home. I had a photo of her. One day I got a phone call and I was told my mum had died. My friend Tony came to Templeton and got me and took me to Mum's funeral.



We went out with the staff to the races. Staff from a different villa took me to the races. Bring me home. Bring me back to the villa. From Rimu back to Beech.

As I got older I started to run away a few times.

I didn't want to stay at Templeton. I wanted to get out. Happy to leave yes. I said to a staff member, Templeton was my life. They said, they knew it was. S said, I'd been there for a long long time. I moved into Beech villa to learn to get out. And I was happy. I was happy with the staff.

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. Yeah. And the parents said, "you can't do that, that's their homes!" And the staff said, "let them get more freedom."

A place was found for me and three others in Halswell. I left Templeton.

I was 40 years.

The trucks brought all our bikes and bags to this place. I can't ride my bike anymore. I'm too big for it.

I like to be happy and enjoying my life. This is a different life. I'm happy going around and seeing people at their houses. I go around them all. When I got out of Templeton I went to different houses to see people. And make friends. I've made a lot of friends.

Living out of Templeton now, has changed me. I'd go down to the supermarket have coffee with friends. They make me coffee in my cup and I go and sit by the table and drink it. I tell the staff where I am going. I can just say I'll be back anytime. I like to go to Hornby and to the Warehouse. Drive down the back road on my electric wheelchair or in the van sometimes - our van has a wheelchair ramp.

My flatmate and me. Us two go to work during the week. We work Monday to Friday at Horizons.

Do contract jobs mostly. But no contract jobs when we're on COVID level 2 . So we go around and help others. And I still get paid for that.

I had a good life at Templeton. I made good friends at Templeton. If we didn't go to Templeton we wouldn't have staff to show us how to cook, do the washing, change the sheets, clean our rooms and polish the floors. I learnt lots at Beech Villa. All the residents have all gone out, they're all gone.

But Templeton is not a home, residents can't work and they end up staying there for a long time. People shouldn't be in places like Templeton because they should be given a chance in a home in their community.

I am 63 years old.



## **“When I Was Small” David’s poem <sup>27</sup>**

When I was small  
Everything was my fault  
But mum knew it wasn’t  
Drink, drunk, punk, dunk

I called out for help when mum and dad were argueing  
I got blamed for getting dad taken away  
But mum knew I wasn’t to blame  
The lady across the road rang the police not me

When I was small  
I did a lot of talking  
Some talking got me into trouble  
Chatter, natter, jabber, blabber.

I just wanted to be heard  
Even my brothers didn’t like my talking  
I would nag my mum for money so I could buy something  
Mum would give me some  
My brothers didn’t think that was fair  
I said to them, “I told mum I was poor and she would hand me some money”  
Mum knew I was being cheeky  
I would take off across the road to the petrol station and spend it all  
on...lollies and coffee.  
Sweet, treat, caffeine, kick.

When I was small  
With a big attitude  
Never shy to speak up  
Boast, brag, bellow, boom.

I would protect girls from being hurt by boys  
Some didn’t think I was protecting them  
Some didn’t think it was protection  
Some thought I was in the wrong  
I was taken away from my family to give mum a break ,they said.  
Let her have a rest from me “I was a handful”, they said.  
I went to Cholmondeley Home when I was around 10 years old  
Then I went to Nazareth House at 12 years old.

<sup>27</sup> David chose to use his real name in his story.



The nuns would take me to church and sit either side of me  
I would be wedged in between them so I didn't run out.  
But my mouth was free and I yelled out, "God is the devil!"  
Nun, shun, spun, no fun.

When I was small  
I went to Campbell Park School in Waitaki Valley.  
I was 13 years old and I went to learn how to put the right shoe on the right foot, and to tie  
my shoe laces.  
But I actually learnt a lot more.  
I got taught woodwork, how to fix a bike and we went camping.  
They had a BMX track and I had a BMX bike.  
There were lots of things to do  
The food was really nice.  
No girls just boys.  
I left when I managed to put the right shoe on the right foot and tie my laces.  
Left, right, left, right.

When I was a little bigger  
I came home and got into trouble again.  
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.  
Soil, toil, ground, found.

I call Templeton "The Dump" and I called the villa I stayed in "Beach Bunny".  
I had my friend J in there too who lives with me now.  
I did athletics and won the 200 metres.  
I had my 21st in Templeton.  
Got a key that everyone signed.  
Someone wrote "xxooxx" – yuck, scrub that out!  
Kiss, kiss, hug, hug.

I had girlfriends at Templeton.  
I talked to lots of girls actually.  
I worked at the printers in Templeton, not paid though.  
I didn't really like my job.  
The ink stunk and it made my hands dirty.



The food at Templeton was not good.  
It came from the kitchens at Sunnyside kitchens.  
I went swimming and to the hall for activities.  
I was allowed to roam around Templeton on my BMX or I walked.

I got put in a laundry bag once by staff and hung up high.  
I told the big boss of Templeton on him – he got a warning.  
I got strangled by another and that staff member got a warning also.  
He later left Templeton cos he didn't like the big boss.  
I saw a staff member slapping a resident's face.  
He kept slapping him. I rang the police. They came.  
They saw marks on his face and knew I was right.  
The police gave the staff member a warning.

Mum would come and see me.  
She took me line dancing.  
She also took me to a rock and roll club.  
I won 3rd place and got a medal.  
Mum danced until she got breast cancer.  
Step, clap, forward, back.

Then she died – she's up there now. In heaven.  
My brother is here in Christchurch and I see him sometimes  
My other brother he took me for a ride on his Harley once  
I loved that.  
And my sister is where the Kangaroos live.

It's bloody hard to describe me as a child.  
Sometimes I would be easy and sometimes people didn't like me.  
I'm used to being in care. I don't mind it.  
I shifted out of Templeton when the big boss said it was closing down.

Came to Halswell with my friends.  
Been here since Templeton shut.  
I can do a lot of things now and can get out and about with staff.  
I like being busy. Making car models, playing x-box, playstation, going to the men's shed,  
making things for me and selling things, and cleaning cars for money. I work at Horizons and  
get paid.



I write up the menus here in my house.  
Fish and chips tonight. Yum.  
I do the gardening here.  
This year I grew sunflowers.  
Sunflowers grow tall – taller than me!  
And the flowers are huge.  
They look real good.  
Big, bright, see, me.

## **“Two Brothers in State Care” by Sarah** <sup>28</sup>

Two brothers, Paul born in 1956 and Ricky in 1964, were institutionalised in two different psychopaedic hospitals in New Zealand. Paul was sent to Templeton near Christchurch at age three in 1959, and Ricky was permanently placed in Braemar, Nelson in 1968 at age four after some earlier respite stays, and was later sent to Ngāwhatu, Nelson. Three other siblings stayed with their family.

The information provided in this account comes from the youngest sibling and only sister, Sarah, who located and met her two ‘absent’ brothers as adults, post deinstitutionalisation<sup>29</sup>. She also includes information from her brothers’ official files which she obtained from the regional DHBs. The brothers never met each other. The files are extensive and cover several decades, although with some gaps in time and years, and include information about their deinstitutionalisation into agency run group homes in two regions of New Zealand. Between them the two brothers spent over 70 years in state institutions.

Paul was sent to Templeton in 1959 after an assessment from his father and two local GPs, signed off by a JP. The application was sent to the Director of Mental Hygiene, Department of Health (Dr R G T Lewis) under the Mental Defectives Act 1911, and the language reflected the requirements of the Act which included he was constitutionally ‘feeble-minded’, ‘unable to appreciate discipline’, ‘attacks his younger brother for no reason’ and ‘never plays with other children’. He was not toilet trained and there was ‘no evidence of emotional attachment to [his] parents’.

Today, these descriptions might indicate a diagnosis of autism, but autism was not widely known about at that time, although ‘childhood schizophrenia’ was sometimes used. Autism was not a diagnosis in New Zealand before 1966, when a British child psychiatrist visited and diagnosed some children with the condition. It took many years to be commonly used. (Although, anecdotally, that diagnosis was not used at all in some institutions including Templeton. A psychopaedic nurse who worked for years at Tokanui till its closure in the late 1990s said she’d ‘never heard autism uttered there.’)

On his application, Paul’s birth date is incorrectly recorded in his father’s handwriting by two months, an error which would have decades-long implications. His mother is not mentioned apart from a suggestion that she had toxæmia during pregnancy. That comment about the mother will be repeated throughout his files for the following decades. In a journey of about three months, the boy is apparently sent from his North Island town to Kimberley near Levin, Sunnyside in Christchurch and eventually to Templeton in November 1959. No mention is made of who accompanied him or how he travelled. Ongoing records suggest he is physically well but has ‘faulty habits’, which is noted on his file for several years.

As a 15-year-old (5 April 1972) Paul had a psychologist’s assessment which stated that: ‘Testing indicates that this resident operates at a profoundly retarded intellectual level, although this may be an underestimation due to the effect of an unstimulating ward situation.’

<sup>28</sup> All names used in this story are pseudonyms.

<sup>29</sup> Sarah and Hilary wrote this story together.



However, he has reached a level of social ability and development of self-help skills which suggests that he could profit from transferral to Maple Ward and participation in the domestic training there.’ He later moved into the large Maple Ward with 33 men at Templeton Hospital, although there is no record of what the ‘domestic training’ involved. He remained there until deinstitutionalised, after 41 years, with the last batch of residents in March 2000 who moved into an agency-provided group home in Christchurch.

His sister Sarah was born seven years after Paul was sent to Templeton and she was a toddler when Ricky went to Braemar. This was the local institution, as the family had moved to Nelson. She was always aware of Ricky’s existence and remembers visiting him at Braemar when she was a toddler and being scared of the place, though these visits soon ceased. Sarah said there was always ‘an atmosphere at home’ about Ricky and an unspoken rule never to mention him. She said ‘everyone knew my father’s volatility at any hint of him, even the neighbours.’ She said she’d ‘grown up with an almost evil, sickly feeling around Ricky.’ There were still photos of him in the family albums and Sarah said he was ‘this gorgeous, curly haired little boy with dimpled, plump arms.’ She found it hard to reconcile what she saw with her eyes (including how dotingly he was dressed, and how mesmerised their father, the photographer, had been) and knowing he was ‘mental’ and had to be sent away. There were also photos of Paul in the albums but Sarah was unaware of the existence of this fourth and eldest brother. She remembers asking her mother ‘who’s that one again?’ as his hair was darker than the other three boys and her mother would tell her it was one of her other brothers. Sarah said that her parents mustn’t have had the heart to completely erase them.

In 1980, the family moved to Australia when Sarah was a teenager. Her mother only told her about Paul’s existence when she was in her twenties. The second eldest brother had always known but was told by his parents not to tell the younger siblings.

The parents left New Zealand without a forwarding address and subsequent letters from the institutions were returned. Sarah believes that her parents’ motivation for moving to Australia was their growing fear about deinstitutionalisation and what it might mean for them - would they have to look after their two boys again, now adult men? Would people find out? Etc.

From their historical records, including photographs and their sister’s descriptions, the brothers were very similar. They were both healthy attractive children and adults with dark curly hair, and distinct personalities. Neither regularly used words to communicate although they used sounds and gestures. Both were medicated from an early age, and later for epilepsy which appears to develop during adolescence, and they each had an early diagnosis of ‘mental retardation’. The label ‘imbecile’ was also used for Paul by a Sunnyside medical superintendent on his entry to state care, and ‘hopelessly retarded’ was used for Ricky by a medical specialist assessing him for entry to Braemar.

The files of the two brothers from the two institutions are also remarkably similar. One major difference is that autism and autistic behaviours are often mentioned in relation to the younger brother from the time of his admission to Braemar. There is even reference to the



theories of Bruno Bettelheim, an untrained psychologist who ran an institution for autistic children in Chicago (from which there were later allegations of abuse of children). He was a popular and internationally read writer and his 1968 book *The Empty Fortress* popularised his theory that cold and distant ‘refrigerator mothers’ caused their child’s autism. The label remained powerful and stigmatising for decades, including in New Zealand, which added to the shame of a diagnosis of autism for families.

As mentioned, autism was a relatively new diagnosis in New Zealand at that time; the Autistic Subcommittee of IHC which would eventually evolve into Autism NZ was founded by parents in 1969.

The Templeton file does not mention autism.

Neither record indicates any access to formal education, apart from a brief note from Templeton, responding to a request from Paul’s mother for information on his wellbeing, suggesting he was attending some sort of Kindy activities on site. In the 1960s it was widely considered that ‘mentally retarded’ or autistic children did not have the capacity to be educated.

The medical director at Braemar found out about the brother in Templeton and in 1974 wrote to her counterpart at Templeton, seeking information about Paul and the nature of his impairment to try and shed some light on his younger brother Ricky’s disability. This request was met with a lack of knowledge and interest from the Templeton superintendent, who wrote back that ‘little is known about the boy, he’s now 10 years old, another patient brought him to me, he seems cowered and small for his age.’ The Braemar director also made inquiries about housing the two siblings together in one institution. However, this possibility is thwarted by their father who writes, in response to the proposal, that two of the other three children do not know about Paul and he wants to keep it that way. Sarah says she grew up sensing her parent’s extreme shame about having disability in the family. She said that people in Nelson, including neighbours, her father’s work colleagues and members of a suburban club/pub that her parents were regular, long-term members of were aware of Ricky’s existence. To have one child with disability known about was more than enough for her parents, and especially her father.

Their father was not an easy person who could be angry and violent and the family were fearful of him. His wife’s voice is not recorded in the files of her sons apart from the very occasional short letter sending money, asking about them and if there’s anything else they need. One reply from Templeton to the mother says, ‘I am sorry to say’ your toddler ‘is happy here.’

The official files contain numerous and regular assessments of the boys as they grew into apparently healthy although slightly built young men. There are differences in how they are described depending on who is writing the report and for what purpose. The same incident or behaviour is portrayed either positively or negatively, sometimes reflecting different staff attitudes. Some staff appreciated the character and personality of the boys and there are



reports that recognise that the environment is not right for them, that they need something with more stimulation, individual attention, more space and less populated/crowded areas and more distraction from other residents, but this does not seem to eventuate. Some reports are infantilising and patronising. What would be seen now as autistic behaviours are frequently pathologised. Both boys/men are portrayed as not interacting with other residents. There are references to Ricky particularly enjoying music and the outdoors and as needing outdoors space, opportunities to walk, use swings and tramps, and that he lost these pleasures when sent to Ngāwhatu (as an adult). One document says that at Braemar, Ricky 'spent most of his time on a trampoline or swing but these have not been available to him at Ngāwhatu' and that since his transfer to Ngāwhatu 'he now shows little interest in walking; when he used to walk some distances.' Another paper, written by the Ngāwhatu Resettlement Project: Independent Service Coordinator states that 'Ngāwhatu was not the best environment for Ricky' but ultimately concludes that 'neither Braemar nor Ngāwhatu were successful with him.'

There are many references in both files to behaviours which to modern eyes look like reactions to sensory overload and many records of bruising and cuts. Extra medication or punishment are often then administered.

There are dozens of incident reports, including about altercations. At one point Paul is injured after running through a glass door, but the circumstances behind this are not reported. There are illnesses that take sometimes weeks to diagnose and reports of problematic behaviour, deemed to be Paul's growing aggression, including his waking early and screaming, which required his being put in the quiet room and medicated - and that turned out to be physical pain requiring surgery for gangrenous appendicitis, and other times, dental problems, which were eventually identified. It is sometimes complicated by the requirement to get consent from the father who has left New Zealand without leaving contact details.

There are frequent references to negative behaviours around food. Both boys are described as stealing food and fast eaters ('gouging'), and apparently always hungry. From reports it is clear that food was used as behaviour control for punishment and reward. Both were described as having pica (eating substances that are not intentional food such as leaves).

There are references to dental treatment but when Ricky met his sister, he had no teeth. Ricky's sister Sarah noticed that when she met him after he had been deinstitutionalised into a group home run by a local agency, she saw extensive scarring up and down his back from injuries such as kicks or blows, but there are no incident reports in the records indicating how these happened. There are anecdotal stories from former staff and residents alike, that sometimes residents were coerced into fights. There are stories that patients, like Ricky, who were bright and energetic, but complex and non-verbal, and likely autistic, were unable to regulate their anxiety and distress caused by a busy, noisy and crowded institutional setting, with its ever-changing staff faces. Such people commonly expressed their frustration and unhappiness by being deliberately disruptive and were in turn punished for 'playing up.' Patients were expected to behave in ways that made sense to the staff but that were



often beyond them. It's well known today that many people with autism are overwhelmed by environmental causes and can only react unhappily. Another document on Ricky's behaviour suggests that 'boredom may be close to the heart of his problems.'

A former Ngāwhatu patient, a verbal man, met Sarah at the group home agency's Christmas lunch, which brought together residents from several houses. He told her, without prompting, that Ricky used to get 'hit a lot by the attendants, they'd really get stuck into him, they set other patients on him. I don't know why they were always hitting him.' Sarah told him she didn't want to know any more.

The agency staff were aware of Ricky's scars but these pre-dated their care and the team leader told Sarah that 'none of us knows what happened to Ricky in the institutions but they were definitely not from self-harming.' It was widely understood among some staff that physical violence was a part of institutional life. Some of the staff had even worked in the institutions. Ricky's voluntary advocate repeated this understanding to Sarah. She had worked at Braemar as a physiotherapist, decades earlier, and knew the stories and fears of goings-on, particularly at Ngāwhatu. She told Sarah it was common to find such scars on former patients and tried to reassure her it wasn't personal to her brother; he hadn't been singled out. She told Sarah 'it happened to so many of them.' Sarah tried to explain to her, she could only see her brother in this moment, and couldn't stop getting images of what must have happened to him, and that she found no comfort in knowing it had happened to so many of them.

The decades of charted medication records indicate a heavy regime of drugs for epilepsy, mental illness, behaviour control, and sometimes pain relief. There is a short letter written in 2000 from Paul's primary care physician at Health Link South for his discharge from Templeton to the group home agency. It outlines his medication regime and says 'there has been a problem with his behaviour in the years I have attended him' and goes on to conclude 'in summary, it appears that his behaviour has been due to his drug therapy.' This physician explains how he/they have been reducing the combination and doses of some of Paul's medications, only in recent times, and have been seeing a corresponding improvement in his behaviour. After deinstitutionalisation and the involvement of psychiatrists from the Ministry of Health, further questions raised about the psychiatric polypharmacy, despite there not being a record of any diagnosis of mental illness, but a comment is made that weaning off any of them might cause new problems. A 2016 assessment for Paul by a Wellington psychiatrist queries why he has had so much polypharmacy with so little revision over the years, but admits that such drug overuse was normal for years of institutionalisation (even though this is now 2016). His sister would later question Paul's GP's 2021 use of the diagnostic label 'mentally retarded' for him. (As Sir Robert Martin has observed, institutionalisation is more than bricks and mortar, it is also words, attitudes and values.)

In Ricky's case, during his early placement with the provider agency from 1998, another agency is drawn on to assist with his problematic behaviour. The coordinator of this agency attends and observes Ricky in person and reads some of his historical notes. He reports



that Ricky's nursing notes from his early life do not emphasise his agitation which is by now so prominent 'but they do however record the very large quantity and wide variety of anticonvulsant and psychotropic medications he received'. He said that 'these drugs were often in combination and at high dose and sometimes changed frequently'; and that most of the medications were for the control of Ricky's behaviour and moods and 'there are several references to his 'psychoses', obsessive-compulsive disorder and depression are among the conditions suggested, although no single condition is diagnosed.' He goes on, that other attempts were made to try and control his behaviour 'mostly through additional PRN medication and physical control such as locking him behind doors,' and writes that 'even as late as 1996, Ricky was prescribed 11 different psychotropic medications, including anticonvulsants and PRN (as required) medications in a single year' and concludes 'it may be that his agitation has been acquired or aggravated as a side effect of some of these medications.' He recommends Ricky 'needs to have his medication and general health reviewed by specialists experienced in treating the medical needs of people with autism as soon as possible' and that 'while they may not be able to offer insights into Ricky's moods and behaviour at present, they will be able to review his medication history and his present pharmacological regime.'

This coordinator also notes that the agency's staff, who know Ricky well, have reported he responds well to different staff, suggesting he reacts differently depending on the individual approach. He said that staff have also told him that Ricky is 'often free from agitation and challenging behaviour when the other residents are out of the house' but that 'his mood and behaviour typically deteriorate rapidly when they return.' He says 'difficulties arise when Ricky is forced to share a space with some of his fellow residents.' He writes that as an autistic person Ricky 'may be having sensory integration difficulties' to noises, sights, smells, touches or feelings and that these factors in his environment 'may be the cause of his distressed behaviour.' He refers again to Ricky's Braemar record, which notes Ricky found it easier to calm down when put in his cot on his own, away from others, and when 'his music' was put on, thereby helping him block out other demanding, unpleasant or irritating sensations around him, including auditory. He highlights that everyone seems to have recognised, early on, Ricky has a clear preference for a quieter, less crowded, predictable and uncluttered environment with consistent support staff and access to space and the outdoors. He advocates that Ricky have staff 'who are well trained in the skills necessary to support a person with autism.'

When Sarah first met Ricky, the agency's team leader told her that when he'd started work with Ricky about a year after his deinstitutionalisation from Ngāwhatu 'he was still on all those horrible medications; they had such a terrible effect on him.' He said Ricky 'rattled with pills when he walked' and 'used to just yell and scream and headbang.' However, under his support team, they investigated Ricky's medication regime and substantial changes were made. This team leader said 'it changed his life so significantly - and everyone else's around him - for the better. His PRNs became less frequent. We had to wean him off his old



drugs first, it took about six weeks of pure hell for him and the staff but it made such a huge difference to his life. He just progressed so much in the time I knew him.'

After deinstitutionalisation, Ricky had two independent advocates and they appear to have attempted some vigilance as 'outside' people in his life. Ricky's second advocate was the above-mentioned former team leader at his house who had developed a strong and trusting relationship with him. However, his attempts to keep an eye on Ricky and continue their connection was hampered by the new house leader; she made him feel unwelcome, didn't involve him in relevant meetings affecting Ricky or share information and encourage and facilitate his ability to fulfil Ricky's lifestyle plan and goals. His plan recognised that Ricky would benefit from regular outings to the advocate's farm, but these didn't occur. The advocate was not informed when Ricky was unwell and bedridden and was unable to visit and support him as his unpaid friend. The new house leader also ceased contact and social activities with other agency houses, which left this home of vulnerable people, already in an isolated rural setting, largely cut off from outside contact and view. It left Ricky with no independent person involved in his life.

In Paul's case, it appears that at Templeton, he had an occasional visitor from a local church group. Otherwise, the only people in his life were paid staff and other residents. There was no notion of 'family'.

This is also the beginning of confusion about the identity of Paul stemming from the incorrect birth date on his file when he was three. His identity appears to have been mixed up over the years with other Templeton residents with similar names.

