

“Institutions are places of abuse”: The experiences of disabled children and adults in State care

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Dedication

We dedicate this work to all the people who have courageously shared their stories of abuse in State care, to those who were unable to do so, and to those who lived and died in institutions including those in unmarked graves. We are your friends, families and communities. We seek justice and apology, and endeavour to do all we can so that it never happens again, e kore ano.

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Artist

Fintan Magee
“Chasing the Thin White Cloud”



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We acknowledge the disabled children and adults who have informed and shaped our own understandings of abuse in State care throughout our respective careers. It is their stories that underpin this research. Many of these individuals are no longer with us to support the call for an inquiry and apology, and will never know that thousands of New Zealanders have recently been demanding an inquiry and apology on their behalf.

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Brigit Mirfin-Veitch and Jenny Conder

FOREWORD

Saying Sorry to our Stolen Generations

Hutia te rito o te harakeke, Kei hea te Kōmako e kō?

If you pluck the shoot from the heart of the flax bush, from where will the bellbird sing?

At the United Nations during the development of the disability convention, my friend Robert Martin proudly stated he has an intellectual disability. He spoke with humility and courageously shared his story as well as the stories and dreams of his friends, they are similar to those shared in this report. The UN diplomats took a step back and recognised that the voices of disabled people with lived experience must be at the forefront. His contribution is reflected in the convention’s principles and many articles, including the articles on community living and freedom from abuse.

Robert represents the underground movement of marginalised people whose activism became a global rights revolution and one of the most significant pieces of international human rights law this century. The disability convention has reached beyond the UN and given hope to the forgotten, abused and rights deprived people in the darkest corners of our global village. Robert is a Nobel Peace Prize nominee and the first person with an intellectual disability elected to the UN committee overseeing the convention. He is a great New Zealander.

Like the rito being plucked from the heart of the flaxbush, Robert was taken from his family and placed in Kimberley as a baby. There is overwhelming evidence that children belong and thrive in families, and because intellectually disabled children are even more vulnerable, the love and stability of their mum, dad, siblings, extended family and communities is crucial. I believe an abusive culture existed whereby the state and professionals coerced families into believing that services rather than loving families should prevail in disabled children’s lives. New Zealand

institutionalised children at three times the rate of other similar countries. Support to enable families to raise their disabled children at home was seldom presented as an option. Inside these institutions, as evidenced by this report, worse was to happen.

Services or love? What we did to disabled children and their families was wrong. The abuse each child experienced in being taken from their family was frequently compounded by physical, psychological, and sexual abuse. Most staff were not abusers, however some staff were abusers who preyed on the vulnerable and voiceless, out of sight, out of mind.

This research “Institutions are places of Abuse” by the Donald Beasley Institute, commissioned by the NZ Human Rights Commission, found that those New Zealanders with intellectual disabilities who were able to give independent testimony about their experiences in institutions cited physical and sexual abuse, even when such information was not being specifically sought.

Personal stories courageously shared in the past have been collated this research: John and David were constantly fearful; Avis was tied to a bed; Mavis was made to feel a slave; and Alison, in prolonged seclusion, drunk her own urine.

This abuse occurred during the same period as reports of abuse in psychiatric facilities documented in “Te Āiotanga” the confidential forum report; the Gallen report into Lake Alice; and the “Some Memories Never Fade” report of the Confidential Listening and Assistance Service. The latter focused on children’s home and foster care abuse survivors where a disproportionate number of tamariki Māori taken from whānau. These are all the stories of New Zealand's stolen generations.

To date, like most other survivors with learning disabilities, Robert has not received an apology nor compensation, in my view people with learning disabilities and autism continually miss out. Other government reports such as “To Have An Ordinary Life” (2003) described the systemic neglect of their health as “disturbing”: 14 years later this has yet to be remedied, and only last year we heard that 6-year-olds with autism were being secluded in dark school cupboards. The



Human Rights Commission’s role includes to protect the rights of all New Zealanders and I would like to give assurances to disabled people and their families that we have learnt the lessons of the past and that systemic abuse is not ongoing and will never happen again. But without a thorough inquiry I cannot give that assurance.

When Kimberley closed, Robert and his friends had a minute’s silence for those who died at the institution and who some believe are buried there in unmarked graves. The Ruahine and Tararua, the wise old women mountains, now look down on the Kimberley site and see the development of an aged care facility. With our aging population, if we are to learn from the past then a new kind of vigilance is needed. If we don't listen to the voices of the effected and learn today, tomorrow we will be haunted by the ghosts of yesterday, it may be each of us that ends our days excluded, voiceless, abused, out of sight, out of mind.

Hutia te rito o te harakeke, Kei hea te Komakō e kō?

If you pluck the shoot from the heart of the flax bush, from where will the bellbird sing?

He aha te mea nui o te ao? He tangata, he tangata, he tangata.

What is the most important thing in the world? It is each person, every person, all people

Let’s celebrate that a Kiwi with a learning disability has changed the world and been nominated for a Nobel Peace Prize.

Let’s honour our commitment to leave no one behind.

Let’s make sure this abuse can never happen again.

But first we need a formal inquiry, so we can learn from our past so that it can guide our future

.



Only then can we say “sorry” with honesty, sincerity and mana.

Paul Gibson

Disability Rights Commissioner

NZ Human Rights Commission

PLAIN ENGLISH EXECUTIVE SUMMARY

The New Zealand Human Rights Commission has asked the Government to do an inquiry into the abuse of children and adults who lived in State run hospitals and homes (State care) between the 1950s and 1990s.

Some people have been able to tell the court about their abuse in State care. Other people have used the Confidential Listening Service to tell their story. However, only a few people with learning disability have been able to access these opportunities to tell other people about their abuse.

To learn more about the experiences of people with learning disability, the Human Rights Commission asked researchers at the Donald Beasley Institute to:

- Find out what is known about the abuse of people with learning and other disabilities in State care
- Find out what we don't know about the abuse of people with learning disabilities and other disabilities in State care
- Make suggestions about what research needs to happen to make sure people are not abused in the future.

The Donald Beasley Institute researchers used an integrative review methodology (Whittemore & Knafl, 2005) to do their research.

This method meant that they could use research, literature, films and audiorecordings. From these they could find examples of the ways that people with learning disability had been abused in State care.

Most of the examples of abuse that were found came from people's stories. In some cases people had told their story by themselves. Others told their stories with the help of assistants. The stories were either written or taken from recordings. All were published and available for anyone to read.

In total there were 17 individual stories, 12 men and five women. Some had other disabilities as well as a learning disability. Three of the people identified as Māori and one Pacifica. If people had used their own name when they wrote or told their story we used it in this research. One person chose not to use their own name.

Information for the study also came from family members, staff who had worked at institutions, and from other studies that had looked at the closure of institutions.

This report includes detailed stories from five people. These are told in the first part of Section Two. The stories provide a picture of institutional life where people experienced different types of abuse and neglect.

The second part of Section Two identifies the main types of abuse that people talked about.

Neglect was common. People talked about having no-one to comfort them when they were upset; nothing to do; no relationship with their family; not having basic care or attention for their injuries; being cold much of the time; and being made to work from a young age.

Emotional and psychological abuse was seen through people talking about being scared a lot of the time. People in this study also talked about seeing other people hurting themselves because they were upset. Many talked about the long term impact of abuse and neglect. For example some people said they were unable to make decisions because they had always been made for them. Others said they did not trust other people, and that they sometimes had nightmares that they were back in hospital.

Most people said they had been physically restrained or controlled in some way. Doors were locked and people were made to stay in certain parts of a building or in special rooms away from others. People were locked up as punishment but doors were also locked to stop people from going into dining rooms or bedrooms at different times of the day. They could not move around freely.

Most people had been physically abused. People who had been physically hurt often said that the physical abuse made them feel angry and powerless. Staff as well as other people living in the institutions and care homes were responsible for the physical and sexual abuse. Sexual abuse started when the person was a child and was often kept secret until they were adults. People did not talk about it because they were ashamed and they thought they would not be believed. Those who did report that they had been sexually abused were not supported.

Not many people said that they had experienced spiritual or financial abuse. However, it was clear that institutional life took them away from their communities. Institutions followed Pākehā customs and did not allow for Māori or Pasifika customs to be part of

people’s lives. Most said they did not have control of their money and things that they treasured were often stolen.

Staff and family who visited the institutions saw people being abused and neglected. Staff, families, researchers and government reports said the same things as the disabled people who lived in State care. They saw people being punished and people being given treatments that were not appropriate. Even when government reports said things had to change, they didn’t.

Section Two of this report says that the neglect and abuse reported by individuals, family members, staff and the ministerial report is systemic. Systemic abuse means that institutions did not make sure they were working in a safe way. This research found that abuse was not taken seriously and that there were not enough staff to meet people’s basic needs. Staff also lacked the training to provide good quality care.

Section Three talks about what we still don’t know about abuse in State care. It was difficult to find stories or other accounts of abuse and neglect. Sometimes there were details missing such as what lead up to the abuse, when it happened and how often it happened. This research has told us a lot but we still need more information and to hear from more people.

Section Four makes some suggestions for research. We need research that:

- Explores disabled people’s experiences of abuse and neglect when they were in State care;
- Explores families’ views about the support they are currently receiving in order to keep their disabled child or young person out of State care;
- Tells us how organisations provide support to disabled people, and how they make sure abuse doesn’t happen;
- Looks at the experiences of disabled children who were, or who are currently, in foster care in order to assure that they are receiving the best support;
- Learns from staff and regular visitors to institutions and care homes about what they saw.

Through the voices of the few people who have managed to be heard, this report provides evidence that people with learning disability were subjected to a lot of abuse in institutions, care homes, educational facilities, and foster homes in New Zealand between 1950 and 1992. For this reason an inquiry into State care during that time is needed. It is also important that people who were abused get an apology from the government.





TABLE OF CONTENTS

Acknowledgements.....	iii
Foreword	iv
Saying Sorry to our Stolen Generations	iv
Plain English Executive Summary	viii
Table of Contents.....	xii
“Institutions are places of abuse”: The experiences of disabled children and adults in State care	1
Introduction.....	1
Background to this report	2
Section One: Research Design	4
Integrative literature review methodology.....	4
Defining abuse in the context of this research.....	5
Where did we find the evidence?	5
Who was included in the research?	6
Section Two: “... I was just so frightened”: Exposing the evidence of abuse of disabled people in State care	9
“...no one ever came to comfort me”: The Lived Experience of State care	10
David and John’s story.....	10
Robert’s story	12
Avis’ story.....	15
Mavis’ story	18
Adding to the voices.....	20
“...to this day cannot remember the names of my abusers!”:	23
Looking more critically at the categories of abuse disabled people experienced .	23
“And she said wouldn’t do nothing about it”:	24
Neglect.....	24
“...I wake up scared that I am still there”:.....	27
Emotional and psychological abuse.....	27
“I didn’t have any freedom”:.....	29
Control and restraint.....	29
“The boys were belting me up”:	30
Physical abuse	31
“Best just keep quiet and hope it wouldn’t happen again”:	31
Sexual Abuse	31
I spent my life locked away from the world and I knew nothing:.....	34
Spiritual abuse.....	34
“They make you a slave...”:.....	35
Financial abuse	35
“The Kimberley cringe, that’s what they call it...”: Third party accounts	36
Was the abuse experienced by disabled people including those with learning disability in State care institutional abuse?.....	39
Was the abuse experienced by disabled people including those with learning disability in State care systemic abuse?	40
Section 3: What is missing - identifying the gaps and limitations in the available evidence about the abuse of people with learning disability.....	43
Section 4: Recommendations for future research	46
Conclusion.....	48
References	50
Appendix 1: search terms.....	52
Appendix 2: Search Locations	53
Libraries for historical resources:.....	53



Libraries for digital and news resources:	53
Academic resources:	53
Activist resources:	53
Other community- or government-based resources:.....	53
Libraries with legal resources:	54
Appendix 3: Definitions of Abuse	55

“INSTITUTIONS ARE PLACES OF ABUSE”: THE EXPERIENCES OF DISABLED CHILDREN AND ADULTS IN STATE CARE

*Titiro whakamuri hei ārahi i ngā uaratanga kei te kimihia
Kia whakatōmuri te haere whakamua*

*We look to the past so we can move forward, understanding where we have come
from in order to understand who we are today...*

Introduction

In February 2017, the New Zealand Human Rights Commission launched a campaign titled *Never Again - E Kore Ano*.¹ The campaign commenced with an open letter to the Prime Minister, which called for a comprehensive inquiry into the abuse of New Zealand children and adults who were forced to live in a range of State run institutions and facilities between the 1950's to 1990's. Abusive practice in State care did happen. It has been tacitly and explicitly acknowledged by those with a connection to this area for many years. It has also been confirmed through research (Stanley, 2016).

