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Abuse in Care Royal Commission of Inquiry
Evidence Brief prepared for the purposes of the Disability Hearing

Author: Brigit Mirfin-Veitch, PhD.

June 2022

Introduction

1. My name is Brigit Mirfin-Veitch. I am the Director of the Donald Beasley Institute (DBI). The DBI is an independent research institute specialising in disability research.
2. I am also a Research Associate Professor with the Centre for Postgraduate Nursing Studies, University of Otago (Christchurch).
3. I am a sociologist, and have been working as a disability researcher since 1994.
4. I provided expert evidence as part of the contextual hearings that were held near the start of the Abuse in Care Royal Commission of Inquiry (Royal Commission) in November 2019 (<https://www.abuseincare.org.nz/our-progress/library/v/63/statement-of-dr-brigit-mirfin-veitch>).
5. I have been involved in a range of research projects that have direct relevance to the Royal Inquiry into Abuse in Care. In summary, my experience includes:
 - a. Assisting a survivor of state care to write and publish her life history (Hunter, 1999).
 - b. Carrying out research into the experiences and perspectives of families who had disabled family-members involved in the deinstitutionalisation of Templeton Centre (Mirfin-Veitch, 2005).
 - c. Involvement in research into the deinstitutionalisation of Kimberley Centre that involved residents, families and staff (Milner, Gates, Mirfin-Veitch & Stewart, 2008).
 - d. Reviewing publically available literature to identify evidence of abuse in care, as a strategy to support the call for a national inquiry into abuse in State care. (Mirfin-Veitch & Conder, 2017).

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- e. Being part of an inclusive research project that sought to understand how people with learning disability experience intimacy, relationships and sexuality, which illustrated more contemporary experiences of abuse in care (Luskie, W., Murphy, V., White, D. & Wallace, C. Milner, P., Mirfin-Veitch, B. Tikao, K., & Frawley, P. (2019).
6. In addition, throughout my 28 years as a disability researcher I have also focused on disabled children in care, parenting by people with learning disabilities, health and wellbeing, and access to justice. All this research has exposed direct and indirect experiences and examples of abuse both in care, and within family.
7. This brief provides evidence about abuse in care experienced by people with learning disability and people who are neurodiverse. In it, I will first provide some background about the DBI and disinstitutionalisation research prior to the Royal Commission of Enquiry. I will then draw on evidence from the range of sources outlined above, as well as new evidence collected during the inquiry through a project called *Tell Me About You: A life story approach to understanding disabled people's experiences in care (1950-2006)* ("*Tell Me About You*").¹
8. *Tell Me About You* was contracted by the Royal Commission in 2021, and was conducted by a team of DBI- and DBI-affiliated researchers (Refer to Appendix 1). The research details abuse that occurred, and how survivors understand the abuse, and its impact on their lives.
9. As I am not a clinician, I do not make clinical assessments of or judgements about any survivor.
10. The findings from *Tell Me About You* will then be compared with the evidence presented at four previous public hearings; the Māori Public Hearing, the Pacific People Hearing, the Lake Alice Hearing, and the Marylands Hearing, and disability-related content extracted from *He Purapura Ora, he Māra Tipu: From Redress to Puretumu Torowhānui* (Royal Commission of Inquiry into Abuse in Care, 2020).

¹ The terms of reference for the Royal Commission relating to the time period of the inquiry were amended after the development and ethical approval of this project from 1950 – 2006 to 1950 – 1999). The project title reflects the original inquiry time period.

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11. The brief concludes by analysing and discussing recommendations for redress in the context of previous and current research, with reference to its responsiveness to disabled people and to the inquiry's aim of identifying "how things can be done better in the future"².

Background

12. The DBI has been involved in disability research since 1984. Over nearly four decades, DBI researchers have witnessed both the closure of institutions, and the development of the community-based disability service system in Aotearoa New Zealand (Aotearoa). The DBI has always prioritised research based on lived experience, and inclusive and transformative research approaches. Examples of the DBI's research can be found at www.donaldbeasley.org.nz.
13. The DBI has always been committed to research that ensures the human rights of people with learning disabilities and other disabled people are upheld. As indicated earlier, in the 1990s and 2000s this included providing research evidence to inform best-practice disability supports and services, and by documenting the closure of large-scale institutions – commonly referred to as deinstitutionalisation research.
14. Deinstitutionalisation research typically focuses on the process of moving disabled people out of institutions (Sobsey, 1994), and, on disabled people lives in their new community-based services and settings (Kim, Larson & Lakin, 2001). Research tells us that the deinstitutionalisation movement gained momentum for three main reasons:
 - a. the appalling conditions in institutions (Blatt & Kaplan, 1974);
 - b. the idea that disabled people should have life experiences like non-disabled people in their particular culture and society (Nirje, 1985; Wolfensberger, 1992);
 - c. the development of a community based service system (Mansell & Ericsson, 1996).
15. Unfortunately, deinstitutionalisation research has not always sought to capture the lived experiences of people while still in, or soon after leaving institutional care. This is one of the reasons that abuse in care has been able to go unchallenged for such a long period of time (B Mirfin-Veitch, Contextual Hearing, 1 November 2019, Transcript 11.27 434-435

² Taken from Royal Commission Terms of Reference – Plain English version
<https://www.abuseincare.org.nz/our-progress/library/v/3/terms-of-reference>

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<https://www.abuseincare.org.nz/assets/Uploads/Documents/Public-Hearings/Contextual/Transcript-Brigit-Mirfin-Veitch.pdf>).

DBI research about institutional care pre-Royal Commission of Inquiry

16. This section of my evidence brief presents what is known about institutional care, and abuse in care settings for people with learning disability in Aotearoa. The purpose of this section is to show that there is strong evidence that disabled people experienced pervasive and systemic abuse in care prior to the Royal Commission's investigation starting. This evidence echoes in the survivor accounts currently being shared.

Templeton Centre deinstitutionalisation research

17. In 1999, the DBI began a research project that explored the closure of Templeton Centre. Templeton Centre was a large psychopaedic institution located outside Christchurch. At the time that the deinstitutionalisation process started in the late 1990s, 480 people lived there. I did my doctoral research as part of this wider project. My research questions were:
- a. What factors influenced families' earlier decisions to choose institutional care for their disabled relatives?
 - b. Who and what influenced the decisions that families make about transition from institutional to community based services?
 - c. How did siblings interpret the experience of institutionalisation and deinstitutionalisation?
 - d. How did families experience the impact of the transition of their disabled relatives from institutional to community based disability services?
18. It is important to be clear that while we met people with learning disabilities whose families and whānau chose to take part in the research, we did not gain their lived experiences of living in Templeton or what they thought about moving into the community. However, we did observe the institution "in action". In doing so, we gained a broad impression of the daily life of 35 Templeton Centre residents. Exploring the questions above provided insights into the impacts on family and whānau when their disabled family member went into care. These earlier findings are instructive to the current inquiry into abuse in care.

