



© 2022 by the author(s). This is an Open Access article distributed under the terms of the Creative Commons Attribution 4.0 International (CC BY 4.0) License (<https://creativecommons.org/licenses/by/4.0/>), allowing third parties to copy and redistribute the material in any medium or format and to remix, transform, and build upon the material for any purpose, even commercially, provided the original work is properly cited and states its license.

Citation: Stace, H. 2022. Aotearoa New Zealand's Royal Commission on Abuse in Care and Making our Disability History Visible. *Public History Review*, 29, 156–167. <https://doi.org/10.5130/phrj.v29i0.8193>

ISSN 1833-4989 | Published by UTS ePRESS | <https://epress.lib.uts.edu.au/journals/index.php/phrj>

Aotearoa New Zealand's Royal Commission on Abuse in Care and Making our Disability History Visible

Hilary Stace

Corresponding author: Hilary Stace, hilary.stace@vuw.ac.nz

DOI: <https://doi.org/10.5130/phrj.v29i0.8193>

Article History: Received 20/05/2022; Accepted 22/07/2022; Published 06/12/2022

The Road to the Royal Commission

A 2014 publication about Robert Martin, *Becoming a Person: The Biography of Robert Martin*, described his experiences as a disabled child growing up in the institutions and foster care of the 1960s and 1970s.¹ It was frequently brutal, but he admits he was one of the lucky ones as he could talk and physically fight back. He was denied cultural markers, such as knowledge of the All Blacks, New Zealand's national rugby union team, and the music his non-disabled peers enjoyed. For him, removal of children by the state was a denial of citizenship and appropriate redress would include a nationwide restorative citizenship ceremony.² In Aotearoa New Zealand, the Abuse in Care – Royal Commission of Inquiry (the commission) is currently investigating abuse in many contexts between 1950 and 1999. It is the biggest commission of inquiry in our history and the final report of its five-year investigation will be delivered to government by June 2023. A public hearing on disability and mental health, one of many investigations into specific aspects of historic abuse, was held in July 2022.³

The road to the commission was long and bumpy, although many have called for such an inquiry for decades. The commission provides an opportunity to hear, listen, acknowledge and consider redress for historic state and faith-based policies and practices, which enabled the removal of vulnerable children from families and communities and their subsequent neglect and abuse. But many disabled survivors do not use spoken words and have minimal engagement with the community or official processes and finding and hearing their stories has been a problem for this inquiry. This article provides some history and context for the commission, describes a research project which gathered stories of hard-to-reach disabled survivors and advocates for collecting, archiving and publicising Aotearoa New Zealand's disability stories.

DECLARATION OF CONFLICTING INTEREST The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article. **FUNDING** The author(s) received no financial support for the research, authorship, and/or publication of this article.



The Kimberley Centre, near Levin, was finally closed in 2006 and the site neglected for many years. (Photograph by Hilary Stace)

Institutionalisation of disabled people in Aotearoa New Zealand peaked from the 1950s to the 1970s, and deinstitutionalisation began slowly following a 1973 recommendation of a government inquiry for transition to community care.⁴ The era ended with the closure of the last psychopaedic institution, the Kimberley Centre, in 2006.⁵ The process often returned a lost family member, or just a brief record that a missing whānau member once existed. In my extended whanau, an elderly great aunt turned up in the 1980s. Family history revealed that she was sent to a local psychiatric hospital many decades earlier as a distressed teenager. Was she the reason that her brother never married, fearful of some hereditary condition that could appear in potential offspring?

Disabled activists and allies long advocated for the closure of the institutions. The Kimberley Centre finally closed after protests, including a march on Parliament, by survivors and allies, but the closure itself was fought by many staff and families who considered that it provided a safe home for their disabled adult children. Hon Ruth Dyson, the Minister for Disability Issues, did extensive negotiation and advocacy to reassure families that community care would be appropriate for their adult children.⁶

Our Aotearoa New Zealand disability and mental health history is not widely known or recorded. The patients of the Lake Alice Child and Adolescent Unit in the 1970s are a rare example of a group which has managed to attract media attention. Lake Alice was a large psychiatric hospital in Manawatu-Whanganui and a major employer in the region, which operated from the 1950s to the 1990s, neatly reflecting the focus era of the commission. Over the decades it housed thousands of people with various types of impairments. Many disabled people spent their whole lives there under the legal guardianship of the state; it was a literal dead end for many. In the late 1980s, after long negotiations, J.B. Munro, the head of intellectual disability

advocacy and service provider organisation IHC, took a bus to Lake Alice to collect some residents who had been given permission by the authorities to be rehomed in IHC's community houses. Others took this one chance at escape, boarded the bus, and refused to disembark.⁷

But it was the significant abuse of young people, including allegations of torture, placed in the adolescent unit in the 1970s, which was a major driver behind the calls for this current inquiry. The commission held a public case study hearing in 2021 with a major focus on the unit and the psychiatrist in charge, Selwyn Leeks.⁸ Survivors are keenly watching the commission's progress.