While children and adults have, in some cases, been able to seek legal redress for the abuse they experienced in State care, not everyone has had the opportunity to utilise such formal processes. This is because some people have not known about the ways in which they could tell their stories and seek help, while others have not had the emotional resilience to do so alone. Within the diversity of individuals who found themselves in State care, there are still people who require the advocacy of others to even be acknowledged as part of this story. The Human Rights Commission, and a number of other New Zealanders recognised this.

The *Never Again - E Kore Ano* campaign was launched with the express purpose of recognising and responding to all the voices - whether loud, quiet, or part of the majority who have remained silent. It calls for the experiences of people in State care to be understood by all New Zealander's, not just those who have had direct involvement in this issue. Perhaps most importantly, *E Kore Ano* has at its core a commitment to achieving a

¹ The *Never Again - E Kore Ano* specifically calls for: an independent inquiry into the abuse of people held in State care in order to identify the systemic issues that permitted this to occur and the broader impact of these events on our communities; a public apology to those who were affected, including those who were abused, their families and whānau; Take other appropriate steps to acknowledge the harm that has been caused to the victims and to provide them with appropriate redress and rehabilitation; and, Take action to ensure this never happens again.

meaningful public apology, delivered by the Government, to all children and adults who were abused in myriad ways while in the care of the State.

Background to this report

This report, contracted by the Human Rights Commission, details research that was designed to capture the voices and experiences of disabled people, particularly those with learning disability, who were abused in State care in Aotearoa New Zealand prior to 1992. In this project, we searched for evidence of neglect, emotional abuse, control and restraint, physical abuse, sexual abuse, spiritual abuse, financial abuse, institutional and systemic abuse in the lives of disabled people.

The report responds to the stated concern that disabled people, including those with learning disability, comprise a significant part of the *silent majority* who have not told their stories of abuse². This is despite their long and significant history within State care in New Zealand. Important research by Stanley (2016), on this issue documents the experiences of people who previously resided in “boys” and “girls” homes but does not include a focus on young people labelled as disabled. Furthermore, 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 important support for people who self-identified as experiencing abuse in State care (Henwood, 2015). Because they did not, or were not able to find their way to the CLAS, the opportunity for people with learning disability to be supported to achieve redress and restitution may have been lost.

The specific aims of this research were therefore to search the evidence, on public record, in order to:

- Determine what is known about the abuse of disabled people, particularly those with learning disability, including evidence of systemic abuse;
- Identify gaps in the available evidence about the abuse of disabled people, with particular focus on learning disability in State care;
- Recommend a research pathway, including an investigation methodology, with the potential to address the gaps in knowledge relating to disabled people, abuse and State care.

² People First New Zealand, a self-advocacy group, promote use of the term “learning disability” instead of “intellectual disability”. They feel the term is more reflective of the difficulties they experience, respectful to them as people, and easier to say. Therefore, “learning disabilities” is used instead of intellectual disabilities throughout this chapter, despite the fact that intellectual disability, and indeed a variety of other terms, were used during the period 1950 - 1992.

It is important to note that due to scope and time constraints, the research undertaken for this report was not able to encompass comprehensive exploration of the available evidence relating to the abuse of people with psycho-social disability.³ Although this work has a narrow focus, it indicates that there is a very strong basis to suggest that people with psycho-social disabilities were abused in State care at least as frequently and severely as children and adults with physical, sensory and/or learning disabilities. Indeed, a number of previous reports strongly attest to this (Gallen, 2001; Satyanand, 2007).

This report has been constructed in four sections. Section One details the research design; Section Two presents evidence related to abuse experienced by people with learning disability and other disabled people in State care; Section Three identifies the gaps in the evidence in relation to the abuse of disabled people in State care⁴; and Section Four discusses the implications of the research findings, and recommends areas for future research that have the potential to address critical gaps in knowledge about the past, present, and future of disabled people.

³ It is noted that many of the individuals whose stories and experiences are included in this report also experienced mental distress themselves, and in many cases, shared the same institutional environments as those labelled as “mentally ill”.

⁴ In a comprehensive overview of learning disability in New Zealand in the 1980s, Singh & Wilton reported that in 1981, 3754 people lived in institutions in New Zealand; 1961 people resided in the four psychopaedic institutions (Braemar, Kimberley, Mangere and Templeton) while another 1793 resided alongside people with mental distress in 13 different psychiatric hospitals (Singh & Wilton, 1985, p.49). It is important to note that many more children and young people were in other forms of State care such as residential schools, and foster care during this same period.

Section One: Research Design

Integrative literature review methodology

In order to develop a useful body of evidence relating to disabled people in State care, we needed to remain open to the range of ways that people may have communicated their experiences. It is well recognised by researchers that people with learning disability have been prevented from joining conversations about things that are directly related to themselves (such as this one). This is mostly due to the fact that they are not always supported to contribute in ways that conform to academic conventions about what constitutes evidence (Johnson & Traustadottir, 2000).

The findings related to abuse in State care contained in this report were developed through implementation of an integrative literature review methodology (Whittemore & Knafl, 2005). Integrative literature reviews combine data from both theoretical and empirical literature, and permit the development and synthesis of theory with the goal of determining practical solutions. This approach offers several advantages over alternative review methodologies, such as meta-analyses (which require data to be of similar nature) or systems analysis (which often exclude qualitative data such as personal story or lived experience based literature).

Integrative reviews permit the inclusion of a wide range of literature, including both quantitative and qualitative academic studies, personal narratives, oral and life histories, creative projects, and other ‘grey’ literature such as reports, policy, and opinion pieces. This approach was appropriate in the context of the current research, as it was recognised that only a small amount of research had focussed specifically on the abuse experienced by disabled people in State care in Aotearoa New Zealand per se. For this reason, we sought to expose evidence relating to this critical issue through the identification and analysis of resources not typically pulled in to the ‘scientific’ evidence base, such as personal narratives, or creative projects that documented examples of abuse in State care prior to 1992.

Defining abuse in the context of this research

Clarifying the definitional scope of what constituted ‘abuse’ was essential to collecting information about individual’s experiences of abuse in State care. Our primary aim within this project was to locate and analyse publically disclosed experiences of abuse, with priority placed on personal accounts. In taking this approach, the research team were attentive to the myriad harms and detrimental impacts on mauri ora (wellbeing), as perceived by those who experienced them. The research team sought to collect and explore disclosures of harm and negative experiences that may have otherwise been excluded from a scope of inquiry that did not approach the research from the perspective of those people marginalised.

The research project utilised a partially deductive method of discovering disclosures of abuse and utilised pre-existing definitions, types, or categories of abuse as codes from which to begin thematic analysis.⁵ It also incorporated an inductive approach in that while we began with some pre-existing codes that were underpinned by commonly understood types of abuse, our coding was responsive to the content and recurring issues raised in the data. For example, while we coded for specific forms of abuse (such as physical, sexual, emotional, spiritual abuse, neglect and issues of control and restraint), the research team recognised that these forms of abuse were inextricably linked and the extent to which elements of these abuses were present in a person’s life compromised mauri ora (Kruger et al., 2004).

Where did we find the evidence?

All members of the research team conducted searches. The searches determined that it was difficult to draw relevant research and evidence sources into the project. Often, search terms drew on research that was of little relevance due to literature employing terms with broad definitional scopes. For example, “institutions” did not merely pertain to “psychopaedic institutions” or “psychiatric institutions” but also pertained to a wide variety of establishments and systems under the State, including boy’s and girl’s homes, boarding schools, and educational facilities.

⁵ Please refer to Appendix 3 for a comprehensive overview of the definitions of abuse used to inform coding and analysis.

The challenge of finding relevant information to the search emphasised that there were few resources that were explicitly aligned with the scope of this project. This was confirmed when library staff at Hocken and IHC libraries were referred to for assistance in finding texts in the project’s scope. The project team received feedback that specific texts pertaining to our inquiry were extremely limited, if not non-existent. Therefore, mining for information in potentially relevant sources was the strategy recommended by librarians representing these specialist historical and disability collections.

In keeping with the desire to prioritise individual accounts and lived experience, the descriptions of abuse in State care contained in this report were largely derived from life stories and other self- or co-constructed narratives. Many of these were written accounts, but some were delivered through visual mediums such as documentaries or other media driven formats, or (in one case) through music.

The stories discovered featured primarily in books and book chapters in which a person’s experiences and history were central. A few life stories were explored through interviews in texts where collecting accounts of institutional living was central. Several of these stories were co-constructed with a person trusted with their narrative. They were all published accounts that can be publically accessed.⁶

Who was included in the research?

When applying an integrative review methodology, demographic information relating to the “participants” is typically positioned with the research findings. However, in order to highlight and prioritise the voices of individuals, we have included demographic details within this research design section. To carry out the aims of this research, as noted above, the researchers searched for resources in the public domain that evidenced abuse experienced by disabled people in State care, placing a particular emphasis on the personal accounts provided by disabled people with a focus on the State care experiences of people with learning disability.⁷ We applied a large number of disability terms to locate resources relating to the abuse experiences of people with learning disabilities and other disabled

⁶ The exception to this is one person’s account, which was provided to the research team via personal communication on the condition that a pseudonym was used.

⁷ An attempt was also made to discover evidence of abuse in State care relating to intersex children or adults. The term “intersex” refers to people who have been ascribed the ‘intersex’ membership on the basis of anatomical or chromosomal characteristics/features that fall outside those characteristics belonging to one of the sex categories in the sex (male-female) binary. No relevant resources were located.

people. We also conducted extensive searches using the names of State run institutions and facilities.⁸

A search of numerous possible sites or sources for relevant resources⁹ led to the discovery of evidence of abuse in State care, relating to disabled people with a range of different impairments, including some with multiple impairments. While most of the evidence of abuse related to boys and men; important stories about the experiences of girls and women were also identified and drawn into this research. No person from the discovered life stories identified with other gender identities.

In total, we drew on the personal accounts of 18 individuals; 13 men and five women.¹⁰ Ten of these people were identified as having a learning disability only; one had epilepsy, two were legally blind, physically disabled, and also had learning disabilities; one person was deaf; one described herself as having developed brain damage as the result of a childhood illness; two people had cerebral palsy; and one person had been misdiagnosed with learning disability as a child, which led to him being institutionalised in a psychopaedic hospital for approximately eight years. Only three of the people whose personal accounts we drew on had been in foster care, but all of these individuals had also spent considerable periods of time in psychopaedic and/or psychiatric hospitals. All other accounts drawn on related to State care in institutions only. Finally, all had experienced State care within the time period 1950-1992, however a small number of individuals (two) had entered State care prior to 1950.

Ethnicity was not clearly stated within many of the data sources, however three people identified as Māori. Another person identified as Pasifika (of Cook Islands descent). The age in which people entered State care, or had lived in particular institutions at particular times was not always clear. However, most of the disabled people whose stories we drew on, indicated that they had lived in State care in childhood, and adulthood, and many remained in “care” in the form of residential disability services for their entire lives. Most individuals were found to have lived in a range of different institutions, moving from facility to facility at the direction of the State.

⁸ A comprehensive list of search terms used in this research is included as Appendix 1.

⁹ A comprehensive list of search locations is included as Appendix 2.

¹⁰ All accounts drawn on were from published accounts except one person’s experience which was provided by personal communication.



Finally, in order for disabled people to have their experiences, and resultant distress recognised as being as significant as others who have told of their abuse in State care, it was also important to be able to include the stories, testimony or research of those who had observed or been told about abuse in State care, such as staff or family. As they embarked on this research, the researchers were aware that people with learning disabilities in particular had most often talked about their experiences within institutional environments within the context of studies of deinstitutionalisation. Much of this research has included the voices, views and perspectives of staff and family and offered a potentially rich source of data for this work. We therefore included evidence of abuse in State care provided by these other sources in the report.



Section Two: “... I was just so frightened”: Exposing the evidence of abuse of disabled people in State care

Come to Seacliff, come to Seacliff,
What a place of misery.
There's a signpost around the corner saying “welcome unto thee”.
Don't believe it, don't believe it.
Coz it's all a pack of lies.
(*Come to Seacliff*, n.d.)

When telling their personal stories, most people have a tendency to want to balance good and bad experiences as a way of maintaining mauri ora. From reading the available detailed stories from people with learning disabilities and other impairments, it is clear that this tendency was also present for them. However, even in the comparatively “good” times, it was clear that their experience was one of pervasive deprivation. We acknowledge that the full original accounts drawn on in this research did not always focus exclusively on abuse, but rather evidenced abusive practice and actions in the context of the person talking about institutionalisation, or more typically, deinstitutionalisation. In some cases, the evidence emerged in the person’s telling of their “life story”. We do not wish to communicate that the people involved did not recount positive experiences and/or relationships within the telling of their ‘life stories’, however positive experiences rarely related to their time in State care but rather to the few relationships that were characterised by genuine warmth and empathy. To elucidate these experiences, we have arranged this section of the report in two parts.