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19. For example, when I revisit the verbatim quotes from parents that I used to develop my analysis of family and whānau experiences of deinstitutionalisation, they are littered with clues that handing over a disabled child to the care of the State was traumatic for families. My analysis identified what I referred to as “a typical family’s story”. This was intended to communicate that regardless of the timing of a family member’s entry into care and despite the differences amongst individual families and whānau, families all described a shared set of experiences. These played out in order over time and were:
- a. A commitment to maintaining the family unit – *“I had that little boy and I need to look after him, he’s my responsibility, he’s got no one else and he’s not going to that dreadful place [Templeton Centre]”* (Mirfin-Veitch, 2005, p. 92).
 - b. The (futile) search for community based services – *“Yeah the strain was beginning to tell on me. Definitely. Because at that time there wasn’t really any support at that time from anybody. Anywhere. There wasn’t any relief or respite care or anything like that. No. So I guess the strain was definitely beginning to tell on me, which is why she went there in the first place”* (Mirfin-Veitch, 2005, p. 93).
 - c. The (ongoing) challenges to caring – *“Well [our non-disabled] daughter is 22 months younger than [son] and I must admit that when I found out that I was pregnant with her I really panicked and it didn’t really help that when I took [son] to Plunket nurse...and when she found out I was pregnant she said ‘Oh I can’t believe it, how on earth are you going to cope?’...That was terrible in fact...I really panicked when I was in [maternity hospital] and I do remember they put me on sedation, I just couldn’t imagine how I was going to cope when I got home – because [son] actually took up more time than [new baby]”* (Mirfin-Veitch, 2005, p. 95).
 - d. The influence of professionals – *“I mean when [paediatrician] said to us – when he told us about [son] and what life would be like, he said ‘when you want care outside of the home you go and get it’. He said ‘don’t hesitate’. I said oh yeah sure, not believing that we would ever do it or need to but [my wife] was a bit more realistic perhaps and decided that, you know, the time had come.”* (Mirfin-Veitch, 2005, p.97)

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e. The catalyst for permanent out of home placement – *“You just cracked up one Saturday didn’t you?”*³ (Mirfin-Veitch, 2005, p.98)

20. Every single parent who took part in the research described the decision to place their disabled child in Templeton Centre as the hardest and most painful decision of their lives (Mirfin-Veitch, 2003). One parent said:

“It was earth shattering, it really was... Oh man, it scared the living daylights out of me. I walked in there and there was all these people sitting in front of a television set, obviously not seeing what was on telly... No, no it really fazed me, and that would have been one of the most traumatic times in my life. It was sort of like the realisation that you’d failed, you know. (Mirfin-Veitch, 2005, p.99).

21. The stories that parents, and siblings told within the Templeton research evidence showed the more subtle abuses that occurred as their disabled family members entered State care. For example, families were told to leave their child and to *not come back for six months*. Most families took this advice and experienced acute guilt and critical damage to family relationships.

22. A sister said:

“Things that I remember my family saying was that they couldn’t have contact with him when he first went out there for six months, she couldn’t go and see him, he couldn’t see her and they both fretted which I think was a barbaric way to handle it back then” (Mirfin-Veitch, 2005, p.100).

23. Other comments spoke to the loss of personhood that parents felt on their child’s behalf.

“I sat up all night sewing little names on all his clothes and everything, and I was just told – you know, take them away. He’ll be having institutional clothes” (Mirfin-Veitch, 2005, p.100).

24. This research shows the huge responsibility that mothers had to bear in relation to their children ending up in care. In summary – mothers made the final decision about care, and

³ The catalyst for out-of-home always centred on the physical or mental health of mothers. The only exception to mothers making this final decision was a father who parented alone.

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then carried the burden of that decision. While it is clear that they made those decisions due to an acute and systemic lack of support, it was often perceived as being a result of them being “unable to cope.”

25. Sometimes fathers walked out on these mothers because they were unable to accept the disabled child – sometimes they left because they were unable to accept the mother’s need to seek out-of-home care. Now we see that a complex mix of disablism, ableism and sexism, in conjunction with a lack of disability supports, were at play. It is unlikely however that any of the mothers conceptualised the position they were in at the time they made these traumatic decisions, which many carried for the rest of their lives.

26. Another key issue to come out of this research was that mothers made decisions about care of disabled child due to concern about their non-disabled child(ren). The following comment was common:

“I should have given him up sooner because my daughter didn’t have a childhood and then at 11 or 12 when other children were developing into other things, she went back to playing with dolls. So she missed out on being the little girl, she was always Mum’s right hand.” (Mirfin-Veitch, 2005, p.106).

27. Despite mothers feeling as though they were doing the right thing for their other children, the non-disabled siblings interviewed for this research frequently talked of the negative impact of their sibling going into care. The title of my doctoral thesis was *Dislocation* to reflect the sense of family and whānau being fractured or broken when their sibling was given over to Templeton Centre.

“I mean why him and not me? A lost brother, yes I don’t quite know what the sadness is, but it’s something quite deep and quite sad. And since piecing the history together over the last nine months and getting clear about the chronology of family events from his birth onwards, I see now even more and having my own children – I see now even more strongly that I had at any other time in my life – the massive dislocation of having someone removed from a family situation at such an early age. When I think about my own family...it’s something I can hardly think about, You know, a five-year old coping on their own. So there’s quite a lot of feeling around it, Yeah, there’s a tremendous amount of feeling there and it’s quite emotional...” (Mirfin-Veitch, 2005, p.117).

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28. And finally, even simply asking family to reflect on the positive impact of community based living highlighted the perceived loss associated with disabled people going into care (as a result of an absence of formal support for families and whānau).

“No I don’t think there’s anything I don’t like [at the community based service]. I just wish the whole thing had happened 20-30 years ago. I just look back and think what a lot he’s missed in his life” (Mirfin-Veitch, 2005. p.239).

29. The purpose of sharing this research about family and whānau experiences is not to give their voice primacy over the the voices of survivors’ themselves, but to illustrate that even when not specifically asked to speak about negative aspects of care or abuse directly, parents and siblings accounts speak to relational and material loss to both the individual and to family and whānau created by institutional care.

Kimberley Centre deinstitutionalisation research

30. Kimberley Centre was a large, psychopaedic institution located near Levin, in the Central North Island. It opened in 1906⁴ and closed in 2006. The Kimberley Centre was the last, large-scale psychopaedic institution to close in Aotearoa and provided a final opportunity to capture outcomes associated with deinstitutionalisation.
31. The Ministry of Health and the Health Research Council of New Zealand jointly commissioned the DBI to conduct research intended to identify the impact of institutional closure for former residents with learning disabilities, their family/whānau and Kimberley Centre staff.
32. This research was mixed-method, meaning that it combined qualitative and more quantitative measures of quality of life. Our research involved many, many hours observing Kimberley Centre residents during the very final months of the institution, and within the first months of their transition to community-based services. In addition to watching and talking, we also administered quality of life and adaptive behaviour measures and counted the communication opportunities for individual participants in both

⁴ The institution that became widely known as Kimberley started in 1906 as Weraroa Boys Training Farm for juvenile delinquents. From 1944 it was known as Levin Farm and Mental Deficiency Colony and in 1957 it was gazetted as a hospital: and named Levin Hospital and Training School. In 1977 it was renamed Kimberley Hospital.