Lake Alice, date unknown. Like many large institutions it was in an isolated rural area and had extensive grounds which were not for the benefit of patients. Such isolation helped abuse flourish. Only the remnants of the water tower remain today. (Wikipedia)

This was not the first inquiry into the unit, as victims had sought justice for decades, but Dr Leeks had never been charged. In 1999, incoming Prime Minister Helen Clark, who was aware of this history, called for an investigation into the unit and officially apologised to some survivors who also received financial compensation. Her apology challenged two of the arguments used against complainants: that what happened was just normal for the time, and that because such things happened several decades ago, it was no longer relevant.

Whatever the legal rights and wrongs of the matter, and whatever the state of medical practice at the time, our government considers that what occurred to these young people was unacceptable by any standard, in particular the inappropriate use of electric shocks and injections.⁹

From 1999 to 2008, Prime Minister Clark's government made several significant apologies for historic injustices, such as the discrimination against Chinese people, and these apologies came with funding for research and memorials. These earlier examples of redress could provide a model for the current inquiry.

Unfortunately, the Lake Alice Child and Adolescent Unit inquiry did not lead to police charges against Dr Leeks, by then in Australia, leaving an ongoing grievance for survivors. But publicity led to many more stories of abuse in psychiatric hospitals and other institutions, and the Prime Minister then established a Confidential Forum for Former In-Patients of Psychiatric Hospitals. It was a small, safe and supportive process for those who had suffered abuse in state care and in 2007 it produced a useful report of the issues.¹⁰ After the forum finished its allocated time, it was followed by the establishment of a Confidential Listening and Assistance Service, which was also time-limited and closed in 2015 with many applicants still unheard.¹¹ Both committees recognised that they were not resourced or sufficiently expert to seek and hear stories of survivors from the 'back wards' of the institutions, or those who had severe impairments.

Ongoing advocacy attempts were made by many groups and individuals for an independent commission to hear such stories. This included a roundtable forum of community activists, disabled people, academics, clinicians, lawyers and government officials organised by the Human Rights Commission in 2014, in which Robert Martin, a survivor of Kimberley, Campbell Park, Lake Alice and foster care, was a key speaker.¹² Advocates around the country sought justice through a comprehensive investigation into the abuse of disabled people and those with mental health conditions in state care, including an apology and redress, but the National Government's attorney general dismissed such concerns.¹³ Meanwhile several other countries, including Australia, undertook similar inquiries.¹⁴

In 2017, outgoing Disability Rights Commissioner in the Human Rights Commission, Paul Gibson, commissioned a report on disability abuse from Dunedin's Donald Beasley Institute called *Institutions are Places of Abuse*, which gathered stories from the public record that proved for the first time that disability abuse had been systemic.¹⁵

In 2016, Jacinda Ardern, as the opposition Spokesperson for Children, launched Elizabeth Stanley's book *The Road to Hell*, based on Professor Stanley's harrowing research about abuse of children in the welfare system, including boys' and girls' homes.¹⁶ At the launch, Ardern promised an inquiry if elected to government. At the September 2017 election, the new Labour-led government's first 100-day plan included a commission of inquiry on historic abuse in state care covering the period 1950 to 1999; its formation was announced on the 100th day, 1 February 2018.¹⁷ After a campaign by survivors of faith-based care, the inquiry extended its terms of reference, but a call to extend the period under investigation up until the present was rejected. Former Disability Rights Commissioner Paul Gibson was appointed as one of five commissioners, and the only one with lived experience of disability.

As well as private individual sessions held with investigators and commissioners, there have been several case-based public hearings. Interim reports have been released, including *He Purapura Ora, he Māra Tīpu* on preliminary redress recommendations.¹⁸ Our largest inquiry, the commission is based on a very formal legal process and is not the inclusive, intimate historical inquiry that many of us had hoped for. Many legal experts, but few historians, have been employed. Notwithstanding, the commission is our one opportunity for justice and the timing is tight with final reporting to government due by mid 2023.

The commission has been seeking stories from survivors as well as acknowledging those no longer with us. In public hearings, commissioners frequently ask survivors what needs to happen to prevent any ongoing or future abuse. The past indicates the way forward as in the well-known whakataukī (proverb): Titiro whakamuri, haere whakamua.¹⁹

Aotearoa New Zealand's Eugenic History

Stories from disabled people with lived experience of state care shine a light on our history of eugenics-based public policy. This history remains largely invisible apart from a few academic studies by historians.²⁰ The commission provides both opportunity and requirement to address this invisibility. Our toxic history of colonisation, racism, ableism and eugenics over the last 100 years is still playing out today, particularly for poor, brown or disabled people. Through this lens it is clear New Zealand has preferred to label and lock away rather than show kindness to our young vulnerable people.