The first offers detailed summaries which have the purpose of contextualising the lived experiences of abuse. Although specific categories of abuse, such as sexual abuse, are prominent within these stories, more frequently the narrative suggests multiple, inter-related and pervasive experiences of harm. The second part of this findings section presents additional information about particular categories of abuse which were identified more broadly within the research and across the collection of individual stories comprising the

study data. In all examples, real names are used to honour each individual’s prior decision to make their personal accounts public.¹¹

“...no one ever came to comfort me”: The Lived Experience of State care

David and John’s story

David Blackett and John Te Kiri told their stories as part of a narrative-based research project titled *Extraordinary Journeys* (Spectrum Care Trust Board, 2010), which explored the impact of deinstitutionalisation for people with learning disabilities. Through this process, they shared much about the realities of institutional life.

Best friends, David and John shared similar experiences as two blind men who had both lived in State care institutions for most of their lives. John summed up his experience with the comment: *“I’ve lived most of my life in institutions.”* (p.97). When asked what the best thing about them he replied: *“I [can’t] think of anything.”* (p.97).

Both John and David’s early lives included time at Homai College, of which they had few memories, however both progressed through other institutions before settling in the community in a flat supported by non-government disability service Spectrum Trust in 1995. John found himself in Kingseat Hospital when he was about 12 years old. He had no family contact, having been born in the Cook Islands in the early 1950s and brought to New Zealand as a baby for eye surgery. John’s memories of Kingseat were of:

“... a solid metal place where you couldn’t get out. Some locations, you used to get locked up. They [other patients] were so mental, they used to throw things at you and chuck things at you all the time, and sometimes they used to get stroppy and things like that... One of the staff came along and said ‘Hey come on, cut that out! You don’t need to chuck that around, that’s not very nice!’ Then one of the other staff members caught one of them and locked him in his room for about four days ...”. (p.91)

¹¹ The only exceptions to this approach is where data relating to sexual abuse was drawn from a reported legal case involving an individual who alleged he had both been sexually abused, and had witnessed sexual abuse while in care, including State care, during childhood, and in the case of the participant who contributed his experiences of abuse via personal communication with the research team.

For John, the memory is of feeling angry at such times. He explained: “...I was just so frightened, I couldn’t see what was coming to me, you know?” (p.92). In addition, he was also locked up when he was in Unit Five “I used to get locked in a side room, down the bottom. You weren’t allowed to go anywhere ... the pictures ... couldn’t celebrate ... I was locked up the whole time.” (p.92)

John and David also experienced life at Mangere Hospital. In contrast to John, David’s very early years were spent at home with his parents, however from the age of three he started residential schooling first at Sunrise Home, then from eight years of age at Homai College. At around 14 years of age he moved into Mangere Hospital. Like John, David talked about being constantly fearful of being hurt by other residents: “The worst thing for me at Mangere Hospital was that I used to get pushed over by other patients. One of them broke my elbow ...” (p.38). Furthermore, he had little independence, and little practical response to his visual impairment: “I use a fold-up cane to help me get around these days, but when I was at Mangere Hospital I didn’t have anything to help me ... I had to hold onto someone’s arm to move around. If there was no one to hold onto, I’d have to wait.” (p.38).

Perhaps a coincidence, but a memory that left both men fearful of swimming relates to being thrown in the pool at Mangere. David said: “I was thrown in at the deep end, for no reason, and, while I could paddle, I’ve been scared of the pools ever since then.” (p.38). John’s independent comment suggests that this was not unusual behaviour on the part of staff as he recounts one of his worst memories: “I used to get chucked in swimming pools, and things like that. I couldn’t even swim ...”. (p.93).

John lived at Mangere at an earlier, and over a longer period of time than David. His early experience of Mangere was little different to that he had at Kingseat. He remembered being locked up: “the whole time” (p.89); sharing clothes on the basis of “first up, best dressed” (p.94) but, in reality, staff choosing for him from whatever was available. There was no social life: “We never used to go out at night, we used to get locked up in villas ... we weren’t allowed out anywhere. I could never, never ever get out of it. It was very hard.” (p.92-3)

The two men first met at St John’s in Papatoetoe, Auckland. From their description, St Johns was a residential home with about 90 people separated into three wings. An internet search identified it as a satellite home for Mangere Hospital which was opened in 1963 in what was once the Papatoetoe Orphan’s Home. David commented: “When I was over at St

John's I wasn't able to get up until I was told. That wasn't good. Staff told us when to get up ... We only had a little bit of choice, not much. You weren't allowed to go into the dining room unless you were told.” (p.35). John further described his experience of the dining room: “It was a big dining room ... lots of noise, lots of people. We used to sit down, we had a nurse who used to come around with a spoon behind his back. He was just telling them to be quiet... He'd bang the spoon on the table if someone talked. We had to eat every meal in silence ... if anyone talked, they would be put outside and they would miss out on their dinner.” (p.93).

John also talked about the lack of privacy, aside from sharing a room with many others: *“there were 30 odd residents in one bathroom ... they would all shower at the same time ... There wasn't much privacy, though there were doors on the showers”.* (p.94).

David further illustrated life at St John's: *“I used to stay in the wing all day and the doors used to get locked. I didn't like that. We were locked in at night, too. ... I was happy to leave St John's.”* (p.39).

Robert's story

Prominent New Zealander Robert Martin, a Human Rights Activist, has spoken about his abusive experiences in institutions and foster care in a wide range of forums. His story has also been documented elsewhere, including in his biography *“Becoming a person”* (McRae, 2014) and the book *“The lost years”* (Hunt, 2000). These books document his admission and readmissions to Kimberley from the age of 18 months through to 15 years, various foster placements throughout his childhood, going home to his parents for short periods, and admissions to Lake Alice and Campbell Park School. From this perspective Robert's experience demonstrates the widespread acceptance of abuse of young people in State care at the time. In a 2014 Attitude Television documentary (Robert Martin: The People's Advocate, 2014) Robert described his own experiences as well as those of the countless other disabled people he had spoken with: *“institutions are places of abuse”.*

Importantly, Robert also reminded us about the distress caused by an absence of memories when he commented in the documentary and his biography in relation to his time at Kimberley: *“But I don't remember being touched and cuddled like other kids are. I was never loved as a child. Me and all those other kids... Even today I find it hard to show affection to other people. I don't trust easily.”* (Robert Martin: The People's Advocate,

2014)

“I didn’t experience what other kids did. I didn’t play sport at school or at the weekend. I didn’t go to birthday parties, visit the zoo, feed the ducks at the park or go to the football with Dad. I didn’t go to family gatherings such as birthdays or weddings. I didn’t visit my relatives. I didn’t know who my relations were.” (McRae, 2014, p.16)

“Me and my friends were denied our basic human rights such as freedom, opportunities to learn and to have ordinary experiences. The only way to express ourselves was by behaving in a way the staff called ‘challenging’. For some of us this meant engaging in self-injurious activities - biting arms and hands, banging heads.”

Furthermore, as Robert recounted in his biography (McRae, 2014, p.32-33), it seemed that staff might: *“... have got a kick out of seeing people lose control. I remember just before they flipped out, some of those people shouting, ‘I’ll get high. I’ll get high!’ which was a warning that they were losing control. All of us who lived in the institutions remember the screams of people who had got high and had to be restrained. Then there were some people who screamed or shouted for no reason. It was just a way of making it through the day.”*

Foster care, however, provided little respite from institutional abuse for Robert as he also experienced severe punishment in these settings. For example, attempts to stop his bedwetting and the consequences for other perceived misdemeanours were met by him being whipped with a jug cord. However, Robert also remembered witnessing his foster mother also being hit in the same manner by her husband, suggesting that he was placed by the State into a site of family violence.

Robert went on to explain how his foster parents responded to his bedwetting when the jug cord failed to make an impression: *“I was made to kneel on the wood pile, for two hours or more. It hurt so much. I knew I had to get away from that place, so one night I took off. I ran and then when I thought I was safe walked ... about five miles.”* (p.28).

Police found him asleep under sacking on another farm, and he was returned to the abusive situation from which he had tried to escape:

“The welfare came ... they took me back to my foster parents. I didn’t tell welfare what was going on. Back then I didn’t know how to talk to people. I was too scared. The man had told me that if I said what was happening to me, I’d be in worse trouble. So, I just stayed

quiet and waited and then when I got the chance ran away again. And again, until after a while the welfare got sick of coming up from Whanganui and they took me away from that place.” (p.29)

Robert’s life of moving in and out of institutions possibly played a part in his recognition that much of what happened in State care was not how life was outside the institution. For example, at Kimberley toilets adjoined day rooms, meaning that people would sit to defecate in full view of others passing by. In his biography, he remembers being embarrassed about this and uncomfortable with sharing dormitories and underclothing with many others. It was at Kimberley that he was first sexually abused:

“... I was caught stealing apples. The nurse took me to the office and while I stood there in fear, he took my file off the shelf and started reading out to me all the bad things I’d done. He lectured me about all the trouble I had caused in my life and then he put his hands down my pants and touched me. I didn’t know what was happening. All I knew was that I was bad and the man touching me was there to take care of me and must be allowed to do what he was doing.” (p.34)

Sexual abuse was also a feature of his life at Campbell Park. The first time he was placed there Robert reported that he had liked the school. However, when he returned, he was placed in a different cottage, with older boys, and this was where he experienced further abuse.

“I didn’t understand. I didn’t know anything about sex and so I didn’t know what was happening to me. I couldn’t understand how people could be so cruel and take advantage of someone who didn’t know what was going on.”

A brief time at home with his parents and a six month stay at Lake Alice separated his two periods at Campbell Park. Robert recalled his tenure at Lake Alice as “... *the worst time of my life.*” Initially he had freedom to move around the grounds and, in this way entertained himself in an environment where he otherwise felt like “... *a fish out of water*”. However, that freedom was quickly curtailed after he was caught shoplifting from the local store. He was then moved to a lock-up ward for about three months before being sent back to Campbell Park where, as detailed above, he was sexually abused again. This time the abuse was perpetrated by older peers rather than by staff. Robert remained at Campbell Park until he was 15 years of age.



No longer a State ward, Robert returned to his family’s home town, and started a life beyond State care and institutions. Although he wanted to continue his education, he was denied that opportunity on the basis of his learning difficulties and instead began a relationship with community-based disability support service IHC.

Years of institutions had seen Robert grow up without knowledge of the outside world. As he noted:

“I had spent my life locked away from the world and I knew nothing. I had grown up in New Zealand but had never heard of the All Blacks or Hillary, never known about the Olympics or the Vietnam war, the death of John Kennedy or Martin Luther King or the jailing of Nelson Mandela. I knew nothing of the British pop revolution. These were the things that had shaped my generation but I had to learn them backwards.”

As he did learn, he reflected:

“I knew that things were not right in my own life. At 15, I’d been freed from institutional life, but in many ways, I was no freer than I had been in Kimberley or Campbell Park. Even within IHC, people treated us with disdain. They treated us as though we were imbeciles, as though we didn’t have any value in society. That we were nothing people and they walked all over us.

I remember lying in my bed one night and thinking about why people like me were treated the way we were. And I can remember thinking it was them and us, and that I had no power because they had taken it. I started to believe that it was the people who claimed they cared about me the most who took my power.” (p.56).

Despite his traumatic early life Robert Martin (MNZM) has lived a remarkable adult life. Robert was the first person with a learning disability to speak at the United Nations, and more recently made history again in 2016 as the first person with a learning disability to be elected to the United Nations Committee on the Rights of Persons with Disabilities.

Avis’ story

Avis Hunter documented her 50 years of State care in her book *My Life* (Hunter, 1997) and later in a chapter contributed to an edited book (Hunter and Mirfin-Veitch, 2005).

