

Witness Name: Paul Milner

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ROYAL COMMISSION OF INQUIRY INTO ABUSE IN CARE

WITNESS STATEMENT OF PAUL MILNER

I, Paul Milner, will say as follows:

1. Introduction

- 1.1. My name is Paul Milner. I am a former disability researcher (and failed retiree). I am 56 years old.
- 1.2. My parents are GRO-B They were part of the Great British diaspora of the 1960s, and so I came out as hand luggage and grew up in Macandrew Bay, Ōtepoti, Dunedin.

Early disability sector work

- 1.3 It would be fair to say that I tumble weeded into the disability sector, somewhere around the age of 23 or 24. Before that I was a geographer – a teaching fellow at the University of Otago, but ended up unemployed for a while and found myself doing the night shift at Park Street – a community facility for people who were coming off a compulsory treatment order. There was nothing intentional about it. It wasn't an deliberate career choice or anything like that.

- 1.4. From there I began to support people at High Street who, at that time, were moving out of Cherry Farm as part of the nation-wide resettlement programme. The work at Park Street was quite challenging – I lasted about a year – but I was intrigued by the deinstitutionalisation process. Patients Aid Community Trust (PACT) had seen my work at Park Street and thought I might be good for the afternoon shift, so I started working at High Street, trying to convince the men who had just moved into the first of PACT's community group homes not to call me "the D-shift". I still love the men who looked after me for six years in the complex and contested space of their "home".
- 1.5. The men I met at High Street thought they had played their "get out of jail free" card, and they moved at the perfect time. Nobody running community group housing back then knew exactly what they were doing. We all met people as strangers, not really knowing how best to construct a life for men beyond the institution – but feeling like they were owed one. Community group homes have subsequently become much more bureaucratised and "knowing", and I think probably less human as a consequence.
- 1.6. I came into High Street completely naive. That was the zeitgeist of the time. The new community services didn't want institutional staff because, they said, they didn't want the old habits of an institution carried out into the community. But it was only a half-truth because, although the model of community care was probably more expensive than the economies of scale you would expect with aggregated care, people like me were certainly cheaper. I started on \$9.50 an hour. Even today, those who work at the intersection of learning disability and what has traditionally been seen as women's work, begin at little more than the minimum wage for this ethically complex and emotionally demanding mahi.
- 1.7. One of the first things I noticed was that the impress of the institution meant that the only person these five men spoke to was me. They didn't talk among themselves. They lived there. It was their house - and yet almost all of their communication was directed at me
- 1.8. It was a pattern I would see repeated again in my work at the Donald Beasley Institute. In the report we wrote about the outcomes of resettlement for those who lived at the Kimberley Centre; we found that residents tended to sit alone and unspeaking more than 80 per cent of the time. Moreover, two thirds of the communication events we observed in the institution lasted for less than a minute and were dominated by staff's fleeting and typically instructional communication. When we revisited people in their community group homes, former Kimberley residents still spent 70 per cent of their time without a communication partner and 84 per cent of their day-to-day interactions continued to be with staff, replicating the way power was organised in an institution villa.

Donald Beasley Institute

- 1.9. From High Street I went and worked as a disability researcher at the Donald Beasley Institute (“DBI”). I worked there for the next 17 years.
- 1.10 There seems to be two kinds of people who find their way to disability research. Those who arrive by accident, and those for whom disability has become an issue of social justice. In those days my engines were fuelled by a kind of moral outrage, and most especially by the way I saw disability support services drift towards orchestrating people’s lives. As services became bigger and processes more bureaucratic, people could become the chattels of service provision rather than autonomous, rights holding and self-defined people.
- 1.11 The DBI didn’t feel like a good fit initially. I struggled with the idea that the researcher’s gaze might be another form of othering but came to see that genuinely inclusive research could offer people with a learning disability the tools and evidence they need to effect meaningful change on their own terms.
- 1.12 I would like to make clear that my statement is something of an amalgam. The body of the statement, and particularly the stories of those I met at the Kimberley Centre have their origins in a conversation I had with Thomas Hunecke and Nathan Regal in a motel room in Ōtepoti. They are personal stories that I have carried in my head for a decade now and I brought them to the room that day because most of the people have now past without being able to tell their story themselves. They are, therefore, second hand readings of the lives of people who shaped my thinking about institutions – and therefore impressions which crystallised, sometimes in fleeting moments we spent together in and out of the Kimberley Centre. Where possible, I have tried to contextualise my narrative by going back to research findings published in the Kimberley Research Project Report, *An examination of the outcome of the resettlement of the residents from the Kimberley Centre*. The report can be accessed at <https://www.donaldbeasley.org.nz/publications/deinstitutionalisation/>.

2. The Kimberley Project

- 2.1. When I started as a research assistant at DBI, it was specifically to work on the Kimberley project – research designed to investigate the deinstitutionalisation process.
- 2.2. The Ministry of Health recognised that the closure of Kimberley was a unique moment in New Zealand history. Deinstitutionalisation was still a highly politicised discourse and Kimberley was the last psychopaedic institution to close, bringing to an end what was a

significant policy shift in the long history of State care of people with a learning disability. It was, therefore, our last opportunity to capture any differences in the life quality of a single population, whose experiences were to be bifurcated by two contrasting models of care. The aim was to document what life looked like for people who were living at the Kimberley Centre and in their first years beyond the institution.