In about 2011, Sarah, aged in her mid-40s, decided to search for her two missing brothers and find out what had happened in their lives. She said it was a huge emotional and mental undertaking for her, particularly as she was breaking her family's golden rule of not acknowledging the existence of these two members. She said 'it took me till middle age to feel like I could challenge our father's grip on this part of our story.'

She tried to locate her oldest brother, Paul, and was told that historical records from Templeton were hard to source, that record keeping hadn't been great, and that some of it had been lost or stolen at deinstitutionalisation.

She established that the agency in Christchurch had taken responsibility for the majority of former Templeton residents. But because of the incorrect birth date on Paul's original file and his common name, she was advised by the manager of the agency at the time that they didn't have a match for her brother's date of birth and couldn't assist her. He did tell her, however, that the agency did have a man in their care with the same name as her brother but that he couldn't possibly have been her brother as he had a different date of birth and parents' names attached to him and had 'already been accounted for.' Sarah understood that this man's family had come forward for him. He told her there had been a few males with her brother's name at Templeton, that Templeton staff may have changed her brother's name for their own convenience so as not to muddle them up and that it was



possible that he may have died. He suggested Sarah try the Salvation Army. She did. They advised her they helped parents and children find each other under adoption circumstances, but didn't have anything to do with separated siblings by disability and institutions. Sarah said that the agency stopped replying to her email pleas for more ideas or information. She was convincingly turned away.

When Paul was committed to Templeton there was no requirement for his birth certificate to be attached to his file. This document was basic proof of Paul's identity. It had his full name, date and place of birth and his parents' names.

At deinstitutionalisation, Paul, and other residents of Templeton were released to private service providers, like the group home agency, without their institutional record accompanying them. Paul's file contained information about the last four decades of his life but this was separated from him at handover and went into the drawers in DHB archives.

The agency was only given a summary on each person, prepared by a middle party, contracted to write up a 'needs assessment' on them as they left Templeton. His summary outlined his disability, problematic behaviour, medication regime and provided a hospital number, NZ income support number, community services card and an IRD number. There is a single sentence that summarises his family background and reason for entering state care as follows: 'Was in Levin Farm Hospital pre-admission to Templeton in 1959 - continuing screaming, attacking younger sibling.' His father's initials and surname are included on his summary with 'address unknown, no family contact.' Paul exited Templeton with the same (incorrect) date of birth he'd entered with. The full names of his father and mother - which were available on his Templeton file - did not go with him into community life, nor does any mention of his four other siblings, including his brother Ricky at Braemar. There is little ability for the agency to link Paul with his family members at any future stage - or for them to find him.

At some point, the agency requested a birth certificate for Paul. All they had to go on is an incorrect birth date and his father's initials and surname. Birth Registrations could only have advised them that they did not have a birth certificate matching Paul's date of birth or father's details. Someone at the agency made a decision to accept or take a birth certificate for a completely different person to the Paul in their care. This other person has the same full name, but an entirely different date of birth and a different father's name. The agency's 'Paul' officially became another person, with another set of parents attached to him for the next 20 years - until it was unpicked by his sister.

Sarah established that Paul's date of birth changed a number of times over the decades. The admission application had the wrong date of birth, his date of birth changed in the institution on some documents, and decades later, the agency had yet another date of birth for him.

By contrast, Sarah was able to locate Ricky easily, by then in his 40s and deinstitutionalised from Ngāwhatu (the institution for adults who had outgrown Braemar). He'd been placed into an agency group home on the outskirts of Nelson. Sarah travelled from Australia several



times to get to know him. They enjoyed each other's company and Ricky allowed his sister to sit with him on his special, exclusive mat. Staff observed Ricky had a strong interest in his sister and could sense something special was happening and being shared between them. He welcomed her visits, would smile, sit next to her, seek her out if she moved, sometimes held onto her as she was leaving the house and would follow her to her car.

While there were some joyful and mending times shared between these two long-separated siblings, Sarah was also getting very affected by some of the more disturbing circumstances around Ricky. These included, not least, witnessing the extensive scars on his back unexpectedly one night. Ricky's voluntary advocate said to her 'I hoped you'd never see them.'

Sarah was also disturbed by the way different staff treated Ricky and his peers. For example, when they shared their first Christmas together, the particular staff had made a special meal and everyone sat and ate together. It was a real communal celebration. However, the following Christmas, with different staff on, they had another attitude towards Christmas with the residents, and chose to eat separately from them and assumed Sarah would wish to do the same. Sarah was heartbroken. She had worked hard, saved up and travelled a long way to break bread with her brother at Christmas. She said it felt like her brother was being separated out from her again, and she realised that he and his peers would never be seen as true equals by others. She watched as her brother and peers were fed separately 'like cattle' and apart from those 'in charge'. She began crying and was unable to stop and couldn't eat her lunch. The staff were bewildered to see her so upset but she was not able to articulate how she was feeling. Her brother came and sat next to her and she didn't want him to see her 'losing it' so she drove back to her motel and had a very dark night.

Sarah also found some of Ricky's behaviour distressing to observe, including his headbanging. His behaviour seemed to vary according to what staff were on; he was much more settled with familiar staff. She felt unable to reach and support him and made the difficult decision to pull back on contact for her own wellbeing. There were staff changes at the house too at this time; Ricky's wonderful team leader was retiring; a new leader was appointed and staff were turning over (as is typical in support work.) Back in Australia, Sarah felt far away and removed. Previous staff had kept in touch and sent photos of Ricky and birthday cards etc, but the newer staff never made contact. Sarah requested to go on the agency's family newsletter list, but never received a copy. She sent Ricky a present a few months before she heard he'd died unexpectedly.

In 2017, Sarah flew to Nelson for Ricky's funeral. He was 52. He had choked while eating a camellia flower after breakfast (he had no teeth) and could not be resuscitated. Sarah was listed on his file as his only known family member and next of kin. The agency had her email address, phone number and physical address in Australia. However, when Ricky died, no one at the house or the agency office could find her contact information. Ultimately, the agency told her they'd lost it. The Police used Interpol to find her in Australia. But before the police found her, Ricky's two voluntary advocates (former and current) were advised of



Ricky's death, and one of them contacted Sarah to share her condolences. This advocate had assumed that the agency would have already notified her, and was shocked and mortified to realise Sarah was unaware of her brother's death. Ricky's other advocate also contacted her and asked her to call him ASAP. It took two volunteers and the NZ police to advise Sarah of her loved-one's death. The government funded agency with full and paid responsibility for his care was at a loss to contact her. Sarah eventually received an apology from the agency. They put in writing they had failed in their duty to maintain family records and said 'it was not acceptable.' They also said they should have kept in contact as they had a duty to maintain links with known family members.

When Sarah attended Ricky's funeral and visited the house, she met the new team leader. Sarah noticed that home facilities and opportunities for residents had deteriorated. For example, a large outdoor sundeck area, previously used by residents and staff alike in summer and spring, was no longer used at all. An outdoor swinging seat on the deck, which Ricky enjoyed, was no longer there. The outdoors table and chair setting for the residents to sit and enjoy the sun and fresh air and sometimes eat meals, was gone. A dedicated, small and separate table for Ricky to eat by himself, which he liked to choose to do sometimes, was gone. The new team leader advised Sarah that he "sat at the table with the rest of them inside." The residents' sensory room was now being used as a junk room. It had previously been a space for residents to go from the main house, sit and have some space and quiet time, listen to music, and one resident liked to play piano. A more rigid approach to supporting the residents had been instituted.

Sarah also established there had been a loss of traditions which had been built up to support Ricky, such as allowing him to make his own toast with marmite before bed - a much prized treat and calming activity for him. She was also told that Ricky had been wearing incontinent pads all day, and for some time, when he had been fully continent when she'd visited him, under the previous team leader's care (apart from a night-time product). Sarah saw that family photos of herself and Ricky had been removed from his bedroom walls, as had a rug she had purchased for him. She found out that prior to his death he'd been unwell and bedridden, yet neither she nor his advocate had been contacted. She also she learnt from staff and inadvertently from the team leader herself that there had been inappropriate physical contact between the team leader and Ricky, which had included 'kissing him on the mouth, repeatedly some days', and sitting him on her knee, which other staff had witnessed and said was 'off' and 'unprofessional' for a house leader, who was meant to set the standard towards the vulnerable, non-verbal, people entrusted in their care.

After returning to Australia, Sarah started inquiries into the team leader's behaviour. It resulted in three investigations. The first was an internal review by the agency which determined that the team leader had been kissing her brother on the mouth and professional boundaries had been crossed. However, the agency said they believed it was more a case of 'misplaced affection' than any dubious or 'sexualised behaviour.' They said it was one of the hazards of the job that staff became 'so familiar with and fond of the people' in



their care. They told Sarah the team leader would be facing appropriate discipline but they weren't obligated to tell her what that was. Sarah went to the health ministry (the agency's funding body) and asked them for their view. She posed the question to both the ministry and the agency: What would happen if, for example, a school teacher was found 'kissing' a vulnerable student 'repeatedly some days' on the mouth? Would the defence of misplaced affection and fondness etc wash?

During this time, Sarah received more incriminating information about the team leader's behaviour in relation to Ricky from some support staff. She continued to relay this information to the ministry and agency management. This led to a second inquiry, and the agency involved a legal firm. The lawyers concluded there was enough evidence to justify further examination and recommended the agency reopen the inquiry.

With the third review, the agency investigated itself again, and advised the ministry and Sarah that, as a result of its findings, the team leader was no longer working for the organisation. A month later, Sarah found out that this person was still working for the agency and had only been moved to another house with vulnerable people. She contacted the ministry officer, who was equally shocked and said that she too had understood the staffer had been dismissed, period. However, the ministry officer apparently lost interest (it had been going on for a year), and without her support, Sarah decided to let it go too; it was taking a toll on her and she needed to go forward for her own health and wellbeing.

When he died Ricky had no possessions.

Sarah says she felt a tremendous sense of guilt after her brother's death. She felt like she'd let him down, had taken her foot off the brake, and should have stayed in closer contact his last couple of years. She felt hampered by different pressures, including not having the money to visit him regularly enough to make a difference, and her memory of how distressed she'd been on her last visit and decision to focus on her own stability, mental health and life in Australia.

Ricky's body was embalmed, as organised by the team leader, and while Sarah was involved in aspects of his funeral arrangements, she was conscious of not stepping on his staffer's toes, and was agreeing to things she didn't necessarily understand or want. On the day of his embalming, Sarah tried to stop it occurring, as she felt his body had gone through enough, including a tracheostomy and autopsy, but it was too late, the procedure was underway. The funeral directors encouraged Sarah to see Ricky's body, and on sighting him, she had to be held up by two funeral staff, as she was in shock. She felt riddled with guilt and was inconsolable next to his body and said to him, over and over: I'm sorry, I'm so sorry. She felt the weight of her whole family having let down this precious person his entire life. She remembered that hands were important to Ricky; he loved to examine her hands and hold them up and turn them over and smile with approval. She asked the funeral staff to see his hands from under the blanket and hoped they'd look the same. They did. She felt much relief and comfort in sighting his hands. She did not want to touch him but gave the funeral staff a sprig of rosemary to place in his hand after she had left the room.



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 and the Superintendent of Braemar had sought to bring the two brothers together. She knew he had lived till at least age 10 but was 'otherwise left to imagine the worst' about his 'evaporation'. She thought 'if he has gone, I just hope it was quick'. But despite trying to let it go and live without knowing, she continued to go back and forth, digging for information.

Although she had never met him in person, she recognised Paul for the strong family resemblance when she came across Gerard Smyth's 1996 documentary on Templeton. She got in contact with the filmmakers and spoke to a father who'd been interviewed in the film. This father had led a parent group during the deinstitutionalisation process. He told Sarah there was a chapel on the Templeton site, still operational today, which had a memorial wall with the names of residents who had died at Templeton. He arranged for someone to visit the chapel on her behalf and check the wall of names. Paul's name was not on it. Sarah felt confident for the first time that Paul was still alive at closure. Again, it took an informal channel to give her such hope; there was no official agency supporting her quest.

Sarah contacted the agency again and a new manager was in place. She emailed numerous photos of Ricky and asked if he resembled the 'Paul' they had in their care. The agency's staff were apparently shocked on seeing the photos, as they were left in no doubt that Paul and Ricky were brothers. Sarah established the Paul in their care was not in fact 'already accounted for' as he had not had any family come forward for him. She booked flights to meet her brother.

However, after the initial excitement and recognition of their family relationship, which included an email from the manager saying it was a '100 per cent match'; the manager appeared to suddenly change her tone. She told Sarah that the agency required official proof that she is Paul's 'real' sister and did not allow Sarah to see any photos of her brother. This was an unexpected blow. Sarah told the manager that when she'd found Ricky, the agency in Nelson had not required she 'prove' she was his biological sister before seeing photos or visiting him. The manager apparently replied that the agency's difficulty was that Paul had a different birth date, place of birth, and parents' names attached to him and said 'the onus of proof is on you' to show this official document is wrong. They suggested she do a DNA test - which Sarah rapidly agreed too - and sent her a DNA form with a cost of nearly \$900 and said Sarah would have to pay for it. Sarah said she'd try and find a way. The manager came back again and told Sarah that Paul's GP had refused to do a DNA test on Paul due to privacy laws. She said if Sarah wanted to go forward, she'd need to take out a Court Order, again at her own initiative and expense, to compel Paul to have a DNA test. Sarah could not afford to do this and lived in another country. She felt utterly demoralised by the response she was getting from the agency, the growing challenges, and the impossible expenses for



her. She couldn't understand why the agency had gotten so difficult and why they, and her brother's GP, wouldn't be doing everything within their power to facilitate a family reunion - for a man in their care who had no family in his life, no advocate, no unpaid visitor.

Sarah could not see a way forward and cancelled her flights to meet her brother. Her tickets were non-refundable. She advised the agency that she was unable to manage it financially or emotionally and was pulling back. She pointed out to the manager that she'd only lost Ricky the year before, had spent much time and energy on the three investigations into the agency's team leader's unacceptable behaviour towards him and that her mother had died shortly after Ricky.

After Sarah cancelled, the manager apparently had another change of tune. She contacted Sarah and says that she wouldn't want to stop a family reunion and that she would waive Sarah having to verify her sibling status and allow her to visit Paul as his 'unofficial sister'. But she reiterated that 'the onus of proof' remained with Sarah to continue the process of authenticating they were genuine siblings, and suggested that Sarah contact a genealogist. Sarah could not recover the money for her cancelled flights but rebooked again for a future trip. In the meantime, she tried, again, to source any information or records which could prove her family relationship to Paul. It bothered her enormously that the agency would not regard her and Paul as true siblings until they had it on a bit of paper.

By a mixture of good detective work and good luck Sarah found a responsive records manager at Princess Margaret Hospital in Christchurch who was able to locate some Templeton archives. The archivist found files for Paul, and with Sarah's extra information about birth dates and parents' names, sourced the correct data from Government records and matched it with the files held for Paul. Ultimately, Sarah was able to prove her family relationship with Paul, once and for all. The records manager contacted the agency's manager directly and asked her to order a new birth certificate for Paul and to dispose of his incorrect one. She also contacted Paul's GP and gave him Paul's correct date of birth and requested he remove the wrong birth certificate from their surgery. Paul received a new NHI number.

Sarah was now allowed to see photos of her oldest brother and flew over to meet Paul in 2019. She was 53 and he was 63. She visited him twice, then with the temporary Covid border openings in 2021, decided to relocate to Christchurch and is now developing a positive and joyful relationship with her sibling. She is also building trust with his staff so that she can come and go. She encourages Paul's dignity of risk by involving him in regular community activities such as visits to the markets, cafes, spas at the local pool and helping her shop by pushing the trolley. Sarah has accompanied and supported Paul on visits to hospital, including an operation on a gangrenous toe, for Covid treatment and dental care.

Community Law in Christchurch supported Sarah's successful application to become Paul's legal welfare guardian. Sarah felt it was important to get their sibling relationship on the record after all she and Paul had been through. The agency is now fully accountable for maintaining Paul's dignity, health and wellbeing.



Sarah wanted to frame some questions and comments for the Royal Commission:

- Why did the state allow disabled New Zealanders to be admitted to psychopaedic and or psychiatric institutions (often intended for life, as in the case of my own two brothers) without requiring that a copy of their birth certificate go with them and stay with them as proof of their identity? There were hundreds of people placed in these facilities. I understand at the closure of Templeton between the 1990s and 2000 some 465 people were released into the Christchurch community, among them, my brother Paul.
- Why did the state rely on the word/memory of a father who was committing his toddler to care without requiring the child's mother also be present, at the very least to confirm such critical details as the child's date of his birth?
- At deinstitutionalisation, why didn't the state provide more, if not all, of the information it had on each person in its care (care that sometimes covered several decades) to agencies at handover? These records had the history of the person - details about how they came into care, their health inventory, who their family was etc. Paul's documents had the names of our parents, both sets of our grandparents, and mentioned the existence of his four other siblings, including our brother Ricky institutionalised at Braemar. The agency was not given this information: Why not? How were wider family members, who wanted to come forward and find their missing loved-one, meant to find them?

The agency had no capacity to link the person in their care with their family members at any point. They couldn't cross-reference or verify whether anything they had in their handover summary was faulty.

- Why did the agency attach a birth certificate to a person in their care that didn't match the date of birth and father's name they had been given by the state for that person? Someone at the agency made the decision to take or accept the birth certificate for a completely different citizen.
- Did the agency seek more information about Paul's identity and family background from the DHB? If it had, Paul's historical files could have been sourced and checked, and the names of his parents and place of birth etc would have been found.

It is shocking to me, as Paul's sister, that the agency 'officially' made Paul a different person. If I hadn't uncovered his true identity, my brother would have died and been buried as someone else. How could this happen in the 21st century? Who is responsible?

At the very least, the State and the agency owed Paul his identity. They both failed to capture and protect this basic human dignity. They also had a responsibility to keep the door open to Paul's right to have a family. They should have realised family members might come forward for him down the track. This path should always have been accessible. No one was protecting Paul's right to a family.

Also, family members, like me, should not have been hitting dead ends when I tried to find my missing sibling. I had to search, research, hoop-jump, imagine he was dead, pay unnecessary expenses, and go through a mixed-up stressful and time-consuming process to



locate and visit my own biological brother. That fact I was on his doorstep, but persuasively turned away, eight years earlier, demonstrates something. It meant our sibling relationship was blocked even longer than it had to be, and we lost more precious time we might have had together. The inadequate record keeping, record sharing, handover notes at closure and the fake identity of Paul were not of his or my making. Yet Paul and I paid the price for these State and agency errors. We almost didn't find each other at all. Without my persistence and happening upon the 'right' person who knew about the archives - and her willingness to devote time to it, and pulling together scattered information that wasn't necessarily compiled in date or subject order - nothing would have happened.

Paul and I have never had an apology from anyone.

Since finding Paul, the manager has told me the agency can no longer completely trust the information they were given on the people at the closure of Templeton. She wonders if there might be other former residents with muddled identities, birth certificates or family members who are looking for them? The agency still has today former Templeton people who they have no family information on. They have tried in recent times to connect residents with unknown families by drawing up a family tree for them, but with limited success in locating relatives, dead or alive. As highlighted: the institutional record and wider history of the person did not leave with them at handover.

Sadly, most of the Templeton population are now elderly or have already died.

Meeting Paul in 2019 has been a life changing and meaningful experience for me. My two disabled brothers were real people to me, however silenced and whitewashed. They mattered to me. I believe it was the same for every member of my family, whether expressed or not. We were all incredibly damaged by this loss and family secret.

Just before I met Paul, the agency told me not to expect too much from him, that I'd get little back, no acknowledgement or interest, that although he'd be aware of my presence as an unfamiliar person, he'd tune me out, that he was hard to reach, hard get to know, that it took him ages to trust people, that he was essentially a loner, didn't like eye contact or physical contact, and was a creature of routine etc. I told the agency I would meet my brother on his terms and accept him however he came.

Paul and I have grown extremely close. Today, I ring the doorbell at his house, and on seeing me, he smiles, rapidly stands up, and comes over to greet me. He reaches for both my hands and initiates the hongki. His staff say they've never seen him greet anyone this way before. Our mother used to do this to us as children - could he possibly remember? I have no idea. He allows me to give him a cuddle, a back scratch, a hand massage, and actively seeks to go on outings with me. His team leader has told me that she has never seen Paul close to anyone before or even wanting to be, until now. She said that he is happier, a changing person, more dimensional and 'satisfied.' I tell Paul, often, that we are family and that he belongs to me. I tell him he's my friend and buddy too. I celebrated Paul's 66th birthday with him recently - on the correct day.



I can't fully explain it, but for me, the need to know and connect with my two missing brothers ran deep, no matter how gagged and disjointed the history. I don't think anyone could underestimate the harm that was done to a lot of individuals and families who got fractured this way. It happened to real people like me and my brothers, and it's still playing out in people's lives.

The files that Sarah has accessed are invaluable. They have revealed details of the lives of two New Zealand citizens that would otherwise have been lost and unknown. Only through luck and good detective work have they now come into the possession of their sister. But such records are at risk. Health records are required to be held for 10 years and many private providers and NASCs (which are non-government organisations) then shred them. Official government records should be kept but are often a casualty of departmental restructuring, and the varying letterheads in these two files list agency names that are now long forgotten. The status of the Templeton and Braemar/Ngāwhatu records is unclear. If asked for by patients and families they are given to them and no copies kept. They do not appear to be deposited into a central repository such as Archives NZ.

Good record keeping requirements by staff in the now closed institutions have ensured that a sister has not only found a long-lost brother, but she now knows what happened to two brothers in two institutions over many decades. These are incredibly valuable records for family, for future researchers and for our disability history. We need to archive what remains. It is one way to provide justice and redress for the distress of institutionalisation and family separation.

## **“Freedom is Acceptance of Who I Am” by Lusi** <sup>30</sup>

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

<sup>30</sup> Lusi chose to use her first name in her story and not to name anyone else.



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.

Where did you go after that?

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.

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.

## **“The Psychiatric Hospital” by Jen** <sup>31</sup>

I will respond to these prompts a few at a time, because doing the whole lot at once might be too much!

What was happening in my life before I went to Kingseat?

I was feeling increasingly on the outer as regards other people. As a youngster, I had commented that I felt like “an alien from outer space”, and this had continued. When navigating social situations outside of my family, I would often inexplicably “get something wrong” and would sometimes end up in an unpleasant situation, without understanding how or why. I found daily life challenging and anxiety-provoking; sometimes too much to cope with.

What was the process for becoming a patient there?

I went to a medical clinic and the doctor recommended that I go to the psychiatric hospital for a while. It was my own choice to follow this advice, i.e. I was a voluntary patient. I had been in Kingseat Hospital once before, and that previous time had been an OK experience. However, the second time I was in Kingseat Hospital turned out to be a very different experience. It is the second stay in Kingseat Hospital that I will be referring to in Q. 4 and onwards.

Describe the physical look and environment of Kingseat..... aspects that I liked.