Avis’ book, written in her own words, is based on her memories and her social welfare records. From her records, Avis discovered that she was just three months old when she was

put into foster care. She lived as part of that foster family until she was four or five years old, in Dunedin where she had been born. At the point that her foster family expressed an interest in adopting her, Avis' social worker advised them not to proceed with a formal adoption because of her seizures (Hunter & Mirfin-Veitch 2005, p. 85). This single act was the catalyst to half a century in and out of institutions, characterised by frequent moves between foster arrangements. As Avis relates:

“When I was about four or five years old I stopped living with the [foster family]. I was moved to Nelson. I can't remember the name of the hospital that I lived in ...I spent two years living in Nelson and when I was seven years old I was moved once more to Templeton Hospital in Christchurch.... I didn't like Templeton - I didn't make any friends there. I hated the staff. They used to tie me to my bed. The other kids were different to me altogether. ... I'd run away and cry by myself sometimes. It might have upset people if I'd cried in front of them - they might have hit me. (Hunter, 1997, p.3-4)

After a few years at Templeton, Avis was moved again, this time to Sunnyside Hospital in Christchurch. In her words ... *The best thing about Sunnyside was that I got to meet Connie. Connie was my friend. She was older than me and looked after me. ... I still got scared sometimes.” (Hunter, 1997, p.5)*

Institutional life was briefly interrupted by another form of State care: *“When I was eleven I shifted to another foster family.” (p.5)* The foster mother in this case had been a nurse at Sunnyside. Avis describes her time with the foster mother:

“She left work to have a baby. She already had two other children. They were both younger than me. I didn't know the children very well. I didn't know her husband very well either ... he wasn't home very often. I used to do a lot of work when I was at [foster mother's] place. I did the gardening, filled the coal buckets, picked fruit and fed the animals. I had to sleep in the sun-porch or wash-house every night. I hardly spoke to [foster mother]. I was too scared to break windows at her place. I would go to the toilet in the tub in the wash-house because I was too scared to ask her to let me out. She didn't always tell me off but she kept me working very hard. [Foster mother] didn't help me when I had fits, but when I would wake up I would have different clothes on. I spent a lot of time by myself.” (p. 6)

When the foster mother left Christchurch Avis moved back to Sunnyside for a short time

before moving to Dunedin and back into another foster family. That foster arrangement was short-lived and she moved for a time to the Elliot Street Receiving Home, which at the time was a Social Welfare home used to assess girls for placement. In Avis’s case, assessment resulted in being admitted to Seacliff Hospital. She describes her time there in the following way:

“At Seacliff, I was locked up a lot of the time. The staff used to give me paraffin to make me go to the toilet. That was really horrible. I used to wet my bed quite a lot. The staff would help me to change. I would get told off for wetting my bed. ...I used to play up a lot. I used to break windows and throw things around ... other patients would say I didn’t have the nerve ... I did these things to show them that I did have the nerve. ...The staff used to lock me up. Sometimes they would put me in a straightjacket. The nurses in hospital were often rough with you.” (p.11)

When she was 21, Avis moved to Cherry Farm, noting in her book *“Nothing much changed”*. She remained scared: *“I would often hide under the building until it was dark. When I came out I would be locked up as punishment.” (p.13)*

Memories of life in the institutions remained with Avis throughout her life. She recounted experiences of communal showers, **being frequently scared, screaming in an attempt to get comfort but instead, her behaviour being interpreted as naughtiness** (Hunter & Mirfin-Veitch, 2005).

While at Cherry Farm Avis became friends with Jack¹²: *“We were girlfriend and boyfriend.” (p. 15)*. At one stage they ran away together but were found the next day and *“Jack was locked up”*, while Avis was returned to Cherry Farm. Although she does not comment further in her autobiography, in the chapter that she co-authored with Mirfin-Veitch, she noted that she was, at times, scared of Jack (Hunter & Mirfin-Veitch, 2005). This fear appeared to relate to Avis being coerced into doing *“things” (p.90)* with Jack.

Avis remained in Cherry Farm until, at the age of 54, she moved into a community-based

¹² Jack is a pseudonym.



disability service in 1992 as part of the hospital’s deinstitutionalisation process.

Mavis’ story

Mavis May shared her story with her then social worker, Ruth Gerzon, which was subsequently published as the Foreword to Dick Sobsey’s (1994) seminal book “Violence and abuse in the lives of people with disabilities: The end of silent acceptance”.

Mavis was admitted to Templeton Hospital as a baby in 1929. She experienced multiple abuses in State care institutions over a thirty-year period:

“In hospitals you get abused: you get hit, and they make you a slave. When I was about 6 years old, I had to help. I never went to school. They wanted me for the work because I was so good at it.

Half the nurses wouldn’t do anything at all. They’d leave it to the patients. I had to help do the dishes and look after the crippled kids in chairs. ... we scrubbed the floor twice a week.

You didn’t get any money, that’s for sure. ... Staff told us when to get up and what to do. We didn’t have any choices.

Some nurses were very strict, and we didn’t get away with anything. They would hit us on the head with a wooden spoon.

Some staff were nice; some were good to me. They would give me cuddles and that. When I was hit, they knew. But they wouldn’t say anything. I would like the bad staff to get caught. The good staff should talk about it and put the others out.

The hardest thing for me was closed doors, locked doors. The staff had keys in their pockets on big chains. They had windows open only that much, so you couldn’t climb out.

We had a special room for when we were naughty. They called that room the naughty room. They shut us up. The door had three locks: one at the top, one in the centre and one at the bottom. We had to stay there all night.



I didn't have any clothes of my own, not even underclothes ... I would wear the ward stuff, the stuff from the store.”

At some point Mavis moved from Templeton to Levin (Kimberley). Her memories of Levin were that: *“It was worse ... the place was dirty. ... The kids had cradle cap in their heads. I had it too. You get sores all over your body, little kiddies too.*

When she was 26 her cousin found her, and arranged for Mavis to live with her, marking the end of her institutionalisation for a long period. However, nearly 30 years later when her cousin died, Mavis found herself in a vulnerable and abusive situation with the person that was supposed to be supporting her. That resulted in a “breakdown” and admission to Tokanui Hospital. There is no information about her time there, but, after a subsequent period of being in the community and then readmitted to a psychiatric ward, she was discharged into a home for the elderly.

Adding to the voices...

Though less detailed than the life histories shared above, the research team identified a number of other examples of frequent and serious abuse of people with learning disability in State care. These “snippets” of important narratives, found in a range of written or audio recorded formats, provide further evidence of the wide-spread neglect and abuse encountered by people with learning disability who were institutionalised between the 1950s and 1990s in New Zealand.

Restraint, being locked up, and being humiliated seem to be a common form of punishment for resisting institutional practices, or in some cases, when they tried to completely escape from State care. Wichmond, for example, described the loss of choice and control he experienced as a (reluctant) resident of Kingseat Hospital:

“I didn’t have any freedom - being locked in all the time - and this was the worst thing for me. It’s not living in a house, a house is different. It’s open and you can walk out of the house when you feel like it... They used to have a room with a bed on the floor. It had a cupboard and an open window, and a door below the window, and they used a key to get in. They always locked it at night. I was locked in a bedroom. ... I used to run away from Kingseat. Kingseat was horrible for me. I used to catch a bus up the road and ask the bus driver to drop me off at Manukau City. I used to sleep out in the community and it was scary. Then I’d get into trouble with the police. I was in a bad way, locked in all the time. That’s why I ran away. Kingseat wasn’t the right place for me.”

“They used to put you in pyjamas. That was a horrible thing. They used to have a square table by the kitchen that was the real bad table. If you run away, they put you in pyjamas and on the bad table. You had to stay in pyjamas all day while the others had their clothes on. You had to sit in one corner by yourself and you don’t have your friends around you” (Spectrum Care Trust Board, 2010, p.137-8).

Like Avis (whose story was recounted earlier in this section), Alison also spent half a century in State care. She remembered her time at both Kingseat (where she was as a child) and Carrington Hospitals as characterised by being:

“locked up for weeks... dragged down the corridor by staff by the feet and the hair and they throw me into a seclusion room. Carrington was a horrible place. They would ... throw you into an empty room ... slam the door and lock it and leave you there. You’d be freezing

cold, you had no clothes on, no toilet facilities, no bed, nothing. And you would be calling out for a drink of water and you'd end up drinking your own urine - that's how thirsty you were. The nurses used to look in and see what you were up to and if they saw you up to no good, they'd get reinforcements and ... come in with a couple of hypodermic needles ... and knock you out” (Alison, 50 Years under the system, 2015).

In *Extraordinary Journeys*, a book about people's experiences of deinstitutionalisation, (Spectrum Care Trust Board, 2010) Rodney described how he was pleased to move from Kimberley, where he had been living a long way from his family in Auckland, to St John's. However, in his new environment he struggled with the constraints, including chemical ones, that were put on him to stop him following up his interest in speedway. *“I didn't like the way the place was run. Not letting me go out to speedway and stock cars and the Easter Show on my own”* He would tend to wander off as a way to deal with being upset at these times but that resulted in him being *“... put under specialists. I think it was because of my behaviour.”* *“I got given the injection for trying to argue the toss and I wasn't, I had my rights. The injection was punishment and it made me feel all drowsy.”* (p.126)

Virginia's brief story (O'Brien, Thesing, & Capie, 1999) provides a further example of the way in which people were prevented from making their own choices. *“I had terrible times there. I was put in those time-out rooms, and in the naughty room. The attendants would come over and get me. When I wouldn't take the syrup they injected it into me, and would sit on me.”* Her mattress would be put on the “bare cold floor” Virginia attempted to leave but the staff would *“come and take me back”*. Asked why she wanted to leave: *“I didn't like how they treated me.”* (p.110).

Sexual abuse was a feature of almost everyone's story. Often sexual assaults were perpetuated by other patients or residents in the institution, and in some case by staff. Common to all stories was a sense that other people were aware of these assaults, and did nothing to stop them. Alison noted how the lack of appropriate supervision as a child at Kingseat saw her *“sexually assaulted at knife point by a male patient when she was aged 11. ... It was horrible what he did ... I reported him and they brought all these guys up the next day and I pointed him out.”* (Alison, 50 Years under the system, 2015)

Serious sexual assaults occurred for both men and women. Norman lived at Templeton for many years after being misdiagnosed as having a learning disability and spoke on the documentary “Out of Sight” of this as being a time when he was: *“beaten by staff and*

patients. Life there was hell.” He also described being: “sexually abused, ahh, sodomised, you know. I suppose you could say that it continued on - not just only me but I think a lot of other people too.”(Smyth, 2004). George also talked about life at Templeton: “A bugger at times ... hard times”. When asked what the bigger boys did to him: “going around sticking it up your backside. ... when you were a kiddie. ... they were all big boys and you were only a little midget.” In addition to this serious sexual abuse, Graham identified: “When I was 13, one of the big boys picked me up by the back of the collar, lift me off me feet, and punched me in the nose, on the side of the nose. And sort of made a bent. I went up to the nurse and told her that me nose was broken. And she said wouldn’t do nothing about it” (Smyth, 2004).

For Dick, who was deaf, other patients were a constant threat: *“I got belted up in Carrington Hospital by a patient. She kicked me in the leg until it bled. She took great big hunks off my leg and I had to go to physio every day to get it put under the lamp. It took a long time to heal. I got belted up by her and she wouldn’t leave me alone. I also used to get doped up in Carrington Hospital... I didn’t like living at Carrington, I always got belted up by the other patients because I was small. I slept in a bed in the ward with everybody.* (Spectrum Care Trust Board, 2010, p.61)

Even very brief accounts about institutional life, such as Vernon’s, emphasise rough treatment from both staff and other residents. In what seems likely to be an understatement he commented: *“it was sort of awkward for me there [Kingseat]... there was a nurse there that used to boss me around too much.”* (O’Brien et al., 1999, p.118)

Whilst most examples of abuse identified through this research occurred within the context of large institutions, Josie reflected similar experiences within foster care when she commented:

When I was two[...] I ended up in foster care. I went through eight families until I came to the one I wanted. I stayed four years until I was seven. I loved that place but they couldn’t keep me. They had three other children. They found out I had a disability and that was it. Then I kept moving to different families. I was raped too. I was devastated. At fifteen, they couldn’t control me. If I said something, I’d get slapped. So, I stopped talking. I was put in an institution in Whanganui. (People First, 2007)

In addition to the physical, emotional and sexual abuse, Alison’s experience of being

expected to work while in the institution is familiar to others from a similar time: *“I used to have very heavy electric [floor polishers] - commercial ones - same with big commercial vacuum cleaners. I used to have to push heavy wardrobes, hurt my back, my wrists ...”* (Alison, 50 Years Under the System, 2015).

People were also deprived of basic supports, as Dick noted: *“I could hardly hear anybody talking to me in Carrington - I didn’t have hearing aids then and I was deaf. I couldn’t hear (my friend) ... talking to me.”* (Spectrum Care Trust Board, 2010, p.61).

For those who knew something about life outside State care like Robert, they were ashamed to admit to others details of institutional life that they perceived as degrading, such as being forced to share clothes. When Angela moved out of Templeton, she was “fascinated” by her locker. *“Something of my own. I had storage for my own clothes beside me - and CHOICE in wearing.* It took a long time for this sudden mind switch to work through fully - *even to this day”...* The defining attributes of Templeton and Burwood were, to Angela, *“places where everything (was) done for you”*. For her too, the culture of having everything done was sustained by competence denied. Angela repeatedly recounted that her primary frustration at Templeton and Burwood was *“when people did not or would not understand what I had to say.”* Like Robert, Angela concluded that, *“so much decision making had gone on for me for so many years that I became trapped inside of a passive mind.”* (Griffin and Milner, 2012, p.12).