For much of the twentieth century in New Zealand, as elsewhere, eugenics-based public policy portrayed disability as something feared and shameful which threatened the 'fitness' and dominance of the white race. State surveillance saw thousands of disabled children and other young people institutionalised, and sent to residential special schools, youth justice or foster homes. Disabled Māori children were at high risk as they were caught in the intersection between colonialism and eugenics. We now know that all types of abuse and neglect was widespread in these institutions. We also know that abuse of disabled people in care remains in many contexts.

An influential 1903 booklet, *The Fertility of the Unfit*, by a local doctor and politician, W.A. Chapple, was a eugenic tract in which the writer encouraged the 'fit' (meaning white people like him) to have more children and to sterilise the 'unfit' (meaning those with disabilities, or those who were poor or brown).²¹ It carried an endorsement by former Premier Robert Stout. While working at the *Dictionary of New Zealand Biography* in the 1990s, I realised how mainstream eugenic views were last century and that many of New Zealand's past leaders, such as Plunket Society founder Truby King, held these views. Prominent eugenicists still have buildings and memorials named for them.²² Eugenicists saw disability, mental illness, poverty and addictions as inherited moral failings, therefore the 'breeding' of these groups must be controlled to prevent them polluting the 'fit'. These false ideas about genetics and morality represented cutting edge science of the day and were widely held by political, academic, medical and religious leaders.

In New Zealand, the major legislative tool for such eugenic views was the 1911 Mental Defectives Act which classified groups of disabled people into six categories: 'persons of unsound mind', 'mentally infirm', 'idiots', 'imbeciles', 'feeble-minded' and 'epileptics'.²⁴ Each label had a specific meaning which indicated how they should be controlled and surveilled. This Act remained in force for over 50 years; the current 1992 Mental Health Act is the latest iteration, with its catch-all deficit label of 'mental disorder'.

Public prejudice about 'feeble-minded' men and women led to a 1925 Committee of Inquiry into Mental Defectives and Sexual Offenders, which reinforced the links between intellectual impairment, moral degeneracy and sexual offending in the public mind.²⁵ Head of the Department of Mental Hospitals, Dr Theodore Gray, wanted children and adults with intellectual disability or mental illness to be registered and sterilised and sent to segregated farm colonies. Under his influence the 1928 Mental Defectives Amendment Bill proposed that children could be taken off families, and a Eugenics Board would keep lists of 'defectives.' A poem of the time reflected that parental fear:

'Oh Mother, save me from Dr. Gray
 'Cause teacher says he's coming to-day
 And if I'm stupid he'll take me away.
 Oh, Mummie, save me from Dr. Gray!
 'I cannot save you, my little child.'
 His Mummie said and her eyes were wild.
 'You belong to the State, you're no more my child!
 But Oh, my darling don't stupid be
 Or he'll say we've tainted heredity.
 And must be eradicated – you and me!'²⁶

After much political debate, sterilisation was rejected under the leadership of Opposition Labour MP Peter Fraser. His was a rare voice against eugenics, possibly because of his own family experiences of mental illness. Even though eugenic sterilisation was never legalised in New Zealand, anecdotally operations and contraception without consent were common.²⁷

The Mental Defectives Amendment Act led to the establishment of Templeton Farm Mental Deficiency Colony near Christchurch in 1929, and Dr Gray personally authorised the first admissions. Over time more psychopaedic hospitals were established, including Braemar (Nelson), Kimberley (Levin) and Mangere (Auckland). Units were also established in some hospitals, or in psychiatric hospitals. There was also a network of residential special schools.

The 1953 the Consultative Committee on Intellectually Handicapped Children, also known as the Aitken Report after its chairman, a doctor who was also the father of a disabled child, recommended extending the existing psychopaedic institutions into large ‘mental deficiency colonies’, with parents encouraged or coerced into sending their disabled children to them by the age of five.²⁸ These recommendations were made despite pleas from the newly formed Intellectually Handicapped Children’s Parents’ Association (later known as IHC), and latest World Health Organisation support for community facilities for disabled children and adults.²⁹

The Aitken Report is a significant reason why we have a Royal Commission today. As a result of this report, the institutions were extended and numbers of residents rapidly increased. A 1964 National Film Unit documentary estimated that one in a thousand children had an impairment that required their institutionalisation. It portrayed institutions as pleasant and busy places full of happy children.³⁰ Smaller units for children were attached to some local public hospitals, while other children ended up in adult psychiatric hospitals. To manage these growing numbers, the new profession of specialist psychopaedic nurse was developed in New Zealand from 1963, with inhouse training.³¹ By 1972, with the establishment of a Royal Commission of Inquiry into Hospitals and Related Services, which would eventually recommend their closure, each institution was home to hundreds of disabled children, young people and the adults who had managed to survive.