- 2.3 My understanding is that Ruth Dyson had a conversation with Anne Bray, who was then the Director of DBI, within which both of them talked about the significance of this moment in time. The research was reasonably well-funded in terms of disability research; and, because of how long the resettlement process eventually took, it became a Partnership Project, with the Health Research Council contributing funding to support the final two years.
- 2.4 Perhaps the great tragedy of the research was that, to get through all of the processes of setting up, and conducting and analysing and reporting, we never got the chance to mine the data for all its worth. The focus of the research was on the impacts of deinstitutionalisation. This resulted in a lack of emphasis on the impact of institutionalisation including a full analysis of the spectrum of abuse in institutional care experienced by the people who took part in the study.
- 2.5 We tried to go into Kimberley every month for a week at a time for 3 or 3 1/2 years, but I'm pretty sure it got to a week every two months by the later stages.
- 2.6 We implemented a mixed-methods approach to capture data, which we replicated after people moved into their new homes, using what is known as a prospective (forward looking), repeated measure design. The Kimberley diaspora was huge. The twelve people I followed took me from the top of the North Island down to Wellington and all over the North Island.
- 2.7 Given the amount of time it took, and how often we were in place at Kimberley, the project included elements of ethnographic research. We were embedded almost as a form of staged-managed ethnography. What I mean by this is that our time on site within Kimberley "villas" was scheduled and it was clearly obvious to the people that were there that we were researchers, however, over the three years the project ran at Kimberley, we did become part of the institutional landscape.
- 2.8 Stories about physical abuse were commonplace. They sat just below the surface of asking. A quieter part of the everyday vocabulary of an institution. There were the "hosings down",

and the unexplained bruises, and what was known as the “Kimberley Cringe”. For example, part of the chatter when we arrived was that one of the women from the locked-in villa had been taken to the hospital to have a pregnancy terminated. In a locked villa, the most obvious way for her to have become pregnant was to have had sex with a staff member. Being privy to this kind of information by virtue of being on site was difficult for us as researchers when it did not relate to the people (participants) who were formally part of the research. While our ethical approval and guidelines provided safeguards for participants, we did not have a mechanism to question or investigate these broader, historic allegations.

- 2.9 These kinds of stories are commonplace in institutions though. Almost everyone, for example, knew what the “Kimberley Cringe” meant. That if you walked towards a resident, some would quickly cower. And they were present enough to normalise many forms of abuse. But to me the real story of Kimberley isn’t that. The insult of an institution is the depersonalisation and otherwise seemingly purposeless lives that make the events that we more readily recognise as abuse – almost inevitable.
- 2.10. Stories of abuse have to be told. It’s part of the witnessing and is essential if we are to understand and remedy that which we need to be accountable for. But they are the tip of an iceberg. One face of a milieu informed by an understanding of personhood that has had a huge impact on those who now live in and beyond State care. Most of the iceberg sits beneath common understandings of abuse and neglect. My evidence draws on both the formal results of the Kimberley research, which are reported in a suite of research reports on the project. It also includes information that was collected as part of the research but didn’t always find its way into these more formal and focused reports; information that illuminates the covert and overt experiences of institutional abuse.

Arrival at Kimberley and the early stages of research

- 2.11. In the first weeks and months at Kimberley, there was a degree of resistance, even hostility by some staff, towards us. But nobody had a choice about our being there. Our presence was supported by Ruth Dyson and the Ministry of Health, which had provided funding, the formal ethical approval granted by the Health and Disability Ethics Committee, and perhaps most importantly, the families who had chosen to be part of the research project.
- 2.12. When we first got there, staff who didn’t know who we were asked if we had come to “window shop”. What they meant by that was: community services would come in as part of the resettlement process and claim particular residents to populate their houses. In the gallows humour of the institution, they called it “window shopping.”

- 2.13. At the beginning, most of the staff at Kimberley thought, in the same way that Cherry Farm staff did, that community services would inevitably fail because nobody knew the residents like they knew them.
- 2.14. I can remember sitting in the locked woman's villa, (which is an interesting concept all by itself, firstly that it was all women, and secondly that it needed to be locked in an institution that was gated anyway). I was so affronted by the place. I can remember being absolutely shocked at the way people were spoken to and the sterility and unfamiliar physical context within which these women's lives were being lived out.
- 2.15. When we sat down to analyse the Kimberley data, we discovered that of the 449, 30-minute observations we conducted at Kimberley, only 1 per cent of resident's time was spent beyond the institution. Ninety-nine per cent of the time the men and women we followed were absent from very ordinary spaces and places. Locations commonly understood as elemental to participatory citizenship – or as destinations that express something of self-determined personhood.
- 2.16. According to Johnson & Traustadottir (2005), institutions were deliberately built to convey a sense of permanence, professionalism and authority to the families who were forced to surrender children to State care. The grand Gothic architecture and the spacious grounds. But the reality was that nobody walked the grounds. The real life of an institution happens behind these facades. At Kimberley, the illusion of spaciousness masked a much more disquieting reality. At the time we went, 96 per cent of our randomized observations occurred in people's villas. Moreover, not only were these adult citizens routinely hemmed into their villa for 70 per cent of the time, the villa dayroom or dorm represented the limits of their life-space.
- 2.17. In most villas, the people who lived there typically sat along the fringes of the dayroom. Days played out on the same second-hand chair they had sat on the day before and most of the days before that. If you were lucky, the villa had enough seats to accommodate everybody. Some stood, or occasionally wandered but most sat, as if held to the villa wall by some centrifugal force – and they watched and sat quietly avoiding attention, waiting for some unanticipated change. In between, was a kind of “no-man's-land” that people seldom entered. A stage that staff didn't often cross either. Instead, they tended to sit and monitor the villa from their desks, fulfilling the role of keepers of dayroom equilibrium or an institutional stasis that everyone had acculturated to. According to this institutional logic, on a good day, nothing happened.