“...to this day cannot remember the names of my abusers!”:

[Looking more critically at the categories of abuse disabled people experienced](#)

While the stories and accounts above have spoken, unequivocally, of the breadth and depth of the shared experience of abuse in institutional and other State care settings, it is important to explore more closely the particular categories or types of abuse that were evidenced within the data. As noted earlier in this report, the data collected as part of this research were coded and analysed with reference to the abuse subtypes: neglect; physical; sexual; psychological (emotional); control and restraint; spiritual; financial; and systemic. These subtypes are defined in Appendix 3. However, we note that it is well established that definitions of specific types of abuse can vary, but the underlying concepts remain constant.

It is important to acknowledge that the way that we have labelled people’s abuse in this section is somewhat arbitrary. We fully recognise that many of the incidences and examples we have used to evidence a particular subcategory of abuse could equally be interpreted as illustrating a different subcategory. The inter-relationship between different types of abuse means it is difficult to ascribe a particular action or event as evidencing only one type of abuse. Indeed, as can be seen here, a single action of restraint for example, could be described as neglect, and emotional/ psychological, and physical abuse.

“And she said wouldn’t do nothing about it”:

Neglect

Within this research, we found that neglect featured more frequently across the different life stories in comparison to any other form of abuse. Arguably, being in State care could be read as synonymous with neglect due to the fact that even if people were not being overtly abused, they were generally exposed to an extremely impoverished relational environment. That is, they felt as though no one cared about them. Neglect is also evidenced through the acute lack of stimulation and purposeful activity within State care facilities, such as institutions. When talking about his peers at Kimberley Centre who were non-verbal and had significant physical impairment, Robert explained: *“People were so bored. There was nothing for them to do”* (McRae, 2014). Robert reflected that at Kimberley **it was common for people to have nothing purposeful to do and commented on the distress that created, especially on rainy days. “In the day room, when it was too wet to go out, people would sit and wait. Some would rock back and forth to comfort themselves”** (McRae, 2014).¹³

Other experiences of neglect could be seen in the lack of emotional support and connection, particularly at times of distress. As Avis recounted in her story, throughout her half a century in State care she continued to feel (and express) a chronic level of distress in institutions and described that she almost never received emotional support for this distress, even when she was particularly upset (Hunter & Mirfin-Veitch, 2005). At the time, Avis attempted to deal with her fears by running away and hiding. Rather than staff being attuned and

¹³ These observations of the lived experience of Kimberley were reconfirmed thirty years later through research on the deinstitutionalisation of Kimberley Centre that also found that adult residents with learning disability were subjected to “purposeless days, few communicative events, and instructive interactions” (Milner et al, 2008).

responsive to these emotional needs (and the way she tried to manage them), she was punished for what was read as challenging and non-compliant behaviour.

Robert also described this severe emotional neglect as being a feature of the “care” he was met with at Kimberley Centre; in fact, the absence of emotional support was central to all his State care experiences. Robert continues to feel the **effects** of this neglect today.

“I howled and howled. No one could console me. But then there wasn’t much of that. Don’t get me wrong, we were taken care of, fed and changed. But I don’t remember being touched and cuddled like other kids are. I was never loved as a child. Me and all those other kids... Even today I find it hard to show affection to other people. I don’t trust easily.”
(McRae, 2014)

Similarly, Avis summarised her life in State care (institutions and foster care) with a sense of loss, of having missed out on positive and enduring relationships with people and places that could have given her a sense of “home”. After her years of institutional living, it was once Avis moved into the community that friends assisted her with her goal to find her family. She describes the news that her siblings had been found as *“the best news of my life”* (Hunter, 1997, p. 21). With a brother and sisters pleased to meet her, she suddenly found herself with an extended family, although her joy was somewhat tempered by the realisation of what she had missed out on.

In these experiences, the absence of emotional connectedness and comfort was apparent and had long term social and emotional consequences for many people.

Other experiences of neglect exemplified a departure from a standard of care that could be reasonably expected in a facility of care. Robert, for example, described circumstances where people were afforded no attention for long intervals, despite the fact that some individuals were highly (or completely) dependent on others to provide their basic needs.

He recalled the smell of people who needed assistance to go to the bathroom and were not provided it. He said: *“There were people who couldn’t move and they would just stay where they had been left in the morning after breakfast. Most of those people were non-verbal and were trapped until someone got around to attending to them”* (McRae, 2014).

The shocking description of drinking her own urine due to thirst recounted by Alison earlier in this section is evidence of her being deprived of the basic necessities; in her case, while

being punished. Alison also described being “freezing”, and the experience of often being cold was a consistent theme in the life stories of others too. Avis resorted to extreme means of warding off the cold in the absence of other options. She said: *“Sometimes I’d hide under the mattress in the cold weather - wintertime. I’d also hide under the building because I knew that was a really warm place. The hot pipes would keep me warm”* (Hunter, 1997, p. 12).

These experiences illustrate how the provision of care in institutions was often inadequate at meeting people’s needs for hydration, food, warmth, and access to personal care and other assistance.

Another little considered aspect of life in State care, was that of being forced to work, or as Mavis stated: *“they make you a slave”* (Sobsey, 1994, p. vii). This emerged as a theme within the evidence collected as part of this research. The experience of being forced to undertake manual labour, both in institutions and foster homes, featured quite heavily in people’s stories. Alison described the immediate and long term injuries she suffered as a result of the heavy lifting she was forced to do, and similarly, Avis described her time as an *“unpaid labourer”* for her foster family. It is important to note that Avis’ foster mother was also a staff member of the institution she had been living in at the time, thus suggesting an abuse of power of a different kind.

The pervasive presence of neglect can also be seen in the failure of the State to provide assistance for pain and injury. Graham described being dismissed when he needed medical attention for his broken nose: *“...sort of made a bent. I went up to the nurse and told her that me nose was broken. And she said wouldn’t do nothing about it”* (Smythe, 2004). In addition to experiences of disregard for physical safety, or lack of medical attention, people routinely experienced total disregard for their psychological safety. David and John, whose stories were told at the beginning of this section, both recalled the abject terror that was the result of being thrown into a swimming pool by staff members when they were children (Spectrum Trust Board, 2010). Their fear was understandable given that not only could they not swim, they also could not see.

All of these examples of neglect evidence both a disregard for the person “in the moment”, and for the long-term impact of such experiences their wellbeing.

“...I wake up scared that I am still there”:

Emotional and psychological abuse

The life stories and other sources of data analysed within this research conveyed a sense of deep fear, hostility, and distress - strong indicators of emotional and psychological abuse. People with learning disability expressed their own feelings of this nature, but because they observed the abuse of their peers, they also interpreted some of their behaviours as being a tangible expression of their distress. Reflecting on his peers at Kimberley Centre, Robert said: *“Sometimes people hit themselves, banging their heads against the wall or picking at their skin until they bled. Biting, too, would puncture the skin. Physical pain could mask the pain in your head.”* (McRae, 2014).

Robert linked the self-injuring of some of his peers with the psychological pain he, and he assumed others felt about being caught in the negative and hostile environment of the “dayroom”. John, also described the sense of feeling unsafe at dinner time, perceiving that staff made mealtimes threatening and intimidating. And although Avis did not refer to specific experiences, she repeatedly conveyed that she felt acutely unsafe in the landscape of institutions and institutional life: *“I just moved from one hospital to another... Just like at the other hospitals I was often scared. I would hide under the building until it was dark”* (Hunter, 1997, p.13).

Her experiences of fear while living in institutions had effects that extended into her later life post-institutionalisation. She conveyed how she re-lived the trauma of her feelings and experiences while in State care through her dreams: *“Sometimes I dream about the hospitals I have been in. It can happen any time. When I dream about those places the dreams always wake me up. They are bad dreams. I wake up scared that I am still there.”* (Hunter, 1997, p.12). Further, in describing the physical labour her foster parent would designate her, she said: *“...hardly spoke to [Foster Parent] I would go to the toilet in the tub in the wash-house because I was too scared to ask her to let me out. She didn’t always tell me off but she kept me working very hard.”* (p. 6).

Similarly, Josie expressed feeling alone and hurt in her foster families and subsequently misunderstood when people later *“couldn’t control me”* (People First, 2007). Drawing the link between how her experiences shaped her behaviour, she commented that in foster care: *“If I said something, I’d get slapped. So, I stopped talking”* (People First, 2007). Both

Josie and Avis' experiences highlighted the feeling of being unsafe from people (in positions of power) who could hurt them if they did not comply with their rules and expectations.

Two people in particular described experiencing the disempowering emotional and psychological effects of having choice denied to them in institutions. As we saw Robert explaining earlier in this section, Angela also noted the psychological and emotional impacts of being seen as incompetent: *“We were seen as incapable of making responsible decisions, so others took over the right.... I have often thought about how I became disempowered. I believe it was the people who claimed they cared about me that most took my power away. When others take over your life, they strip your power from you. You lose confidence. You get used to others deciding everything for you”* (Griffin & Milner, 2012).

The sense of being trapped and disempowered was described by George, who had lived at Templeton for a *“whole lifetime”* since he was a child (Smyth, 2004). George expressed that he had no means of leaving or doing anything about the hardships he had faced in institutions, *“you couldn't do nothing.”* He described his life as: *“a bugger at times... hard times in life”* but reflects on it overall as an experience that makes him angry: *“Oh god, get mad - get mad sometimes I do.”*

The song lyrics included at the beginning of this section were composed by people with learning disability while they were living at Seacliff Lunatic Asylum. Displaying both resilience and resistance, residents made up songs that reflected their experiences of the culture of the institution. The memories and feelings remained strong, and many years after leaving this institution, and now living in disability services in the community, people who had shared this experience came together to record these old songs in acknowledgement of the experiences they had shared.

“What a place of misery.

There's a sign post around the corner saying ‘welcome unto thee’.

Don't believe it, don't believe it.

Coz it's all a pack of lies.” (“Remembrance,” n.d.).

Inherent to the song are sentiments that express misery and an acute sense of mistrust. Working from an understanding that abuse is the overt representation of an imbalance of power relations, Saxton (2009) expressed concern about the impact of people *internalising*

messages of invalidation and powerlessness. It is clear from the evidence presented here that many people who were reliant on State care experienced large and small assaults to their self-esteem and sense of self-worth on a daily basis. Such psychological assaults were not easily shed as people left State care facilities, instead, as shown here people have carried the emotional impacts long after leaving their particular site(s) of abuse.

“I didn’t have any freedom”:

Control and restraint

A common theme in people’s narratives was distress associated with being confined; to the institution itself, within their bedrooms, or to specially constructed seclusion rooms. While such practice could be considered to fall into the abuse categories of psychological and physical abuse, we viewed these practices of control and restraint as comprising such a significant component of data that we analysed it as a separate and distinct form of abuse.

John, for example described himself as feeling trapped in Kingseat Hospital generally, but also of being confined to specific rooms within it: *“Kingseat Hospital was a solid metal place where you couldn’t get out. Some locations, you used to get locked up”* (Spectrum Care Trust Board, 2010, p.89).

Similarly, David described the overwhelming oppression of constantly being confined in St John: *“... the doors used to get locked. I didn’t like that. We were locked in at night too. I just had to leave it, that’s all”* (Spectrum Care Trust Board, 2010, p.36).

For some people, being locked up was almost unbearable. As Wichmond’s comments illustrated: *“At Kingseat, I didn’t have any freedom - being locked in all the time - and this was the worst thing for me... They always locked it at night. I was locked in a bedroom”* (Spectrum Care Trust Board, 2010, 135). Avis also interpreted her frequent experiences of confinement, including being confined to her bed, as abusive. *“I didn’t like Templeton... I hated the staff - they used to tie me to my bed.”* (Hunter, 1997, p.4).

In addition to noting the physical confinement to particular rooms and spaces, people also reflected on the highly regulated and regimented spaces and activities within institution, like David who said: *“Staff came and told us all when to get up and have a shower and*

shave and have breakfast... You weren't allowed to go into the dining room unless you were told. I used to stay in the wing all day” (Spectrum Care Trust Board, 2010, p.39).

Others described the process of establishing and enforcing routine and the physical confinement as excessively harsh. John witnessed such control and restraint and expressed concern about how this impacted on his peers: *“They (other patients) ... used to get stroppy... “Then one of the other staff members caught one of them and locked him in his room for about four days of the week... This young patient... The poor guy used to get locked up and they used to throw away the keys...” (Spectrum Care Trust Board, 2010, p.91).*

Alison echoed the perception of institutions as sites of excessive confinement when she reflected on her time at Carrington Hospital: *“It was a horrible place. They had this fashion of locking people up. They had shutters they could lock over the window. They'd throw you in an empty room as big as that, slam the door and lock it and leave you there.” (Alison, 50 years under the system, 2015).*

Wichmond provided additional evidence of control and (psychological) restraint created by staff restricting the space he was authorised to be in, embarrassing him by “outing” his behaviour, and restricting his ability to interact with his friends:

“They used to put you in pyjamas. That was a horrible thing. They used to have a square table by the kitchen that was the real bad table. If you run away, they put you in pyjamas and on the bad table.” You had to stay in pyjamas all day while the others had their clothes on. You had to sit in one corner by yourself and you don't have your friends around you.” (Spectrum Care Trust Board, 2010, p.138).