Kingseat Hospital was not an unknown location to me, because, during my childhood and teen years, my family had lived relatively close by, on a farm at Karaka. Sometimes my mother, brother and I had attended the annual Kingseat Gala Day (or whatever it was called), which had quick fire raffles and other gala type activities happening. (There was very little local entertainment in that time and place, BTW, so that gala day was welcome as one of the very few events we attended each year!).

The main entrance was impressive, with a long driveway bordered by two rows of huge phoenix palms. On the entrance wall was the inscription “Mens Sana in Corpore Sano.” When one reached further down the driveway, buildings began to appear. These were the villas where patients stayed, and were built of red brick, which is the type of building that I like the look of. At the very end was the big office building. There were trees, lots of grass, and some gardens. Everything looked attractive to me. Plus, as I wrote above, I had happy childhood memories of gala days being held there. Therefore, I had nothing but positive feelings towards the place, at the time of my admissions # 1 and # 2. (It was after being transferred to the “Farm Ward” on admission # 2 that things changed).

Describe what happened on a typical day.

In the regular villas, (at least, the one that I was in, Villa One), life was rather easy-going, punctuated by meals, nurses bringing medications, the occasional villa meeting (staff and patients), and sometimes being called for a private consultation with a doctor. After about

<sup>31</sup> Jen chose to use her real first name in her story.



four weeks in Villa One, (a bit longer than it would have otherwise been, because of the consultant being away), I was transferred to the “Farm Ward,” Claybury House, situated over the road from the main hospital.

It is in the “Farm Ward,” Claybury House, that I spent the most time; (I think it was seven months; added on to my time of one month in Villa One, this added up to eight months in Kingseat Hospital for my second stay).

On a typical day in Claybury House, patients would have breakfast, then patients and staff would meet in the “Therapy Room,” a large separate building. On Mondays, we began with the (to me) dreaded “Monday Mimes.” That is, we had to try to convey, silently, using actions only, something relevant to the group that we had experienced or were thinking, to the rest of the group. It was sometimes hard enough to think of something, let alone mime it. 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,” no matter how unintentionally; this was a pattern carried out daily (often more than once per day) for my whole stay in Claybury House. This had the effect of traumatising me (and presumably some of the others.... i.e. the ones who were more often targeted by the group). If a targeted patient was in tears at the end of the Monday Mimes (or any other group “therapy” session), they were simply left there to cry while the rest went off to morning tea or lunch; the staff members would deliberately leave them in a distressed state. Sometimes another patient would stay behind to try to comfort the crying one, though this was not usual.

After the first morning session of the day (e.g. Monday Mimes, or an ordinary group “therapy” session), there was morning tea, then another group therapy session in the Therapy Room. Again, patients and staff were seated in a circle. The staff would start with a topic (or, quite often, an “incident” or “issue” that some unsuspecting patient had inadvertently “caused”) and the patients were expected to say something about it, in turn. This, again, was terrifying for me.... Especially when I was the patient who had somehow unknowingly, during the course of the previous day or two, “done or said something wrong,” meaning I would be targeted again by the whole group. Thus, “group therapy” was a kind of “group bullying” a lot of the time.

After lunch, there was sometimes an activity or sport arranged by the staff; otherwise, it was more of the same (group therapy). As I am not well co-ordinated and very non-sporty, any physical pursuits were usually an ordeal for me. The staff members’ main choices were indoor basketball (in the main hospital basketball court) or swimming (in the main hospital pool), both of which I hated. I could never get the hang of (compulsory) basketball at primary school, and was no better as an adult, especially as I had trouble catching and throwing the ball, and being “tackled” by another player in order to get the ball off me was another fearful experience.



After the swimming sessions, I would always be in trouble again (from the whole group, but particularly the staff) for “being the last to get dressed.” I absolutely could not help it, because I tried my hardest NOT to be last, because I was terrified of being in trouble again! — but no matter how hard I tried to get dressed quickly, (presumably due to my coordination issues), I always ended up last, which meant being in trouble again, i.e. being reprimanded by staff and other patients, and told that I was doing it for attention. All reprimands and negative comments were always done in front of everyone, so that one was publicly humiliated. (Being in trouble is the LAST sort of “attention” I want, either then or now!)

The sports sessions were not every day; in the afternoon slot there was sometimes some sort of group game, though that, too, could end up with unpleasant consequences, if I “did or said something wrong” without meaning to.... i.e. it could result in more verbal punishment and humiliation in front of the whole ward, with patients taking part in the bullying.

At the end of the day was dinner (in our shared dining room) and “socialising” until bed time. As I did not know how to socialise “in the accepted way,” this was also a potential source of trouble, because if I did or said anything “wrong”, I would be targeted next day during the “therapy sessions” by the staff and patients combined..... (as above).

More details are, of course, in my book, in “The Psychiatric Hospital” chapter.

That is enough for today..... Bye for now and thanks for inviting me to tell my story!

Describe the treatment you had. Were you asked for any consent? Did they ever ask for your opinion about what you needed? Were you told what would happen and why they were doing that?

Did the Farm Ward / Claybury House staff (an offshoot of Kingseat Hospital) ask for consent or our opinions as to our treatment? — No! — because I doubt if many (or any) patients who were in there (i.e. the “Farm Ward, Claybury House”) would have consented to much of this so-called treatment, and some (if not all) of us would have had unfavourable opinions about the so-called treatment. — Mind you, I realise that I can not speak for others, so let me just say that as for myself, I did not consent beforehand to the various “activities” we had to partake in, and I had an unfavourable opinion of them. However, I suppose that one’s “presence” in the hospital ward (“Claybury House”) was taken as “consent” to the treatment handed out there.

It is a slippery slope when considering “consent” of vulnerable people (e.g. those who are already in a mentally / emotionally fragile state when they arrive at the hospital) to their treatment, especially when these people are told that they are in the “Last Chance Saloon,” i.e. you get cured here and now, (while in this facility), otherwise you will be “on the psychiatric scrap-heap for life,” which is what we were told (in either those words and/or in very similar words, as remembered by some other ex-patients also). As a result of these factors, we were not in a totally “consenting” situation, because we were threatened with lifelong psychiatric disability if we did not conform and go along with all of the treatment. I.e. There was a great power imbalance here, tipping us into “you either consent to this, or you



are doomed to the 'psychiatric scrap-heap' for life". Added to this was the fact that some of the activities were unknown to us patients in advance, so we could not have known what was coming and therefore could not have consented to the activities beforehand. I don't feel that this situation was true consent.

As for our opinions of the activities / treatments after they had happened, our opinions did not count, except to make a person even more targeted for group criticism, so one would tend to keep quiet about one's opinions rather than be the target of a group criticism and humiliation session. (Many, if not all, patients would join the side of the staff members when another patient was targeted, so as to [I suppose] keep themselves out of the target range).

What were the short and long term effects of Kingseat on your life?

Short-term effects for me were a feeling of post-"treatment" trauma, combined with relief to be out of there, but also anxiety because I was now back in the real world after a "time out" of the real world, thus needing to re-adjust and get back to "normal life," but finding it hard to do so.

Something which was (to me) both a serious short- and long-term effect was the fact that one could not get any "post-Claybury House / post Kingseat Hospital" after-care or follow-up support, without this being provided exclusively by the Claybury House staff themselves! Apparently it was a policy for ex-Claybury House patients to be allowed NO follow-up support EXCEPT by Claybury House staff members — the very same staff members who had dealt out the above so-called treatment. If one was in distress and went to any mental health clinic / facility, one was refused access / treatment except by the Claybury House staff, i.e. one would be referred back to them. I found this very scary, because, by then, one did not exactly trust those same staff members..... and how would they be able to empathise with one's post-treatment difficulties when they were the exact people who had dealt them out in the first place?

This situation (as described in the above paragraph) gave me a considerable level of anxiety and, indeed, a level of hopelessness / despair, knowing that I could not consult any professional person (for the rest of my life?) who was not a staff member of Claybury House. One time when I DID go to see someone for counselling (who, yes, was a staff member of Claybury House — the only kind of person whom I was allowed to see) — I was then subjected to a demeaning attitude and a very insulting comment which still hurts (if I happen to think of it, which I try not to). I deliberately do NOT think about this time of my life, unless needing to do so, e.g. in order to answer these research questions!

In Chapter 13 of your book you outline many times that you asked for help but didn't get it. What should have happened instead? What needs to happen for people today and in the future asking for help?

What needs to change to ensure people with ASD or other conditions are kept safe now and in the future?



As for how to prevent these sorts of things happening again — I feel that in my particular case, the LACK of an ASD diagnosis (before, during, and for a long time after) my Claybury House experience was the main problem, or certainly a major one in this situation. E.g. I would probably not have even been recommended to go into Claybury House in the first place, had I been previously diagnosed with ASD, because Claybury House was not an appropriate “treatment” for ASD persons. ... (Mind you, Claybury House was probably not an appropriate treatment for any kind of persons). I suspect that I would not have been sent there (by the consultant who saw me in the main Kingseat Hospital setting), or, at least, not for long, because of observing another patient who was swiftly taken OUT of Claybury House while I was there, due to his “being diagnosed with a condition which makes him susceptible to bullying” — which, in retrospect, was possibly ASD.

For an individual who already has a diagnosis of ASD and then seeks mental health support, I would certainly hope (and expect) that their ASD diagnosis would be taken into account so that they would be offered ASD-appropriate support. NOT having this diagnosis (or any idea, at that time, that my issues were due to ASD) was a major factor that contributed to my inappropriate “treatment” in Claybury House.

However, I realise that the mental health field in NZ is still far from an ideal scenario and, as a consequence, a diagnosed ASD person may still not be able to get the appropriate kind of support (i.e. “ASD-appropriate”). Many of the professionals who are familiar with ASD are in private practice, which, typically, puts them out of range of most people who are having mental health difficulties / ASD-related issues.

At least, I would hope and expect that, nowadays, an individual with an existing ASD diagnosis would not be placed in a treatment situation which is totally inappropriate for an ASD person. .... but even now, I realise that there is the danger of a proportion of mental health professionals who are not up-skilled on ASD, hence potentially giving inappropriate care to ASD persons.

## **"She said things about my parents which were not good" by Janet** <sup>32</sup>

What was happening in your life before you went into foster care?

I was born in Christchurch and was a premature baby. Between 2 weeks and 2 months old I was placed into foster care with a woman who was a friend of my father. She was 70 when I went to stay with her. I believe I stayed with her the whole time until I was 9 months old. I was then moved to my foster mother's house, who was a registered foster carer and had cared for children before. She also had her own children, two who were still living in the house at the time I began living there.

Do you know why you went into foster care? How old were you and where were you living?

I think this was because my mother couldn't cope with having me. Apparently she went into a psychiatric ward temporarily. I'm not sure of the timeframe for this. I don't really know the exact reason I was taken into care. I have a copy of some of my social welfare notes, but I want to request all of them. I lived in foster care until I was 17 years old.

My [older] brother never left our dad's house or lived in foster care. I believe social welfare was involved somehow as he went to health camps when he was a kid.

What do you remember about the care/ being in care?

My foster parents' house was a state house in a street where there were a few other state houses, but a few privately owned state houses. My foster dad was good to me but I found my foster mother a difficult woman to live with. She was worse when my foster dad died. The foster family considered me to be 'spoilt', although in reality I wasn't.

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.

As a child I had a few operations in hospital where I had to stay for a few days. I found the nurses and an old lady there to be kind and friendly to me, and I would visit the nurses in the middle of the night when they were knitting. I enjoyed being there because they paid attention to me and were kind to me, in contrast to my foster mother who I called 'Mum'. But later when I left home and had my own children I didn't want to call her mum because it hurt to call her Mum. She was not there for me emotionally. So after I had kids I decided to call her 'Nanna' to get away with no longer calling her mum which I'm sure my foster siblings wouldn't understand, nor try to.

I experienced sexual abuse during my years living in foster care, at the age of 9 in particular. The first incident took place on one weekend when I stayed the night at my foster family's relative's house. There were other occasions, but I can't recall the exact timeframe of these events, but it was when my foster family's relative wasn't around. She was in her bed at the

<sup>32</sup> Janet chose to use her real first name in her story.



time (on the first incident) and then another time. There was inappropriate behaviour from the [abuser] in company of other family.

At age 15 I was learning to drive and there was an indecent assault and other indecent behaviour by the driving instructor (an older man). I told my foster mother and she got angry with me. The rest of the family turned against me and called me a spoilt bitch. Life was harder for me from then. My foster father was also dying. He was good to me but got really sick. He was around 70 at this time. I was 16 years old and my foster parents were in their 70s. They said “if the social welfare knew we had bad hearts they wouldn’t have let us have you”.

I was fed quite well in care, probably overfed. My foster mother was a big (fat) lady but petite stature. She said that my parents were fat but they were a better structure than her. She also accused me of “looking like a [birth family name]”. This wasn’t a compliment, it was a way of saying I was being disloyal to the foster family because I looked like my birth family. I was made to feel ashamed of my birth family. I had to still visit my birth family but was made to feel like I had to be loyal to my foster family.

When I was 7 I had a knife to my throat because my foster family’s relative’s boyfriend threatened to kill her.

From age 8 I felt really disloyal from visiting my birth family. One night, my father dropped me home and I gave him a note which said “I don’t want to see you again”. I never saw him again on a visit. I did see him down the street one time but didn’t talk to him. He came to see me at my school play once.

The fact that I gave him this note has hurt me a lot in my adult years as I didn’t want to tell him goodbye but I felt guilty for being a [family name] and his daughter. I was never adopted but I used the name ‘[foster family name]’ instead of [my family name]. I felt embarrassed to be a [family name]. The foster family told people I was adopted but I wasn’t.

When I was 16 my foster dad went into hospital. I then also saw my real dad who was in the hospital at the same time. I think I went into his room to say hello. I’m not sure if he knew it was me. I felt so guilty for going to see him.

My foster dad died when I was 16. I was devastated. He was the one I predominately spent time with if I wasn’t with the neighbours. He was retired but still ‘worked’. My foster mother was very old school and had some very archaic rules, like I wasn’t allowed to talk to boys, and would question me about what people said if I stayed at their house on the weekend (“did they pump you for information at Mrs X’s house?” or “if you go to Mrs H’s house don’t be very long”). I remember having one picnic with Nanna, but I don’t have many memories doing activities with her. I went on a ‘bus tour’ with Nanna and some older retired people around the south island, which apparently made me ‘spoilt’.

At 17 I had to go to fill out a form for a family benefit/ some payment because I wasn’t going to be getting money any more.



What did you do after you left foster care?

I moved out of the foster home when I was nearly 18 years old. My foster mother said I could go and flat with this girl but when I went to move out my foster mother accused me of being a “certain kind of girl” as “only certain kinds of girls go flatting”. She embarrassed me in front of my friend. I still ended up moving out with her.

At age 21 I married and I had two children. Our family moved to Australia, and later I separated from my ex-husband. I moved out with my daughter, and my son stayed with his dad because my ex-husband said he would fight me for the kids if I took him. I struggled financially for a number of years. I divorced my ex-husband in 2008.

I am currently living with my daughter in Sydney. I am estranged from much of my birth family, although my maternal second cousins have made me feel welcome with their part of the family. I don't really have much family.

I have some connection with some of the foster family, but I am conflicted. I had experienced a lot of psychological abuse and manipulation from my foster mother/Nanna. She died in approximately 2010?

I have been seeing a psychologist for around 10 years.

What are the high points in your adult life? What are your strengths?

Having my children, completing my Bachelor of Health Science, and nearly completing my Bachelor of Laws. Having some true friends who love me for who I am. I am a good speaker and natural advocate. I am resilient and patient, and have been described as having “tenacity and fortitude”.

What would you tell policy makers/the Royal Commission etc about how to ensure children are kept safe in the future?

Better assessments of the foster carers and better matches of families with the foster child. I was from an educated family and placed into an uneducated family who didn't have the security of their own house and were dysfunctional as a family as well.

The welfare/child protection department should understand the risks the child faces outside of the house they're placed in (i.e. my abuse was outside of my actual foster home, but I was still at risk of abuse). The physical abuse I faced was pretty much never in my actual house. It was sexual abuse outside of the actual home, but from my perspective it felt like continual psychological and emotional abuse from my foster mother at home. 18 was too young for me to leave the house, and because payments were ending my foster mother didn't seem to want to care for me after age 17.

More frequent assessments of foster children and visits without an appointment (my foster mother said I had to be on my best behaviour when the social welfare came to visit). They never asked you how I was. They asked general questions. I felt too scared to say anything against my foster mother.



End of first email

Continues

Thank you very much for this Janet. That must have been very hard to do.

Yes it was hard to do but knowing I have only 2 subjects left in my degree to do helps.

The knife to throat incident happened in another house and there was a young baby in the house at the time. That fact was concealed from the Social Welfare. I was either 6 or 7 at the time. I was very upset, crying and they gave me my seizure tablets after I had run two blocks back to my house...

He abused me sexually about 2 years later.

That was traumatic in a different way.

As this is a project focussed on neurodiversity (including autism) and state care would you be able to tell me a bit about that. For example, how and when were you diagnosed? Looking back did this affect your experience in foster care in any way?

Because I know that as a person with a disability that is unseen that any psychological or emotional triggers can affect me but I'm resilient & have coping mechanisms now, but I've only recently this year learnt about 'cognitive overload'.

(I look fairly normal and I don't receive a lot of help because of that and I don't want pity so I go out of my way to seem 'normal' but I struggle with some areas of functioning.)

I was actually born premature and with some brain damage to my brain stem.

As a child I had epileptic seizures (my dad was known to have seizures) I'm not sure if there's any connection. [Janet does not remember having any seizures and is not sure about the accuracy of the diagnosis. Janet remembers some involvement with CCS – Crippled Children's Society - as a child. As a toddler she also experienced IHC respite care.] And I remember that I have got evidence from a letter written from a Dr specialist saying I had epilepsy and would remain "a problem child". I was only 18 months when they said that.

I will have a break of an hour or so before I think about it again, so quickly writing this in reply before I 'escape' in my mind elsewhere ..

My daughter said I did it but also 'disassociated' often to cope in the past & I have complex PTSD from trauma experienced as a kid.

My autism may have meant that I was more vulnerable, but also my foster mother made me feel guilty and ashamed and unworthy

( in 'Hunt for the Wider people '

" no one else wants you Ricki Baker " )

Or Oliver

Or Annie



Harry Potter (Mrs Dursley Etc ..)

My daughter is so helpful as I'm not great at articulating what I want to say given the emotional/ psychological/ traumatic content ( which incidentally may not be as awful as a lot of other people's experience, however it did affect my self-worth, self-esteem and even had suicidal thoughts for feeling like I was not wanted or anyone cared ..)

It's an ongoing feeling at times which I have managed to recover from and know how to cope and know that some people care now ..

A lot of issues because of my Autism / ADHD and learning difficulties ( above average IQ though) but I have fine motor & swallowing difficulties etc ( not even my Dr knows that) ...I'm having a CT scan & MRI soon. Plus other tests ..

I'm now 52 and although I had a full time job, \$10,000 in the bank before marriage ...

I have no extra money apart from a disabilities pension..

I have achieved a lot despite hurdles,

Diagnosed by [a NZ medical doctor friend living in Australia] in 2010 so not a formal diagnosis, but psychologist now backs that up after knowing me for 10 years.

I have nearly 2 degrees, but now have Fibromyalgia/ Chronic fatigue Diagnosed this year ..

Do you think the Royal Commission should make recommendations specifically for those with neurodiversity who are placed in foster care? If so what?

Social Welfare did not come back for me.

My records seem to end at age 10 and I had no more visits from them but I was still in the system until 17 yrs old ..

In 'Hunt for the Wilder people'

The social welfare woman said " No one left behind " ..

Well .. I was left behind..

I feel there's a bigger story so that social welfare ( or whatever it's called now ) amend or consider their policies and the structure etc of children in care or before care.

And especially with disabilities.

Sometimes it's an executive functioning issue and inter-generational.

I was even called a " loser " by my best friend's ex-husband.

He didn't know the back story which is my ex-husband ripped me off from a divorce settlement because of my poor legal advice and without money and support and needing to educate myself.. and many issues to work on ..etc and illness and trauma and relative poverty & no family etc.. [Janet mentions she spent time in a psych ward after the stress of the marriage break up]

And now I have to catch up and find my own way ...



I believe the government systems of welfare etc should be a 'safety net', not 'hammock' but for some people with disabilities the safety net needs to be more supportive and some people need to be in it for longer without feeling they are a burden or no one cares for them.

Comments from Zoom discussion following these emails

Mental health, healthcare, disabilities/ Autism, housing, education, crime

They are all interconnected.

Janet mentions how hurtful that she is excluded from many aspects of the wider birth family because of the hostility of one family member in particular who has turned other family members against her. That family member claims that her father had no children, when there is her brother and herself. That family member told her to get her own identity. But identity is something that she has been seeking for many decades.

From about 7 years old she had her own opinions as well as looking and feeling different from her foster family, but she was turned against her birth family, so identity is still problematic. There is a distinct stigma of her father in family tradition and written records as a difficult man. She resents that she was turned against him.

But relations on her mother's side have welcomed her into that family.

She is proud of her autism diagnosis, but sometimes feels it is like having a 'butterfly brain', or ADHD and wonders if her father did too. She gets extra time for academic assignments.

She advocates that children in care should know about and know their parents. Care should consider not just parents of a child, but the child's needs.

Janet was always kept clean and tidy by her foster mother, but was told she was spoilt and not good looking and didn't feel that she belonged.

Watched friends play – observed but didn't join.

Social Welfare could be overbearing and foster carer strict (Janet mentions the angry school teacher lady in Mathilda or Mrs Dursley in Harry Potter as comparisons).

Janet has some of her Social Welfare records but they appear incomplete.

Janet found out that she had an older sister who died of cot death in foster care, then her brother was born who didn't go into foster care, then Janet. Her mother apparently had two other children who died. Janet also has a younger half-sister (same mother, different father) who was adopted but is not close to her as 'our genes are the only thing we have in common'.

From Facebook Messenger Janet provides more information about her mother.

Yes ....remember her ...I met her officially again when I was 19 the day of my father's funeral .... My grandfather, her father had been injured in the war and was in a hospital in France. One of my friends said "[birth mother's name]" "was a strange name ... but I like it now .... I understand her better now than I did when I was a young mum at 21 and 25 when she died



from diabetes. They said she had schizophrenia, but knowing what I now know, I think she was probably just on the spectrum. My grandparents were about 40 yrs old when they had her I think. Not old today, but back in the day it would have been. My grandmother was a midwife & Granddad a baker. But now I have books on both sides where I can find my family tree. A cousin on my father's side told me "get your own identity" which was meant to an orphan.

My mother's maternal parents are the Jewish ones whose cousin was a solicitor and Privy councillor. (I know you don't need my genealogy, but as part of my identity it was great to know that I had aristocratic, maybe even royalty in my family. At least members of the Peerage. I felt smart and of good breeding rather than the orphan that was taken in who "no-one else would want you" "after all I've done for you" that "Nanna" said to me all the years growing up. )

I'm single now ..I've lived a life of feeling unworthy, unwanted but am hopeful my orphan story will have a happy ending.

