

Witness Name: Caroline Arrell

Statement No.: WITN0601001

Exhibits: [WITN0601002]

Dated: 21 March 2022

ROYAL COMMISSION OF INQUIRY INTO ABUSE IN CARE

WITNESS STATEMENT OF CAROLINE ARRELL

I, Caroline Arrell, say as follows:

1. Introduction

- 1.1. Kia ora, my name is Caroline Alice Arrell (née Barnes). I was born on in [GRO-B] 1962. I currently reside in Wellington and I am now semi-retired.
- 1.2. My evidence relates to the abuse and neglect of children, young people and at risk adults with intellectual and physical disabilities who lived at:
 - a. Tokanui Hospital in the Waipā Region, between 1979 and 1994. I started as a student training officer in 1979, graduating as a training officer and then a senior lecturing training officer during this tenure.
 - b. Kimberly Hospital and Training School in Levin, during the deinstitutionalisation of this hospital from the early 2000s to 2006. My involvement with Kimberly arose via my role as project manager for NZCare. NZCare was responsible for the repatriation of 312 people who lived at Kimberly to their new homes across New Zealand, between 2000 and 2006.
- 1.3. I came forward to provide this evidence after being prompted by Janet Doughty. Janet is a person that I had met through my association with People First, when I was working for IHC as National Manager for Self-Advocacy. I wanted to come forward earlier, but, like many I suspect, I needed that push to record the humanitarian indictments of institutional life for people who were rightly and wrongly diagnosed with an intellectual disability in New Zealand.

- 1.4. I know that the Royal Commission's priority will be the people who were abused and neglected in care. I am also mindful of the psychological anguish of the many good people who worked in these institutions, who witnessed abuse and neglect. They were unable to prevent or report with any effect. I think it is ironic and sad that the information I can provide is the same information I tried to convey throughout my career in these institutions. The "system" did not accommodate any type of advocacy or serious redress. I am now giving evidence 30 years later, when many of those who were abused and neglected have passed away – and the Royal Commission is listening. So, on behalf of those people who endured institutional life and have now passed on, I thank you for this opportunity.
- 1.5. I also note that this evidence is very difficult yet important for me to give. Some of what I saw and was involved in has remained with me for a large part of my life. These experiences are part of why I have devoted my life to training, teaching, managing, and contracting to disability providers, to ensure the assimilation of human rights into human services structures, reviews and planning.

Privacy

- 1.6. My evidence includes information I have gained from people who have passed away. I note that I do not have their permission, nor any family member's permission, to relay these stories. I have lost contact with these families. My evidence also includes information from people who are still alive; similarly, I do not have their permission as I no longer know where they live. Accordingly, I have used first names only in these instances.

2. Tokanui Hospital and Training School

General Background

- 2.1. I began work at Tokanui in 1979. I had just turned 18 years old. I was a Student Training Officer at Tokanui Children's Training Centre, which was attached to the psychopaedic side of the hospital. Tokanui was in fact three hospitals:
 - a. The psychiatric wards of the hospital known as Tokanui Hospital;
 - b. Te Mawhai hospital for elders with dementia and other age-related conditions, known then as the psychogeriatric side of the hospital; and
 - c. The Waipā Community and Training Centre which was dedicated to people with intellectual, physical and developmental disabilities, known then as the psychopaedic side of the hospital.
- 2.2. I did not work in the larger, psychiatric side of the hospital.
- 2.3. I recall that in 1979, about 300 to 400 children, children, adolescents, young adults and adults lived in the Waipā Community and Training Centre. Of that number, approximately 32 young children were housed in a village complex which was comprised of four houses clustered together. This was known as the children's village. These houses were

reminiscent of the early state houses of the 1960s and were meant to resemble a more homely atmosphere with a lounge, kitchen and dining room. Some of the children shared a room but most had their own room. These children who lived in the village setting could be described as more competent in their adaptive and intellectual functioning. Most of these children came daily to attend classes at the Children's Training Centre. The remaining children and young adults were housed in large 22 to 32 bed wards, and they were of mixed gender and abilities.