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the institution- and community setting(s). In summary, Milner et al (2008) reported that Kimberley residents performed poorer on all measures of adaptive behaviour, with their poor performance relative to their age peers which could be attributed to the realities of living in an institution that suppressed ongoing learning. The examples of the realities of Kimberley residents are:

- a. Almost all of the resident's day-to-day lives unfolded within the walls of the Kimberley Centre and whilst the expansive grounds created the illusion of spaciousness, Kimberley residents, on average, spent 97 per cent of their time locked in their villa.

“RESEACHER: Participation and activities in the broader community, you are saying most of her life happens around here other than mum taking her out to the bach and stuff like that. Do they do other stuff? Do they go out?”

STAFF: No she doesn't. I do believe she might experience that sort of thing when mum takes her out but no, it doesn't happen for her here at Kimberley, no.” (p.85)

- b. Residents had limited opportunities to engage in purposeful activity or to engage in roles that might nourish personal development.

“She is actually pretty good really but doesn't get the opportunity to, like practice cooking she can boil water and things like that but she could probably learn. I would say she would be able to cook her own toast and make herself a cup of coffee without too much trouble. It is just that she doesn't really get the opportunity.” (p.65)

- c. During the day, residents ordinarily lined the wall of the dayroom waiting for the unvarying interruptions of lunch, morning and afternoon tea.

“(Staff) Nothing very exciting ever happens. She is always awake when we go to do her cares so that would be about 8.30 I suppose in the morning. She is showered, all her personal needs have to be done for her so she is showered, dressed, put in her chair and she is fed by a nasogastric tube so that's put on and there [Resident] stays.” (p.56)

- d. The research highlighted that residents were seldom spoken to, with 63 per cent of all interaction events lasting less than a minute, and that there was a general

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acceptance of the quiet but distressing denial of the rights of people who could find little use for self-expression through language.

“A lot of these residents here, I can’t understand why they don’t talk more. If they can put a few words together, they should be able to do more than they do. I think it is just chosen, they just choose not to say anything, I really do.” (p.59)

- e. Many residents entered Kimberley speaking but would leave silent.

“I don’t know, probably because I don’t know, maybe it is because they have been told to be quiet and shut up over the years and just decided that is the best thing to do.” (p.59)

- f. Stories of physical and sexual abuse were commonly reported by family and staff who both described the “Kimberley Cringe,” (by residents) as a widely acknowledged part of institutional lore (Milner, et al, 2008, p. 185).

“See I have been here over ten years all up and these people were brought up in fear here and I have seen that. They were brought up in fear, when you look at things that went on in this place, it was horrific. They were cruel, they were very cruel people. We had men out in the courtyard 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.” (p.185)

33. While this research was not designed to comprehensively capture each individual’s complete life story, it has critical importance to the Royal Commission. The key findings outlined here relate to Kimberley residents during the first half of the 2000s. While they undoubtedly captured that the institution was in a phase of transition, they equally captured that evidence-based practice should have been influencing the quality of support the residents were receiving.

34. In short, it can reasonably be assumed that if the deficits in support and the associated abuses of personhood were occurring in this more contemporary context, then we can also safely assume they were even more prevalent during the period covered by the Royal Commission – indeed there is evidence to support this claim.

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“Institutions are places of abuse” literature review

35. In 2017 I co-authored a report titled *“Institutions are places of abuse”: The experiences of disabled children and adults in State Care* with my colleague Dr Jenny Conder. The full report can be accessed at <https://www.donaldbeasley.org.nz/publications/abuse/>. The research was undertaken during the campaign for a Royal Commission of Inquiry into abuse in care, and commissioned by the Human Rights Commission. The research was designed to capture the voices and experiences of disabled people, particularly people with learning disability, who were abused in care in Aotearoa prior to 1992 and responded to a concern that disabled people, including people with learning disability comprise a significant part of the *silent majority* who have not had the opportunity to tell their stories of abuse in care.
36. I provided a comprehensive overview of this research, including the method used to generate data, during the Royal Commission contextual hearings in November 2019 (<https://www.abuseincare.org.nz/our-progress/library/v/63/statement-of-dr-brigit-mirfin-veitch>) but it is instructive to revisit those findings in broad terms as they provide important context for our current research *“Tell Me About You”*.

The motivation for the *“Institutions are places of abuse”* research was to: determine what [was] known about the abuse of disabled people, including evidence of systemic abuse; identification of gaps in available evidence about the abuse of disabled people in care; and recommend a research pathway with the potential to address gaps in knowledge relating to disabled people, abuse and [State] care.

37. As a disability researcher with a significant background in deinstitutionalisation, in my earlier evidence I reflected on the failure of researchers (and others) to pay enough attention disabled people’s experiences while living in institutions due to our collective interest in promoting and exploring the movement of people out of institutions. I also noted that despite this omission, I was also aware that disabled people, including people with learning disability had found ways to tell their stories of abuse in care in a range of ways. I was of the view that the information captured as part of these “other” studies and life history projects could tell us a lot about the experience of living in care – we just need to look in different places, and to “listen” closely to what people had to say.
38. *“Institutions are places of abuse”* drew on publicly available accounts told by people with learning disability and other disabled survivors, and relevant research. All of the survivors

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had experienced care during the period 1950 – 1992, with a small number entering care prior to 1950. The research generated strong evidence that abuse in care was experienced by disabled people, including people with learning disability. The abuse described was serious and pervasive, and encompassed neglect, physical, sexual, psychological (emotional), control and restraint, spiritual, financial. We also found that the abuse was institutional (Sobsey, 1994), and systemic (Robinson, 2013). Specific details of the abuse individual survivor's experienced can be accessed in the full report, and in my earlier evidence.

39. The final aim of the research was to recommend a research pathway with the potential to address gaps in knowledge relating to disabled people, abuse and [State] care. We asserted that while it was not uncommon for people with learning disability, and other disabled people, to share their past experiences of abuse in care, it was often within the context of research not specifically designed for this purpose. This means that the evidence of abuse shared in these settings cannot be sensitively and ethically included.
40. Furthermore, research in this area is also required to be alert to the issue of informed consent, particularly when people might need more support to make a decision about taking part in research, or when they communicate using strategies other than speech. We concluded that:

“Research that has the 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.” (Mirfin-Veitch & Conder, 2017. p. 46).