Locked Away

The normalisation of the institutionalisation of disabled children was hard for individuals to fight. For example, I heard of a mother who had a baby with Down Syndrome in the 1960s. The family doctor and her husband suggested the baby should be put into an institution. The mother resisted until one day the father came home with the GP and an attendant from Kimberley. They forcibly took the toddler off his mother, told her not to visit for at least two years and to forget about him. Terrified and confused by such instruction, the mother did not hear about him again until after his death a few years’ later. Such parental conflicts are reported in a collection of medical students’ notes from the era.³²

Christchurch filmmaker Gerard Smyth has made two powerful documentaries about life in Templeton and its eventual closure.³³ Most interviewees were estranged from families and puzzled as to why they were there. I find it incredibly sad that anyone thought it appropriate to send children away from their families and communities to live their lives in an institution. This happened in my lifetime. It happened to families I know.

Historians are taught not to judge the past by the standards of the present, but we know that many parents and families fought to keep their disabled children at home and for their inclusion in the community. IHC was founded in 1949 by brave parents wanting to do just this.³⁴ But the societal fear of the deviant and defective was very powerful. An elderly man told me sadly that his brother had Down Syndrome and was sent away to an institution. He was not allowed to be mentioned again, as the other siblings were told they would not find marriage partners if this was publicly known.

The commission's public hearings have brought these previously hidden stories to light, showing that disability led to a high risk of removal from families. For example, the February 2022 hearing on Christchurch's Marylands Special Residential School heard first-hand accounts of boys with learning disability who experienced a culture under the St John of God Brothers where abuse was prevalent, students did hard manual labour and formal education was minimal.³⁵

In one case study reported to the commission, the father of a three-year-old boy and his local family doctor applied to the Director of Mental Hygiene for the boy to be institutionalised in one of the 'mental deficiency colonies' for disabled children around New Zealand.³⁶ Under the legislation of the time, the decades-old Mental Defectives Act, 'defect' was indicated in the diagnostic notes that the boy was not toilet trained, did not respond to discipline and did not appear emotionally attached to his parents.³⁷ A paper trail followed the removal of the boy from his family, attending two different hospitals for assessment, before he joined several hundred other disabled children, young people and adults in a large institution on the outskirts of a major city. Records do not mention whether any kind person accompanied the child, or what his mother thought about the removal of her oldest son. He would remain in the institution for four decades until his eventual deinstitutionalisation into a service-provided residential group home.

It can be hard today to understand the fear of and discrimination against disability. Conditions that we now group as 'neurodiversity' (such as Down Syndrome, autism and learning disability) in those days were shameful and signaled that families had possible genetic and/or moral failings. It must have been very hard for a mother who was pressured to send her child away to protect the reputation of the family to then ensure her focus remained on her 'normal' family. Common assumptions were that such removals were 'for the best' and children would be 'with their own kind'.

What was it like to be a disabled child growing up away from family and community? Not only were they removed from those who should and could have nurtured them, but now we know from survivors and testimony to the commission that many were exposed to physical, emotional, psychological and sexual abuse, witnessing and silencing, heavy medication and sometimes medical experimentation. Many also suffered from cultural and spiritual segregation from their iwi (tribal affiliation), language and heritage. Institutionalised children were disproportionately Māori. Basic neglect, without personal possessions or markers of identity, or any ability to make daily choices, was standard. There was no notion of any form of consent.

Tell Me About You

It has been hard for the commission to find disabled survivors to tell their stories. As mentioned above, the last psychopaedic institution, the Kimberley Centre, closed in 2006, and before that Templeton in 2000, with Braemar and Mangere a few years earlier. Disabled adults were also gradually deinstitutionalised from psychiatric hospitals, units or various types of foster care. Survivors now live mainly in group homes or aged care run by NGOs, charitable trusts or private providers. Many are old and frail, without close family, often with missing records, do not use words to communicate, have little access to communications technology and are not engaged with the wider community. Their lives are largely managed by service providers.

The commission has a strong focus on individual survivor testimony, rather than those of siblings or wider family and whānau. But to hear the stories of those who were separated from families and communities, often decades ago, required specific resources and expertise. Investigators and researchers needed to seek out survivors in their group homes or day programmes, to negotiate with the gate keepers and to learn how to communicate with those minimally or non-verbal. This task required a careful person-centred approach and a disability-specific kaupapa (methodology). Examples of this are rare but include Spectrum Care's *Extraordinary Journeys*, which attempted to tell the stories of twelve of their clients, and publications by self-advocacy group People First.³⁸

The Donald Beasley Institute (DBI), whose staff compiled the 2017 report that proved state disability abuse was systematic and widespread, was established in 1984 by the IHC to research issues around intellectual disability (learning disability is the more commonly used term these days). The research centre was named after Dr Donald Beasley, a paediatrician and longtime president of IHC. It has an international reputation for research by and with disabled people, particularly those with learning disability such as the ‘Great Life Project’.³⁹

Disability research can be more complex than other historical or biographical research. DBI’s researchers have developed an Individually Responsive Methodology for disability research, which recognises the expertise of each person and allows them to decide how to be present in their own story. As story tellers, the research participants decide how best to tell their stories. These need not be in spoken words but might use photographs and other archives or walking and remembering around significant sites. Information is provided and consent gained via accessible methods such as Easyread or video. As story gatherers, the researchers and writing partners listen and record.

