## Brief prepared for the purposes of the Contextual Hearing conducted as part of the Royal Commission of Inquiry into Abuse in Care: 1950 – 1992.

- 1. My name is Brigit Mirfin-Veitch. I am the Director of the Donald Beasley Institute, a position I have held since 2007. The Donald Beasley Institute (DBI), is an independent charitable trust that conducts research and education in the area of disability, with a specific focus on learning (intellectual) disability.
- 2. I am also a Senior Research Fellow with the Centre for Post Graduate Nursing Studies, University of Otago, and an Adjunct Associate Professor with Deakin University, Victoria. As a sociologist I have a strong interest in understanding the social lives of people with learning disability and I am committed to initiating and achieving social change through research.
- 3. My research has explored deinstitutionalisation from the perspectives of family members of people with a learning (intellectual) disability who were moving from the Templeton Centre, a large institution for children and adults with learning disability located near Christchurch (Mirfin-Veitch, 2005).
- 4. I was also part of a team of researchers from the DBI who explored the deinstitutionalisation of Kimberley, the last of New Zealand's large institutions to close. The Kimberley Centre research involved a mixed methods approach, and included residents of Kimberley, their families, and institutional staff (Milner, Gates, Mirfin-Veitch & Stewart, 2008).
- 5. I have also engaged with institutionalisation and deinstitutionalisation more recently as a co-author of *"Institutions are places of abuse": The experiences of disabled children and adults in State Care*, which was published in 2017.
- 6. In addition, throughout my 25 years as a disability researcher with the DBI I have also conducted research in the area of parenting by people with learning disability, health and wellbeing, and the justice system. This research has included a significant number of people with learning disabilities who have reported abuse in State Care during research interviews.
- 7. I have been asked to give evidence about the nature and extent of abuse and neglect that occurred to people with learning disabilities in State care between the 1950s-1990s. I will talk about the impacts of such abuse on the individual, and to the extent possible their family and whanau, however I stress that I am not a clinician therefore do not purport to be making a clinical judgement about the impact of abuse. I will also talk about the systemic factors that allowed abuse to occur in institutions, the changes through deinstitutionalisation and what we know about current experiences of abuse.
- 8. Most of the evidence I will draw on for the purposes of the contextual hearing will draw on the research I undertook in collaboration with my research colleague Dr Jennifer Conder "Institutions are places of abuse": The experiences of disabled children and adults in State Care' published in 2017. The full report can be accessed from the

## Donald Beasley Institute http://www.donaldbeasley.org.nz/resources/publications/abuse/

- 9. This research was undertaken in 2017 during the campaign for a Royal Commission of Inquiry into abuse in State Care. The research was contracted by the Human Rights Commission, and details research that was designed, primarily, to capture the voices and experiences of disabled people, particularly those with learning disability, who were abused in State care in Aotearoa New Zealand prior to 1992.
- 10. I note that I use the term learning disability throughout this brief. People First New Zealand, a self-advocacy group, promote use of the term "learning disability" instead of "intellectual disability". They feel the term is more reflective of the difficulties they experience, respectful to them as people, and easier to say. Therefore, "learning disabilities" is the term I use instead of intellectual disabilities throughout this chapter. In doing so I acknowledge that intellectual disability, mentally retarded or mentally subnormal were commonly used during the period 1950 1992.
- 11. As noted above, the research we undertook responded to a concern that disabled people, including those with learning disability comprise a significant part of the *silent majority* who have not told their stories of abuse.
- 12. This is despite their long and significant history within State care in Aotearoa New Zealand. Important research by Stanley (2015; 2017), on this issue documents the experiences of people who previously resided in "boys" and "girls" homes but does not include a focus young people labelled as disabled.
- 13. Further to the above point, the Henwood report on the Confidential Listening and Assistance Service (CLAS), specifically highlighted that people with learning disability did not find their way to this important support for people who self-identified as experiencing abuse in State care (Henwood, 2015) Because they did not, or were not able to find their way to the CLAS, the opportunity for people with learning disability to be supported to achieve redress and restitution may have been lost.
- 14. The "*Institutions are places of abuse*" research aimed to search the evidence, on public record, in order to:
  - Determine what is known about the abuse of disabled people, particularly those with learning disability, including evidence of systemic abuse;
  - Identify gaps in the available evidence about the abuse of disabled people, with particular focus on learning disability in State care;
  - Recommend a research pathway with the potential to the address the gaps in knowledge relating to disabled people, abuse and State care.
- 15. It is important to note that due to scope and time constraints, the research we undertook did not include comprehensive exploration of the available evidence relating to the abuse of people with psycho-social disability. It is noted however that many of the individuals with physical, sensory or learning disability whose stories and experiences are included in this report experienced mental distress themselves, and

in many cases, shared the same institutional environments as those labelled as being "mentally ill".