- 2.18. Life at Kimberley could generally be characterised by long periods of inactivity, interrupted by brief and scripted flurries of orchestrated action. When we coded the observational data more than 50 per cent of residents' time fell into the category of Sedentary Activity. Disengaged time spent, sitting, standing, staring and snoozing. If Wandering and other forms of Self-stimulatory activity were added, the people we got to know spent approximately 80 per cent of their time at Kimberley engaged in no form of obviously purposeful activity.
- 2.19. The following preamble to an observation was included in the Kimberley Report and is typical of villa life for many.
- 2.20. *[Resident] hides his face and lies down on couch in enclosed veranda. Three other residents in there, one sitting (strapped) into arm chair. One man wandering and sitting and 3rd is in a wheelchair with tray attached. This man grinds his teeth. Focus person has a plastic bottle that he is popping bits off. Five other men are in the day room with TV going. One wanders, the rest sit around the walls. One staff is working in there. He looks up from his paper periodically to talk to residents. (p. 139)*
- 2.21. An institution beats to the drum of its own, historical rhythm. There was an appointed time for everything. You only had a certain amount time to get people through all the showers and then it was on to sitting in the dayroom waiting for the tea trolley to get wheeled in at its appointed time. If you were quick you got two cups. If you weren't, you missed out and had to wait for the lunch break.
- 2.22. The whole villa would go for lunch, and you had a certain amount of time to eat lunch before the next villa was marched in. People had their assigned seats because staff knew who would take other people's food or who was likely to fight. They are things that make perfect sense in an institution but make no sense at all in our own human lives.
- 2.23. Everyone was caught by the institution's largely unchanging cadence. At Kimberley there were up to 13 residents to one side of a villa, which was supposed to be staffed at a ratio of 1:5, but in practice, often wasn't. Similarly, all residents were supposed to be sighted every 4-5 minutes, and these constraints together with the acute lack of day-to-day activity meant that it was difficult for villa staff to create opportunities for people to learn, or to acquire new skills or to discover latent competence. Those who lived, and those who worked there, were not afforded any opportunity to engage in any wider contemplation about what might ordinarily give joy and meaning or purpose and momentum to a human life.

- 2.24. In his early work on institutions, sociologist Erving Goffman (1961) wrote that the loss of a progressive personal identity through restrained and regulated circumstance represented the defining attribute of institutional life. These kinds of assaults on human dignity can be invisible to those entangled in the culture of an institution. They are sometimes more visible when you're parachuted into a setting as a young and naive researcher. I think that many of the people who have survived institutions were so acculturated to the setting that they will only report the things we have all been socialised to recognise as abuse. Their selves were forged in these places and are now part of their identity. Sometimes it takes the affront of an outsider sitting for the first time in a locked villa to see the things they may not.
- 2.25. Otherwise unremarkable moments of violence, like repeated exposure to the kicking of one's wheelchair or acts that determine the pecking order of a villa that everyone turns a blind eye to because that's way things get sorted – and here is nothing that can be done to change it. That is the nature of these places, they have their own logic.

The people I came to know

P

- 2.26. P was a non-verbal man with the brightest of blue eyes who'd been in the institution almost all of his life. His eyes did his talking for him.
- 2.27. P's nickname was Hardie because they used to have a building product called a Hardie plank. So, P's name was Hardie, because he was thick as a plank.
- 2.28. While we were working on the Kimberley project I watched a documentary about a Japanese prisoner-of-war camp and their treatment of Chinese prisoners. To legitimise the way that they behaved towards the prisoners, guards needed a depersonalising lexicon. The Japanese guards would call the Chinese prisoners "logs". Beyond human. It was the first thing that came to mind when I heard the reason staff called P, Hardie. "Hardie plank." It is an understanding of someone's personhood that contributes, not just to the way you treat them, but also insulates you from thinking too deeply about it at the same time.
- 2.29. When he could, P would get outside, to a small grassed enclosure behind his villa. Around the perimeter of that enclosure was a deep furrow worn in the ground. There is a Buddhist word "sanskara" – that conveys the idea that we dig a deep impression when we continue to follow a single train of thought. P's sanskara was the circuit he'd habitually walked that had no grass because he trod it every day. It wasn't very big, only about 5 by 8 metres but it

was deep because he followed it day after day, looking amongst other things for the comings and goings of cars in the carpark – seeking some kind of external stimulation.