Research conducted to contribute to the Royal Commission

Tell Me About You: A life story approach to understanding disabled people’s experiences in care (1950-2006)

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41. In 2020, the DBI went through a comprehensive commissioning process to undertake research funded by the Royal Commission. The research received ethical approval from the Royal Commission Research and Ethics Panel (REAP), and from the Health and Disability Ethics Committee (HDEC). The research responded to specific Royal Commission terms of reference including:
- a. The nature and extent of the abuse that occurred while they were placed in State care or State funded care (10.1).
 - b. The physical, cultural and emotional landscape within which abuse was experienced, to throw light on the structural, systemic and practical factors they identify as contributing to reported abuse, neglect or exploitation (10.2).
 - c. The impact of abuse on Storytellers, their families, whānau, hapū, iwi and communities, including their understanding of the immediate, long-term and intergenerational impact of living in State care or State funded care (10.3).
 - d. What storytellers understand of the circumstances that led them to being taken into, or placed into care and the appropriateness of those placements (10.4).
42. The purpose of this research was to create an opportunity for individuals with a learning disability or who are neurodiverse, and who were placed in State or State funded care, to “speak for themselves.”
43. Drawing on the principal study question: ‘what was your experience of care?’, a life story approach was used to support participants to talk about their care experiences rather than abuse per se, in recognition that not all experiences are immediately identified as abusive. This approach is also supported by trauma-informed care approach, which states the importance of shifting the focus from ‘what’s wrong with you?’ to ‘what happened to you?’⁵
44. Trauma informed care is based on the understanding of impacts of trauma on individuals such as how trauma can influence individual’s thoughts and actions (Wilson, Pence & Conradi, 2013). By acknowledging the impact of trauma, it separates the individual from their thoughts pattern or actions, and encourages the practitioners to ask the question

⁵ Center for Health Care Strategies. (2021). *What is trauma-informed care? - trauma-informed Care Implementation Resource Center*. Trauma-Informed Care Implementation Resource Center. <https://www.traumainformedcare.chcs.org/what-is-trauma-informed-care/>

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“what happened to you?” rather than “what’s wrong with you?” (Center for Substance Abuse Treatment, 2014).

45. The five core values of trauma-informed care are (1) safety, (2) trustworthiness, (3) choice, (4) collaboration, and (5) empowerment (Fallot & Harris, 2009). This approach of care shifts the relationship dynamic between the practitioners and clients from hierarchical relationship to collaborating partnership. The important part of trauma informed care is that the individual takes the ownership of their story and healing and the practitioners are there to support the journey (Center for Substance Abuse Treatment, 2014: Wilson, Pence & Conradi, 2013).
46. This understanding of trauma, and its core values were woven into the overall design of the research, alongside carefully considered and culturally responsive recruitment, data collection, and analysis methods. These values also contributed to our decision to invite people who had experienced care to participate as Storytellers rather than survivors. We were aware that some of the people we would eventually work with would tell stories of abuse in care but not necessarily identify themselves as survivors for a range of reasons. The key aspects of our research approach are briefly outlined below.⁶

Individually Responsive Methods (IRM)

47. To ensure Storytellers had choice and control over how they told their stories, the research team used an Individually Responsive Methodological approach. Individually Responsive Methods (IRM) was developed by researchers from the Donald Beasley Institute (DBI) as a way of including the voices of disabled people whose experiences and subjectivities are difficult to access using conventional research methods.⁷ IRM offers people the chance to design and control their research presence by working with a researcher (writing partner, story gatherer) to design methods and narrative forms that are personally meaningful to them. This is also responsive to the trauma informed care approach.
48. Between 2021 and 2022, fifteen Storytellers were recruited via the DBI’s extensive networks with the assistance of project champions working in mainstream and kaupapa

⁶ A comprehensive report on “Tell Me About You” can be accessed from the DBI website (www.donaldbeasley.org.nz) from July 2022.

⁷ Milner, P. & Frawley, P. (2018). From ‘on’ to ‘with’ to ‘by:’ people with a learning disability creating a space for the third wave of Inclusive research. *Qualitative research* pp. 1-17, doi: 10.1177/1468794118781385.

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Māori intellectual and neuro-disability support services, NGO's, or advocates or close supporters of interested individuals.

49. Maximum variation sampling was used to ensure the stories reflected the diversity of the population of people with a learning disability or neurodiversity placed in State care or State funded services between 1950-1999, and the array of possible care contexts.
50. In keeping with the IRM approach, Storytellers were assisted by project champions and/or the project lead to choose the story gatherer (researcher/writing partner) they wanted to work with. Early meetings were focused on building rapport and articulating the supports and accommodations they needed to tell the story they had in mind.
51. When the rapport was built, the story gatherer asked for Storyteller's fully informed consent. This meant several potential Storytellers communicated interest in taking part in the project but could not demonstrate that they had given their informed consent. There were three key components to informed consent: what the project was about; what they were being asked to do as participants; and what was going to happen to the information.
52. It was often difficult for people to communicate their understanding and agreement of this last part of the consent process, even when they knew we were there to talk about their experience in a particular care setting. That is, people in this group had things to say, but we could not (formally) listen.
53. So, while this project reached people with learning disabilities and neurodiversity who, for the most part, had not been part of the Public Hearing and other redress processes, we also reached but were unable to work with another group of people with more complex disability due to our ethical obligations.
54. In order to work with this challenge, ethical approval was given to enable us to talk to family, whānau and close supporters of people who are unable to give fully informed consent. This approval was given on the basis that the family, whānau and close supporters voices were not to be used as proxy to the disabled person's own voice, and was only to be interviewed from their own perspective as family, whānau and close supporter. However, several people we identified through the project champions did not have family, whānau or close supporters who could share the experiences of state care from their perspective. Four other families and close supporters that were approached were hesitant about sharing their experience and did not decide to participate.

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55. The engagement with people who could not give fully informed consent and their families required a significant amount of time, and regardless of our ability to include their stories it is important to note their quiet presence in our project. Significant parts of their lives were lost to institutions and their stories remain untold and invisible.
56. In addition to the challenge of the informed consent, COVID-19 added to the difficulty of recruitment. During the recruitment phase of September 2021 to February 2020, COVID-19 response alert level kept changing. This meant that some of the services, and particularly kaupapa Māori services were under pressure, and understandably did not accept outside visitors during that period. As a result, the original aim of gathering stories from 20 Storytellers was not achieved within the timeframe. Had we had more time and been able to travel freely and enter disability residential services across Aotearoa New Zealand in the absence of COVID-19, we have no doubt we could have easily met the original sample target of 20 storytellers.
57. Of the 16 Storytellers who participated in “Tell Me About You”, 12 were male and four were female. Fourteen Storytellers identified as European New Zealander, one as Sāmoan New Zealander, and one as Māori and European New Zealander. All Storytellers were between the ages of 45 and 75, with a median age of 58-years-old.
58. Ten Storytellers had learning disabilities, three had Autism, and one storyteller had a neurological disability. Among these Storytellers, at least three had known co-existing learning disability and physical disability, learning disability and neurodiversity, or learning disability and psychosocial disability. One participant shared his perspective as a family member alongside the disabled person who had experienced State care. One storyteller contributed to the project as a sibling of two individuals who had lived in care settings for most of their lives.
59. With regards to care contexts, eleven Storytellers had lived in State-run institutions, four attended faith-based schools, and one had lived in foster care. Nine Storytellers had lived in multiple care settings, including faith-based schools and psychiatric institutions. Currently, five Storytellers live independently, with three supported by support workers. Nine Storytellers now live in residential homes run by Disability Support Services (DSS).
60. A key aspect of the IRM methodology is enabling Storytellers to choose how they want to contribute their particular life story. Each Storyteller met with their writing partner

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(researcher/story gatherer) three or four times to co-create and sign-off their Life-story using IRM.