- 2.4. There was a fairly set roster of staff who worked on these wards and in the villas to ensure that staff got to know people well. For the young children themselves, there was a sense of predictability as to who would care for them. This predictability was a mixture of happiness and security for some, and trepidation for others.
- 2.5. These larger wards were Ward 5, Ward 6, Ward 8, Ward 16, Ward 17, Ward 18, Ward 19, and H Ward. Ward 19 was the newest ward and was originally built as an isolation ward, so it was very clinical and medicalised in its appearance and function. However, it became a ward of permanent living mostly for young people and some adults who used wheelchairs for their mobility and were dependent on support for eating, changing their clothes and going to the bathroom. Staff in all the wards were encouraged to wear personalised clothing, however there were still a large number of staff who chose to wear the uniform provided and carry the large key chains to their belts for easy reach and use. The rattling and sight of these keys is something that I will describe later in my evidence as a punitive, symbolic control icon. Many people who lived in these wards felt frightened of these keys.

The Children's Training Centre

- 2.6. As mentioned earlier, I started my training as an 18-year-old training officer in 1979. Training officers were specialist teachers of young children and adults with an intellectual disability. The Training Centre was organised in a series of small classrooms for approximately five to eight students at a time, and there was also a large vocational area. Not all children and young people at Tokanui went to the Training Centre – most stayed on the ward. There were between 20 and 30 children and young people in the larger wards, aged from about five to early 20s. Some had come to Tokanui as babies. As I believe and later learnt, it was strongly suggested to families by medical practitioners and aligned professionals in this era of institutionalisation, that they should place their disabled babies in institutions. This must have been a terrible predicament for families at that time.
- 2.7. As far as I can recall, very few of these children at the Training Centre had families who were actively involved in their lives. It was not until many years later, when I had the opportunity to meet many families in my role as Case Manager for the closure of Tokanui Hospital, and latterly the closure of Kimberley Hospital in the deinstitutionalisation process, that I learnt of parents' anguish and trauma. Parents had been advised by specialists to place their disabled child in the hospital and "get on with their lives". Often the siblings of the disabled person were unaware that they had a disabled brother or sister, and if they did later find out about their sibling, this was met mostly with genuine kind enquiry and the need for reconnection.

- 2.8. It is fair to say that this process, both the reconnection process and the deinstitutionalisation process, was incredibly difficult for families. In particular, in 2000 when I project managed the closure of Kimberley Hospital for NZCare, I was met with what I would describe as a strong parent group that did not want Kimberley to close. Our relationship with these parents then developed into one of trust and respect as the project continued, but not without the enormous and patient efforts of all stakeholders in the project.

Role of training officers a Tokanui Hospital

- 2.9. Training officers facilitated the learning of academic skills such as reading, writing, money recognition and use. We also facilitated learning of functional adaptive behaviour of everyday living, such as learning to dress, cooking skills and social interactions. I remain proud of what we did teach and accomplish, as we did assist many young people to engage in alternative activities, pursue other interests and learn new skills.

Applied Behaviour Analysis

- 2.10. When I began my training, the teaching techniques used at the Training Centre were based on a stringent behavioural approach called Applied Behaviour Analysis (ABA). ABA is a system of respondent and operant conditioning based on behaviourist theories which, simply put, state that desired behaviours can be taught through a system of rewards and consequences. It can be thought of as applying behavioural principles to behavioural goals and carefully measuring the results. This system was being taught and used when I arrived in 1979 and continued until about 1983. In 1983, Tokanui Hospital, like all other psychopaedic institutions, was under increased scrutiny regarding teaching and therapeutic practices. The rigid and punitive ABA models and teaching practice were substituted with QOL (Quality of Life Principles) teaching practices which did not involve aversive techniques such as time out.
- 2.11. During these teaching sessions before 1983, positive reinforcement was used to increase the likelihood of desired behaviours and responses occurring. Positive reinforcement included, but was not limited to, a small mouthful of yoghurt after each correct response, and tokens on a token board that amounted to larger food items and cans of coke. It was mainly food reinforcement.
- 2.12. These positive reinforcement techniques raise ethical questions. There are also questions about the long-term impact this has had on the recipients of this type of learning. I often wonder how these techniques then affected the recipients' learning once they left the hospital. The teaching techniques were devoid of love and compassion and had no broader application outside the hospital. For example, a person could learn money recognition but was not able to apply this skill in a real-life setting - for example by being taken shopping. The impact of this must have been confusing because the person could for example recognise what money was but did not know what to do with it.