One day my story will be told ..

If I have to write the happy ending into it by creating one.

My unique life upsets me & continues to upset me.

Someone I met through twitter who I thought was my friend said to another person that I was an "unusual person"

She barely knows anything about me and I'm far less 'unusual' than her but my circumstances are quite unusual.

I actually felt for a long time during my life that I was a mistake and unwanted.

But my biological aunt always made me feel wanted and part of the family since I was about 5 yrs old or earlier, but it wasn't until about 19 yrs old that I really wanted to know more & my foster mother wrote her a nasty letter saying that she wasn't real family. Why did she have to be two faced ? "

Some of my pain would be less if my connection to my family was still there and unconditional love etc ..

I've never had that until I had my daughter, my first born.

As an aspie person, although in law moots I'm eloquent and articulate, I find it hard to express my feelings sometimes or make people understand what some deep emotional feelings are like for me having to navigate the world sometimes.

I seem so very normal outwardly.

Even the psychologist did not believe my diagnosis at first because I seem so capable and although I'm good under pressure at times, there's also times where I'm not and need to lock myself away for a few days away from people.



I also have body dysmorphia and complex post-traumatic stress disorder.

I'm saddened that a person like Nanna could influence my life so much, but I'm glad that despite any challenges in life and my "nurturing" that there were some kind and lovely people in my life and "nature" won out in the end.

Financially is the hardest part because I didn't have a divorce settlement and my ex-husband took advantage of me plus I was treated like a fifties house wife & perhaps because of my autism I didn't realise that a lot earlier..

I have had to catch up on a lot of social and popular culture things that Nana stopped me from knowing, raising me as if I was someone from the 1900's ..( weird ) we still had a wringer washing machine at home growing up when my peers had front loaders and dryers.

My ex didn't let me have a dryer etc

Maybe not relevant to autism, but increased my workload while having to work as a wife or go to school as a child.

I was chastised for doing my homework or running out of paper at school. Nanna would say "got your nose in a damn book again "

Or " I already bought you paper at the start of the year "

I didn't think to buy any if I had any spare money coz that would be the only time I got money for the canteen for a bought lunch and maybe a cream bun instead of my many sandwiches and a drink.

Nanna was told by the Dr when I was a baby I needed extra care but why did she not continue that care ?

I don't have a Plunket book but would like my birth records from Christchurch from the Salvation Army home where I was born.

When I was in hospital an old lady gave me a bottle of perfume and I liked her coz she was kind. When my foster mother came to take me home I didn't want to go coz I liked hospital better.. I was 8 yrs old ..she said "don't be so silly [foster] dad is in the car waiting .. When I was about 10 yrs old I had an elderly friend who I used to bike to see and spend a few hours with. She was kind to me and took me to the carnival that visited that year and wrote me a poem. Most of the families from the church I went to I stayed with in weekends or spent time with. I never remember doing one thing with my foster mother but spent lots of time with my foster father. My foster mother said that my foster father never wanted to take me as a baby but I think that is a lie or if it's true it's because they were past 45 at least and poor health. My foster mother spent time as a Scout leader until she left after 16 yrs or so. My foster father died when I was 16 but my teachers thought it was my real father who had passed. So my school must have known my real name even though I went under the name of Janet [foster family's family name].

## **“I longed to be a firefighter” by Tim** <sup>33</sup>

I was born in Hamilton in 1965. We moved from house to house. First in Christchurch, then Hamilton, then Tauranga. We moved around. We never quite settled as it were. And when we finally went to Fiji, I was about four years old. It was the best years of our lives.

When I was a child, I was a bit of a rebel! I didn't pay much attention. Boys will be boys at that age. [In my] play centre years, we visited the old fire station in Fiji. And I longed to be a firefighter! But because I've got epilepsy, no fire service around the world would ever take on an epileptic! I mean can you imagine, I mean here's the fire chief and there's the firefighter. I've got to go in whether [I had the time to] take my pills or not, come out or in the fire. So you can see the safety precautions there. But I was fantasising [being] a fire chief [as a young boy]. Dad had a Mazda car and that van was gonna be the fire truck. I would love to squeeze the hose, all that power water coming out of the hose Oh! [Name removed]'s house is on fire. Yahoo! I'm the fire chief, I'm having the time of my life!

It wasn't even primary school years when I started having seizures. They came on so quickly. I had no control over them whatsoever. [But I can feel it when it is coming. My mum said] “Tim, (laugh) if you go in that toilet do not lock the lock from the inside!” This is the toilet, and I locked the door from the other side. And I had a fit. I don't know whether the door was actually wooden but I suppose it was. The rest of [my] family they knew what to do. Tim's having a fit! Knock down the door. [After the fit] it takes another two hours to sleep it off. Cause **all that energy** is gone. And you've gotta restore it all back again in to the body. [When my family asked what it was like, I said] “do you know how lightning and thunder occurs?” Like that.

I remember going to Christchurch [for treatment]. That was about the time the Moscow Circus came to town. And I was staying, after my operation I came out in a wheelchair, [there they were] Camels, lions. Oh yeah! Moscow Circus. I don't think I actually went.

I hated and despised what my father had written in the old passport. And I thought you bastard! And I turned around like that, gave him a filthy look. I think from that perspective whether he knew anything about my disability and he must have put it down as MR [mentally retarded] or IHC is another matter. But it all accounted for the same thing.

[I went to Christchurch again for an assessment]. I remember thinking, what the hell am I doing here in this hospital? They used to have little blocks and I just hated [the assessments]! Thinking, I just want to be normal. I wanna become a firefighter. I wanna become somebody.

My mother said you're going to that school [Marylands]. In those days, [when] you were told to go, you were told to go! And that was the end of it. You had hardly any say in the matter. But you can imagine the reverse mess that my old man said no I'm not, I'm gonna stay in Fiji. I think he probably would have said well Tim you haven't got much say in the matter lad because your mother wants you to go to the school in Christchurch. We've made arrangements and dah dah dah. I guess that's what would have happened.

<sup>33</sup> Tim chose to use his real name in his story and changed other names in the story to pseudonyms. Real names are used for Brothers at Marylands where their abusive actions have been publicly reported and justice has already taken place.



Marylands was a school for boys with disabilities of various kinds back in the day. I remember being taken down to the school [in 1978] and it had a great big sign. Of course in those days I didn't know how to spell. And it said special school for boys, Maryland's big broad letters. Well how the heck do you spell Mary? And then you got lands. So as you entered Nash road you look at the sign. Oh yeah Mary m a r y lands l a n d s. So that in itself was a sign for me to learn how to spell Marylands. when I arrived it was old and it wasn't warm. There were run down radiators, heaters if you will. While I was there, the money was probably there and they decided to knock down the old part of the building and put up new ones in 1979. Villas. One, two, three, four and five. In the new school, or villas rather, the boys were allowed to have photos of their family. And I can't recall ever having one. Isn't that strange? Maybe I did, I dunno.

I had cousins, my uncle John and aunty Colleen in Christchurch. They were my mother's side family. I went out to visit them on the odd weekends. Very lovely people. I loved it. Sense of freedom. We had these other days as well on fete [fair] days. [There were] old tents and bits and bobs. And then mum made a cake and sent it from Fiji. All the way from Fiji to Christchurch. You can imagine the cake would get in to Christchurch stale and not edible. I think my aunt made the odd cake, I think. And other brothers and what not made cakes. I used to take my uncle John and aunty Colleen around to the fete. They would come around and check it out.

So but the building itself, the old classrooms, we had to line up outside of the classrooms. But first we had to go outside. And the headmaster would say you have to, your reports will be sent up to your parents last week. Or who's been a good boy and who's been a bad boy! Or who's played up was playing up with the staff.

That school alone wasn't, I don't think it was designed for [school certificate/academic education]. We were given this notebook with words in it. That was the homework. And I had to get one of the supervisors to go how do you spell this word Tim? A e I o u We had spelling tests. If we were taught words that were given the day before. You had to remember them and take them back. And if you couldn't remember them I think you learn how to spell them again.

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. And you could see the wear and tear on it. I thought ooh! Six of the best. You had to take it like a man. Or young man.

One of the boys who was at the same school as me, my senior, he rolled up, was about 1979. And this is probably why I don't like people crunching their fists and their knuckles. And he said if anyone touches my bike I will bend your fingers. Now I don't know I was probably being a bit ... I thought well I'll take the risk. I did! So I took his bike and he found out who it



was and I ran for my life! And when he caught up with me, he got my hand and he bent my fingers. So I think from that day onwards, I hate it when people bend their knuckles.

Some of the good memories are learning, we did PE, we ran, and we would run up from Nash Road outside of the school and back again. It was a hell of a long run. And you would feel the stitch in your [legs] ooh! And to ease the pain you just put your hand on your hip and run back again. And we'd do soccer and support our teams. And depending on which colour, we're yellow, green and that was just the group we were in.

We had this huge [dining room] bigger than this room! God almighty I've never seen so many boys in me life! You had tables with seats. Oh yeah. We had a bit of a mad bloody cook actually. What cook cooked up that night for the menu, your breakfast, your lunch and your dinner you ate. More please! What? More? So we would come back to the table and sit down and shut up and eat our kai. I remember roast potatoes. Ooh! I have never eaten roast potatoes the way our cook made them in their bloody jackets! Absolutely to perfection! Yesss! And it was just words fail me. Oooohhh! There's the good memories. And I think of all those roast potatoes. I'll keep remembering them til the day I die! If I ever die tomorrow or next week or today at least I'm gonna see a nice, crisp, roast potato up in heaven. The roast potato in heaven! I'm looking forward to it.

And because I'm probably easily adaptable to most things in life. I remember Henry who was on the same table as me. I mean, I look back to the days in Fiji. To actually spread butter or margarine was easy on a piece of toast. But I don't think I actually had the experience of opening up a jam container or butter Fernleaf. And Henry he got that little corner. And helped me out with that. It was about the only decent thing he ever did for me. So I learned from that how you peel the plastic from the jam or the Fernleaf butter. But apart from that he did other bad things for me.

I used to help out in the kitchen, the old kitchen as well as the new one. I probably won't be the only one that did that. It wasn't that much cleaning. It wasn't slave, it wasn't child labour. It was just me volunteering. [One day] the cook had this meat cleaver and somebody must have upset him. I dunno what was said. I must have been twelve going on thirteen or whatever. And he had this meat cleaver! Rararararara! Ok!

[Other thing I did was] my first aid training. And I had this great big wooden bloody trolley to push collecting the patients' dirty laundry [from the hospital that was nearby the school]. Oh it stunk! I thought oh god, where's my peg? It was eeeh! What am I doing this for? How old am I? Fourteen going on fifteen! Just volunteered. [Helping] kind of runs in the family I guess.

I remember having to go to special celebrations like Easter and that sort of thing and sing hymns, 'I'm the Lord of the Dance said he' oh god how does it go? It was one of the things we had to sing. And the pews were just wooden. (sings the song) referring to Jesus. And then I think there was some great big confessional boxes as you come through the tower.

The boys were given work experience. It wasn't paid. It was there for a reason. And that reason was to do with should we ever leave school we might take on those jobs. And I



applied for,,, don't know what I applied for. And the guy that offended me, he worked for the butchery which I am sure now is long gone. And I used to get up about six in the morning and I used to wear a white jacket. That was part of my uniform. And I used to walk down Nash Road to go to the butchery. It was just before you got to the actual city of Christchurch. It wasn't far from school then I'd walk back again. And I mean I didn't learn much about the meat and the cow, pig and so on. Boy, the ingredients weren't even around then. You'd have these dead animals hang up on these hooks in the freezer. [Customers would come and say] "oh a pound, not even a pound, some sausages please or steak" or whatever. There'd be a cabinet and you'd go up this little flight of stairs. And in there would be I don't know, cow or pig, whatever was hanging on that hook in the fridge. And in the back was where they made these sausages. Ooh, the one thing that scared the hell out of me was this revolving machine to make mince. I'm glad I've got my fingers still after all these years. Those blades if you put your fingers in there, you could kiss them goodbye.

That was part of the work experience on Tuesdays. And the boys were all there and that was part of the scheme. Cause we had PE on Mondays and Tuesdays the boys would be sent out to various jobs. And then I went from Gleasons butchery to work in a truck. They had a furniture removal truck. That was the best job I had. Really was. Oh I loved it! I loved it so much. Was riding in a big truck! Opzzland was the name of the driver. It's a Dutch name. I loved just sitting there with him. And one of the trips we used to do. It just made me felt woooo! I'm in seventh heaven here. You can see just the whole road! And you got your driver next to you and I thought wow! This is the life! And years later I sent a letter to Mr Opzzland. Dear Mr Opzzland I wouldn't mind coming in to Christchurch and working for you. Wrote back. No, can't do it Tim. Due to the fact that you've got epilepsy it'd be too dangerous for you. Oh ok, end of story.

One frosty morning we were all tucked up in our beds as us boys were to be expected to do so. And the alarm went off. And I guess it was the central fire station in Christchurch. They came round here. And there were the staff door. And that's the brothers bedroom. The brothers, he wouldn't be in charge of the entire villas. Other brothers would be in charge of their own villas, three, four and five. Anyway, I couldn't get out. I mean I could, but the boys went out the fire escape door. And there's a door just about there. And it was locked from the inside and I couldn't be bothered [un]locking. I had a bad fit and I can't remember what the hell happened after that. If only half my old mates would come now and answer those questions, boy that'll tell you a story. Tim wasn't drunk but he had a few issues. But they weren't very well controlled. I used to take Zarontin and Dilantin four times a day. Back in the day when they were in glass bottles. Now they're in plastic. And the last seizure I had was in 2019. I've been doing pretty good for myself these days. Whether it's my old age or not.

Brother Ephraim was the headmaster. Before his time was brother Bernard McGrath and you may have heard about him in the papers in the past not so long ago. He abused boys. He was the headmaster at the time. Then who came after him? Think it might have been brother, yeah might have been brother Viani. And then after him came brother [name removed].



Oh yes. Sorry, I'll go back a bit. I had brother Ephraim. Then I had brother Garchow. He's dead. He was also an abuser. He was a male nurse. He would do his check up on the boys for anything to do with health. The physical side of things. He had his little consulting room downstairs on the ground floor. And then that was his call. Well not his call, but he would make an announcement which used to go like this. "All boys with medical needs please come to my consulting room now if you think you've got a need to come and see me." But if there was any boys that needed any help that was referred to or needed hospital care, that was referred to Doctor Connor. Or if he needed Doctor Connor to come in to the school and check up on someone then that was arranged.

I didn't personally go in the consulting room. [But] the boys, they must have known before, yeah. There was some abuse going on. I'd like to meet this young man [who abused me]. But I'm not going to go on and on about it for too long. But he would have been there before me and I'd like to meet him. The only thing I wanted to do was I wanted to get away from the one that offended me. But I wanted to know who offended [him] before I came on the scene?

There was no sex education at school. I don't remember dad ever telling me about sex and males making love to women and blah blah blah blah either. The first time I learned anything around sex was when I was in Fiji. I remember reading this book which was in our possession at the time. It must have been in the morning and I read this book and it was clearly illustrated wasn't it? You had the boy growing to a young man and man with the penis and woman lllllaaaahhh! Oh my god! I was somewhat taken aback. I thought, and then they had a photograph of the woman. Who wrote this book?

I knew nothing about circumcision. I just assumed that most boys had non-circumcised penises. Until the day that he took me aside in the old gymnasium and did what he did. I was shocked. As opposed to "what the hell's going on here". He was touching my genitals or genitalia. I was pinned against a brick wall and I thought ... He was like a statue! Basically. I mean, there was an escape route but I was frozen. I thought ... We don't do this in Fiji! I think he might have said this is our secret. He wasn't afraid and that's when I learned that he had a circumcised penis and he did it again when we went away on that field trip. In bed he raped me. And that's when I learned that boys do have circumcised and uncircumcised penises. And I thought hmm, ok. I suppose it was the way I was brought up that you don't assume that most boys would have uncircumcised penises. But I didn't know that for my puberty years until he did what he did. He just targeted me I guess. This is the part of the problem at the moment because I would like to know why and that's why I'd love to meet up with him. They were happy days [till] when he abused me. He was in my class. He was in the same dormitory as me. Oh he was [my friend] until he did that bad thing on me. I thought bugger you! He trapped me how do I put this? I am 56 years of age. In the last 43 years I have lived my life with trying to erase him from my mind. It's not raw but powerful. He should never have done what he did. But with me trying to erase him from my mind and it's a powerful thing to forget about because every single day, I'm not the only one who feels this way. My old comrades would probably feel the same way as I do.



Had I told my uncle when I was about twelve going on thirteen and my parents - my family lived in Fiji. I would imagine in my mind at the time that dad would have said hang on Tim's telling porkies here. Ok John, that's my uncle, go up to the school and find out. Now I would have been telling the truth but Uncle John would have been given porkies himself.

Basically, if I hadn't done all this [reflecting and writing] I wouldn't be here today because I reckon I would be in prison. I probably would have seduced half a dozen teenage boys. And for the tape, I would more than likely have done that years ago but because I'm with an organisation which used to be called DEALS it's now called Community Connections, they put me on the straight and narrow. But that doesn't mean to say that the hurt and the pain is always gonna be there till the day I die. Because we're all angry in one way or another. And as I said I live independently and I love being independent.

I went back to Fiji after the school. I suppose in some ways I was lucky. My family. My first boss was Mr David Ashby. My father knew him and he talked to him to give me a job. He worked in a big company called Stitches and Pierce. And it worked out very well. I had own telephone, own desk, woo! There's a door there and Mr Ashby's office is there. And I was going on seventeen and I loved it! Wow!

I was working in Fiji until my father fell ill. He was bipolar. So then dad decided I'm going to Switzerland. And she [mum] stopped him. You're not going anywhere, you're coming back here! So in some ways he destroyed the family and then he went off to Samoa and he found a Samoan woman. And then he married her. And then he produced another blimin kid, another lad. And at the time I was angry with him. I mean how dare you! Then the rest of the family came back to New Zealand. I'm sure he would have been all right when he had the first lot of boys, Jason, Tim and John. I'm sure he idolised Justine being the only daughter. But he just I don't know.

And when I came back [to New Zealand] I had hell of all these blasted [sheltered] workshops! I thought there's gotta be a better life out there for me. And I was right. One day I just had enough! I mean look! Up at 6, get the 7:15 am train, catching the 3 o'clock bus, and all I got was five bucks for the end of the week. But that was because their manager couldn't get me any more than that. Because if he had done that that would have affected the benefit.

There was this dairy owned by a guy called Steve. That was where the Wellington Girls' College students would get their sweets. I wanted to work there. I spoke to Jenny who is a former epilepsy field officer. Jenny spoke to Steve [Logan]. Cause Steve was a bit cautious. Yeah I suppose he was. What do I do if I have a thing. A fit. And it'll be all right. He took me on and he's never been the same since. He had a restaurant, and I went on to work at the other restaurant. I've been working with him for thirty two, thirty three years as kitchen hand, peel spuds, veggies prep, cleaning. I stopped working [there] when they changed the owner.

And I got this phone call. And believe it or not I was rostered. Before I got rid of my landline. Tim, we need you to come in and do some dishes. It was Steve calling from another restaurant. When I finally went in oh lord! My workload was more than I could bear. I had



forgotten. I had just forgotten how much demands, the pressure! And oh god! They had four bins that needed to be cleaned out. And he wanted me to go and do the dishes. You want this, you want that. And I've gotta change dishwashers. I don't know how to change dishwasher water. Tim we need this. Dishes are getting piled up down here. Tim down to the prep kitchen and ... Tim now to the service kitchen. Tim we need this. I was only working from what? Probably midday to 2 o'clock in the afternoon. Never get out of here. Never. So they reduced my hours from 9 am to midday. I'm glad they did!

I have a retirement plan. Even though Steve did say to me you're not gonna retire until I retire. Oh god! I think he's sixty something and so yeah. So I made the announcement on the 28th of September to the family and I've got their backing and support. I wasn't trying to dominate my older brother's birthday. He's just turned 58 I think. That's my oldest brother Jason. And I had no intention of dominating his birthday but I did prewarn them beforehand. I've got an announcement to make and da-da-da-da through Zoom before we have the Zoom meeting. And we were waiting for mum to come on Zoom but she came in later. "Well what's your big announcement Tim?" And I told them. I already decided the day I will retire. The 30th of the 9th 2025 which is a Friday.

## **“It might be all houses there now” by Allan and Nathan** <sup>34</sup>

A: I was born in a rural town in South Island. I have two half-brothers and a sister. My mum’s still around. I used to have a dad but he passed away a couple of years ago. He lived to a good age. He was 87. But I remember that was a very sad time for the family and me when we lost dad.

I would like to go back to experiences I had in my early childhood ...

Before I went to the school in Christchurch I used to find it very hard to fit in. If I wasn’t sure how to do something, I noticed that some of the teachers wouldn’t listen to me and thought that I was trying to be naughty when I made a mistake of something. When a teacher wouldn’t show me how to do something, I wasn’t sure what to do but they got me to figure it out myself. And then I tried giving it a go and got something wrong, the teachers would sometimes yell at me for getting it wrong and I felt really awful.

I got diagnosed as autistic because I went to Wakari when I was about five to be assessed. I went there with my mum and dad. Teachers didn’t know what was wrong with me before I got assessed. It was a stressful time. I think it got to a stage where other schools couldn’t handle me. I would get stressed because they couldn’t understand me. And from the age of eight I went to a boarding school in Christchurch.

It wasn’t my choice to go and I think my dad had no say in it. Cause I think what happened with the problems I was having, one of the behaviour specialists was going to send me to Cherry Farm Hospital. But my mum and dad decided well no, we’re going to send him to a special school where he can get an education and learn stuff. Cause my mum and dad knew that if I went there I couldn’t learn. So my mum and dad decided to send me to the school and get me an education rather than being locked up in an institution. They wanted the best for me.

But I remember I even had the same problem with the teachers at the school. Like some of the teachers would do the same to me even at Hogben. They wouldn’t show me how to do something. When I wasn’t sure what to do, I ended up looking in the wrong place and I ended up getting yelled at. That made me very annoyed and angry. They told me to think for myself because if I did things wrong they just thought I was trying to be naughty. And it wasn’t good. It didn’t work for me. Cause if I’m not sure about something I always like to be shown so then I can remember where it is. Rather than them telling me to use my head. Other times when teachers didn’t explain things to me in a way that I understood, I sometimes would get it wrong and then I’d be yelled at. I think sometimes I would have outbursts and then I’d be sent to sit on the hot seat. It’s a chair in a corridor right by the principal’s office where you sit by myself. I was sort of isolated from the rest of the pupils. It wasn’t helpful.

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

<sup>34</sup> Allan and Nathan both chose to use their real first names in this story.



used to send me back to the villas. I had to go back and stay quiet by myself until other students finished school.

A: At the school, we basically learned about cooking. But my favourite things to learn were maths and artwork. Before I went to Hogben I think when I was seven I used to do three dimensional pictures with crayons. Like I used to do a picture of a hillside and I used to draw the things on the hills and then the ocean. Cause that's how I did my art.