61. Researchers began by seeking permission from each Storyteller (participant) to make an audio recording or take notes of the conversations they shared together. The purpose of the recordings was to provide an aide memoire to the pair when it came to co-creating the final story. Life-stories were then documented through data collection methods that included, but were not limited to:
 - a. Semi-structured interviews/ 'Just sitting and talking': Loosely structured interviews about the 'different faces' of care, experiences and nature of abuse and the paths to recovery.
 - b. Walking Methods/ 'Walking and talking': Storyteller's orientating their writing partner to their life by taking them to places that were important and telling them why as they walked.
 - c. Personal Archives/ 'Sharing things that say who you are and what you have experienced': Storytellers could select and share personal archives such as photos, film, music or text that helped them to talk about their experiences of Care and abuse.
 - d. Art based ethnography/ 'Finding creative ways to tell a story': Using art or poetry as a way of thinking and talking about abuse and relationships.
 - e. Telling their story with the help of trusted whānau, friends or advocates.⁸

62. The kaupapa of the project was that the Storytellers were the experts when it came to representing their own experiences of care, including abusive experiences. Taking an IRM approach opened space for Storytellers to reflect, interrogate, refine and control the way they were present in this research.

⁸ Although not taken up in this research, all DBI projects utilising IRMs include Kaupapa Māori methodologies as part of the suite of methods offered, for example Storytellers can explore Māori imagery and mythical stories as culturally referenced ways of relating significant life events or of communicating the Storyteller's feelings.

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63. By adopting an IRM approach to story gathering, any Māori Storytellers could choose to shape their participation in a range of culturally responsive ways, in accordance with kaupapa Māori research methodologies and tikanga Māori.
64. While significant efforts were made to invite Māori Storytellers, only one Māori Storyteller ultimately took part. This person made an informed decision to work with two researchers' who did not identify as Māori due to the rapport they had built with them when learning about the research.

The “Tell Me About You” Findings

65. The research findings are presented in two ways in the final report; as a series of individual stories in a range of formats, and as a thematic analysis of the collective stories. For the purposes of this brief, individual examples of abuse are drawn on to highlight the range of experiences across the group of Storytellers who chose to take part in the research. More detailed personal context and thematic analysis is contained in the full research. Each standalone quote comes from a different Storyteller. In this brief none of the Storyteller's are referred to by name however some people did choose to use their own names in their stories, which are included in the full report.
66. The quotes I use below illustrate abuse in both its most violent and more subtle forms, mirroring the evidence identified in our earlier review of published research and accounts (Mirfin-Veitch & Conder, 2017). The abuse recounted here occurred in psychopaedic and psychiatric institutions, schools and, in one case, a foster home. The abuse was experienced by men and women.⁹

⁹ Only one Storyteller had a positive account of care, however her story is instructive as it relates to a particular (more contemporary) time in one institutions history. It also speaks to a heirachy of disability at play whereby people perceived as “less” disabled had a better experience. This is discussed in our full report.

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67. Storytellers understanding of the reason why they went into care was mixed. Some people had no idea why they ended up in care, while others knew exactly why they went there:
- a. *"I moved to Cherry Farm from Seacliff. I can't remember how old I was. When I got there, my arms were shaking. It was scary and frightening. The tablets for my turns made me all better. They made me feel calm and tired out."*
 - b. "I was in Cherry Farm, sort of at the side. I think I was about 28 years old [when I went there]. I don't know how I got there. I feel like I was born in Cherry Farm. Did you find out how I got there?"
 - c. "My mum found it difficult to manage me so I went to stay at Templeton for short stays and then eventually these stays got longer."
 - d. "My family thought it would be a good idea for me to live at Seaview. One of my sisters' worked there. Going from living with my mum in our own house in the community to living in Seaview was a big change. I was thirty-nine years old when I moved in!"
 - e. "I was two years old when I was diagnosed with cerebral palsy. There was little support for disabled children and their families when I was little. The doctor instructed my mum for me to go to an institution, he said, 'it would be better this way'. Soon after I was moved to Kimberley centre."
68. One of the most frequently mentioned and traumatic experiences for Storytellers who were in psychopaedic and psychiatric was seclusion:
- a. *"I would be bashing on the walls and me hands bleed and then all of a sudden I would hear the key in the lock, the big steel one and man's would rush in there, hold me on the floor, give me a needle in the backside thing to calm me down a bit and then they would lock it all again, big steel key, like that young fella had before, a big steel key and um. And um I would lie on the floor in there, the lock up room in [institution villa name], I don't know how many hours they would leave me in there and ever since then I have had a fear of the dark"*

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at night ya know [I still] I have a bedside lamp going beside me bed while I'm in bed".

- b. *"I didn't like it there. They locked me up and I don't like that. I don't know why they locked me up. It was cold and made me sad. I was falling off the chair. Someone helped me up. She was nice to me. I would have turns and fall onto the floor. The staff didn't help me... I was in there, but I was sad there. Don't talk about it. Let's stop talking about it."*
- c. *"The staff were no good to me at Cherry Farm. They used to give me a needle in the arse. They would stab it into me. And give me lots of pills. I hadn't done anything. I was scared of them. [They would] just knock me around because I used to play up and that. They used to ah, hit me. I got locked up in Cherry Farm. The room was empty. Only floor boards and a big door. I was in that room for a long time. Sometimes I used to hurt people too - I don't know why I done that."*
- d. *"My worst memory was seclusion. I don't remember why I was put into seclusion. In the seclusion room there was a small bed with a mattress on it. There was a small square window that other people could look through. A lady came and checked on me sometimes. Once I got angry in seclusion and threw the sheets around the room. Another time when I went to seclusion, two staff members got hold of me and twisted my arm and broke it. I had to have a sling for that. But finally someone came and opened the seclusion door in the end. I had to take a blue pill while I was in Cherry Farm to calm me down. All my life I've had medication but um these people at Cherry Farm weren't very nice to me. There were two seclusion rooms in my ward. Yeah, everybody would have hated [getting locked up], I should've felt for them more."*
- e. *"And of course there is a feeling of guilt, we sent him there you know. If [our son] hadn't have gone there, he might not be as educated, but he wouldn't have black memories. We went up there once and he was in confinement, we couldn't see him. I asked them why, what had he done and they told us he had pinched the night watchman's lunch."*