DBI was contracted by the commission to gather the stories of up to 20 people with learning disability and other neurodiverse conditions who spent time in state care in various sites, including psychopaedic and psychiatric hospitals, foster care and special schools, between 1950 and 1999 in a project called ‘Tell Me About You’.⁴⁰ It has a focus on the story tellers’ life in state care, not just the abuse. Sadly, some do not recognise abuse as for them it was normal life.

Authentic ethical research with disabled people who have experienced removal from home and community, trauma and abuse, requires time, respect and skill. Every part of the process involves building and maintaining relationships and trust with potential participants, providers and family and whānau. It is very slow and can take months to negotiate around the many barriers and gatekeepers in order to find, explain and conduct research with potential participants, who may then withdraw at any time.

The ethics approval processes required by the commission and the Ministry of Health’s Health and Disability Ethics Committee are complex. Although we have New Zealand guidelines acknowledging the need for research with disabled people, those on ethics committees tend to focus on the vulnerability of disabled participants, not the mitigation of that vulnerability.⁴¹ Under the terms approved by the ethics committees, participants are required to provide written, spoken or signed consent or by using assistive communication devices. The translation of participant information sheets and consent forms into Easyread, including Easyread te reo, can be slow and expensive, but it is ethically essential.

As well as a research team based around the country, a reference group of Māori researchers was gathered to respect Te Tiriti o Waitangi partnership principles and provide input and help find participants. As mentioned earlier, Māori were disproportionately affected by all aspects of historic abuse. Māori make up less than 20 per cent of the population of Aotearoa New Zealand, but in some preliminary estimates (ethnicity statistics were poorly recorded) represent up to 70 per cent of those affected by abuse in state care.

After analysis of the stories, which were limited to 16 because of the tight ethics requirements and Covid-related delays, an ecological model of abuse was developed to show that abuse was individual, relational, community and systemic levels. Findings from the ‘Tell Me About You’ project were reported to the commission’s public disability hearing and will inform its remaining work, including insights into how to prevent future abuse. One participant also told their story to the commission in the public hearing. The stories in the report were carefully curated with the story tellers and most chose pseudonyms.

I was privileged to be part of this project. Hearing the stories of those who have lived experience of abuse while in the care of the state brings a new level of shock about our history, and urgency to do better. As Robert Martin often asks, ‘how can humans treat other humans like that?’

Collecting, Archiving and Making Disability History Visible

Many families and whānau have a story of an institutionalised family member, and there are remnants of old institutions and unmarked graves across the country. There are stories to be uncovered in every community. To make this history visible, heard and known, we need it to be archived and resourced. Many official records are missing or incomplete. Abuse is rarely recorded in those that remain. We do not have a dedicated disability archive or repository in Aotearoa New Zealand and much valuable material has been lost or destroyed. There is a role for historians in helping disabled people tell stories, researching and publicising this history and developing educational resources.

The commission is considering how best to provide redress for the horrors its hearings have brought to light. To honour those who suffered under eugenics, I would like to see the establishment of a disability archive and associated collections to gather, collect and curate stories of disability abuse and activism, and funding for scholarships, exhibitions and resources for schools, as well as the boosting of Disability Studies. This archive needs to be governed by disabled people, whānau and allies in partnership with archivists, librarians and historians. We need to enable those who know how to fill the gaps to do so.

This form of redress will help Aotearoa New Zealand confront the remnants of eugenics that remain as systemic ableism and end that disability whakamā, or shame, that over 60 years ago caused the cruel separation of a child from his family reported in the case study above, and which is now part of the commission's record. Now, as an elderly man, he lives in a group home with other survivors. He and his sister, who never knew him as a child, are developing a new sibling relationship.

The Crown Response Unit in the Public Service Commission and its Minister, the Hon Chris Hipkins, will oversee the official government response. The Minister of Internal Affairs, the department with responsibility for the Royal Commission, is the Hon Jan Tinetti. Archives New Zealand and the National Library of New Zealand are part of the Department of Internal Affairs and therefore also lie within her ambit. Minister Tinetti grew up in a house in the grounds of a psychopaedic institution, where her parents were on the staff, and, as a teenager, she worked in the wards, which she reflected on in her 2017 maiden speech.⁴² She understands the injustice of institutionalisation, inadequate records and invisible history.