- 2.30. In the Kimberley project we tried to interview everybody, regardless of whether they were verbal or non-verbal. I'd sit and spend the time with P, and to interview him I sat across a table and he'd look at me with his striking eyes and would hit himself in a way that must have hurt and was probably harming him. And I'm sitting there, feeling complicit because there may be something about our interaction that is causing P to hit himself, so I tried gently to hold his hand, I tried to distract him. I tried everything.
- 2.31 In the end, in order to circuit break what was happening I hit myself in the same way, and P, bless him, took my hand and held it gently on the table. So, we stayed like that because for as long as P held my hand, he couldn't hurt himself.
- 2.32. These are the kind of abuses I mean. Here is a man who walks a track every single day without intervention. Without anybody curious about what he's looking at. And here is a man who hit himself in a way that was harmful, and it didn't appear to be important enough to do anything, to understand what's going on inside of P's head. Whether the lack of stimulation in the institution might be responsible for him doing physical harm to himself. The standard response appeared to be to medicate behaviour like this. Eighty-eight per cent of the people we followed had been prescribed psychoactive medication, 76 per cent of whom were administered two or more psychoactive drugs.
- 2.33. There is no end to these kinds of stories.
- 2.34. John O'Brien said of time, that nothing of value ever happens in productive or orchestrated time. It is most likely to happen in wasted time. The privilege of research is that although I knew I was never going to get a spoken interview from him, I was afforded the chance to sit across the table from P while he looked inside of me and I got to look inside of him.
- 2.35. That is the insult of 13 people lining walls with nothing but the institutional rhythm to keep them safe. There's no real opportunity for discovery. No opportunity for staff to change their understanding of people, to be surprised by them, to look for talent, to look for possibility. There's almost no opportunity for that in an institution.

R1

- 2.36. It's important to contextualise Kimberley. Kimberley was closing and it had been closing for a long time, so there was no vocational services and staff were dispirited. The people who

lived at Kimberley when we went didn't even have the dignity of feeling a sense of productivity or purpose about much at all. The lucky few, the oligarchs that had made it to the top of the villa tree, did sometimes get to act as proxy staff by doing the vacuuming. Or more capable women would sometimes act as a surrogate mum for people who were more impaired. An extra pair of eyes who had an opportunity to access the experience of caring for someone else.

- 2.37. R was such a person. That first day, while I was sitting in the locked woman's villa, another resident ran in naked, quickly followed by R. There wasn't a flicker amongst staff – for them this was an everyday event. And so, I got to watch R lovingly steer her away and get her dressed against the backdrop of staff calling out across the room, sometimes in the most disparaging of ways. Black, institutional humour – that's what they called it.
- 2.38. The vacuuming is interesting because R's life flew to pieces when she moved out. She had gone from the very apex of an institutional life, where she was kind of an ancillary staff member who had a role and felt valued.
- 2.39. Beyond Kimberley, she came out and into a community group home where people avoided the vacuum cleaner. She went from the very ceiling of a social hierarchy to the floor, with her life in Kimberley leaving her bereft of the skills, insights or social capital she needed for people who had never lived in an institution to imagine her differently. As a consequence, the person who I thought had the most to gain from community living struggled, like a fish out of water.
- 2.40. R spent at least a year in Te Mata Hou because she would destroy her room. I don't know what happened to R afterwards, but life beyond Kimberley was a real struggle for her. One of the failings of deinstitutionalisation was not to recognise just how pervasive people's sense of who they were was forged in these places.

D

- 2.41. D was another man that I was following. During the time I spent with him I became convinced D may have had locked-in syndrome. I reached this conclusion because every time I asked D a question his gaze, to me, was always purposeful – but I couldn't convince anyone else.
- 2.42. D never made it out of the institution. He got pneumonia and the way the quality-of-life formula may have worked for D in hospital was that his wasn't a life worth saving. His

prognosis certainly wasn't great – and yet, here was a locked-in man on the cusp of coming out of an institution. He had everything to live for.

- 2.43. While I was there, I saw no real curiosity about who he was and what his potential might be. There was no time, no time to look for that and little inclination or reward for doing it. An institution has a particular logic. In an interview I did with one of the staff at Kimberley, he told me that the institution had a prescribed work ethic. That it was important to do enough so that the next shift didn't have to work too hard or to do the work you didn't, but that you couldn't do more than enough, because that starts to set the bar too high for those who follow. It's a small window to work in and a small lens with which to see people.
- 2.44. In another interview I did, I can recall clearly a staff member describing D as "not user friendly", as if he was an appliance. I laughed. "Shit," I said, "you're talking about him like a he's a jug." For this person, even D's body had become little more than the uncompliant object of her work.
- 2.45. The last day that we were in Kimberley I went and visited D. He was lying on his bed and I was just talking to him, telling him "D, I'm going." He looked at the calendar. "That's today, I said, D; I'm leaving today."
- 2.46. As we talked, I told D I was so glad I got to meet you. That I was so pleased I got to know him. And he looked at me like, "You absolute asshole". He completely shook me. My only way of interpreting what he was saying was, "I allowed you to see a little bit of me. I think you got that there was more to me and – you prick – you just walk away."
- 2.47. In the culture that I witnessed, it was next to impossible for anybody to do anything more than walk away. You finished your shift, you clocked out. You'd done your work. You couldn't do much more.
- 2.48. The thing that scared the life out of me was after, maybe eight months, maybe a year, I caught myself in the woman's villa with the sun shining on the back of my neck and I'm sitting there with my observation sheet and I know everybody in the room. Feeling completely comfortable. I was no longer affronted.
- 2.49. And that is the nature of an institution. So, you forgive staff. The things that I was completely affronted by and recognised immediately as abuse, I no longer saw. In the same way that nobody saw P's track or the purpose in D's gaze.