Overall, a common theme in the feelings communicated was the sense of being trapped in State care, and confined and restricted on a daily basis in a manner that people perceived as hurtful, excessive and humiliating.

“The boys were belting me up”:



Physical abuse

As previously mentioned, abuse categories overlap and are interrelated, including that of physical abuse. Many of the examples of neglect cited earlier in this section could also be examples of physical abuse. As noted earlier, both John and David focused on the psychological impact of being thrown in a swimming pool when they were unable to swim (Spectrum Trust Board, 2010), however this equally could be seen as physical abuse. Similarly, the act of being locked in a room, put in seclusion or strapped to a bed, evidence of abusive control and restraint practices could also be interpreted as examples of physical abuse.

Within the body of evidence collected for the purposes of this research, a key finding was that children and adults in State care were physically abused by both peers and staff members. Dick, who was Deaf, described being beaten by his peers frequently and severely while in a boys home: “...*the boys were belting me up. One of them was always hitting me every time I made a cup of coffee.*” (Spectrum Care Trust Board, 2010, p.63). As noted in an aspect of his story presented earlier, he was also physically assaulted on a regular basis by a peer at Carrington Hospital. Many other stories included reference to physical abuse and assaults by staff and patients. When talking about his experiences of Kimberley Centre, Robert described an excessive response to an accident with a ball: “*I tried to bounce it over... the villa but I hit the... light window. A [staff member] caught me and he kicked my ass from the time he caught me to the time I got to my own villa.*” (Robert Martin: The People’s Advocate, 2014). Alison also talked about receiving rough physical treatment as punishment, commenting that she: “*Used to get dragged down the corridor by staff by the feet and the hair...*” (Alison, 50 years under the system, 2015)

“Best just keep quiet and hope it wouldn’t happen again”:

Sexual Abuse

In keeping with the Crimes Act (1961) and more contemporary definitions, we defined sexual abuse as any form of sexual contact that was not consensual, or any form of sexual contact that happens with and to children. Both of these elements of the definition were identified within the personal accounts we explored. We found that both children and adults were sexually assaulted. We also found that the assaults occurred in large institutions, residential

schools, and within the “family homes” of their foster carers. While sexual abuse was frequently divulged within the narratives that informed this research, understandably, it was often only touched on briefly in people’s stories. This is likely to be because many of the resources that included relevant evidence were not designed, methodologically or ethically, to respond to disclosures of abuse. That said, it is clear from the evidence that is available, that sexual violence may well have been a seemingly inescapable and unchallenged reality for a significant number of both boys and girls, and men and women in State care. Some of the narratives drawn on included graphic experience of the person’s abuse, including when it happened, where it happened, and who the perpetrator was.

As described earlier when in Kingseat Hospital Alison, at the age of 11, was sexually assaulted at knife point by an older peer. Despite being able to “*point him out*”, there was no indication within Alison’s story that the perpetrator was punished, kept away from her, or that she received any psychological support for the sexual violence she experienced. Similarly, and also shockingly, George’s rape by older peers appeared to go unchallenged (Smyth, 2004).

Norman, who was assumed to have a learning disability and lived at Templeton Centre for many years, before being assessed as having been misdiagnosed, described being sodomised by a staff member at Templeton. He stated that he was abused multiple times by staff and peers while he was there (Smyth, 2004).

One man recounted his experience of sexual abuse at a residential school via personal communication with the researchers, on the condition that his identity remained anonymous. His enrolment at the residential school, which although privately run, was acting as an agent of the state, was intended by his parents to be a positive educational opportunity for him. Unfortunately, instead of receiving an education he was sexually abused. The following is a description of the abuse in his own words.

“In 1978, in the old building (before it was knocked down) a boy took me into the old gymnasium and showed me a room in the gym.

From what I remember of this room, it was quite dark inside and there was no front door. There was a floor, which had iron bars across it, and at the end of the floor there was a tunnel and old brick walls plus an old back door, which had a small glass window.

I was standing against a brick wall when I was first sexually abused. Soon after that my class went on a South Island tour, and in one place we stayed in a motel with two boys to a room. I wanted to share with some other boy but it was not to be, and I had to share with that boy. He sexually abused me again that night and when we got back to school he abused me in the showers and used to interfere with other boys, too.”

The man described having kept his abuse a secret for many years: *“After we boys left our residential school we had a secret we could not tell our parents or anyone else, either. Until 2002, when someone finally told, we boys had lived in fear for many years. Knowing the secret we had all carried for so long, I well remember having a rest in my flat and listening to Talkback 2ZB and hearing people who had been abused at my school talking about it.”*

Robert also described experiencing sexual abuse from both staff and his peers at Campbell Park School (McRae, 2014). He and his biographer, McRae, described the sexual abuse as being part of a pattern of sexual violence perpetrated by older peers and reinforced by staff in a culture of mutually-reinforcing violence. He also experienced sexual violence perpetrated by staff at the Kimberley Centre. Robert’s experiences in State care facilities like these resulted in long-lasting negative self-image including feeling *“dirty and worthless”* and psychological impacts such as having difficulty trusting and feeling safe with people. Robert noted that his abuse occurred in a vacuum of understanding or knowledge about sex or sexual violence, thus rendering people doubly compromised.

Robert’s story also highlighted the re-victimisation that occurred for some people, not just through repeated assaults, but also through silencing: *“Best just keep quiet and hope it wouldn’t happen again. But it did.”* Robert’s views on people being silenced are echoed in a judgement relating to legal proceedings taken by a man with learning disability who had resided in a St John of God facility in Nelson, and later in Ngawahatu Psychiatric Hospital.

The judgement evidences that this complainant felt his voice was devalued by staff, thus leading to the dismissal of his complaints within State care and his subsequent re-victimisation. To this end the judgement read:

“Despite the complaint, the plaintiff says that sexual acts continued to be forced upon him by that, and another, nurse for several months... The plaintiff says that he did not complain

to other staff because he thought it would be dismissed and he was scared of what could happen... He says that he did not report the events [of witnessing sexual assaults on others] because he was scared of the consequences of the Charge Nurse not believing him.” (Knight v Crown Health Financing Agency, 2007).

Recurring experiences of sexual violence was a common theme. Some people were able to clearly identify their abuser(s). Others used more global terms like “the boys”, or the “bigger boys”, or staff, which may be indicative that the person did not know the person by name, not necessarily that they could not identify them. Roly, for example did not identify who his abusers were but highlighted that this sort of abuse happened for him in Tokonui “*Very much*” (People First New Zealand, 2010). Similarly, the individual involved in the case Knight vs Crown Health Financing Agency expressed during his case that sexual abuse was prevalent both with regard to other patients and himself while he resided in State care at Saint John of God in Nelson and Ngawhatu Psychiatric Hospital (Knight v Crown Health Financing Agency, 2007). With particular reference to Ngawhatu, he disclosed having witnessed or experienced sexual abuse in bathrooms and bedrooms but also in the grounds surrounding the hospital. It would be reasonable to suggest that other individuals would have also been repeatedly exposed to sexual violence in State care, and that this would result in lasting psychological impacts.

I spent my life locked away from the world and I knew nothing:

Spiritual abuse

Spiritual violence in the form of denial of culture featured in Haki’s experiences of State care as told to a researcher exploring deinstitutionalisation (O’Brien, 2005). Haki’s experiences in Kingseat and other institutions conveyed a sense of loss with regard to being disconnected from his culture since he was a child. The State care facilities in which he was placed were both Pākehā-centric and lacked cultural competence for Māori and iwi tangata. O’Brien (2005) tells the story of Haki who was denied access to his culture as a Māori man, and more specifically to his iwi Ngāpuhi while in State care. Connecting with his ethnicity and his iwi was essential to his process of healing and achieving wellbeing. O’Brien described that having the opportunity to reconnect with Ngāpuhi tikanga, Reo, turangawāewāe, and whanaungatanga were essential components to Haki developing a sense of his place in the

world or locality. Similarly, John’s Pasifika heritage was ignored once he entered State care, (Spectrum Trust Board, 2010) and Robert recognised a broader disconnection from New Zealand and world culture and critical historical events (McCrae, 2014). Spiritual abuse could also be seen in the denial of interests and passions, for example Rodney being actively prevented from giving expression to his passionate interest in the speedway (Spectrum Trust Board, 2010).

“They make you a slave...”:

Financial abuse

Only a few people directly referred to their financial or material deprivation, however the fact that people experienced a significant lack of education or support to develop the skills required for meaningful employment could be seen as evidence of long-term financial abuse. It could also be seen in people being denied the opportunity to have possessions or to enjoy the money they potentially could have earned, if their forced labour both in institutions, and in State sanctioned foster-care had been recognised. Mavis’ story highlights how financial abuse, including obstruction from having schooling and participation in money management, featured in her life while at Templeton Hospital: *“they make you a slave. When I was about 6 years old, I had to help. I never went to school. They wanted me for the work because I was so good at it... You didn’t get any money, that’s for sure. We didn’t get any money.”* (Sobsey, 1994, p.vii).

In another example, Robert recounted how staff members or peers would steal possessions at the Kimberley Centre. His co-narrator detailed the experience: *“Once he had owned a treasured thing. It was a watch his dad had given him. The watch had belonged to Robert’s grandfather... But it didn’t last long. Robert says that if a staff member hadn’t stolen it, another resident had. Staff were adept at taking things and keeping them safe for you. You were unlikely to ever see the object again.”* (McCrae, 2014, p.30)

Robert’s life story highlights how he was denied the opportunity to have treasured things because there were no means of keeping things safe and because there was a culture of stealing amongst both peers who also had little, as well as staff. These experiences resonated with Mavis’ experiences, who also found herself with little opportunity to own

items: “*I didn’t have any clothes of my own, not even underclothes. I didn’t have anything of my own*” (Sobsey, 1994, p.viii).

In addition, Avis described how she was denied opportunities to get a job and, subsequently, have greater opportunity to make financial decisions. Of particular concern to her was that she was not able to buy her own clothes while she was living in institutions (Hunter & Mirfin-Veitch, 2005).

“The Kimberley cringe, that’s what they call it...”: Third party accounts

Previous research (for example, Gates, Stewart, Milner, Mirfin-Veitch, & Schumayer, 2008; Milner, Gates, Mirfin-Veitch, & Stewart, 2008; O’Brien et al., 1999) eyewitness accounts and reviews (for example, Askew, 1986; Broad, 2013; Henwood, 2015); document significant examples of neglect and abuse of people with disabilities in State care. Eyewitness accounts from relatives who visited their family member in the institutions accompany some of the above stories. Often a close relative or friend spoke for those without independent means of communication, as occurred in the writing of *Extraordinary Journeys* (Spectrum Care Trust Board, 2010). Other eyewitness accounts are from researchers’ observations and staff reports. Evidence from these sources was included in this research as a way of providing additional support for the personal testimonies provided by people with learning disability themselves.

Most notably, the process of deinstitutionalisation has provided an opportunity for both staff and families to talk about the neglect and abuse that they witnessed in the various institutions. Within the New Zealand research that has explored the process of institutional closure, staff members testified that abuse was an issue at the Kimberley Centre, and they had witnessed abusive practice or actions themselves. For example, staff members from Kimberley Centre told researchers:

“See I have been here over ten years all up and these people were brought up in fear here and I have seen that.”¹⁴ They were brought up in fear, when you look at things that went on

¹⁴ The staff quoted in this section were largely employed at Kimberley Centre during the 1990’s to its closure. Their quotes have been included to illustrate two important points: (1) that abuse was occurring in the institution beyond the focus period of this research (1950 - 1992); and (2) that the physical fear exhibited by residents and observed by staff, labelled as the “Kimberley Cringe”, was understood to be the result of a long-term pattern of abuse within the institution. It is acknowledged

in this place, it was horrific. They were cruel, they were very cruel people. We had men out in the court yard here, do you know how they got showered? With the fire hoses. And they used to get beaten. If you rush up to one of these people quickly, they will cower and that's when they have had hidings at a very, very young age. The Kimberley Cringe. That's what they call it.” (Milner et al., 2008) (p.185)

For caring staff, the unresponsiveness of the institution to abuses they witnessed placed them in an unenviable ethical position as the following quotes illustrate:

“They say when you go for a job here and you see a resident getting hit or anything like that, don't hesitate, get in touch with management, we will sort it out, no problem, but it's not as easy as that.” (Gates et al., 2008)(p.44)

“There are staff that shouldn't be there ... they talk nasty to the residents, they are rude to the residents, they are rude to the staff that they work with ... and the way they speak to them [residents] it is almost abuse, well it is abuse” (Gates et al., 2008)(p.35)

“I have seen residents hit, I have seen residents sworn [at] and treated like shit.” (Gates et al., 2008)(p.35).