There is a risk that the commission will only skim the surface of disability abuse and, as has happened in Australia, a fuller and more specific inquiry will be needed.⁴³ However, the cost of such major inquiries makes this unlikely in the near future. On a positive note, an August 2022 Cabinet paper signaled that preparation for post-commission work was occurring in several areas, including a new ongoing listening service, the provision of financial redress and addressing problems with records.⁴⁴

Conclusion

The commission hearing is personal for me. As a parent of a disabled adult, I am relieved that we are living in an era when expectations for inclusion in schools, employment and independent living in the community are accepted norms. New laws cite the 2006 United Nations Convention on the Rights of Persons with Disabilities, the development of which New Zealanders had a significant role.⁴⁵ The Mental Health Act, which has century-old bones with its focus on deficit, defect and deviance, is currently being revised to reflect a more compassionate concept of wellbeing.⁴⁶ A new ministry, Whaikaha – Ministry of Disabled People, developed through a co-governance tripartite arrangement between disabled people, Māori and government, was established in July 2022.⁴⁷

The Royal Commission is revealing difficult histories about the abuse of those who were supposed to be in the care of the state or faith-based institutions. Those who were young and had impairments or were disabled were at particular risk. But it is also an opportunity for New Zealanders to hear personal stories, learn the value of historical research and understand how we can come together to prevent it happening again.



Sir Robert Martin receiving his KNZM for services to people with disabilities from the Governor General Dame Patsy Reddy, 19 October 2020. (Office of the Governor-General)

Sir Robert Martin, our most famous survivor of these institutions, is now a member of the United Nations Committee monitoring the implementation of the Convention on the Rights of Persons with Disabilities. He is an international advocate for people with learning disability and runs global campaigns to close the institutions – which during the Covid-19 pandemic he continued doing by Zoom from his home in Whanganui.

I will leave the last words to him.

Though it's great that New Zealand closed its last institution (Kimberley Centre), being institutionalised is not just about the buildings – the bricks and mortar – it's also about values, beliefs, actions and activities. It's about the way things are done, the decisions that are made, who makes them and who has the control. In New Zealand we still need to work hard to ensure that people with disabilities do not continue to be institutionalised even though they live in community settings.⁴⁸

Endnotes

- 1 John McRae, *Becoming a Person: The Biography of Robert Martin*, Craig Potton, Nelson, 2014.
- 2 Royal Commission of Inquiry into Abuse in Care, 2018. Statement of Robert Martin. (Online). Available: <https://www.abuseincare.org.nz/assets/Uploads/Documents/Public-Hearings/Contextual/17.-Robert-Martin.pdf> (Accessed 27 August 2022).
- 3 Royal Commission of Inquiry into Abuse in Care, 2022. Disability and Mental Health (Online). Available: <https://www.abuseincare.org.nz/our-inquiries/disability-and-mental-health-2/> (Accessed 5 May 2022). 'Disabled people', the official term used in New Zealand, reflects the social model of disability whereby people have impairments but are disabled by society.
- 4 C.P. Hutchison et al, *Services for the Mentally Handicapped: Third Report of the Royal Commission of Inquiry into Hospital and Related Services*, Royal Commission of Inquiry into Hospital and Related Services, Wellington, 1973.
- 5 Paul Milner, *An Examination of the Outcome of the Resettlement of Residents from the Kimberley Centre*, Donald Beasley Institute, Dunedin, 2008.