- 16. **Research design**: We used an integrative literature review research methodology (Whittemore & Knafl, 2005) to conduct the research. It is well recognised by researchers that people with learning disability have, in particular, been kept out of conversations about matters that relate directly to them. This is because they are not always supported to contribute in ways that conform to academic conventions about what constitutes evidence (Johnson and Traustaddoittir, 2000).
- 17. Integrative literature reviews combine data from a wide range of literature, including both quantitative and qualitative academic studies, personal narratives, oral and life histories, creative projects, and other 'grey' literature such as reports, policy, and opinion pieces. This approach offers several advantages over alternative review methodologies, such as meta-analyses (which require data to be of similar nature) or systems analysis (which often exclude qualitative data such as personal story or lived experience based literature).
- 18. Because it was recognised that only a small amount of research had focussed specifically on the abuse experienced by disabled people in State care in Aotearoa New Zealand per se we sought to expose evidence not typically pulled in to the 'scientific' literature, such as personal narratives, or creative projects that documented examples of abuse in State care prior to 1992.
- 19. Definitions of abuse: Another important consideration in the research design was clarifying the definitional scope of what constituted 'abuse' when collecting information about individual's experiences of abuse in State care.
- 20. Our primary aim within this project was to locate and analyse publicly disclosed experiences of abuse, with priority placed on personal accounts. In taking this approach, the research team were attentive to the myriad harms and detrimental impacts on mauri ora (wellbeing), as perceived by those who experienced them.
- 21. To this end, the research team sought to collect and explore disclosures of harm and negative experiences that may have otherwise been excluded from a scope of inquiry that did not approach the research from the perspective of those people marginalised.
- 22. We did this in two ways: (a) by utilising pre-existing definitions types or categories of abuse as codes from which to begin thematic analysis and (b) by being responsive to the content and reoccurring issues raised in the data as other less well-recognised forms of abuse.
- 23. Where did we find evidence of abuse in state care?: In keeping with the desire to prioritise individual accounts and lived experience, the descriptions of abuse in State care contained in this report were largely derived from life stories and other self- or co-constructed narratives. Many of these were written accounts, but some were

delivered through visual mediums such documentaries or other media driven formats, or (in one case) through music.

- 24. The stories discovered featured primarily in books and book chapters in which a person's experiences and history were central. A few life stories were explored through interviews in texts where collecting accounts of institutional living was central. Several of these stories were co-constructed with a person trusted with their narrative.
- 25. Detailed information about both the research methodology and the search strategy is contained in the full report at <u>http://www.donaldbeasley.org.nz/resources/publications/abuse/</u>
- 26. Who was included in the research? While most of the evidence of abuse related to boys and men; important stories about the experiences of girls and women were also identified and drawn into this research. No person from the discovered life stories identified with other gender identities.
- 27. In total, we drew on the personal accounts of 18 individuals; 13 men and five women. Eleven of these people were identified as having a learning disability only; two were legally blind, physically disabled, and also had learning disabilities; one person was deaf; one described herself as having developed brain damage as the result of a childhood illness; two people had cerebral palsy; and one person had been misdiagnosed with learning disability as a child, which led to him being institutionalised in a psychopaedic hospital for approximately eight years.
- 28. Only three of the people whose personal accounts we drew on had been in foster care, but all of these individuals had also spent considerable periods of time in psychopaedic and/or psychiatric hospitals. All other accounts drawn on related to State care in institutions only. Finally, all had experienced State care within the time period 1950-1992, however a small number of individuals (two) had entered State care prior to 1950.
- 29. Ethnicity was not clearly stated within many of the data sources, however three people identified as being Māori, with one of these people specifically identifying his iwi as Ngāpuhi. Another person identified as Pasifika (of Cook Islands descent).
- 30. The age in which people entered State care, or had lived in particular institutions at particular times was not always clear. However, most of the disabled people whose stories we drew on, indicated that they had lived in State care in childhood, and adulthood, and many remained in "care" in the form of residential disability services for their entire lives. That is, most individuals were found to have lived in a range of different institutions, moving from facility to facility at the direction of the State.
- 31. The institutions represented in these life stories spanned across both Te Ika a Maui (North Island) and Te Wai Pounamu (South Island), and many of these institutions were repeatedly named as sites of abuse.

- 32. Finally, in order for disabled people to have their experiences, and resultant distress recognised as being as significant as others who have told of their abuse in State care, it was also important to be able to include the stories, testimony or research of those who had observed or been told about abuse in State care, such as staff or family.
- 33. We aware that people with learning disability in particular had most often talked about their experiences within institutional environments within the context of studies of deinstitutionalisation. Much of this research has included the voices, views and perspectives of staff and family and offered a potentially rich source of data for this work. We therefore included evidence of abuse in State care provided by these other sources in the report.
- 34. We presented the findings of the research in two ways. Firstly, we developed several detailed case studies of institutional life drawn from the life stories that were publicly available. We got the appropriate permissions from individuals or publishers to enable us to do this.
- 35. The case studies had the purpose of illustrating, in a survivor's own words, what daily life was actually like in an institution or other form of State Care during the inquiry period. The case studies showed the multiple ways that survivor's experienced abuse while in State Care, and that abuse does not just relate to things that are done to you. Being consistently exposed to the maltreatment of others, and being powerless to stop it is also abusive.
- 36. The second way we presented the research findings was via common themes. By looking across all the evidence we collected, we were able to identify common, and consistently occurring themes reported by the entire group of survivors. In this way we were able to see very clearly what types of abuse people experienced, how often, and how that made them feel.
- 37. What kinds of abuse did people experience and how did it impact on them?: The stories and accounts we explored unequivocally showed the breadth and depth of the lived experience of abuse in institutional and other State care settings. The abuse subtypes we explored were: neglect; physical; sexual; psychological (emotional); control and restraint; spiritual; financial; and systemic.
- 38. The inter-relationship between different types of abuse meant that it was difficult to ascribe a particular action or event as evidencing only one type of abuse. A single action of restraint for example, could be described as neglect, and emotional/psychological, and physical abuse.
- 39. **Neglect:** Within this research, we found that neglect featured more frequently across the different life stories in comparison to any other form of abuse. Arguably, being in State care could be read as synonymous with neglect due to the fact that even if people were not being overtly abused, they were generally exposed to an extremely impoverished relational environment. That is, people *felt* as though no one cared about *them*.