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69. It was common for stories to include descriptions of regular physical and emotional abuse, including the lack of care or redress storytellers received if they did try to report bullying by other children they lived with or abuse by staff who were supposed to be caring for them:
- a. *"I got put in a laundry bag once by staff and hung up high.
I told the big boss of Templeton on him – he got a warning.
I got strangled by another and that staff member got a warning also.
He later left Templeton cos he didn't like the big boss.
I saw a staff member slapping a resident's face.
He kept slapping him. I rang the police. They came.
They saw marks on his face and knew I was right.
The police gave the staff member a warning."*
 - b. *"He was a good boy ol' [GRO-B] He knows what is going on. I look after [GRO-B] cos I don't like people hitting him. Staff were hitting sometimes, and I like ol' [GRO-B]. Don't know why they did that must have been mean. Not all staff were mean just some of them. I really liked S at Templeton. She was my main caregiver, she knitted me a jersey and was kind to me. I bought the wool."*
 - c. *"I used to be called rabies and ra-ra woof-woof by other pupils because I was scared of dogs. There was some people that would even hit me and even throw stones at me and even do all sorts of things because I had a disability such as Asperger's autism. I used to sometimes tell the staff and tell the teachers. But some staff would just say I got upset when I was being bullied. They were not being very helpful because some of the staff you know, thought I was just over reacting when all I was just trying to do was get my point across and ask staff to help me and support me when I didn't feel safe around some of the pupils. Or you had to go and sit outside the seniors office. I remember that. If you were outside the senior's office you had to stay there till bedtime. When everyone else was in bed, they took you over then. You had to be nice and quiet when you went in."*

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- d. *“The whole group (patients and staff) would often gang up on one patient who had “said or done the wrong thing,” no matter how unintentionally; this was a pattern carried out daily (often more than once per day) for my whole stay in Claybury House. This had the effect of traumatising me (and presumably some of the others.... i.e. the ones who were more often targeted by the group). If a targeted patient was in tears at the end of the Monday Mimes (or any other group “therapy” session), they were simply left there to cry while the rest went off to morning tea or lunch; the staff members would deliberately leave them in a distressed state. Sometimes another patient would stay behind to try to comfort the crying one, though this was not usual.”*
- e. *“[Do you feel comfortable talking about what happened to you?] I don’t feel like talking about that part.”*
70. One Storyteller shared about her experience of neglect and alienation from her own culture:
- a. *“I only remember small amount from my years at Kimberley. I was sharing a room with other children there. During the day, we sat in the recreational room but there were no activities going on – we hardly interacted with each other. In the shared space there were people of all ages with different disabilities. The institute felt “dark and cold”... No one knew about my Samoan heritage or if they did there was no recognition, interest or inclusion. Even I didn’t know.”*
71. Two Storytellers openly shared their experiences of sexual abuse in care:
- a. *“I experienced sexual abuse during my years living in foster care, at the age of nine in particular. This was by my foster brother-in-law. The first incident took place on one weekend when I stayed the night at my foster sister's house. There were other occasions, but I can't recall the exact timeframe of these events, but it was when my foster sister wasn't around. She was in her bed at the time (on*

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the first incident) and then another time. There was inappropriate behaviour from the brother-in-law in company of the other family.”

- b. *“There was some abuse going. I'd like to meet this young man [who abused me]. But I'm not going to go on and on about it for too long. But he would have been there before me and I'd like to meet him. The only thing I wanted to do was I wanted to get away from the one that offended me. But I wanted to know who offended [him] before I came on the scene?”*

72. Storytellers reflections on leaving care also provide important insights into their care experiences, and what it has made them value in their current lives:

- a. *“I've got no family now, only this family. I like it here. I don't get locked up here. I wouldn't want to go back to Cherry Farm.”*
- b. *“A good life is going and looking around shops, getting coffee. I'll tell you a good thing right, if I'm on a radio show, you might hear my voice everywhere. I was on a radio show and I can still be on it. There's a song I like. “I'll be home for Christmas, you can count on me”. It makes me a bit happy. One thing that I know, stand up for your rights. You get together with someone and stand up. That means rights. That means rights.”*
- c. *“I always say this, that everyone should be treated equally. I didn't feel like I was treated equally before I started living in the community. I think when you are out in the community you have your own freedom and you're not, you're not told when to shower or when to eat and you have choices of what you want to do. Rather than what you were told to do. I have control on my own choices and more freedom too. I have a good landlord, a new couch and a new chair. I've been very settled here ... I'm going to be living in the community until I'm an old man.”*

73. The small selection of quotes used here answer the four aims of *Tell Me About You*. They tell us about the nature (bullying, emotional/psychological abuse, physical abuse, sexual abuse, medication abuse, cultural abuse, neglect) and extent (pervasive and

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violent) of the abuse that occurred. The quotes also speak to the physical, cultural and emotional landscape(s) within which abuse was experienced (isolated, relationally and culturally impoverished and (largely) devoid of systems that either prevented abuse, or provided a pathway to complain). Disablism and ableism were inherent within care settings and underpinned the abuse. The impact of abuse is clear in the distressing descriptions that Storytellers have shared – even when they do not use a lot of words. The impact of abuse is clear in the words of whānau who describe their enduring guilt. And this small number of quotes provide insight to the pain of being dislocated from family and whānau, and the reflections on their current lives and living situations show very clearly that they now experience greater recognition of their personhood, and choice and control over their lives.

74. In our previous research *Institutions are places of abuse* we considered whether the abuse that we found in a range of published accounts was systemic abuse. We asserted that it was.
75. When we considered the evidence embedded in the stories people with learning disabilities and people who identified as neurodiverse were brave enough to share in *Tell Me About You*, it was impossible not to come to the same conclusion.
76. Systemic abuse (also referred as institutional abuse) refers “not only to the direct physical abuse” but “*violence inherent in a system*” (Žižek 2008: p.1–8). Systemic abuse has a range of features, including to routinely prioritise order of a place over an individual’s needs (Goodley & Runswick-Cole, 2011; Minshull, 2004); power dynamics where staff are dominant and vulnerability is created for residents (Jones, 1994); and conditions and policies that are abusive, for example allowing abusive interactions or depriving an individual of their potential and optimal development (Gil, 1975). Furthermore, some argue that even if the professionals and people in care-taking roles did not personally agree with abuse and violence, practices such as inappropriate punishments and neglectful oversight are prevalent in institutions (O’Rourke et al., 2021; Minsull, 2004). Finally sustained and pervasive prejudice that considers disabled peoples’ bodies and minds as deviant from the norm and in need of intervention to adapt to the order of the society is considered systemic abuse by disability studies academics (Goodley & Runswick-Cole, 2011).
77. It is not necessary to be a critical disability studies theorist to see all these elements at play in the stories contributed by the storytellers in *Tell Me About You*.