- 6 Personal interview, November 2021.
- 7 Hilary Stace, *JB Munro: Community Citizen*, IHC, Wellington, 2019, p135.
- 8 Royal Commission of Inquiry into Abuse in Care, 2021. Public Hearing: Lake Alice Child and Adolescent Unit (Online). Available: <https://www.abuseincare.org.nz/our-inquiries/abuse-in-state-psychiatric-care/public-hearing-lake-alice-child-and-adolescent-unit/> (Accessed 6 May 2022). Dr Leeks died in January 2022.
- 9 Clark, H. 2001, Settlement for Former Lake Alice Patients (Online). Available: <https://www.beehive.govt.nz/release/settlement-former-lake-alice-patients> (Accessed 7 May 2022).
- 10 *Te Āiotanga: Report of the Confidential Forum for Former In-Patients of Psychiatric Hospitals*, 2007 (Online). Available: <https://ndhadeliver.natlib.govt.nz/ArcAggregator/arcView/frameView/IE12126512/http://www.dia.govt.nz/Agency-Confidential-Forum-for-Former-In-Patients-of-Psychiatric-Hospitals-Index> (Accessed 6 May 2022).
- 11 *Some Memories Never Fade: Final Report of the Confidential Listening and Assistance Service*, 2015. (Online). Available: <https://www.dia.govt.nz/Final-Report-of-the-Confidential-Listening-and-Assistance-Service> (Accessed 6 May 2022).
- 12 The author organised this roundtable forum, which took place at the end of a short contract at the Human Rights Commission. It was attended by about 50 people who had advocated in various ways for an inquiry on abuse in care.
- 13 This correspondence was given to the Royal Commission to be retained within their records.
- 14 Australian Government, Royal Commission into Institutional Responses to Child Sexual Abuse, 2012-2017, Canberra.
- 15 Brigit Mirfin-Veitch and Jenny Conder, *'Institutions are Places of Abuse': The Experiences of Disabled Children and Adults in State Care*, Donald Beasley Institute, Dunedin, 2017.
- 16 Elizabeth Stanley, *The Road to Hell: State Violence Against Children in Postwar New Zealand*, Auckland University Press, Auckland, 2016.
- 17 Ardern, J. 2018, Inquiry into Abuse in State Care (Online). Available: <https://www.beehive.govt.nz/release/inquiry-abuse-state-care> (Accessed 10 May 2022).
- 18 Royal Commission of Inquiry into Abuse in Care, 2021, *He Purapura Ora, he Māra Tipu: From Redress to Pūretumu Torowhānui* (Online). Available: <https://www.abuseincare.org.nz/our-progress/reports/from-redress-to-puretumu/https://www.abuseincare.org.nz/our-progress/reports/from-redress-to-puretumu/> (Accessed 8 May 2022).
- 19 A whakatauki is a te reo proverb. This one loosely means 'let the old path show the way to the new path' or learn from the past.
- 20 For disability and welfare history, see Peter Beatson, *The Disability Revolution in New Zealand: A Social Model*, 2nd edition, Massey University, Palmerston North, 2004; Barbara Brookes and Jane Thomson (eds), *'Unfortunate Folk': Essays on Mental Health Treatment, 1863-1992*, Otago University Press, Dunedin, 2001; Bronwyn Dalley, *Family Matters: Child Welfare in Twentieth-Century New Zealand*, Auckland University Press, Auckland, 1998; Margaret Tennant, *The Fabric of Welfare: Voluntary Organisations, Government and Welfare in New Zealand, 1840-2005*, Bridget Williams Books, Wellington, 2007; Sullivan, M. and Stace, H. 2020, A Brief History of Disability in Aotearoa New Zealand (Online). Available: <https://www.odi.govt.nz/guidance-and-resources/a-brief-history-of-disability-in-aotearoa-new-zealand/#:~:text=Disability%20timeline%3A%20Aotearoa%20New%20Zealand&text=1975%20The%20Disabled%20Persons%20Community,and%20building%20access%20code%204121> (Accessed 5 May 2022).
- For eugenics, see P.J. Fleming, 'Eugenics in New Zealand, 1900-1940', MA Thesis, Massey University, 1981; Diane B. Paul, John Stenhouse and Hamish G. Spencer (eds), *Eugenics at the Edges of Empire: New Zealand, Australia, Canada and South Africa*, Palgrave Macmillan, London, 2018.
- 21 W.A. Chapple, *The Fertility of the Unfit*, Whitcombe and Tombs, Melbourne, Christchurch, 1903.
- 22 He was a member of the Eugenics Education Society. Brookes, B. 2011, King, Frederic Truby (Online). Available: <https://teara.govt.nz/en/biographies/2k8/king-frederic-truby> (Accessed 27 August 2022); Brunton, W. 1998, Gray, Theodore Grant (Online). Available: <https://teara.govt.nz/en/biographies/4g19/gray-theodore-grant> (Accessed 27 August 2022).
- 23 See for example, Paul, Stenhouse and Spencer, op cit.
- 24 New Zealand Government, The 1911 Mental Defectives Act (Online). Available: http://www.nzlii.org/nz/legis/hist_act/mda19112qv1911n6240.pdf (Accessed 5 May 2022). The 1911 Mental Defectives Act remained largely unchanged through several rewrites, and its influence can still be seen in the most recent 1992 Mental Health Act.
- 25 W. Triggs et al, *Mental Defectives and Sexual Offenders: Report of the Committee of Inquiry Appointed by the Hon Maui Pomare, Minister of Health*, New Zealand Parliament, Wellington, 1925.
- 26 Stephen Robertson, 'Production Not Reproduction': The Problem of Mental Defect in New Zealand 1920-1935, in Barbara Brookes and Jane Thomson (eds), *'Unfortunate Folk': Essays on Mental Health Treatment, 1863-1992*, University of Otago Press, Dunedin, 2001, pp200-214.
- 27 Carol Hamilton, 'Sterilisation and Intellectually Disabled People in New Zealand – Still on the Agenda?', in *Kotuitui: New Zealand Journal of Social Sciences Online*, vol 7, no 2, 2012, pp61-71.
- 28 R. Aitken et al, *Report of the Consultative Committee Set Up by the Hon. The Minister of Education in August 1951*, New Zealand Parliament, Wellington, 1953.