This abusive treatment, and the resultant fear it provoked in Kimberley residents, (the Kimberley Cringe) was noted by Brian Box's sister who reported:

“When I went to visit Brian, I would sometimes pat his hand and he would have an odd look on his face. I asked a staff member what they thought was wrong and they said “Brian thinks you're disciplining or hurting him.” It made me cry because I was just patting his hand and he was showing fear. He must have thought I was disciplining him and that really hurt me. I cuddled him. He had tears and I had tears. Brian didn't understand that patting his hand was a good thing, not a bad thing.” (Spectrum Care Trust Board, 2010) (p. 25).

Following the deinstitutionalisation of people from Kingseat, O'Brien asked people about their experience in the institution (O'Brien et al., 1999). The majority preferred to remember the better times, but staff working in their community disability service added

that both staff and residents may have been involved in the abusive practice or actions that led to the development of the Kimberley Cringe.

examples of abuse and neglect that the person had disclosed to them, such as for Simon:

“Staff said that they had been told by him that he remembered that he used to get a lot of shock treatment while in the hospital. It happened every time he did something wrong, that he would go to the room where he got shock treatments.” (p. 94)

Natalie’s sister recalled visiting Natalie at Kingseat: *“I hated all the locked doors, and they were just sitting inside looking into space, and there were screaming people around the place... I’ve got nothing good to say about Kingseat.”*

When asked about Natalie’s health she went on to say: *“How could you tell, she was over medicated?” (O’Brien et al., 1999) (p.124)*

In summarising the memories of nine people, which were presented as case studies, O’Brien et. al. (1999) noted that they: *“...were strongly influenced by punishments, such as being hit, use of side rooms, shock treatment, being injected for behaviour control and sleeping on mattresses on the floor.” (p.136)*

This small amount of third person testimony aligns with the evidence provided by people with learning disability themselves. Those who observed State care of people with learning disability as staff, whanau, or researchers described people as exhibiting fear and reported that the use of chemical restraint as punishment and isolation in “side rooms” was common. Perhaps most tellingly, some staff reported a difficulty in recognising and reporting abuse and having it appropriately responded to by management.

Also supporting the individual stories presented in this report are the findings of a Ministry of Health review of psychiatric and psychopaedic hospitals undertaken in 1984 and 1985 (Askew et al, 1986). In that report, Askew described the conditions for seclusion as “Dickensian” despite institutional reform that occurred through the 1970’s and 1980’s that included improving people’s right to privacy. Some staff in the institutions reporting to the review team that “the ‘time-out’ boxes and cupboards in some wards for the intellectually handicapped” (p.7) were used more for punishment than any therapeutic effect, which was deemed to be appropriate practice for modifying behaviour at the time. Furthermore, they found “deficiencies in dignity and in the basic elements of appropriate care” (Askew et al., 1986, p. 8), commenting, for example, that some units in psychopedic hospitals had “toilets of a bench type nature and communal showers” (p.17).

Recognising the importance of cultural appropriateness for psychiatric care, the review team further identified “a widespread lack of formal recognition of cultural needs in many aspects of patient care” (Askew et al., 1986, p. 10). Although reviewers visited all New Zealand psychiatric and psychopaedic hospitals, it is interesting to note that findings related to the treatment of people with a learning disability who were placed in psychopaedic hospitals do not feature in Askew et al’s report findings. Taken together, however, it is reasonable to assume the deprivations they detailed were pervasive across State institutions. What they saw led Askew et al to conclude that “*Staff shortages and low morale seriously affect patient care and the availability of alternative methods of treatment, and lead to lack of awareness and general acceptance of substandard conditions*” (Askew et al., 1986, p. 11). It could be argued that this review, conducted in the 1980’s, has long provided the “evidence” that neglect and abuse in State care did occur, and that policies governing practices relating to control and restraint were not being appropriately applied.

Was the abuse experienced by disabled people including those with learning disability in State care institutional abuse?

In 1994, eminent disability researcher Dick Sobsey defined institutional abuse as the *neglectful, psychological, physical or sexual abuse that takes place in managed institutional care of human beings*. He identified the key features of institutional abuse as:

- extreme power relations between residents and staff;
- collective nature of the abuse;
- abuse is covered up or knowledge of it is not shared outside of the institution,
- and clearly defined patterns of environmental influence (pp. 90-93).

The policy of deinstitutionalisation that (slowly) led to the closure of large-scale State care facilities in Aotearoa New Zealand, was seeded by a plethora of largely international, but also some New Zealand, reviews and reports conducted in the 1960’s, 70’s and 80’s that exposed the prevalence and severity of abuse being perpetrated against people in institutional environments (for example Askew 1986). We have no reason at all to expect that State care facilities and institutions in this country were not also the sites of such abuse. In fact, the evidence presented here, based on the published experiences, memories and reflections of disabled people show very clearly that abuse was an everyday reality for this group of vulnerable individuals.

Was the abuse experienced by disabled people including those with learning disability in State care systemic abuse?

Throughout this report we have detailed the diverse ways in which 18 men and women with the courage to tell their personal stories were abused in State care. Their stories, regardless of age, ethnicity, gender or the type of State care are remarkably similar. It was common for people to be abused throughout life, and for them to be exposed to all types of abuse causing both psychological and physical distress. Many of the participants described long term impacts as a result of their abuse. Given this evidence, it is important to consider whether their abuse could be defined as systemic. Systemic abuse is defined by Robinson (2013) as having causal roots that are located in organisational systems or policy, despite sometimes being perpetrated by a person. In this definition, abuse cannot be categorised as systemic due to prevalence alone; instead the abuse must be attributable to system-level factors or failures that have worked actively or passively to enable or facilitate abuse under the particular system. That is, systemic abuse takes us beyond the notion of “bad things being done by bad people” independent of the system, to a recognition that the system has operated in ways that has both provided the opportunity for abuse to occur, or for it to continue unchallenged.

At a fundamental level and as previously mentioned, researchers such as Sobsey (1994) have posited that institutions are inherently abusive. This would be a view shared by the disabled people whose stories informed this research. The long term, acute pain created by being separated from family was central to everyone’s story. For a range of reasons, including a lack of formal support for families, disabled children experienced the trauma of being dislocated from their families at a very young age.

No effort appears to have been made by the State to ensure that they were able to form safe, healthy and positive emotional attachment, despite growing awareness of attachment theory, which had its antecedents in Bowlby’s (1944) academic paper. Not having someone to love, or to love them, had a powerful, negative impact on the psychological wellbeing of disabled people in State care. Although not within the scope of this research, it is well recognised that even families who were positively connected with their disabled children were frequently told not to visit their children after they had entered State care (Mirfin-Veitch, 2005, Milner et al, 2008). This could be seen as a purposeful interruption of

attachment by the State, and one that had significant and distressing long term impacts on both disabled people and their families.

It could also be argued that the widespread and pervasive abuse seen in the individual stories drawn on for the purposes of this research had its roots in other organisational and policy level failures. At another very obvious level, a repeated refrain in the stories (and confirmed in some of the presented third party evidence) was that those in power knew individuals had been abused but did nothing to stop or address it. Furthermore, these same individual's almost without exception noted that they knew their peers were being assaulted but that they felt they were unable to call it to the attention to anyone with the power to stop it. Some went as far as to say they knew nothing would be done anyway.

Throughout this report, personal accounts have detailed a range of system failures, including:

- Neglect in the form of people not having their basic needs met, possibly due to under staffing or inadequate training;
- Indications of institution wide failure to attend to the emotional and psychological development of children due to understaffing, inadequate training or an abusive culture;
- The use of control and restraint practices, whether environmental, physical or chemical for reasons of punishment rather than for therapeutic purposes;
- Repeated exposure to physical violence, resultant injuries being left untreated, and no meaningful attempt being made to stop the assaults;
- Being repeatedly sexually abused, or exposed to sexual violence in the absence of any ability to achieve meaningful redress in the form of a person being held to account, or counselling for psychological trauma;
- A State care system that allowed staff and foster carers to repeatedly abuse children and adults.

This cannot be interpreted as anything other than systemic abuse; a system that worked to enable abuse to continue unchecked. However, because the evidence on record about the experiences of abuse has largely been collected as part of research with an alternative focus, both in terms of the nature of the data collected and the way it has been and is (able to be) analysed, there is still a need for further comprehensive exploration. To ensure we learn from our mistakes of the past, we need to examine the context in which the abuse occurred, and the policies, processes and procedures that were or were not in place to assess the likelihood of similar abuses permeating future systems. It is also important to look closely at organisational culture at a broader level, again to generate important



learnings to ensure the State does not let down another generation of vulnerable children or adults. These factors provide strong rationale for a comprehensive inquiry into abuse in State care in Aotearoa New Zealand. There is incontrovertible evidence that many disabled children and adults were abused while in care. The people who experienced this trauma now deserve the opportunity to learn how their abuse was able to happen within a system that had responsibility for protecting them. Instituting an honest and open approach to a comprehensive inquiry, with a specific focus on understanding the role of systemic abuse, would give meaningful expression to the campaign, Never Again -E Kore Ano.

Section 3: What is missing - identifying the gaps and limitations in the available evidence about the abuse of people with learning disability

Despite the comprehensive range of key words and databases we applied in the search for the evidence of abuse of disabled people in State care, it was difficult to isolate specific examples. This finding in itself, points to a lack of visibility of disabled people, including people with learning disability in the literature. Many of the stories that were presented in findings section were identified through mining a diverse range of literature and other resources, much of which is not found through ‘conventional’ search strategies.

The accounts were relatively few in number, were often limited in terms of contextual detail, and were presented in formats that were not easily accessible. Therefore, it might be easy to dismiss the suggestion that abuse in institutions was a frequent and widespread occurrence for people with learning disability who were fostered and/or institutionalised in Aotearoa New Zealand. However, as the results of this research now show, we can categorically refute the view that abuse did not occur, or that it occurred in only a few isolated incidents. Those people who have had the opportunity to share their lived experiences of State care with independent and safe third parties have highlighted abuse as a pervasive presence within their lives - something that was perpetrated by their peers, as well as by people appointed by the State to care for them; something that occurred when they were children and when they were adults; and as something that was experienced through seemingly small abuses of power, as well as acute assaults to their minds and bodies.

Another explanation for the relative invisibility of people with learning disability from the narratives of abuse, is that their stories are most often contained within a broader research focus. They have been told after leaving an institutional environment as part of their pathway to community living (for example, Gates et al, 2008; Milner et al, 2008; O’Brien et al, 1999; Spectrum Care Trust Board, 2010). That many chose these forums to tell more about negative experiences of institutional life in contrast to their greater freedoms in community living could be seen as an indicator of the research participant’s new-found awareness of the deprivations and abuse they received in institutions. To tell their story, virtually all narrators had the support of another person, helping them to select from their memory what would be included in the written account. As researchers reading these accounts we were aware that they had a specific purpose; that they were not claiming to

offer a particular focus but rather an opportunity to share experience. For many, doing so may have been a cathartic experience. In addition, they demonstrated support for deinstitutionalisation in a way that might be meaningful to the wider community.

This points to a major gap in the published research; a significant lack of detailed accounts of abuse and neglect of disabled people in New Zealand institutions. For example, from the stories we have analysed, we can reasonably conclude that abuse occurred over a long-time period, but dates are rarely mentioned; experience is often codified, such as Avis’s comment that *“he made me do things that I didn’t want to do”* which is highly suggestive of sexual abuse, but does not state it overtly. In addition, abusive practices, such as the use of seclusion, ECT and inappropriate use of medication were often interpreted by the person as punishment for a misdemeanour, including a challenge to the authority of the institution. As noted previously, people were very clear about what happened, but for a range of reasons, they did not, and possibly could not, unpack the circumstances that led to such practice or actions. This is an important area of focus for future investigation, particularly the analysis of whether policy and practice in State care was based on acknowledged best- or evidenced-based practice of the time. It is clear, through the Askew review of the 1980’s, for instance, that models of care being practised in psychiatric and psychopaedic institutions did not comply with what was accepted and promoted as best practice at the particular time (Askew, 1986). It is therefore unethical to simply explain away the high incidence of abuse in State care as being reflective of “the time.”

As we have already established, the current research confirms that neglect and abuse happened and there is incontrovertible evidence that both staff, and other patients were abusers. Furthermore, those who were abused may also have been abusers themselves. It is important to also note that the higher profile of some institutions as sites of abuse may be attributable to the fact that they have been the source of research relating to their closure whereas others have remained unexamined in a rigorous way. Given the experience of the people whose stories are told in the previous section, it seems unlikely that life in the other institutions was markedly different. Indeed, the results of the Confidential Listening Report (Henwood, 2015) would suggest otherwise.