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78. However, a deeper level of analysis was also undertaken across the collective body of the stories. The theoretical framework used for this analysis process was the ecological understanding of disability violence and abuse (Sobsey, 1994; Hollomotz, 2013; Fitzsimons, 2009) . This framework facilitates an ability to explore the interrelatedness of factors that both impact on disabled people, and create environments where violence and abuse of disabled people is prevalent and pervasive. The model explores these factors at four levels: individual; relational; community; and societal levels. It is believed that the learning that can come from this layered analysis can help to build understanding of why abuse occurs, what responses are needed; and how to prevent violence and abuse from occurring.
79. Across the body of stories, applying this analysis generated more nuanced understanding of the storytellers' experiences of abuse. While more detailed analysis and findings are contained in the full Tell Me About You report, for the purposes of this brief, key findings relating to each of the levels of the ecological model of abuse can be summarised in the following way.
80. When the stories were explored at the individual level it was clear that while living in care, storytellers were not seen as having individual agency or autonomy – in other words, they were not seen as rights holders. Linked to this, they were viewed as inherently incapable and as not able to express or enact their own will and preferences. This was underpinned by the fact that care institutions labelled, wrote about and “treated” people in a way that denied their personhood.
81. When stories were analysed at the relational level, it was clear that the storytellers experienced a lack of power, others making decisions about them, being prevented from maintaining existing relationship or creating new ones due to the rules of the care setting. In summary, at a relational level, the storyteller’s lives were characterised by people having power over them, others determining the rules of relationship(s), which resulted in limited or no opportunities to form, manage or mediate respectful social, family, peers or intimate relationships.
82. Analysis at the community level of the ecological model of disability violence and abuse alerted us to the fact that being a survivor of care meant that storytellers were not able to make choices about their housing, or their education or employment. These restrictions applied while living in care, but continued to impact on their lives beyond the

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care settings that are the focus of the Royal Commission. Linked to this point, for example, storytellers often had a lifetime of being the recipients of services and supports, or as reliant on the state for financial supports and consequently seen as non- or unproductive members of the community and as non- or at least unimportant citizens.

83. Finally, at the society and system level of the ecological model, when the context of the storytellers' care experiences were examined, it is clear that the system operated on the basis of laws and policies that diminished (at best) or completely eroded people's personhood. As one storyteller expressed – "*it is built on a system that dehumanise[d] disabled people*". At the societal and systems level, the stories illustrate very overtly, that storytellers experiences were shaped by models of care, health, education and employment that segregated and 'specialised'. Furthermore, while there may have, in theory, been systems for protection or complaint, in real terms storytellers had no access to legal or social protections during their time in care.
84. These four levels of the ecological model of abuse and violence in the lives of disabled people intersect to create and to explain the realities and circumstances of care that the storytellers shared.

The disability evidence from other public hearings

85. While the storytellers' accounts are accepted without question as their truth and their lived reality, it is instructive to explore what others have said within the Hearings that have already taken place.
86. As part of our research process, we applied a disability lens to *He Purapura Ora, he Māra Tipu: From Redress to Puretumu Torowhānui*, and to *Tō muri te pō roa, tērā a Pokopoko whiti-te rā: Māori Public Hearing*, *Tulou – Our Pacific Voices: Pacifica Public Hearing* and the *Marylands* and *Lake Alice Hearings*, to explore survivor accounts and other evidence that spoke directly or indirectly to the experience of disabled survivors.
87. Across all documents, disabled survivors were not highly visible - there were only a small number of disabled survivors, and only a small number of people who spoke about disabled survivors. In the case of the *Marylands* investigation, *Marylands* itself was described as being a residential school for boys with learning disabilities, however the

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investigation and hearing focused on the faith- rather than disability-based aspect of Marylands. Ultimately, like the previous DBI research outlined at the beginning of this brief, and the current “*Tell Me About You*” research, a brief thematic analysis of the interim redress report, and the previous hearings, highlighted the same disturbing key findings, which are outlined below:

88. In *He Purapura Ora, he Māra Tipu: From Redress to Puretumu Torowhānui* (Royal Commission of Inquiry into Abuse in Care, 2020), which pre-empted the individual hearings mentioned above, it was identified that ableism¹⁰ and eugenics¹¹ underpinned the institutionalisation of disabled people.
89. Families and whānau were recommended to place their family members with disability in institutions by medical professionals and the State. Families did not have sufficient support at home at that time, and therefore, could not challenge the recommendation. Once they were placed in institutions, disabled people were there for long periods of time, and sometimes they died in the institutions and were buried in unmarked graves.
90. Disabled people experienced abuse and neglect at these institutions including physical and sexual violence, psychological/emotional, racial/religious, and medical abuse such as improper use of Electroconvulsive Therapy (ECT) and forced injection. Some disabled girls and women experienced forced sterilisation.
91. During the 1990s, the main psychiatric and psychopathic hospitals closed down, and more than 10,000 people moved into community-based care settings. Since then, many survivors of these institutions have come forward to share their experiences of abuse in care, to seek redress and make sure that it is not repeated in the future.
92. However, disabled people, especially Deaf people and people with learning disabilities and neurodiversity have often been excluded from the process. They often did not know that what they had experienced was neglect and abuse. They also did not know what

¹⁰ Ableism is a value system that favors “certain typical characteristics of body and mind as essential for living a life of value” and therefore label disability as “suffering and devalues human life” (A definition by a United Nations Special Rapporteur: p.40).

¹¹ Eugenics ideology perceives disabled people as “subnormal” beings, whom should be segregated from society for the betterment of the rest of the population (Royal Commission of Inquiry into Abuse in Care, 2020: p.41).

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redress was and there was no accessible information or support for them to understand or navigate the redress process. Disabled people also experienced barriers when trying to access lawyers.

93. Moreover, people with learning disabilities are one of the largest groups of people who still remain in care facilities, with recent reports demonstrating the continued use of concerning practices within the current community-based residents, such as the over-use of seclusion.
94. Many disabled people also receive funding or support “from the same District Health Boards or government departments that were responsible for their historic abuse and may be responsible for abuse they still experience today” (p.220) which makes navigating the system tricky.
95. Some disabled survivors identified also as Māori or Pasifika, and they faced additional barriers in seeking the redress due to the intersecting nature of racism and ableism.
96. There is also consistency within the individual experiences of abuse recounted by survivors of state care across the range of public hearings that have already occurred including: *Tō muri te pō roa, tērā a Pokopoko whiti-te rā: Māori Public Hearing, Tulou – Our Pacific Voices: Pacifica Public Hearing and Lake Alice Hearings*
97. It is clear that the systems put in place by the State to support and protect children and young people, categorically failed them - repeatedly and catastrophically – constituting systemic abuse.
98. Children and young people who entered care were children and young people who were needing support either for their disability, or due to their circumstances at home, or for both reasons. Neither tamariki or whānau were appropriately supported or protected.
99. During *Tō muri te pō roa, tērā a Pokopoko whiti-te rā: Māori Public Hearing*, there were cases where survivors’ mothers were deemed to be mentally unwell but instead of receiving support, these mothers were placed in psychiatric hospitals.
100. As a result, the tamariki of these mothers’ were placed into state care, exposing them to greater and wide ranging abuse. This dismantling of whānau is characteristic of and evidences ableist policies.