2.50. The tragedy of an institution, to my mind, isn't the kind of things that are going to make the headlines. It's the things that make those abuses inevitable. It's the culture that sits behind those incidents. It's this everyday oppression that constitutes the real human rights abuse.

M

2.51. M lived in Kimberley and her mother was S. When S visited her daughter, she also kind of adopted P. "There are two of us," she said to her husband. P didn't have a family and in S's mind, the two of them could each push a wheelchair.

2.52. I thought I knew M. She would spend most of her time in her wheelchair fingering beads and kind of talking to herself in a language of her own making. She was suspicious of me and we didn't have a great rapport, M and I.

2.53. Once the research was done, I went to visit M's mum. We were just kind of debriefing about what we saw and all sorts of stuff, and she pulled out a box of photographs. And there was M, as a 6-year-old girl, standing up, holding a walking trolley, wearing a lemon dress with her brothers just out of frame. And I realised I didn't know M at all. I'd watched her for five years and I had no idea who M was. All of the staff would have benefited from seeing M in her lemon dress.

2.54. An institution changes the way you see, in a way that I thought I wouldn't be affected by. S said, that "there are two victims to an institution. There are the people who live there - but there is also the people who are forced into a social knowing of my daughter by having to work there".

2.55. I once heard John O'Brien talk about the ethics and purpose of support. He talked about how important it was to discover and reveal the light of somebody's being. To emphasize his point he said he had distilled ethics down to a single thing and showed a slide of a mum looking lovingly into the eyes of her Down syndrome daughter and her daughter looking lovingly back. "It's somewhere in there," he said. The care people received in Kimberley was a million miles away from that gaze.

2.56. When the men were resettled from Cherry Farm, it took us 6 to 7 years to find one man's family. His birth date was also wrong, but none of that seemed to matter.

2.57. I heard a similar story of a man in Kimberley who had, his whole life, been called by his brother's name. To get into an institution you had to have a birth certificate and his mum

couldn't find his, so she handed over his brother's. Those are the things that don't appear in files.

- 2.58. We know from the work of Hillary Stace and Martin Sullivan (2021), that in the wake of the Aitken Report of 1953, the construction of psychopaedic institutions expanded greatly together with the population required to fill them. The Aitken report recommended that parents should be encouraged to send their learning-disabled children to a psychopaedic institution before the age of five – for their own benefit. As a consequence, State care came to be viewed as an inevitable trajectory for families with a learning-disabled child, with the body of medical opinion and the absence of other forms of support folding about this assumption. According to the indicative analysis conducted by Martin Jenkins for the Royal Commission, by 1971, 40 per cent of people with a learning disability in New Zealand lived in a psychopaedic institution. By 1977, Kimberley had become the largest specialist learning disability hospital in the southern hemisphere with a resident population approaching 800 – or an estimated 15 per cent of all learning-disabled New Zealanders.
- 2.59. I think Kimberley became M's "home for life" at the age of 9 or 10. In this respect, she was little different from the other men and women we got to know at Kimberley. The average age at admission for the men we followed was 10.7 years, and for women, 7.9 years. By the time we met them, more than 80 per cent of the men's lives had been lived out at Kimberley and 87 per cent of the women's.
- 2.60. M never made it out. Like her dorm-mate P, she too would die before knowing a life beyond Kimberley.
- 2.61. In Sir Robert Martin's statement about his years at Kimberley, he said that he wanted to be with his family. That he missed them and that he wanted them to take him home. That he cried for them, but that they didn't come and in the end, he gave up crying. He also said that whilst he was cared for as a child, he couldn't remember being picked up, or loved, or cuddled – and that he had no-one to call his own.
- 2.62. It would take until 1985 for the New Zealand Government to announce it was adopting the policy of community living for people like M who were in long-stay institutional care. Between the Aitken report and this announcement, Harry Harlow had already demonstrated the significance of contact and comfort for human development, including a monkey's preference for a terry-cloth frame over the succour of a wire mother. Bowlby, Baritone and Ainsworth had long concluded their research into the importance of an attachment to

“someone you could call your own”, the WHO had recommended home care for people with a learning disability and the British Medical Association had condemned the Aitkin report.