Despite their institutionalisation being historical and their stories tending to focus on improved quality of life in the community, the years of institutional neglect and abuse have had ongoing implications in the lives of people whose stories we have drawn on here. However, many of the stories did not specifically explore the outcome of the years of



institutional abuse. Amongst other populations where childhood abuse and neglect have been documented there are identified health and social consequences (for example, Norman, Byambaa, De, Butchari, Scott, & Vos, 2012, Spertus, Yehuda, Wong, Halligan, & Seremetis, 2003). While institutional abuse continues to be treated as a practice of the past, there is an obvious gap in our knowledge of the current impact of this abuse on the health and social outcomes of people with learning disability in New Zealand.

Section 4: Recommendations for future research

As noted earlier, our experience of interviewing people with learning disabilities for a wide range of research, has shown us that it is not uncommon for them to share past experience of abuse in State care. However, reports inevitably focus on the alternative aim of the research and these examples are not always able to be ethically and sensitively included. Language expression can also be a challenge for disabled people, particularly those with learning difficulties. This means that people sometimes struggle to put words to their experience, and it can be difficult to draw out further information on which to report. Research that has the specific purpose of exploring disabled people’s experiences of abuse and neglect when they were in State care is the best way to document what has happened to a (now) aging generation. There is some urgency in terms of the age of many of the people concerned, and the time that has elapsed since the large institutions were closed. Such research would need to be designed carefully to ensure that it upholds the rights of the participants, including that it has the capacity to respond to unmet need in terms of redress for psychological trauma or distress.

A particularly concerning aspect of the stories that are presented in this research is that a number of the people who were institutionalised came from homes where they were also abused. State care should have provided a safe place for these young people, but it did not. If we are to learn from this experience, it highlights the need to support families that include disabled children. As pointed out in Robert’s biography in relation to a comment from his sister *“Heather wonders whether, had her parents received some counselling in how to cope with their little boy, things might have been different.”* (McRae, 2014, p.25). Family abuse is often hidden, with children hesitant to complain (as Robert, Avis and Josie all identified as being a feature of their foster care). We have to ask the question whether the State is providing sufficient support to families of young disabled people today?

Attention should also be given to the services that have replaced institutions in supporting disabled people, and particularly those with learning disabilities. As Roguski (2013) identified, abuse and neglect are not in the past. Various approaches have been used to audit and otherwise assess quality of care in the non-governmental organisation sector (NGO’s), however gaps remain that make it possible for abuse and neglect to go undetected. As Sobsey (1994) noted, *“there will always be isolated incidents of abuse, but we do not need to accept it and must have in place strategies that make it less likely along with policy*



and practical mechanisms for reporting and responding”. That is, we must remain vigilant for opportunities for systemic abuse.

We are conscious that this research is weighted toward evidence of abuse in institutional settings. What became obvious very early in the literature search process was that experiences of foster care were more difficult to locate. This was not surprising given that institutions were the “first port of call” for people with learning disability, with foster care a less common pathway within State care during the period under study. That said, a number of the stories that were drawn on within the research detailed abusive foster settings. Future research should focus on the experience of foster care for children with learning disability, past, present and future as a topic of relevance in the current support environment.

Finally, the closure of the Kimberley Centre provided the opportunity to interview staff (Gates et al., 2008). As outlined earlier, staff supported the stories told by people with learning disabilities who had been resident at Kimberley. It is clear that we should continue to learn from individual accounts about the reality of everyday life within institutions and other State care facilities. Future research should also consider the value of drawing on witness accounts, such as those related by people who were employed in these settings, or visited on a regular basis.

Conclusion

The purpose of this report was to identify evidence of abuse experienced by disabled people, particularly those with a learning disability, in State care. The personal stories included here represent the few people who have managed to have their voices heard. Their stories are no different to the stories told by others placed in State care during the same period (Stanley, 2016), but who did not carry the label “disability”. They have provided stark and compelling evidence that people with learning disability were subjected to wide-ranging abuse in institutions, care homes, educational facilities, and foster homes.

In 2001, the Donald Beasley Institute commenced a 5-year study of the impact of leaving New Zealand’s last remaining institution, the Kimberley Centre (Milner et al., 2008). Whilst beyond the time-frame for this report, the Kimberley research provides one of the only windows with which we have to look backwards in a rigorous way at the lives of the people whose stories infuse this report. It also allows us to answer the critical question: *how deeply entrenched were the systemic abuses retold in this report?* To this end, key findings of the Kimberley research included:

- Institutional placement severed people from the families in ways that profoundly affected the life quality of parents and their disabled children. After leaving Kimberley, how much access former residents had to the love of a family member was found to be the most significant predictor of former resident’s life quality.
- Kimberley residents performed poorer on all measures of adaptive behaviour, with their poor performance relative to their age and sex peers attributable to the realities of living in an institution suppressing ongoing learning.
- Almost all of resident’s day-to-day lives unfolded within the walls of the institution.
- Whilst the expansive grounds created the illusion of spaciousness, Kimberley residents, on average, spent 97% of their time locked inot their villa.
- Residents had limited opportunities to engage in purposeful activity or to engage in roles that might nourish personal development. During the day, resident’s ordinarily lined the wall of the dayroom waiting for the unvarying interruptions of lunch and morning and afternoon tea.
- Living in an institution severed residents from their community. Residents were observed in a community setting for 1.1% of the total time they were observed.
- Residents were seldom spoken to, with 63% of all interaction events lasting less than a minute. A general acceptance of the reality that many residents had entered Kimberley speaking but would leave silent represented a quiet but distressing denial of the rights of people who could find little use for self-expression through language.

- Stories of physical and sexual abuse were commonly reported by family and staff and the “Kimberley Cringe,” was acknowledged as part of institutional lore (Milner, et al, 2008).

These findings validate the narratives of the 18 people whose stories are presented here. Both pieces of research speak for the men and women and children with whom they shared villa dayrooms, dorms and some of the darker corridors of State care.

The story of Kimberley is, in many ways, the story of an institution resistant to change. Many of the social practices and systems of care described in the research appeared rooted in the same negative social construction of people with a learning disability that had led to the construction and populating of New Zealand’s major institutions with some of its most vulnerable citizens. This understanding of people with a learning disability as less deserving of an ordinary life persisted at Kimberley, despite the attempts to reform institutional care that occurred throughout the 1970s and 80s (Thomson, 1995), and was certainly still present when researchers spent time there in the early to mid-2000’s. The fact that individual and systemic abuse was clearly observed at that time, despite “best practice” in terms of models of care for disabled people being well established makes it almost impossible to refute the argument that abuse has always been a feature of State care for disabled people. It is also impossible to accept that Kimberley was a unique site of abuse; indeed we know it was not, as the personal accounts drawn on within the current research attest.

We close, as we began with a whakatauki. A literal translation of this whakatauki is “ *Set fire to the overgrown bush and the new flax shoots will spring up*” - or, in other words, clear away what is bad and the good will flourish. This, to us, expresses a message pertinent both to the findings of this research, and to the call for a comprehensive inquiry into, and apology for the abuse experienced by disabled New Zealanders while they were in the care of the State. Until we permit disabled people the same chance to make transparent the systemic abuses they endured between the 1950’s and 1992, and acknowledge their personhood through the dignity of a meaningful apology, we are unlikely ever to get to a place where we might confidently assert “ Never Again.”

“Tungia te ururua kia tupu whakaritorito te tupu o te harakeke”

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APPENDIX 1: SEARCH TERMS

The research team employed a variety of search terms that included historical and more contemporary terminology in order to collect a variety of texts from the period of inquiry that may have utilised older terms (1950-1980) and recent disclosed stories and experiences that may have utilised more contemporary terms. These were as follows:

disabled/disability	impairment/impaired
deficient	handicap/handicapped
intellectual/learning	mental/ly
retard/ed/ation	intersex
hermaphrodite	psychopaedic
Psychiatric	hospital
Blind	Deaf
institution	home
story	abuse
sexual	physical
suffer/ed/ing	foster care
State care	wards of state
Tokoroa	Tokanui
Kingseat	Kimberley
Mangere	Cherry Farm/Hawksbury
Seacliff	Sunrise Home
Seaview	Carrington
Oakley	Homai
Templeton	Campbell Park School
New Zealand	Ngawhatu Hospital
Porirua Lunatic Asylum	Carrington Hospital
Mental	Auckland Mental Hospital
	Avondale Asylum
	Burwood

APPENDIX 2: SEARCH LOCATIONS

The potentially relevant texts retrieved from these sites were then examined for their relevance to the people the research team were searching to hear from (people with disability, hauā Māori, intersex people, and intersex takatāpui). Two members of the research team performed the searches in the described databases. The research assistant on the project (LS) searched in case law for potentially relevant cases in Aotearoa New Zealand.

Libraries for historical resources:

Te Ara - The Encyclopedia of New Zealand.
Archives New Zealand - Te Rua Mahara o te Kāwanatanga.
National Library of New Zealand - Te Puna Mātauranga o Aotearoa.
DigitalNZ - Ā-Tihi O Aotearoa.
The Confidential Listening and Assistance Service - Ratonga Matatapu mō te Rongo me te Āwhina.

Libraries for digital and news resources:

NZ On Screen.
NZ Film On Demand.
Flicks.co.nz.
ThreeNow & The Hui.
Māori Television (Whakaata Māori) & Native Affairs.
Attitude TV.
Google News: For aggregating news stories.

Academic resources:

Google Scholar. To search for studies and research on Aotearoa New Zealand.
Otago University Library Search Ketu. For accessing University of Otago electronic and print resources.
NZ Research. For accessing post-graduate publications.
Hocken Collections - Uare Taoka o Hākena. For accessing the historical and cultural archive on Aotearoa New Zealand.

Activist resources:

Male Survivors of Sexual Abuse. For accessing abuse disclosed in this advocacy blog.
New Zealand's Historic Abuse Claims: For accessing abuse disclosed in this advocacy blog.

Other community- or government-based resources:

IHC Library. For accessing texts on and by people with learning disability.
CCS Disability Action Library. To search for texts on and by people with disability.
OUTLineNZ. To search for information or links to information on the experiences of intersex people and intersex takatāpui in Aotearoa New Zealand.
Intersex Youth Aotearoa. To search for any information that pertained to historic stories of intersex youth in Aotearoa New Zealand.
It's Not OK. To search through stories of hope and change that pertained to growing up in State care.



Libraries with legal resources:

Westlaw
Lexis Nexis

APPENDIX 3: DEFINITIONS OF ABUSE

Neglect: Conduct that, (when either passive or active), causes or is likely to cause suffering, injury, adverse effects to health or wellbeing (mauri ora) or any mental disorder or disability to a person in a way that signals a departure from a reasonably expected standard of care and/or duty of care. This code was informed by the Crimes Act 1961.

Emotional and psychological abuse: Battery of a person's psychological, (emotional, and/or social wellbeing. Includes committing the following against the person: manipulation, coercion, intimidation, degradation (including when internalised to self-degradation), terrorisation, kangakanga (verbal abuse or cursing), exploitation, and exposure to violence. This code was informed by the definitions and types recognised by Child Matters (2017) and the Mauri Ora Framework (Kruger et al., 2004).

Control and restraint: This code was added in addition to the original codes in response to the frequent mentions of experiencing being “locked up” and confined in State care. The addition of this code was consistent with a report with a scope of inquiry into more recent abuse of people with disability in Aotearoa New Zealand and the unique harmful experiences people with disability can face from staff (Roguski, 2013).

Physical: Mistreatment through violence and injury) or any other form of contact or assault that is meant to hurt or injure and undermine a person's physical wellbeing. The definition of this code was informed by Ministry of Health, Wellington, New Zealand.

Sexual: Any form of sexual contact that happens without active, enthusiastic, voluntary, and ongoing permission or any form of sexual contact that happens with and to children (The Crimes Act, 1961).

Spiritual: Conduct that causes or is likely to cause the denial, restriction, prevention, or limitation of a person's spiritual or religious beliefs, interests or passions, and cultural ties. And therefore involves any conduct that, active or passive, undermines spiritual wellbeing. This code was informed by the recognition of spiritual wellbeing recognised by the Mauri Ora Framework (Kruger et al., 2004), and Women's Refuge (n.d.) pertaining to spiritual violence.

Financial: Conduct that causes or is likely to cause the denial, restriction, prevention, or limitation of a person's economic accessibility, including financial, employment, and educational accessibility. This code's definition was informed by the Domestic Violence Act 1995.

Institutional: Refers to neglectful psychological, physical or sexual abuse that takes place in the managed institutional care of human beings. This code was informed by Sobsey (1994).

Systemic: Examples of abuse that, although sometimes perpetrated by a person, have causal roots located in organisational, policy or funding structures. This code was defined by Robinson (2013).



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