- 29 IHC New Zealand, Deposited Papers, 1949-2003, MS Papers 2003-211, Alexander Turnbull Library, Wellington.
- 30 National Film Unit, *One in a thousand* [documentary], 1964.
- 31 Beatson, op cit, p462.
- 32 Barbara Brookes, 'Cherishing Hopes of the Impossible: Mothers, Fathers and Disability at Birth in Mid-Twentieth Century New Zealand', in Tracy Penny Light, Barbara Brookes and Wendy Mitchinson (eds), *Bodily Subjects: Historical Essays on Gender and Health*, McGill-Queens University Press, Montreal, 2014.
- 33 Gerard Smyth, *Out of Sight* [documentary], Frank Films, Christchurch, 1996; Gerard Smyth, *Out of Sight, Out of Mind* [documentary], Frank Films, Christchurch, 2004.
- 34 IHC New Zealand, op cit.
- 35 Royal Commission on Abuse in Care, Marylands School Public Hearing, 2022 (Online). Available: <https://www.abuseincare.org.nz/our-inquiries/abuse-in-the-care-of-the-catholic-church/marylands-hearing/> (Accessed 6 May 2022). For more information about Marylands and attitudes of the time see Damien Keane, 'A Survey of the Graduates of a Residential School for the Retarded', in *Australian Journal of Mental Retardation*, vol 2, no 12, 1972, pp7-131.
- 36 Donald Beasley Institute, 'Tell Me About You' (Online). Available: <https://www.donaldbeasley.org.nz/projects/tell-me-about-you/> (Accessed 10 May 2022). The full report will be available from November 2022.
- 37 Today this would probably indicate that the child is on the autism spectrum, a diagnosis that was not widely known or understood in New Zealand at that time. The author has a copy of the archival record. The legislation cited on the form is incorrectly named as the Mental Health Act 1911.
- 38 Spectrum Care Trust Board, *Extraordinary Journeys: Twelve Extraordinary People Retrace their Journeys from Institutional Care to Supported Community Living*, Spectrum Care Trust Board, Auckland, 2010; People First New Zealand, *A Place of Our Own: Living with the Legacy of Institutionalisation*, Wellington, 2010; Standards Plus, *Seeking Community: Living with a Learning Disability*, Whitireia Publishing, Auckland, 2007.
- 39 Donald Beasley Institute, *The Great Life project; A Report Prepared for IHC/IDEA Services by the Donald Beasley Institute in Collaboration with the IHC Self Advocacy Advisory Committee*, Donald Beasley Institute, Dunedin, 2009.
- 40 Donald Beasley Institute, 'Tell Me About You' (Online). Available: <https://www.donaldbeasley.org.nz/projects/tell-me-about-you/> (Accessed 10 May 2022).
- 41 National Ethics Advisory Group, *National Ethical Standards for Health and Disability Research and Quality Improvement*, 2019 (Online). Available: <https://neac.health.govt.nz/publications-and-resources/neac-publications/national-ethical-standards-for-health-and-disability-research-and-quality-improvement/> (Accessed 11 May 2022).
- 42 Tinetti, J. 2017, Maiden Speech (Online). Available: <https://www.parliament.nz/en/mps-and-electors/members-of-parliament/tinetti-jan/> (Accessed 6 May 2022).
- 43 The Australian government's Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability was established in April 2019.
- 44 Hipkins, C. 2022, Responding to the Royal Commission into Historical Abuse in Care's Redress Findings – Immediate Projects to Improve Survivors' Experience of Seeking Redress, p2 (Online). Available: <https://www.abuseinquiryresponse.govt.nz/assets/Uploads/Cabinet-paper-Immediate-projects-to-improve-survivors-experience-of-seeking-redress.pdf> (Accessed 21 August 2022).
- 45 United Nations, *Convention on the Rights of Persons with Disabilities*, New York, 2006. According to conversations between the author and the Hon Ruth Dyson, the Minister for Disability Issues at that time, and others who participated, New Zealanders had significant input into many aspects of the process and the New Zealand delegation was one of the first to include disabled members.
- 46 New Zealand Ministry of Health, 2021, Transforming our Mental Health Law. Public Discussion Document (Online). Available: <https://www.health.govt.nz/publication/transforming-our-mental-health-law-public-discussion-document> (Accessed 5 May 2022).
- 47 Whaikaha – Ministry of Disabled People (Online). Available: <https://www.whaikaha.govt.nz/> (Accessed 21 August 2022). Whaikaha means to have strength or ability.
- 48 People First New Zealand, op cit, p9.