- 2.63. For M, the stepping stone to Kimberley, like so many others, was the Respite Care it provided families all over the North Island, and the eventual breakdown of a loving mum trying to bring up a family, when the hope of some Kimberley respite was the only assistance she could draw on. She also had a GP who kept telling her, it was the right thing to do.
- 2.64. The untold stories of Kimberley are the ones we listened to from families who had to have seven goes at admitting their children. Stories of setting out for the long drive to Kimberly and of emotionally breaking down en-route, only to turn back and take them home.
- 2.65. This one family in particular, I sat in their lounge – and it was the most uncomfortable interview I've ever done. They hadn't spoken about that moment and the impact that surrendering their son to the institutional had had. It had wrecked their marriage.
- 2.66. When you took your son or daughter to Kimberley, you weren't allowed to see them for months because, families were told, they needed to settle into the culture of an institution and to reach an understanding that your family weren't coming to take you home. They needed to give up crying.
- 2.67. M lived in a “Multi's villa” (so named because the people who lived there had multiple support needs). As is made clear in the Kimberley Report, these villas tended to have quite personalised spaces. The dorm had beds in a row with a divider between and a small lounge at the end of the row. The people adjacent to you could see into your space, but there was a high degree of personalisation, in contrast to other villas where nobody had much of anything at all because their possessions might get stolen or broken. For them, there were few opportunities to declare who you were by writing yourself into your surroundings.

B

- 2.68. The Palm Grove villa at Kimberley was an absolute outrage. Palm Grove was for the men seen as the most challenging. It was concrete, double-locked and the windows were too high to see out of. There weren't enough seats for all the men to sit down on in the lounge and the television screen was way up high because somebody would try and rip it off the wall.

- 2.69. I was terrified of the place, not least because B would come and try to scratch your face, or tear your glasses off, much to the amusement of staff. Once while I was doing an observation, the staff invited me to “watch this”. A tradesperson was approaching the locked doors and, as they accurately predicted, B frightened them with the speed and seeming hostility of his approach. B wheeled away laughing at what appeared to be a well-practiced and reinforced induction. He was quite an intimidating character because B was hard to read. I was with him in the hall one day and my observation sheet fluttered to the ground and B picked it up. I thought, shit, what happens here? But he picked it up and handed it to me so gently.
- 2.70. When I went and visited him in the house he moved to, I thought he might be happy to see a familiar face – that is before he almost instantly poured hot coffee into my pocket.
- 2.71. In the report we ultimately wrote there is a sentence that goes “a pervasive acceptance of the reality that many residents had entered Kimberley speaking, but would leave silent represented a quiet but distressing everyday denial of personhood” (p. 58). It captures staff’s reflection on a comment made by B’s mum that when he first went into Kimberley he spoke, but when he came out, he didn’t.
- 2.72. Staff at Kimberley almost always spoke admiringly of B. His resilience. *“He has never been crushed by this place”*, they told us, *“no matter what he had done or what anyone had done to him, he would still be B.”* (p193). The clear implication being that Kimberley had “crushed” others who were no longer able to be their true selves. Perhaps because of the way he was socialised or perhaps because M was always going to be a self-made man, the unkindness of Kimberley for B and his mum, seemed to me to be, that it had become next to impossible for B to forge any kind of deep human relationship beyond the institution. He had no template for it.
- 2.73. B, his mum told us, used to drive the tractor on their farm before he went into Kimberley. They weighted the pedal and B steered while his parents threw hay off the back of a trailer. It always struck me as a great injustice, that the boy who could speak and steer a tractor became the man who would live beyond intimate and ordinary relationships outside of State care.
- 2.74. Imagine the deprivations that would make you lose your language. That language had no use to you in an institution. I struggle to imagine that.

- 2.75. While I was visiting B in Palm Grove, Arthur Taylor had just taken a case against Corrections because of the inhumane conditions that prisoners were exposed to. I think it related to not being able to get out of their cells to recreate for long enough or that they lacked amenities. Like most of the cases he took, he won. At that very moment I was sitting in Palm Grove with men who had done nothing other than to be born with a learning disability and who had to spend 90 per cent of their time sitting in a room without windows or enough furniture.
- 2.76. Men whose liberty had already been taken from them.

R2

- 2.77. Running around the walls, both in and outside of Villa 7, was a frieze of the finest hieroglyphics. They were the pencil work of R, who would spirit away leads and tuck them into air pockets beneath the insole of his shoes, so they didn't get taken off him. It was a work that looked to me as if had been decades in the making.
- 2.78. I can remember R repeatedly saying, "I'm going home. I'm going home." And the staff member I was with telling me, "He always does that when he elevates."
- 2.79. I met him again later, once he'd been resettled by Te Roopu Taurima. He was Māori and they had got him close to his home marae. I remember sitting outside and saying to him, "You made it home, R."
- 2.80. You would have thought that saying, "I'm going home", was an invitation to a much bigger conversation about where and why home was – but I saw no evidence of it. Instead "going home" was a sign of elevating. R lived with a biomedical understanding of turangawaewae.
- 2.81. This extract from an interview with R's community staff, published on the very last page of the Kimberley report, is how I choose to remember R's deinstitutionalisation.
- 2.82. *Researcher: When I first met [Resident] three and a half years ago, he would say to me in a quiet moment, 'going home, I am going home' The staff interpreted that as a sign that [Resident] was beginning to elevate. They saw it as a sign he was becoming unwell. I like to think now [Resident] had it right all along. Do you think [Resident] is home?*

Staff person: I think yeah, we had a powhiri like you saw today but it was at the whare and his sister was there and all our other whares and he came in to the house and he got to meet the staff, he got to meet the other mokopuna and he wasn't even with us for an hour and he was telling his workers to go home. It is almost like when he got that powhiri he knew he was home. He knew, it in himself and it is not something that you put there

because it was our first time meeting him you could feel it, almost feel it, you could feel it, it was like somebody who was lost and came home (p. 194).