- 40. Other experiences of neglect could be seen in the lack of emotional support and connection that people received, particularly at times of distress. One survivor through her story of half a century in State care, talked about how she continued to feel (and express) a chronic level of distress in institutions and reported that she could not remember ever having received emotional support for her distress, even when she was particularly upset. She said she was constantly scared so she would scream, hide her face, and run away and hide.
- 41. Rather than staff being attuned to and responsive to these emotional needs and the way she tried to manage them, she was punished for what was read as challenging and non-compliant behaviour.
- 42. Neglect affected survivor's self-esteem, with a number of people linking their institutional experiences with their lifelong feelings of feeling unwanted. An acute absence of affection and emotional support was the reason that some survivor's attributed to the difficulty they had as adults to show affection and to trust other people.
- 43. An number of people also summarised the impact of State care (institutions and foster care) as leaving them with a sense of loss, of having missed out on positive and enduring relationships with people and or places that could have given them a sense of "home or family. This was exacerbated for people who had had multiple foster placements, with some talking about ending up with a family they felt that they could love before being moved again. This was devastating to them.
- 44. In these experiences, the absence of emotional connectedness and comfort was apparent in a way that a number of people recognised as leading to them having long term social and emotional consequences.
- 45. Neglect was also evidenced through the acute lack of stimulation and purposeful activity within State care facilities, such as institutions. Survivor's talked about experiencing acute boredom because there was absolutely nothing to do apart from sit in a day room.
- 46. Other experiences of neglect exampled a departure from a standard of care that could be reasonably expected in a facility of care with survivor's describing circumstances where their peers received no attention for long intervals, despite the fact that some individuals were highly (or completely) dependent on others to provide their basic needs.
- 47. One survivor recalled the smell of people who needed assistance to go to the bathroom and were not provided it. He said: *"There were people who couldn't move and they would just stay where they had been left in the morning after breakfast. Most of those people were non-verbal and were trapped until someone got around to attending to them"* (McRae, 2014).
- 48. Another shocking survivor account included a description of the person drinking her own urine due to thirst. This person also described being *"freezing"*, and the experience of often being cold was a consistent theme in the life stories of others too.

- 49. These experiences illustrated how the provision of care in institutions was often inadequate at meeting people's needs for hydration, food, warmth, and access to personal care and other assistance.
- 50. The pervasive presence of neglect can be seen in examples of the State's failure to provide assistance for pain and injury, for example not receiving medical attention for broken bones
- 51. In addition to experiences of disregard for physical safety, or lack of medical attention, people routinely experienced total disregard for their psychological safety. Two survivors who with learning disabilities who were also blind both recalled being terrified being thrown into a swimming pool by staff members when they were children. Their fear was understandable given that not only could they not swim, they also could not see.
- 52. All of these examples of neglect evidenced both a disregard for the person "in the moment", and for the likely long-term impact of such experiences their wellbeing.
- 53. **Emotional and psychological abuse**: The life stories and other sources of data we analysed within this research conveyed a sense of deep fear, hostility, and distress strong indicators of emotional and psychological abuse.
- 54. As noted earlier, abuse could be seen in both to personal maltreatment that people experienced, and due to their repeated and ongoing exposure to the maltreatment of others.
- 55. People with learning disability also interpreted some of the behaviours of their peers as being a tangible expression of their distress. Self-injurious behaviours in particular were seen both as a way that people communicated their distress, but staffs' failure to respond to such behaviour was also seen as abusive.
- 56. Emotional and psychological abuse could be seen in the accounts of institutional life, and the constant feelings of being unsafe, with one survivor describing mealtimes as a particularly hostile time due to staff being hostile and intimidating to residents.
- 57. The constant fear that survivors lived with had lasting impacts. For some people, their fear was re-kindled by persistent dreams about being back in the institution. For others, the fear of being physically hurt for comments they made or behaviours they engaged in meant that they simply chose to stop talking.
- 58. An overarching theme was that survivors left State Care with an entrenched understanding that people in positions of power could hurt them if they failed to comply with their rules and expectations.
- 59. Linked to the above point, two survivors in particular described experiencing the disempowering emotional and psychological effects of having choice denied to them in institutions. These people talked of feeling incompetent and unable to make their own decisions.