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101. Children and young people who deviated (or who were perceived to deviate) from “normative” or “typical” behaviour were put into State care, including into the Lake Alice Hospital Child and Adolescent Unit. Rather than receiving the appropriate supports, they became the survivors of horrific abuse. Abuse took many forms included physical, emotional/neglect, psychological, medical and sexual abuse. Abuses also included assaults on cultural identity such as cultural alienation, deprivation and discrimination.
102. Children and young people were removed from home often without giving their own consent, and/or without the consent of their whānau. As well as being separated from their parents they were also split away from siblings and wider whānau.
103. Survivors were clear that the impacts of the abuse affected the rest of their lives and, as frequently testified, often passed on to the next generation(s) of their whānau. State care was framed as a safe space where children and young people would be protected, but instead they experienced significant harm in such settings, often for the full duration of their time there.
104. Staff members were often aware of the abuse yet remained complicit and complacent by not reporting abuse. When children and young people disclosed their experiences of abuse, they were dismissed and often accused of lying. Sometimes disclosing their abuse subjected them to increased abuse.
105. State care evoked feelings of being unloved, unworthy, and as deserving of abuse within children and young people who internalised ableist thinking and behaviour that were consistent and pervasive in care settings. Children and young people also experienced extreme loneliness. These experiences had long-lasting implications on their lives. Some survivors shared how they learned to become violent to survive care settings. In some cases the victims went on to become perpetrators of violence towards other people both in care settings, and in later life.
106. Survivors who contributed to *Tō muri te pō roa, tērā a Pokopoko whiti-te rā: Māori Public Hearing Māori Public Hearing* and *Tulou – Our Pacific Voices: Pacifica Public Hearing* described feeling painful cultural loss. By entering State care, they lost connection to their whakapapa and whenua, resulting in significant intergenerational harm. Survivors shared how they were deprived of any cultural support and education. These experiences were fuelled by structural racism.

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107. Many people who shared their experiences at these earlier Public Hearings had lifelong experiences of not being heard by the system, including within attempts to engage with ACC and/or other compensation processes.
108. Survivors across the Public Hearings were adamant that they did not want others to experience what they had – which was sometimes their motivation for telling their story.
109. The experiences of disabled survivors that have been shared through these Royal Commission processes and reports mirror the experiences of the Storytellers in *“Tell Me About You”*.
110. An area of difference is that (most of) the Storytellers in *“Tell Me About You”* did not have a clear idea about what redress should be. This was likely to be because they did not know that they could ask for acknowledgement of their abuse, or expect an apology.
111. In *He Pura Ora he Māra Tipu* and across the public hearings that have already happened, some survivors have asked for broad and genuine public apologies, while others have sought to be heard through careful listening by the State, followed by personal validation and acknowledgement of what they had gone through.
112. A series of recommendations were included in *He Purapura Ora, he Māra Tipu: From Redress to Puretumu Torowhānui*, on the basis of the the vast and growing, past and current evidence.

These include that:

- a. The development of any redress schemes must be done so in full compliance with the UNCRPD (United Nations Convention on the Rights of Persons with Disabilities) and all staff involved in redress must have education about the UNCRPD and understand the rights-based approach to redress.
- b. Redress schemes must provide equitable access, consider diverse needs and identities and consider barriers that may discourage or prevent disabled people from engaging with redress.
- c. Redress schemes must be developed in consultation with disabled people including the development of paid advisory roles and with supported decision-making (SDM) frameworks to enable inclusive consultation.

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- d. Accessible redress includes responding “to service gaps, such as shortages of New Zealand Sign Language interpreters, mental health professionals for disabled people (particularly people with learning disability), specialised disability legal services and specialist pathways for people with complex needs” (p 85).
- e. Redress schemes must include broader forms of abuse “such as neglect, loss of family and ongoing relationships, restraint and seclusion, failure to provide adequate education, emotional abuse due to ableist treatment and language, lack of privacy, loss of culture and cultural abuse, and financial abuse” (p 85).
- f. Redress Schemes must respond to intersectionality where survivors may need disability support as well as cultural support and should occur in line with obligations to Te Tiriti o Waitangi.
- g. Redress schemes should account for the experiences of Pacific disabled survivors where cultural abuse and neglect occurred.
- h. Redress should not be limited to historic abuses but should also be available for contemporary and future abuses.
- i. Redress payments should not be considered as income, as to avoid impacting income support payments and efforts must also be made to avoid future financial abuse.
- j. Elderly survivors and those who are terminally ill should be prioritised and consideration must be given to survivors who have shortened life expectancies due to psychosocial or learning disabilities.
- k. Public acknowledgements, commemorations and national apologies were suggested by survivors to give visibility and prevent future perpetuations of abuse in care.

113. On the basis of the evidence to date, these recommendations remain relevant and appropriate. They are informed by survivors, and their allies, and should be adopted. It is also important to note a further recommendation embedded in *He Purapura Ora*, which stated:

"Care and support systems, whether for restoration for past abuse, recovery from mental distress, or for enabling better lives, are needed, as are systems for keeping people safe. To ensure abuse is not repeated, the systems that enabled it need to be transformed." (p.66, in 1.3 Disability rights concepts) ” (He Purapura Ora, p 65).

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114. This could be seen as the recommendation most critical to the achievement of the Royal Commission's commitment to "looking forward" and ensuring that systemic abuse on the scale that is emerging through this investigation "never happens again." Aotearoa is on the crest of major transformation of the disability support and services system. This transformation must respond to the findings of the Royal Inquiry, and occur in the full knowledge that disability supports and services have enabled systemic and institutional abuse to flourish, and that features of the past remain apparent in contemporary care settings.

115. *Tell Me About You* has also alerted us to potential approaches to redress that speak to the particular group of storytellers we worked with. These align with the list above, but are more nuanced and respond specifically to what both the storytellers confirmed about their own lives, and what previous research has told us about abuse and violence in the lives of disabled people. For example, redress approaches *in compliance with the UNCRPD* must include rapid and complete progress toward the implementation of Article 12, via both legislative, policy and practice change. Redress must also include the opportunity for disabled people to access right-based information and education about respectful relationships and recognising and challenging abuse. And finally, redress schemes must actively seek out and include disabled people who are likely only to receive redress with the active and significant support of others.

Statement of Truth

This statement is true to the best of my knowledge and belief and was made by me knowing that it may be used as evidence by the Royal Commission of Inquiry into Abuse in Care.

GRO-C

Signed

Date 27 June 2022

Mirfin-Veitch, 20 June 2022

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Appendices

Appendix 1: "Tell Me About You" Research Team

- Associate Professor Brigit Mirfin-Veitch, Director, Donald Beasley Institute
- Dr Kelly Tikao, Senior Kairangahau Māori Researcher, Donald Beasley Institute
- Dr Robbie Francis Watene, Senior Researcher, Donald Beasley Institute
- Ms Umi Asaka, Junior Research Fellow, Donald Beasley Institute
- Ms Eden Tuisaula, Research Assistant, Donald Beasley Institute
- Dr Hilary Stace, Disability Historian / Independent Researcher
- Associate Professor Patsie Frawley, Programme Lead, Master of Disability and Inclusion, University of Waikato and Honorary Associate Professor, Donald Beasley Institute