I used to be called rabies and ra-ra woof-woof by other pupils because I was scared of dogs. There was some people that would even hit me and even throw stones at me and even do all sorts of things because I had a disability such as Asperger's autism. I used to sometimes tell the staff and tell the teachers. But some staff would just say I got upset when I was being bullied. They were not being very helpful because some of the staff you know, thought I was just over reacting when all I was just trying to do was get my point across and ask staff to help me and support me when I didn't feel safe around some of the pupils. I'm not too sure if I trusted anyone in the school. But I did have some friends that would stick up for me if I was being bullied. And those people that used to bully me I used to be too scared to go near them. But it didn't matter if I walked away from them. They would follow me. Well then my friends used to stick up for me and bully them back. My friends were stronger. They had my back. They were friends from back home. I used to go on the same plane from Invercargill to Christchurch and they used to be good friends with me. I remember I used to have lots of good friends.

I first met my friend Nathan in the mid 1980s. We used to meet at the Invercargill airport cause we used to go to the same school together. I would have only been thirteen. Nathan came later. You are a little younger than me.

N: Yeah. I didn't like the school I went to in my home town either. The teachers were not great. It didn't work for me. So my mum and dad sent me to Hogben's school. I felt better there than the other school.

A: I notice that Nathan used to sometimes get bullied at school too. There was a person who used to be in the same class as him. But I think some people would stick up for Nathan.

Nathan also told me about what happened in the villas after school. We sometimes used to play on the adventure playground together.

N: I used to throw bark and I got told off. [laughs] There might be houses where those playground used to be now.

A: There were lots of time for playing when we weren't doing school work. We would sometimes go to the field and play games, we would play at the adventure playground, we would do all sorts of things like play in the sand dunes behind the villas. I think the villa staff would sometimes play with us, supervise and make sure it didn't get too rough.

N: They used to call us when it was tea time.



A: The food was good at the school! There used to be a big kitchen where they used to cook all our meals. I used to sometimes help with bringing the trolley with the Bain Marie with the food back to the villa from the kitchen. It used to be like a trolley that had wheels on it. We used to wheel it. Not lift it.

N: If it was raining we had to stay and the staff went and got it and brought it back. I think they would have gotten rid of the trollies by now.

A: Hogben school wasn't only just a school but it also had villas where you could stay and sleep in. There were five different villas in the school, there was villa five, villa four, villa three, villa two and villa one. When I first went there I was in villa five that was from the age of 8 until 12, and when I was 12 I went to villa four until I was 14, and then when I was 14 I went to villa two right up until I left school at the age of 16. That's where I used to live with Nathan also. Villa five was the junior villa, and I think villa four was more like the intermediate villa, I think villa three, villa two and villa one were more the senior villas. There were quite a few people, about 24 to each villa, so, there were easily over 100 pupils in the school.

I think there was one big dormitory in each villas. They had beds in each cubicle in the dormitory and there was lockers as well. But I don't think in there you got your privacy. It was sort of embarrassing sharing the dormitory with so many other students. Cause I'm a person who likes to have my own privacy. There were curtains to the windows but I think the cubicles, they were all open to the dormitory. We had separate showers. It was all in the same room but they had doors and stuff. There were three showers each in the bathroom.

N: Where the villas are, it's all houses and where the offices were, there's all houses there now.

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 over reacting. And after a while it made me a bit scared to go to that staff member. So I would go to someone else who I could trust and who would be more supportive of me.

If we played up in the villa's we were put on restrictions. Because one day when I used to do things that weren't good, I used to be put on isolation or restrictions.

N: Or you had to go and sit outside the seniors office. I remember that. If you were outside the senior's office you had to stay there till bedtime. When everyone else was in bed, they took you over then. You had to be nice and quiet when you went in.

A: When you are put on isolation, you had to sit in a chair by yourself, and you had your meals by yourself. You weren't allowed to talk to anyone. I think the longest that it went on for me would be 24 hours. They usually would put you on it for 24 hours or 48 hours, depending on what you did.

If I could change what happened, I would have wanted the staff to listen to me and talk to me. Because when staff didn't understand me and expect me to do things that I wasn't sure about, then yell at me for getting it wrong, then I would explode, they would just see me as a



person who was trying to be naughty or out to be dangerous. And that wasn't the case at all. I think there was a misunderstanding and I wasn't being listened to is what the problem was. I think there were abuse that happened in the early-mid 1970's, but that didn't happen when I started in 1980.

N: It might be all houses there now. I don't know where Mr things office was, I don't know what'll be there though.

A: Every time it was holiday, we went back to our family. Christmas holidays would go from mid-December to late January. Sometimes even early February. And we would be back at school for term 1. That would go right till early May. And the May holidays would be from early may till late May. And from late May till mid to late August would be the winter term. Then we'd go home for August holidays from late August to nearly mid-September. Then we'd go back for term 3. Term 3 would start from early to mid-September right till mid-December and that's when it would be the end of the year. But sometimes even in the winter term 2 we used to have a mid-term break. I will say at the end of the school holidays Nathan and I used to take the same flight to go back to the school, and his parents and my parents met at the airport. We used to talk about what we got up to in the holidays.

N: When I was home sick they used to tell the air hostess on the plane. Cause I had to be kept an eye on. At the end of the flight, the air hostess used to say see you again in the holidays.

A: I used to also be very sad to leave my parents and go back to school cause I used to get what's called home sick. When I was sad, talking to staff who understood was helpful.

N: There were certain nights our parents would ring, but we couldn't talk to them. The staff would take the phone and shut themselves in the room to have private conversation.

A: Yeah we were told to go and sit in the lounge. If there was something important, then the staff told me afterwards. But once a week I used to write a letter to my mum and dad about fun things I got up to and they used to send letters back to me. That's how we used to keep in touch.

And I had good times too at Hogben because we used to go on outings. We used to sometimes even go on school camps to Arthurs Pass and play in the snow. Go for bush walks. On the weekends, we used to go on van rides and we used to go out to a local dairy, get an ice cream and lollies and fizzy drink. I remember those good old days. Sometimes we used to play hide and seek, we used to play ball rush, in the fields we used to play games like cricket, hockey, football, softball, all sorts but my favourite sport was going swimming in the pool there. I always used to like going to QEII for a swim and I always liked jumping around in the water. It was a swimming pool centre in Christchurch. I couldn't go swimming whenever I wanted to, I could only go if the staff was able to let us go swimming. I will say I miss QEII being there because that was my favourite place in Christchurch.

Me and Nathan had a savings book when we were at the school and we used to go into the bank in Addington.



N: I used to go in with a teacher, they would walk with me and show me how to catch the bus. But one time I bought fish and chips before catching the bus and the bus came earlier. I had to throw the fish and chips in the bin. Who would have told it to come early? What a waste.

A: I remember I used to go into the big chapel there at St John of gods. When the brothers used to run the school, we used to have church services every Sunday morning. We sang at the church. It was quite big inside, interesting stain glass windows in it. I have never been a catholic but I had to go to the church even though I didn't want it. That's what the school wanted me to do. I'm not generally a religious person. I would be saying no if I had a choice to not go to the church. I didn't have the choice at the Hogben, at the Maryland's. It's something that we were told that we had to do.

Well I was there at the Hogben school for eight and a half years nearly. They used to keep people up there till seventeen eighteen. But I think when I left the school they only would keep people there till sixteen. I was there from 21st July 1980 to the 15th December 1988. Then I went back home in Invercargill. While I was back home, I learned to paint, and I have done painting ever since. It's easier to mix colour with paints and it's not the same when you use crayons or pastel.

I stayed at home up until I was 20. But I had a lot of problems around home because they didn't understand me. So I was sent to Cherry Farm. I was being assessed and then I was there for two weeks because Cherry farm was soon going to close down so they sent me to ward 12 in Invercargill hospital. To tell you the truth I didn't like ward twelve because they fed me on a lot of pills.

N: I also went to Cherry farm. I don't remember where I went there from. I was also at ward 5 in Invercargill hospital. I wasn't allowed any visitors there, even though other people had visitors, I wasn't allowed. I didn't think that was fair.

A: After three months of being in ward 12 in Invercargill hospital, I joined Invercargill home support. I didn't get very good support there. I was only getting half an hour support a week. That's really not what I call support. Basically they left me on my own to defend myself. If I wanted to do important things like learning how to cook, there wouldn't be staff there to support me. I was in there from early 1993 till September 1997 and then I went to Wakari and I was there for nearly two years until August of 1999. I went to 9A and then I went to 10A, and then 8C and then back to 10 A. When I was in 10 A, Nathan and I lived together.

N: I don't know how they put us together. But I think the nurses decided. We didn't have choice.

A: Every Monday we went on van rides.

N: We went to buy fish and chips but we had to go back and eat them in the ward.



A: Sometimes we did but sometimes we even ate them at the domain in Milton. And other times we would go tramping on Friday, we would go for a walk and we would take a cut lunch with us. Do you remember on a Friday when we were in 10A we used to get given a beer.

N: : Oh, I remember getting a beer on a Friday. They used to come with a beer in their hand.

A: I don't know about you but I liked Wakari better than Cherry farm. Cherry farm you were half an hour out of Dunedin, at least if you were in Wakari you were right in town. They used to catch a shuttle from Wakari into the hospital and I used to sometimes walk from there to art centre. In 10A they would sometimes teach me to be independent. But even at Wakari, there was a nurse that would make assumptions about me. There was a nurse that wanted me to open a gate and I couldn't do and I tried and I couldn't do it and he tried to make me.

N: There might be all new staff there now.

A: After I left Wakari I joined the community trust and I lived at the Carls street and I was there for a year. After I moved out of the Carls street I lived here at my own flat and I've been in my flat for 21 years, 4 months. I was glad to leave Whakari and be out in the community. At the moment I get 14 hours support a week. I get support for 2.5 hours on a Monday, and I get support 1.5 hours on a Tuesday and I get about 6-6.5 hours on a Wednesday and I get 1.5 hours on a Friday. The only day I don't get support during the week is Thursdays and in the weekends.

N: I also moved to community after Wakari, and I moved to a different house once. We have good food where I live now.

A: Nathan and I quite often have pizza and chips in my house. And I've provided the fizzy drink. After our food sometimes we've even play yatzy. That Yatzy game I've got I've had it for just on 36 years. I got it on Christmas day 1985. So I've had it all that time.

I always say this, that everyone should be treated equally. I didn't feel like I was treated equally before I started living in the community. I think when you are out in the community you have your own freedom and you're not, you're not told when to shower or when to eat and you have choices of what you want to do. Rather than what you were told to do. I have control on my own choices and more freedom too. I have a good landlord, a new couch and a new chair. I've been very settled here with the community care trust and I'm very happy to stay with the community care trust forever. I'm going to be living in the community until I'm an old man.

## **"Father and Son" by Michael and Trevor** <sup>35</sup>

### **Father's Perspective**

I think to myself, if only he can say what happened. I've always believed that he would be happier. But he is happy.

Annabel and I were very young when we had Michael. He was born in Dunedin in 1968. When Michael was born, the doctor said his heart went a bit wonky but he was alright. We didn't think much of that and I guess at about 6-7 months old, when babies start sitting up and doing those sorts of things, he wasn't doing it. Eventually, we went to see Professor H. I remember him saying, he seemed to think that I was very upset about all of this and I wasn't but I remember he said to me, "how do you think Michael is going to be in his life"? I said "if Michael wants to fly a plane he will, it will just take him a bit longer to learn it". And he came right up to me, right into my face and said "Michael will never fly a plane". I ignored that. I was only 20 years old but I was thinking, "don't tell me my son won't fly a plane".

Michael was a loveable boy. We wanted him to start school at the age of five but they wouldn't allow it so he started school at age six. When the year finished, they told us they don't have the staff there to support him. So he went through a special class in George St school. He got a taxi to school, funded by the government which we were very grateful for. Michael went to George St School until he went to Maryland's School at the age of 10. Why did we send Michael there? I was thinking about that this morning.

In between, Michael's behavior, like he used to hit Lisa a wee bit. I had bad depression too from what happened to me all those years ago. Jack Austin was the psychologist, I remember that. So, I had all this depression and he thought it was better for the family that Michael go to Maryland's School. Jack Austin said that he would fix it all up and he did. They told us that the school would be excellent for Michael, for learning and it was. Like he was great with money. He was great at spending it too. He can be a miser though. He could have \$50.00 in his pocket but if you owed him \$2, he'd want it. So that way, he's very articulate when he speaks sometimes. He has grown this ability to communicate and talk. Sense of humour. What a sense of humour. And I remember hating the idea but I do remember thinking it's a relief. We were excited too but then Michael had to leave. The reality of it was huge. And Lisa sometimes was at the wrong end of Michael - he would sometimes hit her. Although he loved her. But the person that was most upset was Lisa. So it was a funny time. I remember my father, he is an amputee. He had his leg off when he was seven years old. So he knew a bit and I remember him saying to us, no don't send him there. You're putting a label on him. I'll always remember that.

Michael was taken to Marylands and the first time we all went up he was in a play. Mid-term we'd all go and stay up there for a weekend in a motel. They were doing a play in the mall of Christchurch. And Michael was an Angel. And this little kid, well he was 10, maybe 11, singing. He sang like a bird and he was an Angel in this play. But the brothers never made themselves known. And when we went up there for weekends it was the cook we saw,

<sup>35</sup> Michael and Trevor both chose to use their real first names in this story.



mostly. I used to draw pictures of Fred Dagg and all that and I used to always draw that with the letters. And I've never seen evidence of one of those letters yet and there were heaps of them. And he didn't know what I was talking about when I told him.

I remember one time when we got there, I was early. I went to the school early and they were playing cricket. Michael was a great bowler. We used to play in the back yard from the age of about four. And he used to bowl me out. I watched for a while and Michael came into bowl. And all of a sudden, this is toward the end of Michael's stay there, it's just something, and he bowled, he bowled this boy out. And then the boy picked up the bat and started chasing Michael. Running after him. Michael saw me on the bank and said what will I do Dad. I said, just turn around and flatten him. And he did. Well not right there but he ran around the back of the wicket and he flattened him. He had to. And this teacher came running over and grabbed Michael by the hair and pulled him off and said "hey, I've told you you've got to be very easy with this boy". Like this is the boy with the bat. What hurt so much about that was, I didn't do anything. And later on I was having tea with the boys and this teacher came over and said "I'm sorry about that". I said, it's ok but it wasn't ok. It stayed with me. I should have told him to bugger off, you know I was so angry.

The ladies that did the meals and the staff that looked after the boys, they were wonderful people. They were, truly. Michael continued playing the guitar up there and a little Māori boy, a nice lad he was, him and Michael seemed to get on. So they played the guitar together but I don't think it was celebrated much. The lack of..... you know these brothers, where were they? And of course there is a feeling of guilt, we sent him there you know. If Michael hadn't have gone there, he might not be as educated, but he wouldn't have black memories. We went up there once and he was in confinement, we couldn't see him. I asked them why, what had he done and they told us he had pinched the night watchman's lunch.

In the school holidays, Michael always flew home and sometimes he'd have the captain's hat on. They were wonderful, those people. But going back, he never wanted to go back. He'd run away. I chased him all through town one time. Annabel worked at a shop and I was taking Michael to the airport and we called in to see Annabel and he took off. They're some really painful memories. I went up there on a train one time and I remember Michael wanting to come back with me but I couldn't take him. Probably the last year or so it didn't matter so much. The last couple of years. In the last few years Mike became aloof - not so welcoming, withdrawn, Marylands had become his home. I thought he had a wee weight on his mind.

I remember Michael's final day there. They had this wee thing. There was more than one boy. Two boys I think, maybe the wee Māori boy. And the principal of the school, I think she was the principal and there was a brother there too, that woman was crying. She broke down and cried. And I thought this is odd. She wasn't crying like she was just going to miss the boys. She was breaking her heart. God I'd love to have a word with her now. What did she see?

Michael was 16 years of age when he finished at Marylands. When he came home it took him a while to settle. His personal hygiene was a problem, washing hands, he hated having a shower. Different now though, he showers everyday. We got him into some training centre



down Anzac Avenue there and the hours, everything about it, I thought this is going to be hard for him. He hated it. Used to run away. And that's probably when he first started riding the buses. He had a monthly bus pass. He knew all the bus drivers and they all knew him. Outside our house, there was no bus stop there but they'd all pull up there to let Michael off. And then we got in with the other IHC. Michael worked with them pulling starter motors to bits and all sorts of things which is fair enough. I'd probably enjoy doing that myself. But once again riding the busses, you know. Then he got gardening through the IHC which he liked but then he got pulled off that. In the finish, IHC did a good thing. There was a recycling company starting up and IHC had a contract with them. And part of the contract was that they sent two young men to help and so when the contract finished about a year later, the recycling wanted to keep Michael. So they did. And man those guys were great. And they taught him how to work and what it's all about. They taught him.

He had a girlfriend. I remember coming home one day and Michael, I suppose he was about 20 or so, so that would have made me 40. And Annabel said to me, go through to the lounge, Michael is here with his girlfriend. And she was about 60 [laughs]. It was a shock that she was older than me. But I don't know what happened to her. He had another girl that was in a wheelchair for quite a long time. And they're still friends but this girl, I knew her family and that too. Whenever she has a birthday party, I go around there and play the guitar and I ask Michael if he wants to come but he always says "I'll see Dad". Then later I'd say, "oh you weren't there." And he'd say "no, if I go there she will start ringing me up every day." So relationships are ruined. He doesn't know. And I don't think that's the brain damage. Because I have seen how people with...mind you, we're not all the same. But I've seen intellectually disabled can still love someone. And I think [for] Michael, that's all affected.

While Michael was going through these services, there had been a few comments made about Michael and his behavior. A staff member had said something about sexual things, I think it was to [his girlfriend]. Michael saw a Psychologist leading on from all that. She told us she believed it was likely something had happened to Michael but she didn't get explicit about anything. She dealt with Michael; she didn't need to consult us about everything because he was an adult. But if there was anything then, there is nothing now. There are no reports of Michael being like that. You get a fear that that sort of thing might happen. Especially, Michael loves children and they love him. He is wonderful with kids, especially little babies. And he always has, right from a little kid himself. You know, if a lot of bad happens, how much good does it take to get rid of it? Well it's not that much anyway, could be about that much. Good has such a big effect.

A friend of mine had a lot to do with all the brothers getting charged. Her son committed suicide. And he was dressed as a woman and he was married as well. You know, they screwed him up. I know when I saw that brother McGrath on TV, I wasn't surprised. There is another guy that worked for the [community service]. And he was a counsellor of some sort. And Michael told me one day, he had been at an interview with this counsellor who had been had up for interfering with clients. When I made enquiries about it they said "oh no". So we're



talking about how nobody is up front about these things and as for hearing about Brother McGrath, I think I knew. When he was on TV, that was when he was charged, or put into jail for a few years.

I can't remember if we were contacted, or if we had to enquire, but we had the interviews. First of all, it was the brothers in Australia. And a psychologist was with them. It's so unbelievable really because Michael denied everything. And they said, well we will send photo's over of where the molestation took place and see if that can remind Michael. They never did. But part of this was the police wanting interviews as well. And they interviewed Michael and me together. But no, he couldn't remember. And then they interviewed Michael on his own. But once again they left things, like the brothers saying we will send photos and then never did. But I think I was pleased to get out of there myself.

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.

Michael used to go to church with me and I played guitar in church. Michael was an altar boy, And he actually received communion off the pope so this was after Marylands of course. So he saw the pope in 84, he had finished school by that time and he received communion off the pope as one of the representatives for the disabled.....I hate that word. Disabled or abled. So, church was big. I started taking Michael to church when he was just a wee fellow. I've always had a firm belief in God and I still do but I don't necessarily believe in the manmade rules. Especially around what you hear and see. But you can't blame God for everything. And I remember when it all came out, first the brothers were cheating people. People were blaming the church and it's true. Cover ups and no thought of the victims or anything like that. I think what it's put me off, It's put me off Church but it hasn't put me off belief. And sometimes you go through the motions. Fortunately for me playing music, that's a huge aspect of my faith. That's how I got by and are still getting by.

Michael with music, it's done so much for him. He wanted to learn that guitar. We've all got gifts. I remember he was playing down Gold Guitars one year and the stage manager was a chap about my age I suppose and I was out the back looking through at Michael on the stage and this old guy was standing there and the tears started flowing out of his eyes. I understand where he's coming from. He said, " is he your boy? He's incredible". He's a great pool player too. The only thing he did win at the school was a cup for champion pool player. He likes doing things that he wants to do. He doesn't, like if I just said "come on Mike, we'll go for a walk." He'd say he'd have things to do. He's very independent and self-determined.

I remember one time, this is quite a few years ago. I was half asleep and half awake and I was saying this eulogy and it was all about Michael. And how much Annabel, Lisa and I had given to Michael. Then all of a sudden of how much he had given us. And it filled the room. It was massive. I tell you what, this was so real. He got breakfast in bed for about a week. I've



never forgotten that. It was just so real. Michael and I have a wonderful relationship, I know I've done a lot for Michael, and he's done a lot for me.

I know I've had something happen to me in my life. I've lived with it all my life and one day, I talked about it and man, it was like a weight coming off my shoulders because I talked about it. You know, that's my experience. You might walk out of here today feeling great because you have talked. But sometimes with things that are so hard to talk about, once you start talking about them it just starts rolling out.

### **Son's Perspective**

When I went to Marylands, I was a bit nervous at the start but then after a wee while, I think I got used to it. Mum and dad came up and visited me, but it was hard leaving, saying goodbye to them. I think I wanted to come home but I couldn't. I had friends there. I have a friend who I live with now who went to Marylands.

I played soccer there and I worked in Laundry. Nice staff worked there, they always said "Hello, Michael". I had a nice teacher, all teachers were nice but I just had one that was nice. She was good to get along with. One teacher wasn't great with me. Like if I said I was a bit upset with something she would just ignore me and everything. But this other teacher, if I had a problem, would give me 10 minutes and ask if I wanted to talk. Having people around who listen to you and help with problems is important. Staff were nice. Food was beautiful.

One time when it was lunchtime at one of the villas I was in, they gave me eggs and I'm allergic to eggs, and I was sick. I spewed up and everything and the staff made me clean it up. I had to do it then dad walked in the door and he said "what are you doing, Michael?" and I said "we've just had eggs for lunch." Dad said to the staff, "did you read Michaels notes? He's allergic to eggs". Dad told them to look at my folder, they did then they stopped me and told me they didn't know I was allergic to eggs then they cleaned it up. Next day we had eggs again but they gave me something else, Baked beans I think.

Beach house was good. You had to be selected to go. I think I was one of the lucky ones that got selected to go. Dad, remember I went abseiling? It was scary and when I got to the bottom I said "can I go again?". The brothers were there. I went about four or five times. I think I was made to go the second or third time but after that I wanted to go again. We did a play and I was a Dove.

[Michael is asked if there are things that he had to do that he did not want to do].