- 60. Most significantly, despite being angry about what happened to them, none of the survivors felt that they could do anything about it, suggesting that there were no processes or pathways for making complaints.
- 61. Working from an understanding that abuse is the overt representation of an imbalance of power relations, Saxton (2009) has expressed concern about the impact of people *internalising messages of invalidation and powerlessness*.
- 62. It is clear from the evidence presented here that many people who were reliant on State care experienced large and small assaults to their self-esteem and sense of self-worth on a daily basis. Such psychological assaults were not easily shed as people left State care facilities, instead, as shown here people have carried the emotional impacts long after leaving their particular site(s) of abuse.
- 63. **Control and restraint**: A common theme in people's narratives was the distress associated with being confined; to the institution itself, within their bedrooms, or to specially constructed seclusion rooms. While such practice could be considered to fall into the abuse categories of psychological and physical abuse, we viewed these practices of control and restraint as comprising such a significant component of data that we analysed it as a separate and distinct form of abuse.
- 64. Being "locked up" was a prominent experience, which many survivors described in detail, and were extremely distressed by. Being locked up was sometimes due to their perceived challenging behaviour, but sometimes just the practice of the institution.
- 65. In addition to noting the physical confinement to particular rooms and spaces, people also reflected on the highly regulated and regimented spaces and activities within institution, including being told (but not limited to) when to shower, when to shave and when to eat.
- 66. Others described the process of establishing and enforcing routine and the physical confinement as excessively harsh, with some survivors sharing evidence of control and (psychological) restraint created by staff restricting the space people were allowed to be in and restricting their ability interact with his friends. Sometimes this was achieved by making the person dress in their pyjamas (while others were dressed in day clothes) and to sit at the "bad table".
- 67. Overall, a common theme in the feelings conveyed was the sense of being trapped in State care, and confined and restricted on a daily basis in a manner that people perceived as hurtful, excessive and humiliating.
- 68. **Physical abuse:** Within the body of evidence collected for our research, a key finding was that children and adults in State care provided were physically abused by both peers and staff members.

- 69. Survivors talked about being beaten by peers frequently and severely. They also clearly identified that physical assaults were carried out by staff with one survivor describing being dragged down a corridor by either her feet or hair as a punishment.
- 70. Sometimes small misdemeanours were met with excessive force such as being repeatedly kicked as for accidentally breaking a window.
- 71. **Sexual Abuse**: In keeping with the Crimes Act (1961) and more contemporary definitions, we defined sexual abuse as any form of sexual contact that was not consensual, or any form of sexual contact that happens with and to children.
- 72. Both of these elements of the definition were identified within the personal accounts we explored. We found that both children and adults were sexually assaulted. We also found that the assaults occurred in large institutions, residential schools, and within the "family homes" of their foster carers.
- 73. While sexual abuse was frequently divulged within the narratives that informed our research, understandably, it was often only touched on briefly in people's stories. This is likely to be because many of the resources that included relevant evidence relevant were not designed, methodologically or ethically, to respond to disclosures of abuse.
- 74. That said, it is clear from the evidence that we drew on, that sexual violence was a seemingly inescapable and unchallenged reality for a significant number of both boys and girls, and men and women in State care. Some of the narratives drawn on included graphic experience of the person's abuse, including when it happened, where it happened, and who the perpetrator was.
- 75. For example, one survivor was sexually assaulted at knife point by an older peer when she was only 11. Despite being able to *"point him out"*, there was no sense within her story that the perpetrator was punished, kept away from her, or that she received any psychological support for the sexual violence she experienced.
- 76. Similarly, and also shockingly, another male survivor's rape by older peers appeared to go unchallenged. And a different survivor who lived at Templeton Centre for many years, before being assessed as having been misdiagnosed, described being sodomised by a staff member at Templeton. He also recounted being abused multiple times by staff and peers while he was there.
- 77. Another survivor described experiencing sexual abuse from both staff and his peers at Campbell Park School and it was clear that the sexual abuse was part of a pattern of sexual violence perpetrated by older peers and reinforced by staff in a culture of mutually-reinforcing violence.
- 78. Survivors reported that sexual violence, whether perpetrated by staff or peers resulted in long-lasting negative self-image, feelings of being dirty and worthless, and psychological impacts such as having difficulty in trusting and feeling safe with people. Robert noted that his abuse occurred in a vacuum of understanding or knowledge about sex or sexual violence, thus rendering people doubly compromised.

- 79. Survivors also consistently echoed the same sentiment in response to the repeated trauma that they experienced, commenting that they would *"just keep quiet and hope it wouldn't happen again"*. Similarly to the reports of physical abuse, there was a deep seated understanding that complaints would go nowhere, and may even make your situation worse.
- 80. This view is echoed in a judgement relating to legal proceedings taken by a man with learning disability who had resided in a St John of God facility in Nelson, and later in Ngawahatu Psychiatric Hospital.
- 81. The judgement evidences that this complainant felt devalued by staff, thus leading to the dismissal of his complaints within State care and his subsequent re-victimisation. To this end the judgement read:

"Despite the complaint, the plaintiff says that sexual acts continued to be forced upon him by that, and another, nurse for several months... The plaintiff says that he did not complain to other staff because he thought it would be dismissed and he was scared of what could happen... He says that he did not report the events [of witnessing sexual assaults on others] because he was scared of the consequences of the Charge Nurse not believing him." (Knight v Crown Health Financing Agency, 2007).

- 82. Recurring experiences of sexual violence was a common theme. Some people were able to clearly identify their abuser(s). Others used more global terms like "the boys", or the "bigger boys", or staff, which may be indicative that the person did not know the person by name, not necessarily that they could not identify them.
- 83. It is reasonable to suggest that from the testimony of survivors, repeated exposure to sexual violence was common in institutional environments, and that this would result in lasting psychological impacts for those who were abused, and those who witnessed such attacks.
- 84. *Spiritual abuse*: While less recognised, spiritual violence featured heavily in the account of a person with a learning disability who was Māori whose experiences in Kingseat and other institutions conveyed a sense of loss with regard to being disconnected from his culture since he was a child.
- 85. The State care facilities in which this survivor was placed were both Pākehā-centric in culture and lacked cultural competence for Māori and iwitanga. He was denied access to his culture as a Māori man, and more specifically to his iwi while in State care. Connecting with his ethnicity and his iwi was, from his perspective, was essential to his process of healing and achieving wellbeing. As was described, re-connecting with Ngāpuhi tikanga, Reo, turangawāewāe, and whanaungatanga were essential components to him developing a sense of place in the world or locality: *"Who am I? Where do I belong? Where am I from?"* (O'Brien, 2005).
- 86. Similarly, another survivor's Pasifika heritage was ignored once he entered State care, and Pākeha survivors recounted a broader disconnection from New Zealand and world culture and critical historical events. State care appeared not only to ignore or deny

cultural ties; spiritual abuse could also be seen in the denial of interests and passions that people had.