- 2.83. I also remember the same staff person telling me that not long after R arrived, the Māori Queen died. Some of the men in the house said they would like to go to her funeral. Their first response was to buy this man and the other institution survivors beautiful black coats. Because of what they had been through, they became the service's kaumatua. Those men marched into Dame Te Atairangikaahu's funeral in their beautiful black coats, ahead of all others.

The bell-ringers

- 2.84. There were exceptions to the lack of curiosity at Kimberley. The one shining example I saw was the bell-ringers.
- 2.85. The bell-ringers would meet, and everyone had a note. My guy, he was E-flat and so when it came time for E-flat, the conductor would point and his bell would go off. You could just see the ecstasy in people who were blind or had other sensory impairments and perhaps who hadn't made a sound that entire day.
- 2.86. The best thing about the bells was that he used to take his E-flat out, to rest-homes. Some had gone as far as Australia, adding value not just to their lives, but to other people's too. Finding opportunities to embed reciprocity in relationships is so elemental to human dignity. Those things that cement you in place are the things you gift. Bell-ringing was an oasis in a place where almost all of the men and women got no real chance to gift anything.

3. Drawing conclusions from the project

- 3.1. We found that the quality of life outcomes for people, once they left Kimberley, was generally better the closer they moved to a relative. This was especially true for the development of new, or perhaps more accurately, the discovery of latent skills and capacities.
- 3.2. When we visited residents in their new homes and measured their adaptive behaviour six months after resettlement, we discovered a flourishing in their perceived competence, particularly in, if you excuse the vernacular of the Adaptive Behaviour Scale, the domains of *Domestic Activity, Language Development, Economic Activity, Numbers and Time and Responsibility*. This finding wasn't unanticipated. Other studies had previously found that the more homelike settings they moved to allowed people to participate and to practice or to

alert others to long buried competencies. What was new, and completely unexpected, was what appeared to explain most of the variance in the adaptive behaviour changes we observed.

- 3.3 Most deinstitutionalisation studies look for what impact differences in elements of service design or delivery make to the acquisition of skills and competencies, or whether any variation might be explained by differences in the personal attributes of individual study participants. What we discovered when we modelled adaptive behaviour change was that the two factors that explained most variance were how geographically close residents moved to their Welfare Guardian and whether that person was their parent.
- 3.4 The way we began to theorise this finding was that one of the major impacts of the Kimberley diaspora was to re-locate people within the ambit of the once severed love and aspiration of their mums and their dads.
- 3.5. The implications of this finding have been under-researched because, not only was distancing people from whānau and family central to the design of institutions like Kimberley, the visions and promise of embedding people with a learning disability within relationships that approximate familial care remain at the very margins of service design and delivery.
- 3.6 At Kimberley, staff couldn't give themselves any opportunity to love or to hold lofty aspirations for the men and women who lived there. It was difficult even to act in ways that recognised and nurtured the very human possibilities of learning and self-expression. They loved the residents for sure, but in their own institutional way, where the horizons of care barely crept off the floor of Maslow's hierarchy.
- 3.7. When we re-visited residents 12 months after their resettlement, the acquisition of adaptive competencies had almost completely stalled. Families who had once had the opportunity to make an important decision about where their family member might live also said they now felt marginalised or that they needed to manage the perception they that they were somehow intruding on service-led care.
- 3.8. Like I had done a decade before, Kimberley residents first met staff as strangers and both appeared to be enveloped by an ethic of discovery. Twelve months later, however, this kaupapa seemed to have been displaced by an antithetical ethic of "knowing". Residents had re-aculturated to the role of passive recipients of care that was largely moderated by their staff.

- 3.9. When we wrote the Kimberley report, I don't think we explored enough the difference between approaching people with curiosity and approaching them with knowing. Institutions think they know people inside-out. They never give themselves the chance to see M in her lemon dress the way her mother or her “just out of frame” brothers did.
- 3.10. When the UN Special Rapporteur on the Rights of Persons with Disabilities, Gerard Quinn and Abigail Rekas-Rosalbo (2016) wrote about the legal status of people with a learning disability, they appropriated the phrase “civic death”. It had previously been used to describe the way the rights of personhood for women had been transferred to their husbands via the institution of marriage. Women historically became “objects” or “chattels” managed by others, with this evisceration of their legal status legitimised as a form of “protection” – something done for their own good.
- 3.11. Jan Walmsley (2005) tells us that two forms of “protection” loomed large in the campaigns orchestrated by the Eugenic Societies, whose lobbying led to the Mental Defectives Act 1911 and a century of institutional segregation in New Zealand. The construction of institutions were required, so the argument went, to protect society from those palpably unfit to breed and to protect people with a learning disability from a hostile and unscientific community. It was, the Aitken report would conclude 40 years later, for their own good.
- 3.12. Quinn and Rekas-Rosalbo (2016) argue that then and now, the imagining of a material and moral difference between people with a learning disability and the wider “normal” community was and is significant enough to maintain some regime of civil death.
- 3.13. Even at first blush, the design and population of institutions that intentionally located people beyond the sight and minds of their community can be read as violating all 50 of the rights to full, equal and equivalent participation in society that now find expression in the United Nations Convention on the Rights of Persons with Disabilities. But the impact of places like Kimberley for each person who lived there were more nuanced and arguably more dehumanising than their inability to access a codex of individual rights.
- 3.14. For R, Kimberley took him from the place he never forgot was his own – it dis/placed R from his Marae, and his reo and the tukutuku and poutama that would have told him who he was and where he rightfully belonged. It was replaced instead, with a concrete villa, iconography of his own laborious stencilling and a biomedical understanding of Rs unfaltering desire to “go home”.