Yeah. I can't think of what ones they were.

[Were there things that they asked you to do that made you feel uncomfortable?]

Yeah, I think there were some but I can't think of what they were.

[Do you feel comfortable talking about what happened to you?] I don't feel like talking about that part.



I didn't like going to Church. I can't remember what happened at church. [Dad asks "what would happen if you didn't go?"] "Can we stop that now please?" [Michael's tone is urgent and pleading].

[Dad tells Michael that Brother McGrath is in prison for 30 years]. Good. Throw the key away, or get someone to do the same thing to him and see how he likes it. That might wake his ideas up. This is not good what I have done, I'm getting it done to me.

I was happy at that school. I enjoyed my time there. It was sad leaving Mum & Dad but good times when they visited me or when I visited them. It was hard to leave to go back to school. When I left Marylands, I wanted to go back.

I feel good about life. I play Futsal and Petanque. I love playing music, guitar and singing. I have a job that I like. A good life is to have fun things that you want to do. And having people who help with your problems. I have got my staff where I am and all I need to do is say I need to talk and they might say to me "give me 5 minutes Mike" or 20 minutes and as soon as they are done they will be free to talk if I have got a problem or anything. I feel supported.



## 7. Kitenga/ Analysis of the Findings

The full stories of the storytellers in *Tell me About You* stand strongly on their own, and answer the question put to people ‘what was your experience in care’?. This is answered through peoples’ recollections, retelling of incidents and reminiscences. The previous section of the report presented the stories in full, as a way of honouring each storyteller’s journey into, through and beyond care; acknowledging that most of the storytellers remain dependent on the disability or health system in some way. A key task of the research was to understand the physical, cultural and emotional landscape within which abuse occurred. This required an overarching view of these landscapes through the stories. We have used the ecological model of disability, violence and abuse along with an intersectional perspective of lived experience, to approach the stories of the storytellers. This includes understanding the historical, policy and socio cultural contexts of State care and of disability at the time the storytellers were reflecting on, and recollecting from. It also includes a close examination of values and attitudes, structures and approaches at the individual, community and societal levels that were operating and interconnecting around these storytellers and their stories of State care. This collective findings section begins with an overview of the ecological model of disability violence and abuse, followed by the presentation of themes and sub-themes relating to how violence and abuse operates at each level of the ecological model of abuse.<sup>36</sup>

### 7.1 The ecological model of disability abuse and violence

The ecological model of disability violence and abuse has been developed by disability researchers and advocates to inform a systemic rather than individual approach for understanding, preventing and responding to violence and abuse in the lives of disabled people. The model draws on the World Health Organisation violence prevention model that is used internationally to inform violence and abuse prevention. This work includes prevention of violence against, women, children, older people and disabled people. The WHO leads this international work and has an established evidence base for the use of the ecological model in this work (See Appendix C for overview of the development of ecological model of understanding disability violence and abuse) (World Health Organization, 2002).

The ecological model that has been applied to the stories of *Tell me About You* continues the development and application of this model to understand, prevent and respond to disability violence and abuse. The model provides a framework for exploring and understanding the relationship between 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

<sup>36</sup> Initially stories were read through the lens of the ecological model for understanding disability violence and abuse by one of the researchers to determine whether the model had utility as an analysis framework for this project. After determining that it worked well, each of the stories were coded according to each of the four levels of the ecological model by multiple members of the research team. The data that was coded to these broad conceptual themes (levels) was further analysed to identify sub-themes within each of these levels. Following this, the research team collectively re-applied the themes identified within the stories via a manual thematic analysis process, and each research team member responsible for annotating the original story/transcript compared the themes with the narrative/text to ensure the ethos of the data was retained.



abuse occurs, what responses are needed to address it, and how to prevent violence and abuse from continuing to impact disabled people.

Violence and abuse of disabled people occurs in societies where attitudes, values, myths and misconceptions 'about' disability intersect with ideas about gender, sexuality, sexualities, age and culture that operate to oppress, devalue and 'other' disabled people (Hollomotz, 2013; Fitzsimmons, 2009).

Disabled people experience violence and abuse where they live, work and play; in their homes, communities, neighbourhoods, workplaces and educational institutions. They also experience abuse and violence in health services, and in the disability services and systems that their lives intersect with - largely 'because' they are labelled as disabled (Hollomotz, 2013).

The systemically focused ecological model offers a way of challenging ideas that link a disability 'label' and lived experience to being vulnerable to violence and abuse (Hollomotz, 2009). It refutes pervasive assumptions that disabled people are inherently vulnerable to abuse by requiring close and critical exploration of how such assumptions have interacted to shape the social, structural and relational environments where violence and abuse occurs.

In the following section, the four ecological levels inherent to the model are first explained by drawing on existing theorising and research, and then illustrated using the data gathered (in the form of stories) in *Tell Me About You*.

## 7.2 The individual level

As previously noted, a major critique of individualised approaches to understanding and responding to violence and abuse is how they often place the 'blame' for violence and abuse with the victim. This approach and belief system explains the pervasiveness of disability violence and abuse as an individual characteristic 'of' disabled people and links these characteristics to 'reasons why' violence and abuse happens (Hollomotz, 2009). For example: : it asserts that disabled people experience violence and abuse because disabled people don't know the difference between right and wrong, they are hypersexual, they don't feel things the same way as non-disabled people, they cannot give consent because they do not have the mental capacity, they are physically, mentally, sensorially 'weak'. This understanding ascribes to the conceptualisation of disabled people as inherently vulnerable to the abuse outlined above (Hollomotz, 2013).

Sobsey and Calder (1994) note that while there may be direct effects of impairment on lived experience of disability violence and abuse, it is "...*the inherent disempowerment of [disabled people that] is typically magnified rather than corrected by our social responses to disability [violence and abuse]*" (p.12). These responses or ideas include infantilising disabled people, questioning or not recognising the personal agency of disabled people, expecting and reinforcing dependency, not acknowledging and respecting the will and preference of disabled people, and questioning disabled people's capacity to determine what 'safer' means for them.

Central to understanding disability violence and abuse at the individual level of the ecological



model is that there is no evidence to suggest the experience of any impairment is inherently linked to an increased vulnerability to violence and abuse. Instead, it is the inter-relatedness between individual characteristics and how they have been responded to that create environments and experiences that position disabled people as being ‘at risk’ (Hollomotz, 2009). When the collective body of stories were analysed at the individual level, three sub-themes were identified that speak to this conceptualisation. *Tell Me About You* storytellers were not inherently vulnerable and did not inherently lack capacity, but while in care they universally experienced a: lack of agency, lack of rights, lack of (recognition of) their will and preferences, and a lack of recognition of their personhood.

### 7.2.1 Lack of agency

Despite storytellers all sharing their enjoyment of the freedoms associated with community living and having agency over their lives now, this sharply contrasted the lack of agency they experienced while in care. Almost without exception storytellers talked explicitly and implicitly about repeated restrictions and assaults on their individuality and personal agency, often by highlighting what was important to their sense of wellbeing now.

“I like my room here, it’s comfortable. I have things in my room, I have a T.V set. I have more control and can be myself, look after myself. I do my dusting. It makes me happy. I can relax in my room.” [Graham P]

As well as being able to enjoy the simple pleasure of everyday tasks, some of the storytellers communicated a sense of created dependence. It is reasonable to attribute this learned dependence or lack of confidence to the care settings and system(s) that restricted their ability to progressively learn the life skills and gain the life experiences critical to becoming more independent. When they emerged from the care system, some storytellers felt as though they had changed so were now able to “do things for themselves”, not always recognising that they were always capable of doing those things, but the system had prevented them from doing so.

“Living out of Templeton now, has changed me. I’d go down to the supermarket have coffee with friends. They make me coffee in my cup and I go and sit by the table and drink it. I tell the staff where I am going. I can just say I’ll be back anytime.” [Jabert]

Being (inter)dependent on support from other people is often part of the disability experience (Bostad & Hanisch, 2016). Even so, agency can still be exercised while being cared for. Although some storytellers had transitioned to supported independence, aimed at increasing their ability to exercise agency, a lack of choice and control, or individual agency was ongoing due the nature of the care system itself. For one storyteller, this meant that she felt that she was “lost in care.”

“There was no freedom of choice in entering care. I was lost in care. There was no acceptance, belief or trust from others that I needed freedom. Freedom is acceptance of who I am as an individual.” [Lusij]

<sup>37</sup> Rosie’s experiences can be seen as one exception to this pervasive finding.

### 7.2.2 Lack of (recognition of) rights, will and preference

Storytellers' experiences indicated that they were not seen as rights-holders and, relatedly, were assumed to lack the capacity to express their will and preference. Consistent across all care experiences<sup>37</sup> was a failure to acknowledge or seek the will and preferences of storytellers. One storyteller was critically compromised in this regard due to a lack of tools and strategies to support her communication - without this right she was unable to communicate her will and preferences. Expression of will and preference was inherently linked to the storytellers' self-concept and self-expression. Without the opportunity to communicate and express their will and preference, storytellers felt invisible to, and in, the world. The storyteller above, Lusi, also referred to rebelling, stating that what she wanted for herself was her way of finding freedom and expression once she moved out of institutional care. The ability to freely express herself was not possible while in care and consequently she felt like she did not know who she was until she left the care:

“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.”

[Lusi]

Another salient example of how will and preference was ignored was the universal experience of being disconnected from whānau. Regardless of the quality of home life, storytellers commonly expressed that they wanted to stay with their whānau. Enjoyment and connection to whānau, and their desire to maintain that connection was often ignored or disrespected, and, in some cases actively discouraged and prevented. Storytellers struggled with being away from their loved ones, including saying goodbye if they were able to have visits.

“Mum and dad came up and visited me, but it was hard leaving, saying goodbye to them.” [Michael]

### 7.2.3 Cultural alienation and loss of identity

An important aspect of the sense of self is one's connection to culture. One of the impacts of colonisation is cultural alienation. When a young person's cultural identity is not recognised and respected it takes away their fundamental ability to get to know who they are (Schwartz et al., 2008). One storyteller articulated what being disconnected from her culture meant to her:

“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.” [Lusi]

While it is not possible to assert that his time in State care was wholly responsible for his lack



of knowledge about his cultural identity, Rawiri's comment illustrates the extent of his cultural alienation and uncertainty about his identity:

My father, he's Māori, they're both Māori – my father and my brother. I think I am too. I might be half cast, part Māori? [Rawiri]

Loss of identity was central to all stories, and starkly illustrated in the case of Sarah and her brothers'.

Sarah noticed that Paul's date of birth had changed about three times over the decades. The admission application had the wrong date of birth, his date of birth had changed in the institution on some documents, and decades later, [the agency] had yet another date of birth for him. It would turn out that [the agency] had the birth certificate of a completely different person to Paul. The Christian and surnames were correct, but the date and place of birth and the parents' names were all incorrect for Paul. He had another man's identity. After Sarah managed to prove their sibling relationship a new birth certificate was ordered and the old one ripped up. [Sarah]

Another storyteller, Janet has been seeking identity for decades since both her foster family and members of her birth family did not welcome her.

'A cousin ... told me "get your own identity" which was mean to an orphan'. [Janet]

Feeling lost and invisible, or as in the case of Paul actually being lost and invisible, is inherently personal, however these dehumanising experiences are created, reinforced and maintained by colonisation, racism, and ableism and disablism. All of these oppressions are expressed throughout the other three levels of ecological model.

#### **7.2.4 Lack of recognition of personhood**

In the context of this research 'personhood' refers to 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.<sup>38</sup> The personhood of storytellers who contributed to *Tell Me About You* was challenged by medical practitioners and other staff in the care settings they had lived in. Storytellers were infantilised and devalued through the use of labels and language. Labels such as "feeble-minded" were used as justification for the removal of human rights and agency, with the quote below reflecting on the language inherent within institutional records and highlighting the erosion of personhood of a young disabled child.

<sup>38</sup> 'Personhood' is a socially constructed term with differing meanings determined by cultural beliefs and understandings. Mehrotra and Vaidya (2008) explain that Western definitions of personhood are problematic in the sense that they perceive individualistic aspects such as self-reliance, autonomy, independence, success and initiative with associated attributes of intelligence, productivity and literacy. In this way, personhood constructed through individualistic characteristics is reflective of ableist ideologies, and excludes disabled people from having 'personhood'. Cultures that value collectivism highlight attributes of relatedness, interdependence and affiliation (Mehrotra & Vaidya, 2008). Goodley and Runswick-Cole (2016, p. 3) propose a construct of personhood that encapsulates "choice, a sense of autonomy, being part of a loving family, the chance to labour, love and consume." Personhood constructed in this way aligns personhood with the essence of being human. Personhood should not be a title or status that is awarded by society, a reality highlighted by Buron (2008). Instead, the personhood and agency of all individuals should be recognised and respected, irrespective of whether a person is disabled or not (Mehrotra & Vaidya, 2008).



“The application was sent to the Director of Mental Hygiene, Department of Health [...] under the Mental Defectives Act 1911 and the language reflected the requirements of the Act which included that he was constitutionally ‘feeble-minded’, ‘unable to appreciate discipline’, ‘attacks his younger brother for no reason’ and ‘never plays with other children’. He was not toilet trained and there was ‘no evidence of emotional attachment to [his] parents’.” [Sarah]

At times, storytellers identified themselves by the labels that others had attributed to them. That is, their identity and perceptions of themselves became echoes of the labels and attitudes they were subjected to. Social discomfort was a common experience.

“When I was at high school, I wouldn’t speak to anyone or anything or any peoples. I was what do you call it, I was sort of wouldn’t even speak to people’s or anything aye. I don’t really know why but I was a bit worried people would tease me.” [A]

“I used to find it very hard to fit in.” [Allan]

“When I was small Everything was my fault” [David]

Another common assault on personhood was inhumane treatment including overt abuse, such as being “locked up” and injured to the point of scarring.

“I don’t know why they locked me up. It was cold and made me sad.”  
[Graham P]

“Sometimes I would get angry and yell out and put holes in the walls. I find it a wee bit hard to talk about [being at Cherry Farm]. And I don’t like thinking about it. I don’t like Cherry Farm.” [Graeme]

The universality of the assaults on the personhood of the storytellers was expressed starkly by a family-member storyteller as, “it happened to so many of them.” [Sarah]

The sub-themes detailed above were experienced at the individual level and in alignment with the ecological model of abuse. It clearly illustrates how this treatment increased their risk to violence and abuse in the care system where they were not seen as or responded to as valued human beings because of the stigma attached to their disability. In the section below, the nature of the relationships in the storyteller’s lives and their role in abuse and violence in care settings are further explored as per the second level of the ecological model.

### 7.3 The relational level

The relationships or relational level of the ecological model of disability violence and abuse invites and enables critical consideration of power and control in the relationships disabled people have with family/whānau, peers, intimate partners, co-workers and others in their day to day lives. Importantly, it also asks questions about the relationships disabled people are a part of ‘because’ of their label of disability, including relationships with paid carers, educators, health and allied health professionals, and workers in the disability service system past and



present. Research confirms that whānau hauā me tāngata whaikaha Māori and disabled people in Aotearoa experience violence and abuse at higher rates than non-disabled people. Gender, race and disability intersect in ways that increase the risk of all forms of violence and abuse, and demonstrate the significance of this contemporary issue in Aotearoa (Malihi et al., 2021). This and other research has also found that the violence and abuse is occurring in intimate and non-partner relationships for men and women, and for wāhine whaikaha, all experiences of violence and abuse are experienced at higher rates (Fanslow et al., 2021). In addition, it was also found that “[t]hose who identified as Māori were overrepresented among those with any disability (26.3 per cent) compared with European New Zealanders (20.3 per cent) and those of other ethnicities” (Fanslow et al., 2021, p. 322).

Key features of the relational context of disability violence and abuse are that others have power over and are the decision makers about the way relationships are conducted and managed. Further, there are limited opportunities for disabled people to form, manage and mediate equal and respectful relationships across all contexts of their lives. Research has found that this is particularly the case in relationships that people are a part of ‘because’ of their lived experiences of disability. Paul Cambridge, a UK researcher framed this as ‘corruption of care’ (Cambridge et al., 2011; Cambridge & Carnaby, 2000), finding that within disability service environments disabled people are at risk of abuse due to the way these relationships frame disabled people as being of lesser value, dependent and without agency. This has played out in historical and contemporary reports of violence and abuse of disabled people within services in the UK (Care Quality Commission, 2021, p. 2), Australia (Ryan & Jackson, 2013) and Aotearoa (Mirfin-Veitch & Conder, 2017).

Echoing the assumptions and presumptions about their lack of agency, identity and personhood that storytellers experienced at the individual level, when their stories were analysed at the relational level similar patterns were seen. Three sub themes were identified: others holding power over (disabled people); others making decisions about their lives including dictating the rules of relationship(s); and lack of opportunity to form, manage, or mediate equal and respectful social, familial, peer and intimate relationships.

### **7.3.1 Others holding power over**

Storytellers experienced direct and repeated physical abuse, 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. These experiences evidence that people who were supposed to ‘care’ for them had power over the storytellers. When storytellers reported their experience of bullying or violence by other residents or staff, or sexual abuse by a relative of the foster family, the response was often negative. Their efforts to report abuse were diminished, not treated seriously, or led to retribution or retaliation for ‘telling’. Only one storyteller talked of his complaint leading to action against a staff member who was violent, but no lasting change appeared to result from his self-advocacy. Others shared the negative responses they had received through reporting their experience.



“At age 15 I was learning to drive and there was an indecent assault and other indecent behaviour by the driving instructor (an older man). I told my foster mother and she got angry with me. The rest of the family turned against me and called me a spoilt bitch.” [Janet]

“But some staff would just say I got upset when I was being bullied. They were not being very helpful because some of the staff, you know, thought I was just over reacting when all I was just trying to do was get my point across and ask staff to help me and support me when I didn’t feel safe around some of the pupils.” [Allan]

“I would hear the key in the lock, the big steel one, like that young fella had before. Men would rush in there, hold me on the floor, give me a needle in the backside thing to calm me down a bit and then they would lock it all again, big steel key. I would lie on the floor in there, the lock up room in [villa name]. I don’t know how many hours they would leave me in there and, ever since then, I have had a fear of the dark.” [A]

A few storytellers described how they used to “play up” and they were sometimes involved in “hurting people” as well. They shared how they were told that the violence and abuse against them by institution staff were due to their own 'bad behaviour', suggesting they were the cause of and to blame for the violence and abuse they experienced. Contemporary understandings of communication and behaviour evidence that “playing up” is a common way for some disabled people to communicate and to express their lack of power when other people fail to listen to them (Goodley & Runswick-Cole, 2011). In the case of the storytellers, their efforts to communicate in care settings tended to result in punishment - most often metered out in the form of violent physical restraint and forced isolation.

“Because when staff didn’t understand me and expect me to do things that I wasn’t sure about, then yell at me for getting it wrong, then I would explode, they would just see me as a person who was trying to be naughty or out to be dangerous. And that wasn’t the case at all. I think there was a misunderstanding and I wasn’t being listened to is what the problem was.” [Allan]

“I got locked up in Cherry Farm. The room was empty. Only floorboards and a big door. I was in that, room for a long time. Sometimes I used to hurt people too - I don’t know why I done that.” [Graeme]

“There are illnesses that take sometimes weeks to diagnose and reports of problematic behaviour, deemed to be Paul’s growing aggression, including his waking early and screaming, which required his being put in the quiet room and medicated - and that turned out to be physical pain requiring surgery for gangrenous appendicitis, and other times, dental problems, which were eventually identified.” [Sarah]

### 7.3.2 Others making decisions about their lives, including dictating the rules of relationship(s)

For many of the storytellers, their experiences did not happen in isolation - they were always connected to someone making decisions about them or for them. It was also clear that these (substitute) decision makers did not have meaningful relationships with the storytellers who were affected by the decisions. Storytellers went unconsulted and remained voiceless in decisions that directly affected them. This was particularly obvious in the management of family and whānau interactions and relationships. Storytellers shared how they missed their family while they were in care. However, decisions about when family members were able to visit or when they were able to return to their family were controlled by their care providers. One father shared his experience of not being able to see his son when he was in a particular care setting, despite having travelled a long distance to visit.

“We went up there once and he was in confinement, we couldn’t see him.”  
[Trevor]

Another family member storyteller reflected on how her emotional response to how her disabled sibling, and his peers were treated by staff.

“the following Christmas, with different staff members on, they chose to eat separately to the residents and assumed that the sister would want to do the same. Sarah was dismayed. She had worked hard, saved up money and travelled a long way to break bread with her brother again on Christmas Day. She said it felt like her brother was being separated out from her again, and she realised that he and his peers would probably never be seen as true equals by others. She watched on as her brother and his peers were fed separately, like cattle, and apart from the people ‘in charge’.” [Sarah]

A storyteller showed his awareness that his attempts to create a sense of family through opening himself up to the potential of having a relationship with staff were not reciprocated. His need for emotional support was also ignored.

“I missed my family. It made me feel sad a bit. I used to dream about my Mum and Dad a lot. Mum and Dad are up in Heaven and I was sad about that. I liked them. I treated the staff like family. They didn’t treat me like family. Made me sad a bit. No one would comfort me when I was sad.” [Graham P]

This final comment further reinforces the knowledge that disabled storyteller’s held about their status in relation to staff in care settings.

“There were certain nights our parents would ring, but we couldn’t talk to them. The staff would take the phone and shut themselves in the room to have private conversation.” [Nathan]

<sup>39</sup> With the exception of Rosie who appreciated the opportunity to develop romantic relationships on her own terms while in care. This was something she was unable to do when she lived at home.

### 7.3.3 Lack of opportunity to form, manage, or mediate equal and respectful social, familial, peer and intimate relationships

The aforementioned sub-theme regarding a lack of control over decision making and having the rules of relationship dictated by others can be further understood via a third, related sub-theme. Storytellers shared an overall experience of having little or no opportunities to form, manage, mediate equal and respectful social, familial, peer and intimate relationships while being in care.<sup>39</sup> Even if family-whānau relationships were not critically damaged when storytellers entered care, they still experienced limited connection with family members as institutions did not appear to value or have mechanisms in place to support the maintenance of family relationships. For some storytellers, the maintenance of family relationships were overtly prevented and, in some cases, loss of family connection was irreversible. The deprivation of significant relationships for storytellers can be described as a covert form of violence and abuse.

“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.” [Lusi]

For family-whānau storytellers, the trauma of being deprived of relationships of their choosing with children or siblings was also clear.

“Meeting Paul in 2019 has been a life changing and meaningful experience for me. My two disabled brothers were real people to me, however silenced and whitewashed. They mattered to me. I believe it was the same for every member of my family, whether expressed or not. We were all incredibly damaged by this loss and family secret.” [Sarah]

As also identified at the individual level, at the relational level storytellers were rarely recognised as having rights and agency in relationship, therefore there was little support to form relationships with those around them. One storyteller who lived in Kimberley as a toddler shared that there was no support for her and other residents to interact with each other. Another storyteller described the psychiatric hospital they lived in as a hostile environment, which prevented the development of any meaningful relationship with other residents.