- 87. **Financial abuse:** Only a few survivors directly referred to their financial or material deprivation, however the fact that people experienced a significant lack of education or support to develop the skills required for meaningful employment could be seen as evidence of long-term financial abuse. Financial abuse however, could be seen as being illustrated within the evidence drawn on here through the experiences of compromised access to education, which subsequently eroded people's ability to be meaningfully employed.
- 88. It could also be seen in people being denied the opportunity to have possessions or to enjoy the money they potentially could have earned, if their forced labour both in institutions, and in State sanctioned foster-care had been recognised. A number of the accounts highlighted how financial abuse, including obstruction from having schooling and participation in money management had featured in people's lives while at Templeton Hospital: "they make you a slave. When I was about 6 years old, I had to help. I never went to school. They wanted me for the work because I was so good at it... You didn't get any money, that's for sure. We didn't get any money." (Sobsey, 1994).
- 89. The restrictive environments of State Care also denied opportunities to get work and, subsequently to have any level of financial autonomy: *"I'm disappointed that I've never had a job I never got the chance. Money is not everything in life but I would like to be able to buy clothes"* (Hunter & Mirfin-Veitch, 2005).
- 90. As briefly touched on above, a little considered aspect of life in State care that links to financial abuse was the finding that survivors were forced to undertake manual labour, both in institutions and foster homes. This surprising finding featured quite heavily in people's stories. One survivor described the immediate and long term injuries she suffered as a result of the heavy lifting she was forced to do, and another also described her time as an "unpaid labourer" for her foster family. It is important to note that this person's foster mother was also a staff member of the institution she had been living in at the time, thus suggesting an abuse of power of a different kind.
- Evidence from third parties: Previous research (for example, Gates, S., Stewart, C., Milner, P., Mirfin-Veitch, B., & Schumayer, F, 2008; Milner, P., Gates, S., Mirfin-Veitch, B., & Stwart. C., 2008; and O'Brien et al, 1999) eyewitness accounts and reviews (for example, Askew, 1986, Broad, 2013; and Henwood, 2015); document significant examples of neglect and abuse of people with disabilities in State care.
- 92. Eyewitness accounts from relatives who visited their family member in the institutions accompany some of the above stories. Often a close relative or friend spoke for those without independent means of communication, as occurred in the writing of Extraordinary Journeys (Spectrum Care Trust Board, 2010).
- 93. Other eyewitness accounts are from researchers' observations and staff reports. Evidence from these sources was included in this research as a way of providing

additional support for the personal testimonies provided by people with learning disability themselves.

- 94. Most notably, the process of deinstitutionalisation has provided an opportunity for both staff and families to talk about the neglect and abuse that they witnessed in the various institutions. Within the New Zealand research that has explored the process of institutional closure, staff members testified that abuse was an issue at the Kimberley Centre and that they had witnessed abusive practice or actions themselves. For example, staff members from Kimberley Centre told researchers:
- 95. "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 court yard here, do you know how they got showered? With the fire hoses. And they used to get beaten. If you rush up to one of these people quickly, they will cower and that's when they have had hidings at a very, very young age. The Kimberley Cringe. That's what they call it." (Milner, P. et al., 2008)(p.185)
- 96. The staff quoted in this section were largely employed at Kimberley Centre during the 1990's to its closure. Their quotes have been included to illustrate two important points: (1) that abuse was occurring in the institution beyond the focus period of this research (1950 1992); and (2) that the physical fear exhibited by residents and observed by staff, labelled as the "Kimberley Cringe", was understood to be the result of a long-term pattern of abuse within the institution. It is acknowledged that both staff and residents may have been involved in the abusive practice or actions that led to the development of the Kimberley Cringe.
- 97. For caring staff, the unresponsiveness of the institution to abuses they witnessed placed them in an unenviable ethical position as the following quotes illustrate:

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

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

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

98. This abusive treatment, and the resultant fear it provoked in Kimberley residents, (the Kimberley Cringe) was confirmed by a sister who reported:

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

- 99. Following the deinstitutionalisation of people from Kingseat, O'Brien asked people about their experience in the institution (O'Brien et al., 1999). The majority preferred to remember the better times, but staff working in their community disability service added examples of abuse and neglect that had disclosed to them by people with learning disabilities who had left the institution: *"Staff said that they had been told by him that he remembered that he used to get a lot of shock treatment while in the hospital. It happened every time he did something wrong, that he would go to the room where he got shock treatments."* (p. 94)
- 100. Another family member recalled visiting her sister at Kingseat: "I hated all the locked doors, and they were just sitting inside looking into space, and there were screaming people around the place... I've got nothing good to say about Kingseat."
- 101. In summarising the memories of nine people, which were presented as case studies, O'Brien et. al. (1999) noted that they: "...were strongly influenced by punishments, such as being hit, use of side rooms, shock treatment, being injected for behaviour control and sleeping on mattresses on the floor." (p.136) Some of this information was provided directly from people with learning disabilities themselves but it was also confirmed and supported by the comments of family, and by staff currently working with the person.
- 102. This small amount of third person testimony referred to above aligns with the evidence provided by people with learning disability themselves. Those who observed State care of people with learning disability as staff, whanau, or researchers described people as exhibiting fear and a lack of trust of the purpose of physical contact, and reported that the use of chemical restraint as punishment and isolation in "side rooms" was common. Perhaps most tellingly, some staff reported a difficulty in (recognising) and reporting abuse and having it appropriately responded to by management.
- 103. Also supporting the individual stories that were explored in our research are the findings of a Ministry of Health review of psychiatric and psychopaedic hospitals undertaken in 1984 and 1985 (Askew et al, 1986). In that report, Askew described the conditions for seclusion as "Dickensian" despite institutional reform that occurred through the 1970's and 1980's, which included improving people's right to privacy.
- 104. Some staff in the institutions reporting to the review team that "the 'time-out' boxes and cupboards in some wards for the intellectually handicapped" (p.7) were used more for punishment than any therapeutic effect, which was deemed to be appropriate practice for modifying behaviour at the time. Furthermore, they found

"deficiencies in dignity and in the basic elements of appropriate care" (Askew et al., 1986, p. 8), commenting, for example, that some units in psychopedic hospitals had "toilets of a bench type nature and communal showers" (p.17).

- 105. Recognising the importance of cultural appropriateness for psychiatric care, the review team further identified "a widespread lack of formal recognition of cultural needs in many aspects of patient care" (Askew et al., 1986, p. 10). Although reviewers visited all New Zealand psychiatric and psychopaedic hospitals, it is interesting to note that findings related to the treatment of people with a learning disability who were placed in psychopaedic hospitals do not feature in Askew et al's report findings. Taken together, however, it is reasonable to assume the deprivations they detailed were pervasive across State institutions. What they saw led Askew et al to conclude that "Staff shortages and low morale seriously affect patient care and the availability of alternative methods of treatment, and lead to lack of awareness and general acceptance of substandard conditions" (Askew et al., 1986, p. 11).
- 106. It could be argued that this review, conducted in the 1980's, has long provided the "evidence" that neglect and abuse in State care did occur, and that policies governing practices relating to control and restraint were not being appropriately applied.
- 107. Was the abuse experienced by disabled people including those with learning disability in State care institutional abuse?: In 1994, eminent disability researcher Dick Sobsey (1994) defined institutional abuse as the *neglectful, psychological, physical or sexual abuse that takes place in managed institutional care of human beings.* He identified the key features of institutional abuse as:
- extreme power relations between residents and staff;
- collective nature of the abuse;
- abuse is covered up or knowledge of it is not shared outside of the institution,
- and clearly defined patterns of environmental influence (pp. 90-93).
- 108. The policy of deinstitutionalisation that eventually led to the closure of the large-scale State care facilities in Aotearoa New Zealand, was preceded by a plethora of largely international but also a number of New Zealand reviews and reports conducted in the 1960's, 70's and 80's that exposed the prevalence and severity of abuse being perpetrated against people in institutional environments (for example Askew 1986).
- 109. We have no reason at all to expect that State care facilities and institutions in in this country were not also the sites of such abuse. In fact, the evidence we found, which was based on the experiences, memories and reflections of disabled people showed very clearly that abuse was an everyday reality for this group of vulnerable individuals.
- 110. Was the abuse experienced by disabled people including those with learning disability in State care systemic abuse? In our research we detailed the diverse ways

in which 18 men and women with the courage to tell their personal stories were abused in State care.

- 111. Their stories, regardless of age, ethnicity, gender or the type of State care they were in are remarkably similar. It was common for people to be abused throughout life, and for them to be exposed to all types of abuse causing both psychological and physical distress. Many of the participants described long term impacts as a result of their abuse.
- 112. Given this evidence, it is important to consider whether their abuse could be defined as systemic. Systemic abuse has been defined by Australian researcher Sally Robinson (2013) as having causal roots that are located in organisational systems or policy, despite sometimes being perpetrated by a person.
- 113. According to this definition, abuse cannot be categorised as systemic due to prevalence alone; instead the abuse must be attributable to system-level factors or failures that have worked actively or passively to enable or facilitate abuse under the particular system. That is, systemic abuse takes us beyond the notion of "bad things being done by bad people" independent of the system, to a recognition that the system has operated in ways that has both provided the opportunity for abuse to occur, or for it to continue unchallenged.
- 114. At a fundamental level and as previously mentioned, researchers such as Sobsey (1994) have posited that institutions are inherently abusive. This would be a view shared by the disabled people whose stories informed this research. The long term, acute pain created by being separated from family was central to everyone's story.
- 115. For a range of reasons, including a lack of formal support for families, disabled children experienced the trauma of being dislocated from their families at a very young age. No effort appears to have been made by the State to ensure that they were able to form safe, healthy and positive emotional attachment, despite growing awareness of attachment theory, which had its antecedents in Bowlby's (1944) academic paper. Not having someone to love, or to love them, had a powerful, negative impact on the psychological wellbeing of disabled people who had been in State care.
- 116. It is well recognised that even families who were positively connected with their disabled children were frequently told not to visit their children after they had entered State care (Mirfin-Veitch, 2005, Milner et al, 2008).
- 117. This could be seen as a purposeful interruption of attachment by the State, and one that had significant and distressing long term impacts on both disabled people and their families.
- 118. At another very obvious level, a repeated refrain in the stories (and confirmed in some of the presented third party evidence) was that those in power knew the

individual had been abused but nothing was done to stop or to address it on an ongoing basis. Furthermore, these same individual's almost without exception noted that they knew their peers were being assaulted but that they felt they were unable to call it to the attention to anyone with the power to stop it. Some went as far as to say they knew nothing would be done anyway.