- 3.15. For D, Kimberley dis/placed him from his family – without anyone caring enough to record who they were. His family's care was instead replaced by routines that made it difficult for staff to see anything beyond a defiantly articulated body, or to spot the purposefulness of a gaze that might have opened up the whole world to him.
- 3.16. For P, Kimberley dis/placed him from proper acknowledgement of the deep rooted kindness that lay just behind his electric blue eyes, and a failure to be affronted by a furrow that circumnavigated the 5 by 8 meters that represented the material universe beyond his dayroom.
- 3.17. And for the man who drove tractors and went into an institution speaking, Kimberley forever dis/placed him from the loving touch of a mum who had tried desperately not to give him up and similar forms of human reciprocity.
- 3.18. But perhaps most disturbingly, Kimberley forever dis/placed generations of men, women and children from the citizen selves they might have been and become.
- 3.19. Had R1 & D & P & B & M & R2 been able, they probably would not have chosen to appear before the Commission today. In addition to lacking the vocabulary needed to make us fully appreciate what they experienced, the unvarnished and unpalatable truth is they may not have even recognised those experiences as abusive. "We were", Sir Robert Martin told this Commission, acculturated to the idea "that we were being punished for who we were". Human rights abuses were ordinary, every-day and socially sanctioned. They were quiet and went unnoticed in addition to being loud and unequivocal.
- 3.20. The challenge for all New Zealanders, therefore, is to look beyond the social scripts used to explain the presence of institutions like Kimberley by restoring R1 & D & P & B & M & R2 to their full personhood. To do so, we simply need to decide whether all of the deprivations and dis/placements they experienced would be morally defensible for any and all other Rs or Ds or Ps or Bs or Ms, and if not, why might we have ever thought so.

4. Personal Impact

- 4.1. I never experienced my time at Kimberley as traumatic. I'm so grateful I got the chance to meet R and M and P et al. I think I'm one of the luckiest people. I always came back richer. People with a learning disability will do that every time.

- 4.2. We got into the habit at the DBI of asking people why they chose to participate in the research we conducted. Almost invariably, the answer was “because I want people to know who I am”.
- 4.3. It led us to title the Article 19 Project the DBI conducted for CCS Disability Action, “*I am here*”. It’s the second half to a traditional South African greeting that goes: “I see you”, to which the expected response is, “I am here.” Research, if it’s done well, can allow people a small window to be present in a way that they might say, “I felt here, and I felt you here with me”.
- 4.4. Institutions, in all of their configurations, tend to be hard of hearing. They are places that make it difficult for residents and staff alike to de-stabilise and deconstruct pre-existing prejudice because they are also places where it hard to be wholly and humanly present. Changing how we see and hear people with a learning disability across the whole of society is essential, because those who enter an institution walk in and then, if they are lucky, walk out. Institutions and institutional thinking is bigger and beyond a single person and will carry on, unless interrupted by the accumulated weight of a new script and new ways of seeing and hearing.
- 4.5. Without either wanting to, or being able to claim their histories, the people who lived and who worked at Kimberley are us. And we are them.

References

Goffman, E. (1961). *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. New York. Anchor Books.

Johnson, K. & Troustadottir, R. (Ed.s). (2005). *Deinstitutionalization and People with Intellectual Disabilities: In and Out of Institutions*. Jessica Kingsley Publishers.

Quinn, G. & Rekas-Rosalbo, A. (2016). Civil Death: Rethinking the Foundations of Legal Personhood for Persons with a Disability. *Irish Jurist*, 66; 286-325.

Martin Jenkins (2020). Indicative Estimates of the Size of Cohorts and Levels of Abuse in State and Faith-Based Care. Royal Commission of Inquiry into Historical Abuse in State Care and the Care of Faith-Based Institutions. Available at; <https://www.abuseincare.org.nz/our-progress/library/v/195/size-of-cohorts-and-levels-of-abuse-in-state-and-faith-based-care-1950-to-2019>

Milner, P., Gates, S., Stewart, C., McDonald, T., Mirfin-Veitch, B. & Bray, A. (2008). An examination of the outcome of the resettlement of residents from the Kimberley Centre. Dunedin. Donald Beasley Institute.

Walmsley, J. Institutionalization: A historical perspective. In Johnson, K. & Troustadottir, R. (Ed.s). (2005). *Deinstitutionalization and People with Intellectual Disabilities: In and Out of Institutions*. Jessica Kingsley Publishers.

Stace, H. & Sullivan, M. (2021). A brief history of disability in Aotearoa New Zealand. Office for Disability Issues. Available at <https://www.odl.govt.nz/guidance-and-resources/a-brief-history-of-disability-in-aotearoa-new-zealand/>

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 _____

Dated: 20/6/22