When reflecting on his time in institutions, one storyteller communicated his sense of a need to focus on his own survival, which provided little space for him to notice or build relationships with other residents in a meaningful way. His humanity shone through when he commented:

“Yeah, everybody would have hated [getting locked up], I should’ve felt for them more.” [Rawiri]

A family-member storyteller provided his perspective that his son’s ability to form a relationship and to show love and show affection was irretrievably damaged by his time in care.



“So relationships are ruined. He doesn’t know. And I don’t think that’s the brain damage. Because I have seen how people with...mind you, we’re not all the same. But I’ve seen intellectually disabled can still love someone. And I think [for] Michael, that’s all affected.” [Trevor]

At a relational level, abuse was also felt through a pervasive lack of respect for relationships of importance to some storytellers. People in ‘caring’ roles, expressed their power by denigrating people and relationships, including intentionally creating a culture of fear of (some) family members.

“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.” [Janet]

Further evidence of relational abuse occurred through examples of storytellers being convinced that they could not seek professional treatment or support beyond the care setting they found themselves in.

“a considerable level of anxiety and, indeed, a level of hopelessness / despair, knowing that I could not consult any professional person (for the rest of my life?) who was not a staff member of Claybury House.” [Jen]

## 7.4 The community level

In ecological models of disability violence and abuse, the community level represents the places and structures that already exist or are formed by society when people come together, participate and contribute. For many these are places of belonging and civic contribution. However, for many disabled people they are experiences and places of exclusion. The ecological model challenges us to critically consider how disabled people are framed within communities, including how this framing impacts on and shapes how they are positioned and responded to alongside other members of their communities. Ecologically this is referred to as the ‘exosystem’ which indicates it is outside or external to the individual and relational contexts (microsystems) or closer relationships which are ‘nested in’ the exosystem of community or communities.

Applying this analytical lens to life stories of disabled people who have experienced violence and abuse in care is instructive. This level of the model illustrates how the way communities position disabled people impacts on the experiences available to them, and the extent to which they experience the benefits or risks associated with being inside or outside of a community. It is important to note here that social structures like welfare systems and the ‘total institution’ (Goffman, 1961) were developed as ‘specialist’ responses to disability and have formally placed disabled people outside ‘community’ and ‘communities’, increasing the ‘other’ status of disability. This extends to ideas about and access to equal citizenship rights, for example, the benefits associated with home ownership, employment and education, access to voting rights, and the overarching risks associated with not being assigned the status of full citizen. The community level sub-themes were specifically identified within



the stories as: a lack of access to housing/employment/education; understood as non/unproductive community members; understood as recipient of services and supports and ‘in servitude’ to the state; and understood as non-citizens.

#### **7.4.1 Lack of access to housing/employment/education**

The stories shared in *Tell Me About You* illustrate a fundamental erosion of the right to make decisions about where to live and make a home.<sup>40</sup> Some storytellers described that they entered care due to a lack of support for their family-carers. Others shared that they did not know why or how they ended up in State care. One storyteller shared that her two siblings entered care, in part, because they were perceived as being unable to participate in education. The perception was that they could not be educated as they were “mentally retarded.”

“In the 1960s it was widely considered that ‘mentally retarded’ or autistic children did not have the capacity to be educated.” [Sarah]

Another storyteller reported that she was told she was not able to access psychological support away from the former psychiatric hospital she was admitted in. As evidenced below, restrictions imposed included an inability to make self-determined decisions about whether they were subjected to care in the first instance, and whether they were able to access services and supports offered in the(ir) community.

“I had a lot of problems around home because they didn’t understand me. So I was sent to Cherry Farm.” [Allan]

“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.” [Graeme]

#### **7.4.2 Understood as non/unproductive community members**

Running through most of the stories was an understanding or social construction of storytellers as non/unproductive members of their communities. This was clearly reflected in their work experiences when their work was unpaid or underpaid. 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. One storyteller shared that his pathway to being institutionalised was tied to his struggle to learn the job quickly enough, or when mastered, to perform the required tasks sufficiently. This reflects a capitalistic notion of productivity, which positions some people’s labour as unworthy of monetary recognition and security of living.

“I worked at the printers in Templeton also, not paid though. I didn’t really like my job in the printers. The ink stunk and it made my hands dirty.” [David]

<sup>40</sup> The right to choose one’s residence, to determine where to live and to freedom of movement are recognised as part of the right to an adequate standard of living in article 25 of the 1948 Universal Declaration of Human Rights and in article 11.1 of the 1966 International Covenant on Economic, Social and Cultural Rights, which both apply to the timeframe and scope of the RCOI and *Tell Me About You*.



“I used to go on this invalid’s benefit. I don’t know how much I got. Hmmm, a bit of money.” [Rawiri]

“A carpenter’s labourer. Yeah, I liked that job. I was slow, slow, slow as hell you know and they sacked me because I was too slow and all that. Ah, [I was] 18 I think. Oh, I sort of got all emotional about all the different jobs I had. From one job to the other and I couldn’t stay long on one job, [I had] a nervous breakdown.” [A]

### **7.4.3 Understood as recipient of services and supports and ‘in servitude’ to State**

As identified at previous levels of the ecological model of disability abuse and violence, at the community level storytellers were not perceived as having any right to individual agency (choice and control). Relatedly, many of the storytellers were fundamentally and permanently assigned the role of ‘recipient of services and supports’ through the initial act of being placed in care. Being the recipient of services and supports sometimes meant that they were placed in different institutions, one after another, without choice or control.

“When I left Cherry Farm I went to Wakari Hospital. They had seclusion there too. The staff were a bit hard to get along with and the patients sort of, patients [were] quite, quiet.” [Rawiri]

Sometimes they stayed in a single institution for a long time. Either way, being in care meant that storytellers were perceived as passive beings, without their own voice.

“As I got older I started to run away a few times. I didn’t want to stay at Templeton. I wanted to get out.” [Jabert]

And once in support, most storytellers remained as recipients of services or supports even after deinstitutionalisation. Some storytellers were able to eventually find a house of their own with individual support workers coming to their house, and some storytellers remained living in residential homes managed by community services. For one storyteller, his barometer of quality in his current disability support service was clear; a sense of family, not being locked up, and no chance he would ever return to an institution.

“I’ve got no family now, only this family. I like it here. I don’t get locked up here. I wouldn’t want to go back to Cherry Farm.” [Graeme]

Only a small number of storytellers completely broke free and lived their lives free of systemic support.

### **7.4.4 Understood as non citizens**

Institutions intentionally segregate the individual’s who reside within them from their natural and local communities (French & Swain, 2001). Unsurprisingly, storytellers in *Tell Me About You* were placed outside of their immediate natural community (family network), into structured environments (State care) outside of their local communities. 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. Due to their containment, storytellers were excluded from being authentic members of their communities, including the sense of belonging typically associated with being part of a community.

“And that place [over there] with the fence around. That was so we wouldn’t escape or whatever yeah, that was that place where they built an ICU intensive care unit and the lock up rooms.” [A]

Sometimes the most instructive comments about the erosion to community and belonging could be seen in storytellers reflections on life beyond the particular care setting(s) they were subjected to.

“We had a choice about who we got to live with, and I moved out with friends, and over the years I have lived in three different houses. I found it was great to be in the community and I didn’t look back.” [Rosie]

“I like it here because it’s handy to the shops. Seacliff and Cherry Farm were far away. I live close to everything now. I like to be part of things.” [Graham P]

## 7.5 The societal level

Understanding how social structures impact on and shape disability violence and abuse requires recognition that the way society works and is structured is framed by privilege and power embedded in economic, political and social policies and practices that focus on the dominant and most ‘productive’ members of society. These are the ‘larger’ forces and structures that reinforce exclusion including laws, policies, and the systems that give people access to power and privilege, including education, employment and the networks embedded in these that enable access to valued social roles, opportunities and networks. For disabled people there is a history of exclusion from these systems and discrimination within them. Ableism is a concept used to describe and understand the total ‘discounting’ of disability and the framing of society and social structures using a ‘corporeal norm’ of body, mind and life experience (Campbell , 2008). Ableism is embedded in society and operates at the societal level in the way social structures are designed, accessed and used. Analysis of disability violence and abuse looking at experiences from a societal level and using Ableism as a lens can support a critique of these systems and the privilege that is embedded in them; privilege that is not afforded to disabled people who are excluded from or treated inequitably by and in these systems and structures. Hollomotz (2011) and Fitzsimons (2009) in their application of an ecological model of disability, violence and abuse note that while this level of the model is the furthest from the individual it has a significant impact on and shapes the structures, ideas and attitudes that have a more direct impact on individuals and their experiences of violence and abuse. This includes for example the fact that institutions and other segregated services exist exclusively ‘for’ disabled people sends a message that they are ‘outside’ the society and its structures that others benefit from and enjoy the protections of.

### 7.5.1 Laws and policies that deny personhood rights

It is clear that policies relating to support for disabled people in the era of institutionalisation were developed in response to a system which valued segregation and neglect. As one storyteller expressed, “it is built on a system that dehumanise[s] disabled people” [Lusi]. Policies that provided the mandate for disabled people to be isolated in environments that were cold, dark and empty blatantly denied the personhood of storytellers. Isolation within care settings was amplified by the general positioning of those who lived in such environments as being ‘away from’ society. Storytellers described being forced to attend church against their will as a policy of the institution, and in doing so prioritising religion over personal agency (choice). In another story, the identifying documents for a disabled sibling of a storyteller was lost, which had ongoing impacts on her access to her sibling. With regard to denial of identity and information, the family-member storyteller explained:

“These are incredibly valuable records for family, for future researchers and for our disability history. We need to archive what remains. It is one way to provide justice and redress for the distress of institutionalisation and family separation.” [Sarah]

As stated in the individual level, need for care by other people is often an inherent part of being disabled, which can be provided in a way that enhances one’s wellbeing. However, one storyteller highlighted that the residue of neglect still exists in the current system of care in Aotearoa, asserting:

“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.” [Lusi]

### 7.5.2 Education, employment and health models that segregate and ‘specialise’

Support for disabled people who told their stories in this research followed a model of segregation. Storytellers described being segregated from their families; taken away from home to institutions that were ‘special’ services. Often these separations were brutal, occurring against the will of disabled people, and often in the absence of any involvement of them in the decision making. For one storyteller, segregation due to being placed in care prevented the continuation of their learning.

“I liked the learning. I learned to read and write, but I don’t remember how to any more. I never went to High school... 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.” [Graeme]



One storyteller, A, experienced painful memories and feelings when visiting the institution he had lived in during the story gathering process. However, he swiftly reassured himself that institutions, and being separated and segregated, were a ‘thing of the past’:

“That big steel key made me remember things. I’m not upset—I’m ok with that, cause the psych hospitals, the national government closed them all down didn’t they?” [A]

### 7.5.3 Limited access to legal and social protections

It can reasonably be asserted that disabled people in care had little effective control over the way they were treated, no clear pathway(s) to justice or for seeking accountability for violence and abuse. One family-member storyteller shared that her siblings had been overmedicated with medication usually prescribed for psychiatric disorders they had not been diagnosed with. At the time, there was no pathway to question or challenge the treatment regime being administered to her siblings - this did not occur until they moved into the community as part of a deinstitutionalisation process.

“The decades of charted medication records indicate a heavy regime of drugs for epilepsy, anti-psychotics, behaviour control, and sometimes pain relief. Only after deinstitutionalisation and the involvement of psychiatrists from the Ministry of Health are questions raised about the psychiatric polypharmacy despite there not being a record of any diagnosis of mental illness.” [Sarah]

### 7.5.4 ‘Outsiders’ in Society

For all storytellers, support and treatment was provided outside or away from mainstream 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 geographic and/or relational margins of their communities. As already asserted, decisions to segregate and place in other care settings such as foster care occurred against storytellers’ wishes. What they experienced in care settings fell short of support and, for some, resulted in lifelong impacts and dark memories.

“But Templeton is not a home, residents can’t work and they end up staying there for a long time. People shouldn’t be in places like Templeton because they should be given a chance in a home in their community.” [Jabert]

## 7.6 Weaving the four levels together

As explained at the beginning of this collective findings section, analysing disability violence and abuse using an ecological model requires understanding factors at each level, as well as the complex interplay of these factors across each level. Through this responses to violence and abuse, including prevention strategies, can be holistic and systemic. Disability abuse and violence researcher Andrea Hollomotz notes that an ecological model:



“... enables us to understand how social and individual factors interact in the formation of risk of ...violence. This allows us to focus our gaze beyond an assumption of ‘vulnerability; and with this to move away from dominant explanations of individual causation” (2011, p. 38).

In keeping with contemporary ideas about violence and abuse, the ecological model enables disability violence and abuse to be seen as a social issue and problem that requires a social response, including transformation of laws, policies, practices and attitudes that are ableist, and also intersect with beliefs and structures that are further shaped by sexism, racism and other ‘isms’ that are understood to be central to the issue of violence and abuse (UN Women, 2019). The model also draws attention to more covert abuses that may be viewed as less salient or serious in contrast to other abuses such as physical or sexual violence. This aspect of the model is particularly relevant for the storytellers in this report whose stories may not have been told, or understood in a way that connects and explores individual, relational, community and societal factors. Even though these factors (presented here as themes and sub-themes) were, and remain central to their experiences of care and abuse in care, they were factors they had no control over, and which ultimately shaped their whole lives.

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.



## 8. Kōrerorero / Discussion

In 2021, three key documents with the potential to shape the way society understands violence and abuse were published in Aotearoa New Zealand; *Te Aorerekura: The enduring spirit of affection. The National Strategy to eliminate family violence and sexual violence* (New Zealand Government, 2021), along with two reports developed by the Human Rights Commission, *Whakamanahia Te Tiriti, whakahaumarutia te Tangata - honour the Treaty, protect the person. Violence and abuse of tāngata whaikaha Māori in Aotearoa*; and *Whakamahia te tūkino kore ināianei, ā muri ake nei - Acting now for a violence and abuse free future* (NZ Human Rights Commission, 2021a; 2021b). These documents identify several positions that need to underpin all work on violence and abuse that include: violence is a Te Tiriti and human rights issue; tāngata whaikaha Māori rights have, and continue, to be breached; disabled people's human rights have, and continue, to be breached; violence is an abuse of power; and violence toward disabled people is also an epidemic with disabled people experiencing even higher rates of violence than non-disabled people (New Zealand Government, 2021, p. 1). These contemporary publications reflect an ecological model for recognising, responding to, and preventing violence - the lens that also guided the analysis of stories told by the storytellers who generously shared their experiences within the *Tell Me About You* project. Analysis of the collective body of stories using the ecological model of understanding violence and abuse identified and confirmed that systemic abuse within care had a pervasive impact on the experiences of storytellers at all levels of the ecological model.

Systemic abuse (also termed institutional abuse) refers “not only to the direct physical abuse” but “violence inherent in a system” (Žižek 2008: p.1–8). The system is a broad term, and in this report, it refers to two specific mechanisms. The first system is the wider social system that placed disabled people into segregated environments and settings to ‘deliver’ care. The second system is the one that functions within institutions, and other care settings, where maintenance of the order of a place is prioritised over individuals’ needs, and will and preferences (Goodley & Runswick-Cole, 2011; Minshull, 2004). Both of these systems were maintained in ways that did not acknowledge or respect the storytellers’ individual autonomy and will.

At the beginning of each storyteller’s care journey the system granted power and authority to professionals to make decisions about where they would live and how they should be cared for. Storytellers, and often their families, were almost totally voiceless in the decisions about care. When storytellers moved into institutions and other care settings, the day-to-day carers continued to hold power over the storytellers, creating the potential for violence and abuse to occur (Jones, 1994). Systemic (institutional) abuse may also include conditions and policies that are abusive (Gil, 1975, as cited in Daly, 2014). Inappropriate punishments and neglectful oversight were prevalent in institutions (O’Rourke et al., 2021; Minsull, 2004), and occurred unchecked, even if institution staff and other people in care-taking roles did not personally agree with this abuse and violence. Policies which allow for abusive interactions contribute to



the deprivation of an individual's potential, and optimal development (Gil, 1975) - experiences that were common to the storyteller's in *Tell Me About You*.

These two interrelated social and care systems were (and are) underpinned by both ableism and disablism. Ableism is underpinned by 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). It is a root concept, also used to understand all of the other 'isms' such as sexism, classism and racism as it justifies placing one group over another according to certain characteristics (Francis, 2018).

Disablism is an 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). Disablism acts as the by-product of ableism; disablism cannot exist without ableist assumptions and practices. When disabled people encounter disablism, they encounter discrimination, oppression and/or behaviour that is abusive towards them because of external beliefs that they are inferior due to their disability status (Francis, 2018; Healy, 2020). As Francis (2018) explains, acts of disablism can occur in ways that are either blatant or subtle. As Gappmayer (2021) highlighted, disablism practices are those that are oppressive, that marginalise and exclude disabled people from society and every-day life. Freedom and rights afforded only to non-disabled people echoes the preferential treatment characteristic of an ableist system and society.

The most prominent example of disablism from the stories gathered and presented here relates to the fundamental segregation that almost all storytellers experienced. The differential treatment of disabled people which led them into care because they are disabled should be considered as an overt example of disablism through discriminatory and oppressive practices. 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.

Ableism and disablism were not always 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.

In the early 20th century, the false science of eugenics became popular with influential groups and policy makers and created fears about disability and reproduction (Chapple, 1903). The 1911 Mental Defectives Act classified people into groups which could and should be segregated and surveilled. This Act remained in force for many decades and provided the framework for the institutionalisation of many disabled children, young people and adults. The intersection of colonisation and eugenics meant Māori children were disproportionately affected.



It is important to draw attention to these intersectional experiences. The term “Intersectionality” was coined by the Black feminist legal scholar Kimberlé Williams Crenshaw, who pointed out that by generalising white women’s experience as “the women’s experiences”, it marginalises experience of black women and other women of colour (Carastathis, 2016). In the same way, generalising disabled people’s experience who experienced care pose a risk of overlooking intricacy of intersectional experiences such as cultural alienation shared by two storytellers in this report. Intersectionality invites understanding that encompasses how marginalisation and power dynamic plays within different identity groups, and encourage people to be aware of the overlapping experience people have to truly transform the power dynamic (Carastathis, 2016).

With this intersectional lens in mind and while not seeking to authenticate the stories told by *Tell Me About You* storytellers, it is relevant and important to note that the experiences of disabled survivors, which have now been shared within a range of Royal Commission hearings<sup>41</sup> and reports, mirror their experiences. From survivor testimony, is clear that the systems put in place by the State to support and protect children and young people, categorically failed them - repeatedly and catastrophically – constituting systemic abuse. For example, children and young people who entered care generally needed support either for their disability, or due to their circumstances at home, or for both reasons. Neither tamariki or whānau were appropriately supported or protected.

During Tō muri te pō roa, tērā a Pokopoko whiti-te rā: Māori Public Hearing, there were cases where survivors’ mothers were deemed to be mentally unwell but instead of receiving support, these mothers were placed in psychiatric hospitals. This resulted in tamariki being placed into state care, exposing them to greater and wide ranging abuse. This dismantling of whānau is characteristic of, and evidences, ableist policies.

Children and young people who deviated (or who were perceived to deviate) from “normative” or “typical” behaviour were put into State care, including into the Lake Alice Hospital Child and Adolescent Unit. Rather than receiving the appropriate supports, they became the survivors of horrific abuse. Abuse took many forms included physical, emotional/ neglect, psychological, medical and sexual abuse. Abuses also included assaults on cultural identity such as cultural alienation, deprivation and discrimination.

Children and young people were removed from home often without giving their own consent, and/or without the consent of their whānau. As well as being separated from their parents, they were also split away from siblings and wider whānau.

Survivors who contributed to these Royal Commissions hearings and investigations were clear that the impacts of the abuse affected the rest of their lives and, as frequently testified, often passed on to the next generation(s) of their whānau. State care was framed as a safe space where children and young people would be protected, but instead they experienced significant harm in such settings, often for the full duration of their time there.

<sup>41</sup> For example: Tō muri te pō roa, tērā a Pokopoko whiti-te rā: Māori Public Hearing, Tulou – Our Pacific Voices: Pacifica Public Hearing, Lake Alice, and Marylands Hearings



Staff members were often aware of the abuse yet remained complicit and complacent by not reporting abuse. When children and young people disclosed their experiences of abuse, they were dismissed and often accused of lying. Sometimes disclosing their abuse subjected them to increased abuse.

Survivors who contributed to *Tō muri te pō roa, tērā a Pokopoko whiti-te rā: Māori Public Hearing* and *Tulou – Our Pacific Voices: Pacifica Public Hearing* described feeling painful cultural loss. By entering State care, they lost connection to their whakapapa and whenua, resulting in significant intergenerational harm. Survivors shared how they were deprived of any cultural support and education. These experiences were fuelled by structural racism.

Survivors also talked about State- and faith-based care evoked feelings of being unloved, unworthy, and as deserving to be abused; suggesting that they have internalised ableist thinking and behaviour due to the care settings they were exposed to. Children and young people also experienced extreme loneliness. These experiences had long-lasting implications on their lives. Storytellers in *Tell Me About You* told similar stories and reported the same long-lasting impacts.



## 9. Titiro whakamuri, kōkiri whakamua - Recommendations for redress

An important aim of *Tell Me About You* was to contribute to the conversation about redress, including the implementation of actions to ensure 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 State care and in the care of faith-based providers;
- inclusive of systemic transformation to prevent the perpetuation of abuse and neglect within care settings (RCOI, 2021b).

The extent of the denial of respect for personhood, and overt abuse and violence experienced by storytellers in *Tell Me About You* is reflected in the difficulty many storytellers experienced in even contemplating that they had the right to expect redress. As a result, there were very few direct recommendations for redress within the stories. What is clear is that what the storytellers in *Tell Me About You* experienced and expressed resonates strongly with the evidence presented in other population and settings based hearings, and with the series of recommendations for redress identified in He Purapura Ora, he Māra Tipu: From Redress to Puretumu Torowhānui (RCOI, 2021b). Those existing recommendations must be implemented.

Because this research directly sought and analysed the stories of people with learning disability and people who identified as neurodiverse, some additional considerations based on their respective experiences and needs are also offered. The recommendations outlined here are also informed by redress recommendations developed in response to disabled people's involvement in relevant inquiries internationally, including recent research articles focused on redress.

The recommendations are organised and presented in alignment with the ecological model for understanding disability abuse and violence but it is important to amplify two key issues, which are directly relevant to many of the storytellers with learning disabilities who contributed to this research, as well as to those we encountered but were unable to formally participate.

- The redress framework must be implemented quickly.

A recent Australian study (Cortis & Katz, 2022) identified that timeliness was crucial to the redress process. For survivors who had carried their trauma into their older years, there was fear that they may die before receiving redress or may have limited time to utilise redress payments. This finding is applicable in the Aotearoa context, particularly for a significant



group of the storytellers in this project; older people with learning disabilities who had spent many years in care.