- 119. In our research the personal accounts showed that people with learning (and other) disabilities evidenced:
  - neglect in the form of people not having their basic needs met, possibly due to under staffing or inadequate training constitutes systemic abuse.
  - an institution wide failure to attend to the emotional and psychological development of children due to understaffing, inadequate training or an abusive culture constitutes systemic abuse.
  - the use of control and restraint practices, whether environmental, physical or chemical for reasons of punishment rather than for therapeutic purposes constitutes systemic abuse.
  - repeated exposure to physical violence, resultant injuries being left untreated, and no meaningful attempt being made to stop the assaults constitutes systemic abuse.
  - repeated sexual abuse, or exposure to sexual violence in the absence of any ability to achieve meaningful redress in the form of a person being held to account, or counselling for psychological trauma constitutes systemic abuse.
- 120. This is all suggestive of systemic abuse; a system that worked in such a way that abuse was able to continue unchecked. However, because the evidence on record about the experiences of abuse has largely been collected as part of research with an alternative focus, both in terms of the nature of the data collected and the way it has been (able to be) analysed, there is still a need for further exploration.
- 121. In particular, we need to examine the context in which the abuse occurred, and the polices, processes and procedures that were or were not in place to assess the likelihood of similar abuses permeating future systems. It is also important to look closely at organisational culture at a broader level, again to generate important learnings to ensure that another generation of vulnerable children or adults are not abused in State Care.
- 122. **Gaps in the evidence.** As researchers we always consider what our research has not been able to tell us. With regard to our research into the personal testimonies of people with learning (and other) disabilities who had been in State Care, these were a number of issues that made it difficult to find evidence on this issue.
- 123. Despite the comprehensive range of key words and databases we applied in the search for the evidence of abuse of disabled people in State care, it was difficult to isolate specific examples. This finding in itself, points to a lack of visibility of disabled people, including people with learning disability in the literature.

- 124. Many of the stories we drew on were identified through mining a diverse range of literature and other resources, much of which is not found through 'conventional' search strategies.
- 125. The accounts were relatively few in number, were often limited in terms of contextual detail, and were presented in formats that were not easily accessible. Therefore, it might be easy to dismiss the suggestion that abuse in institutions was a frequent and widespread occurrence for people with learning disability who were fostered and/or institutionalised in Aotearoa New Zealand.
- 126. It is quite clear, however, that those people who have had the opportunity to share their lived experiences of State care with independent and safe third parties have, to a person, highlighted abuse as a pervasive presence within their lives something that was perpetrated by their peers, as well as by people appointed by the State to care for them; something that occurred when they were children and when they were adults; and as something that was experienced through seemingly small abuses of power, as well as acute assaults to their minds and bodies.
- 127. Another explanation for the relative invisibility of people with learning disability from the narratives of abuse is that their stories are most often contained within a broader research focus. They have been told after leaving an institutional environment as part of their pathway to community living (for example, (Gates et al, 2008, Milner et al, 2008, O'Brien et al, 1999, Spectrum Care Trust Board, 2010).
- 128. That many chose these forums to tell more about negative experiences of institutional life in contrast to their greater freedoms in community living could be seen as an indicator of the research participant's new-found awareness of the deprivations and abuse they received in institutions.
- 129. To tell their story, virtually all of the narrators had the support of another person, helping them to select from their memory what would be included in the written account. As researchers reading these accounts we were aware that they had a specific purpose, that they were not claiming to explore institutional abuse but rather the experience of deinstitutionalisation.
- 130. This points to a major gap in the published research; a significant lack of detailed accounts of abuse and neglect of disabled people in New Zealand institutions. For example, from the stories we have analysed, we can reasonably conclude that abuse occurred over a long-time period, but dates were rarely mentioned and experience was sometimes codified, such as the comment "he made me do things that I didn't want to do" which is highly suggestive of sexual abuse, but does not state it overtly.
- 131. In addition, abusive practices, such as the use of seclusion, ECT and inappropriate use of medication were often interpreted by the person as punishment for a misdemeanour were referred to but often not described in great detail.