- Once operationalised, the redress framework must be transparent, timely, and universal and accessible to all.

Cortis and Katz (2022) also reported that survivors found the process of applying for the redress both time consuming and inaccessible. Waiting for decisions of results of personalised redress was described as demeaning for survivors and redress support services were essential to survivors continuing to persevere with their applications for personalised redress. This research identified that when responses to survivors were systemic and scripted feelings of disempowerment and frustration were heightened (Cortis & Katz, 2022). Linked to this, it was also highlighted that the wait times and bureaucratic flaws associated with redress processes have the potential to be more damaging than healing for survivors (Cortis & Katz, 2022).

## 9.1 Redress from an ecological model perspective

### 9.1.1 Individual level

“I would probably not have even been recommended to go into Claybury House in the first place, had I been previously diagnosed with ASD, because Claybury House was not an appropriate “treatment” for ASD persons.” [Jen]

In addition to the overtly physical nature of the abuse and violence storytellers’ experienced, the abuse and violence experienced at the individual level can be conceptualised as an erasure of personhood. Therefore, redress that responds at the individual level needs to be respectful of individuality. A strong redress scheme will be inclusive of all and based on trauma-informed approach. Because a foundational factor in the abuse and neglect of disabled people in care was segregation from mainstream society, it is important that the redress scheme for Aotearoa challenges ableism and disablism through the co-design and implementation of a fully inclusive approach.<sup>42</sup>

The redress scheme must also directly respond to intersectional experiences of survivors including cultural abuse and neglect. Individuals’ experiences are always at the intersection of different societal conditions and oppressions. It is important to recognise what kind of conditions (such as disableism and racism) led to the survivors’ experience, and to explore ways to respond to these conditions. Redress schemes must include broader forms of abuse<sup>43</sup> and must be ongoing. In particular, there needs to be continuous efforts to ensure that new systems are not seen as a panacea to the past and must include an understanding of how abuse prospered as one strategy for ensuring it never happens again.

<sup>42</sup> An inclusive redress scheme will ensure that disabled people have access to support (such as New Zealand Sign Language Interpreters) to access mainstream services, and mainstream services have the support to recognise each individual’s personhood. As part of the inclusive approach, redress schemes must be developed in consultation with disabled people (RCOI, 2021b), especially with those who often have not had the opportunity to talk about their own experiences. Their involvement should be facilitated using supported decision-making (SDM) approaches, in accordance with Article 12 of the UNCRPD (United Nations Convention on the Rights of Persons with Disabilities).

<sup>43</sup> 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).



As recently highlighted by Cortis and Katz (2022), the timeliness of the redress is important. Many of the survivors are ageing, and consideration must be given to survivors who have shortened life expectancies due to psychological or learning disabilities, as well as other intersecting factors such as gender and ethnicity (RCOI, 2021b). Therefore, redress should be immediate, and offered to all in that first instance. Further supplementary redress in multiple forms can be added or offered later. Redress payments should not be considered as taxable income to avoid impacting income support payments, and efforts must also be made to avoid future financial abuse of people receiving redress payments (RCOI, 2021b).

### 9.1.2 Relational level

“If I could change what happened, I would have wanted the staff to listen to me and talk to me.” [Allan]

The development of any redress schemes must be done so in full compliance with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and all staff involved in redress must receive education about the UNCRPD and understand the rights-based approach to redress (RCOI, 2021b). Particularly important is education about Article 12 of UNCRPD - Equal Recognition Before the Law - to ensure that the personhood of disabled people (especially people with learning disability and neurodiversity) is recognised and respected; including the right for all disabled people to be responded to as citizens with legal and mental capacity. It is also important to extend this education to people who have experienced State and faith-based care themselves. Storytellers have highlighted that they felt (and were) defenceless in the abuse and violence they experienced. Having access to education about rights can provide tools to defend themselves. In order to address and prevent further abuse and neglect, education about disability rights is imperative.

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. It was highlighted through the recruitment process undertaken for the purposes of this project that people with learning disabilities or neurodiversity who experienced State care are unlikely to seek redress via official pathways without serious attention being paid to community education and relationship building. It was possible to reach the storytellers only through the existing networks and relationships of trust that the researchers had with disabled people, project champions and disability services. Therefore, it is crucial that any redress scheme prioritises developing these relationships to ensure equitable access for people who may otherwise not be reached.

### 9.1.3 Community Level

“I always say this, that everyone should be treated equally. I didn’t feel like I was treated equally before I started living in the community. I think when you are out in the community you have your own freedom and you’re not, you’re not told when to shower or when to eat and you have choices of what you want to do. Rather than what you were told to do. I have control on my own choices and more freedom too.” [Allan]



Public acknowledgements, commemorations and national apologies were suggested by survivors to give visibility to past experiences and to prevent the repetition of abuse in care in the future (RCOI, 2021b). Steele (2022) recently suggested establishing Sites of Conscience as a way of acknowledging and commemorating survivors of abuse. Historically, justice has been seen to be served by the closure of disability institutions via the process of deinstitutionalisation. Closing down institutions provides temporary justice but also “allows society to move on without reckoning with and redressing the full complexity, scope and ongoing impacts of that institution” (Steele, 2022, p. 9). Following their closure, institutions are typically repurposed or abandoned and left in derelict states. Both repurposing and abandoning these sites can act to erase the abuses and violence that had occurred there, and from the collective conscience. Sites of Conscience provides society with a way of remembering the injustices that occurred and to prevent further occurrences - through a community led approach. Redressing disability institutional violence using this method allows dialogue to emerge from the communities that ‘hosted’ care settings where abuse and violence occurred.

Sites of conscience activities have been identified as including education programmes, walking tours, social histories authored by survivors, and art work at sites where abuses have occurred. This approach provides a vehicle for the voice and perspective of survivors to be at the forefront of a redress process. Sites of conscience also allow for transitions “from isolation to community, from social invisibility to cultural legitimacy, from looking away to looking at, from neglect to vitality, and, finally, from safely in the past to powerfully and palpably present” (Tumarkin, 2019, p. 16, as cited in Steele, 2022, p. 10). Through the process of story gathering led by *Tell Me About You* storytellers, we have seen for ourselves that mana is enhanced and restored when people become the experts of their own experience - including experts about the sites of disability abuse and violence.

Along with the creation of Sites of Conscience, the disability support system needs to transform to a person-led system. Many of the storytellers were admitted into institutions based on the lack of support in the community, resulting in a loss of community. Therefore, all of the support moving forward needs to be provided within the community and needs to include engagement with whānau, hāpu and iwi to determine what they require to enable them to care for tāngata whaikaha. This approach is supported by the recent launch of Whaikaha - Ministry of Disabled People<sup>44</sup>, which is underpinned by Te Tiriti o Waitangi and Whānau Ora; and the national roll out of Enabling Good Lives (EGL), which focuses on supporting the choices and self-determination of disabled people.<sup>45</sup>

<sup>44</sup> For further information about Whaikaha - Ministry of Disabled People refer to <https://whaikaha.govt.nz/>

<sup>45</sup> EGL is a set of principles that are used to guide new way of providing support for disabled people in Aotearoa, for more information refer to <https://www.enablinggoodlives.co.nz/>

### 9.1.4 Systems level

“These are incredibly valuable records for family, for future researchers and for our disability history. We need to archive what remains. It is one way to provide justice and redress for the distress of institutionalisation and family separation.” [Sarah]

Collecting, safeguarding and using records needs to be overseen by co-governance arrangements between disabled people and professionals.

In order to cement the legal rights and personhood of disabled people, especially people with learning disability and neurodiversity, relevant legislation needs to be reformed to adhere to Article 12 of UNCRPD - Equal recognition before the law.

As highlighted by the analysis of abuse at a systems level, segregation is one of the main conditions of systemic abuse. In order to redress this, exclusion of disabled people in all social systems - education, health, housing, and justice to name a few - must be addressed. The UNCRPD and the monitoring by civil society on the progressive realisation of UNCRPD provides a solid model for how these exclusion can be detected and addressed (Watene, et al., 2021).

On the basis of the evidence to date, aforementioned recommendations remain relevant and appropriate. They are informed by survivors, and their allies, and should be adopted. 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. It is also important to note a further recommendation embedded in He Purapura Ora, which stated:

"Care and support systems, whether for restoration for past abuse, recovery from mental distress, or for enabling better lives, are needed, as are systems for keeping people safe. To ensure abuse is not repeated, the systems that enabled it need to be transformed" (RCOI, 2021b, p. 65).

This could be understood as the recommendation most critical to the achievement of the Royal Commission's commitment to "looking forward" and ensuring that systemic abuse on the scale that is emerging through this investigation "never happens again". Aotearoa is on the crest of major transformation of the disability support and services system. This transformation must respond to the findings of the Royal Inquiry, and occur in the full knowledge that disability supports and services have enabled systemic and institutional abuse to flourish, and that features of the past remain apparent in contemporary care settings.

## 10. Kupu whakamutunga / Conclusion

*Tell Me About You* set out to explore and answer the four key questions, taken from the Royal Commission's own terms of reference:

- 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).

Both the stories and collective findings 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 abuse that occurred.

The stories and collective findings also speak to the physical, cultural and emotional landscape(s) within which abuse was experienced. Storytellers were isolated, relationally and culturally impoverished, and largely deprived of systems that either prevented abuse, or provided a pathway to complain. They were systemically segregated from mainstream society as a result of disablism and ableism.

The impact of abuse is clear in the distressing descriptions that storytellers have shared – even when they do not use a lot of words. Stories told by the storytellers in this project highlighted both blatant and overt, and more subtle and covert abuse and violence. The impact of abuse is clear in the words of whānau who describe their enduring guilt. The stories and collective analysis provides insight to the pain of being dislocated from family and whānau, and the reflections on their current lives and living situations show very clearly that they now experience greater recognition of their personhood, and choice and control over their lives.

The stories and collective analysis reveal that the storytellers had little knowledge of, or control over, the circumstances that led them being taken into care. However, all but one of the storytellers viewed their care placement(s) as inappropriate at the time they entered care, and continue to hold this opinion many years and decades on.

Some people believe that history should not be judged by today's standards. However, while what *Tell Me About You* storytellers have told us about their experiences might have been common, it does not mean it was right and should not be explained away as 'the practice of the time'.<sup>46</sup>

<sup>46</sup> The examples below can all be found in the stories

- 
- Taking young people away from whānau and fracturing cultural identity is not acceptable practice, and never has been;
  - Ignoring the rape of a child within foster care is not acceptable practice, and never has been;
  - Administering medication using violence or as a punishment is not acceptable practice, and never has been;
  - Locking people up and isolating them from others without lawful reason is not acceptable practice, and never has been;
  - Punching people you are paid to care for is not acceptable practice, and never has been;
  - Hanging disabled children from a clothes line is not acceptable practice, and never has been;
  - Not knowing why you were living somewhere, and not being able to leave that place is not acceptable practice, and never has been;
  - Having clinicians encourage your peers to verbally abuse you in the context of therapy is not acceptable practice, and never has been.

These are just some of the stark examples of abuse and violence in the lives of disabled children and adults in care recounted by the storytellers; all are a denial of personhood. We also must recognise that abuse and violence did not stop in 1999. Therefore, we need to continue to be vigilant, we need to be activists, we need to keep listening and ensure that there is a formal mechanism to implement and embed the recommendations that emerge from this Royal Commission.

This project has captured the stories of only a small number of disabled people - there are many more disabled people in Aotearoa New Zealand 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 *Tell Me About You* forced them to relive the māmae they felt while in care.

We are deeply grateful for their contributions. Justice for the storytellers, and the many others who undoubtedly shared similar experiences will only be achieved if redress is underpinned by Te Tiriti o Waitangi, and implemented swiftly and universally in a way that is inclusive of and accessible to all.

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## 12. Tāpiritanga/Appendix A: Timeline of Royal Commission Inquiry into Abuse in Care

On February 1st, 2018, the Aotearoa New Zealand government announced the long-called-for Royal Commission of Inquiry into historical abuse in state care to acknowledge survivors of abuse in state care as well as to protect children from future abuse in state care (Martin, 2018).<sup>47</sup> It was an election manifesto commitment from incoming Prime Minister, Jacinda Ardern.

Following the announcement, a period of consultation on the draft Terms of Reference took place which received over 400 submissions. A report was presented to the government encompassing the submissions on the Terms of Reference on May 31st, 2018. The final Terms of Reference were confirmed and released on 12th November 2018. An amendment to the Terms of Reference was made and subsequently finalised in July 2021 (Royal Commission of Inquiry [RCOI], 2022b). The scope of investigation outlined in the current Terms of Reference include abuse and neglect that occurred in state and faith-based care institutions between 1950-1999; experiences outside of that period were considered also to inform recommendations (RCOI, 2021).

In January 2019, Commissioners of the inquiry were appointed. The Commissioners were Judge Coral Shaw, Ali'imuamua Sandra Alofivae, Paul Gibson and Dr Andrew Erueti.

In March 2019, Government agencies and faith-based institutions were issued with a Preservation of Documents notice prohibiting the disposal and/or destruction of any information of relevance to the Royal Commission's inquiry (Satyanand, 2019). The notice issued stated that it would be an offence for any evidence to be destroyed, falsified or withheld.

The RCOI private sessions began in May 2019, to provide survivors of abuse in care with a confidential environment to share their experiences; with the first session being held in Otago (Winter et al., 2020). During this period, a Survivor Advisory Group of Experts (SAGE) was appointed, representing survivors of abuse in State- and faith-based care institutions to ensure that the voice of survivors were listened to and respected throughout the Inquiry.

In June 2019, a preliminary hearing was held in Auckland outlining information about the RCOI including why it was established, what it is and how it would work (Winter et al., 2020). During this period, a memorandum of understanding was signed by the RCOI and the Department of Corrections to ensure survivors in prisons could participate in the Inquiry. From September 2019, survivors of abuse in care began sharing their experiences with the commissioners.

An Issue paper was published by the RCOI in August of 2019, calling for public submissions regarding redress (financial and civil litigation) (Winter et al., 2019). The first procedural hearing in Auckland was also held in August 2019, to provide "information about the logistics of public hearings, such as how individuals can apply for leave to appear or how

<sup>47</sup> The references for this section is included in the reference list of the main report.



organisations can apply to be a participant of the Inquiry” (Winter et al., 2019, p. 11). During this period, the Crown announced a confidentiality waiver for survivors who had engaged in settlement agreements with Crown agencies. This meant that survivors could engage with and speak freely with the RCOI including details about their settlements. The Catholic Church followed suit soon after by waiving confidentiality of survivors who had engaged in settlement agreements with the Catholic Church.

The contextual hearing was held from 29th October 2019 until the 8th November, which was the first of the RCOI’s public hearings. The contextual hearing included evidence from survivors and experts encompassing the wide scope of abuse in care, as well as the wide scope of the Inquiry. During October, a Memorandum of Understanding was signed with the New Zealand Police, enabling a pathway for survivors of abuse in care to seek justice and for referral of abuse incidents to police. At this time, a fono was held for Pacific people in Whanganui a Tara (Wellington). The Tāmaki Makaurau (Auckland) Pacific people fono was held in November 2019 (RCOI, 2022a). Subsequent Pacific people fono were held in February 2020 (Wellington) and March 2020 (Auckland).

In March 2020, the RCOI released New Zealand Sign Language videos to inform the Deaf community on how they could engage with the Inquiry and share their experiences of abuse in care. Members of the Deaf community assisted in the production of the videos.

In May 2020, a Memorandum of Understanding was signed with VOYCE – Whakarongo Mai, an organisation which advocates for care-experienced children. The purpose of the memorandum was to remove barriers and create ways for safe engagements. As such, the memorandum set out key principles for organisations working together, these included: good faith, cooperation, autonomy, timeliness and communication.

In August 2020, the RCOI launched eight investigations into State- and faith-based settings where abuse and neglect had occurred. The investigations included: Redress - State and faith; Pacific People’s experiences of abuse in care; Māori experiences of abuse in care; Abuse in State Psychiatric care; Abuse in children’s state residential care; Case study examining abuse at the Lake Alice Child and Adolescent Unit; Case study examining abuse of children at Marylands School; Abuse in disability care and the experience of people with disabilities; Abuse in the care of the Anglican Church; and Abuse in the care of the Catholic Church .

In September 2020, the State Redress public hearing commenced which involved the RCOI hearing evidence from survivors. In October 2020, the RCOI heard from witnesses for the crown in a separate State Redress public hearing (RCOI, 2022a). The Redress public hearing provided a pathway for survivors to give evidence relating to their experiences of making allegations, complaints or taking civil proceedings against the State. The faith-based Redress public hearing for Survivor evidence took place in November 2020, while the faith-based witness evidence took place in March 2021.



## 13. Tāpiritanga/Appendix B: Disclosure of Abuse

### 'Tell me about you'

#### Protocol for the disclosure of abuse

Given that the focus of this study is the experiences of people with learning disabilities and / or who are neurodiverse in State care, the research team is aware that abuse and rights violations are likely to be raised by some storytellers. For example, disabled people have been found to be at greater risk of abuse than members of the general population.

For this reason, we cannot ignore the possibility that the research team may become aware of historical or current abuse through their discussions with storytellers (participants). There are a number of different possible scenarios relating to the manner in which abuse may be present in a storyteller's life. The possible scenarios are outlined below, along with the specific procedure to be implemented in each case. In the case of disclosure of abuse, the storyteller will be made aware of the procedures outlined below before any action is taken. It should also be noted that each storyteller will be informed of the research team's obligations relating to the disclosure of abuse during the informed consent process, before the first interview occurs.

#### **A storyteller may disclose that they have been abused in the past.**

Procedure: In the situation of historical abuse the research team will check with the storyteller as to whether they received any assistance with their abuse in the past. If the storyteller wants to receive support or counseling at this time the research team would provide advice on the appropriate place to seek help through the RCOI.

#### **A storyteller may disclose they are currently being abused.**

Procedure: Integral to any action relating to the disclosure of abuse is that the person who is being abused must agree they want to take the matter further. The only exception to this would be in a situation where the abuse was being perpetrated by a person in a position where they could abuse other adults or children. The research team will address this situation by alerting the appropriate authorities immediately (for example, the storyteller's support service management or child protection services). The research team will always inform the storyteller that this action is going to occur.

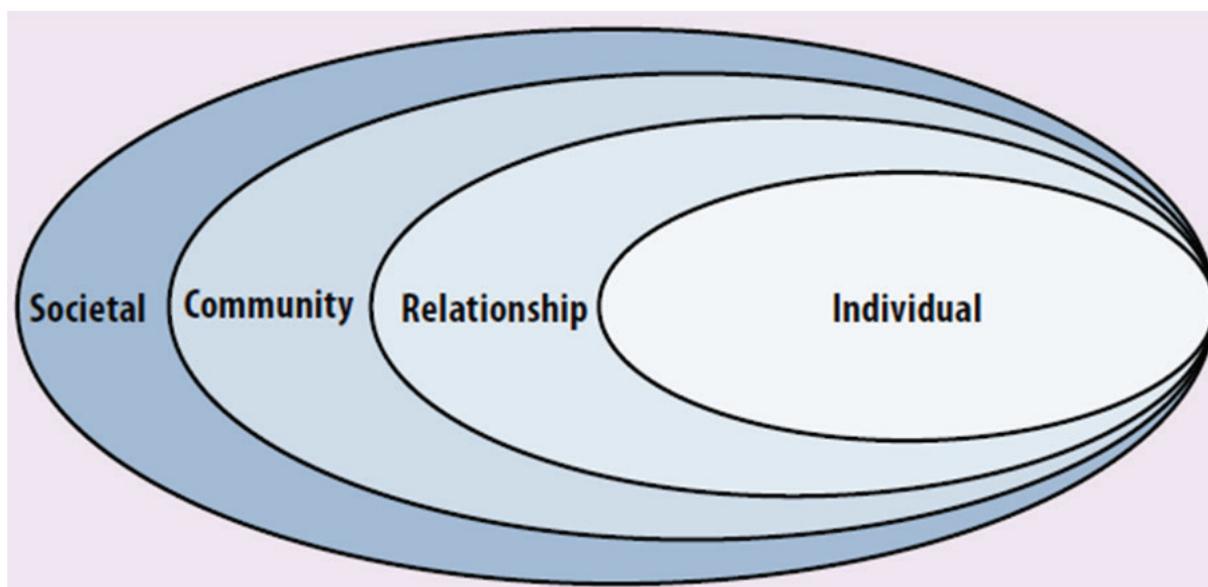
#### **A storyteller may disclose that they are currently abusing a child or adult.**

Procedure: The research team will encourage the storyteller to report the neglect or abuse immediately to their support service or to child protection services on their own behalf. If the storyteller refuses to report the neglect or abuse the research team will report the matter to the appropriate authorities immediately (for example, the storyteller's support service management or child protection services).

## 14. Tāpiritanga/Appendix C: Overview of the development of ecological model of understanding disability violence and abuse

Bronfenbrenner introduced the initial ecological model theory in the 1970s which was then formalised in the 1980's. Bronfenbrenner developed the model to understand human development through individual and environmental/social factors (Kilanowski, 2017). This conceptualisation involved placing the individual within the centre of an initial circle, called the microsystem (individual level). Within the microsystem lies the individual's personal attributes and their immediate social environment (e.g. family, carers, and immediate relationships). The microsystem sits within a larger circle, called the mesosystem (relational level), relating to an extension of the social environment consisting of direct interactions of the individual (e.g church, school, workplace). The mesosystem sits within an even larger circle, called the exosystem (community level), relating to the social environment of the individual where interaction may not be direct but can still have influence on the individual. The exosystem refers to social networks and community networks (e.g. regional and local councils, school board, organisation/service board). The exosystem sits within an additional circle, called the macrosystem (societal level) which relates to cultural and societal influences and belief systems. The macrosystem underpins the inner systems. The outer circle is called the chronosystem, which relates to history and time - through influential events that occur within an individual's lifespan. This can include policy and legislation that impacts the individual (Kilanowski, 2017; Reifsnider et al., 2005).

The ecological model acknowledges and focuses attention on the complex interplay between individual, relational, community and societal factors that influence violence and abuse.



(World Health Organization, 2002)



In 1994 Dick Sobsey, a Canadian disability researcher published a book, ‘Violence and abuse in the lives of people with disabilities: The end of silent acceptance’ (Sobsey, 1994). In this he adapted the generic violence prevention model and applied it to the experiences of developmentally disabled people. Over the past two decades other disability researchers and advocates have drawn on this model in prevention work. In Australia, the model has been used for over a decade by disability researcher Patsie Frawley and colleagues to underpin a peer education program ran by and for disabled people (Frawley & O’Shea, 2019, 2018; Frawley et al, 2017; Frawley & Anderson, 2014; Frawley, Barrett & Dyson, 2012). In the USA, Nancy Fitzsimons a Social Work researcher has published a text for practitioners in disability and human services (Fitzsimons, 2009). Fitzsimons’s work has led to the ecological model of disability violence and abuse being used to inform state and national disability violence prevention plans (Fitzsimons & Olmstead Implementation Office, 2018).



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