- 132. Furthermore, while people were clear about what happened, for a range of reasons, they did not, and possibly could not, unpack the circumstances that led to such practice or actions. This is an important area of focus for future investigation, particularly the analysis of whether policy and practice in State care was based on acknowledged best- or evidenced-based practice of the time.
- 133. It is clear, through the Askew review of the 1980's, for instance, that models of care being practised in psychiatric and psychopaedic institutions did not comply with what was accepted and promoted as best practice at the particular time (Askew, 1986). It is therefore unethical to simply explain away the high incidence of abuse in State care as being reflective of "the time."
- 134. Our research established that neglect and abuse happened and there is incontrovertible evidence that both staff, and other patients/ residents were abusers. Furthermore, those who were abused may also have been abusers themselves. The research also named certain institutions as places of abuse. It is important to note, however, that the higher profile of these institutions may be attributable to the fact that they have been the source of research relating to their closure whereas others remain unexamined.
- 135. Despite their institutionalisation being historical and their stories tending to focus on improved quality of life in the community, the years of institutional neglect and abuse have had ongoing implications. These implications range from the subtle, such as a sense of learned helplessness, to the overt, or thorough survivor's own sexual offending. However, many of the stories did not explore the outcome of the years of institutional abuse.
- 136. Amongst other populations where childhood abuse and neglect have been documented there are identified health and social consequences (for example, Norman, Byambaa, De, Butchari, Scott, & Vos, 2012, Spertus, Yehuda, Wong, Halligan, & Seremetis, 2003). While institutional abuse continues to be treated as in the past, there is an obvious gap in our knowledge of the current impact of this abuse on the health and social outcomes of people with learning disability in New Zealand.
- 137. It is important to acknowledge that our research is weighted toward evidence of abuse in institutional settings. What became obvious very early in the literature search process was that experiences of foster care were more difficult to locate.
- 138. This was not surprising given that institutions were the "first port of call" for people with learning disability, with foster care a less common pathway within State care during the period under study. That said, a number of the stories that were drawn on within the research detailed abusive foster settings.
- 139. **Evidence of Abuse in State Care beyond the inquiry period:** Attention should also be given to the services that have replaced institutions in supporting disabled people, and particularly those with learning disabilities.

- 140. As Roguski (Roguski, M., 2013) identified, abuse and neglect are not in the past. Various approaches have been used to audit and otherwise assess quality of care in the non-governmental organisation sector (NGO's), however gaps remain that make it possible for abuse and neglect to go undetected.
- 141. The deinstitutionalisation of Kimberley provided the opportunity to interview staff (Gates, S. et al., 2008). As outlined earlier, staff supported the stories told by people with learning disabilities who had been resident at Kimberley.
- 142. In 2001, the Donald Beasley Institute commenced a 5-year study of the impact of leaving New Zealand's last remaining institution, the Kimberley Centre (Milner et al., 2008). Whilst beyond the time-frame of the Inquiry, the Kimberley research provides one of the only windows with which we have to look backwards in a rigorous way at the lives of the people whose stories infuse this report. It also allows us to answer the critical question: how deeply entrenched were the systemic abuses retold in this report? To this end, key findings of the Kimberley research included:
  - Institutional placement severed people from the families in ways that profoundly affected the life quality of parents and their disabled children. After leaving Kimberley, how much access former residents had to the love of a family member was found to be the most significant predictor of former resident's life quality.
  - Kimberley residents performed poorer on all measures of adaptive behaviour, with their poor performance relative to their age and sex peers attributable to the realities of living in an institution supressing ongoing learning.
  - Almost all of resident's day-to-day lives unfolded within the walls of the institution.
  - Whilst the expansive grounds created the illusion of spaciousness, Kimberley residents, on average, spent 97% of their time locked inot their villa.
  - Residents had limited opportunities to engage in purposeful activity or to engage in roles that might nourish personal development. During the day, resident's ordinarily lined the wall of the dayroom waiting for the unvarying interuptions of lunch and morning and afternoon tea.
  - Living in an institution severed residents from their community. Residents were observed in a community setting for 1.1% of the total time they were observed.
  - Residents were seldom spoken to, with 63% of all interaction events lasting less than a minute. A general acceptance of the reality that many residents had entered Kimberley speaking but would leave silent represented a quiet but distressing denial of the rights of people who could find little use for self-expression through language.
  - Stories of physical and sexual abuse were commonly reported by family and staff and the "Kimberley Cringe," was acknowledged as part of institutional culture.
- 143. These more recent findings validate the narratives of the 18 people whose stories were presented in the Institutions are places of abuse research report. Both

pieces of research speak for the men and women and children with whom they shared villa dayrooms, dorms and some of the darker corridors that charactersied State care.

- 144. Many of the social practices and systems of care described in the Kimberley research appeared rooted in the same negative social construction of people with a learning disability that had led to the construction and populating of New Zealand's major institutions with some of its most vulnerable citizens.
- 145. This understanding of people with a learning disability as less deserving of an ordinary life persisted at Kimberley, despite the attempts to reform institutional care that ocurred throughout the 1970s and 80s (Thomson, 1995), and was certainly still present when researchers spent time there in the early to mid-2000's.
- 146. The fact that individual and systemic abuse was clearly observed at that time, despite "best practice" in terms of models of care for disabled people being well established makes it almost impossible to refute the argument that abuse has always been a feature of State care for disabled people. It is also impossible to accept that Kimberley was a unique site of abuse; indeed we know it was not.
- 147. It is important to conclude by mentioning that the ongoing story of abuse in State Care has continued to be seen in current Donald Beasley Institute (DBI) research. Qualitative research with individuals with learning disability with involvement in the justice system found that over half of the 40 participants had been in out-of-homeplacement in childhood. Some of these people reported that they had experienced abuse in State Care via violent foster placements (Mirfin-Veitch, Diesfeld, Henaghan & Gates, 2014). Abuse in State Care has again been seen in soon to be released DBI research which includes the story of a young person with learning disability who, during the past 15 years experienced not only an unacceptably high number of foster placements, but also violence in some of those settings.

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