Abuse

Positive punishment

- 2.13. "Positive punishment" was another technique employed at the Training Centre. This meant adding an aversive consequence after an undesired behaviour to decrease further responses, or in other words introducing an unpleasant consequence to the subject to discourage their behaviour. For example, for many children and young people in these small classes and in one-to-one teaching sessions, one of the aversive consequences for an incorrect answer was to be told "no" very loudly and placed into a time out room that was in each of the classrooms. The door was locked from the outside and they remained in time out for three minutes, and then one minute of silence. They were not told they had to be silent while remaining in the room. Once they were out of time out, understandably distressed, subdued or disorientated, or perhaps feeling many other emotions, they had to resume the teaching session.
- 2.14. We were expected to demonstrate competence in these practices if we were to pass our qualification. Many students from the 70s and early 80s, including myself, now deeply regret the teaching and interactional practices such as the above. The practice of time out for incorrect responses never sat well with me, or many of the training officers. Thankfully this practice stopped in 1982 with the move away from the practice of aversive techniques. These practices were increasingly under the supervision of psychopaedic governance structures, such as the nursing council and the Training Officer professional bodies, which followed and endorsed the international trends of appropriate and ethical practice. It was a significant event when it stopped – the timeout rooms were removed from the classrooms, and an evolution in teaching practices was acknowledged. However, I know these prior earlier practices must have caused significant harm to young people. I expect they may not trust people in power. Our teaching interactions in general were devoid of love or compassion, and I deeply regret the use of time out in teaching practice, even though I was instructed to comply.

Use of ammonia in other hospitals

- 2.15. During this time, I heard about a "change behaviour practice" used at Mangere Hospital and Training Centre, Kimberley Hospital and Templeton Hospital in Christchurch. An available punishment for a failure to perform/respond as required was an ammonia capsule being snapped open under the person's nose. We never used that practice at the Training Centre within Tokanui Hospital. It was however witnessed by my friend and colleague Linda, a training officer from Kimberley. A young woman had been banging her head so severely that she was referred to an external consultant psychiatrist Doctor GRO-B. He was regarded by some as a guru in behaviourism. Dr. GRO-B was contracted to travel to Kimberley to treat this young woman as all pharmaceutical and mechanical interventions had failed. Dr. GRO-B administered ammonia capsules to this young woman on two occasions witnessed by my colleague, to stop her banging her head. The use of ammonia capsules did not work. My colleague Linda administered a health checklist process and found out that this young woman was having severe migraine headaches. The migraines were pre-existing, and undiagnosed at that time.

Forms of punishment

- 2.16. Food and water would be withheld for alleged misbehaviour or non-compliance. Other punishments included enforced social isolation, when people in boyfriend-girlfriend relationships were not allowed to see each other because "they had been too naughty". Another punishment included not allowing phone calls or communication with family, or people being told that they would be reported to their families for inappropriate behaviour.

K

- 2.17. I recall K from Ward 18, in the early 1980s. She was about 10 years old and was one of my pupils who was regarded as taciturn and morose, slow in concentrating on activities of daily living, and of low intellect. Today, K would have been diagnosed on the Autism Spectrum. However, back then she was diagnosed with a type of melancholy schizophrenia and given electroconvulsive therapy (ECT) on three occasions that I can remember. I supported K to go to two of these sessions, where she had to be highly sedated. As a witness to this, I saw this prescribed procedure as a barbaric and cruel intervention that took K three to four days to recover from. K would come over to the classroom, like a zombie. I would build a bed for her in the classroom, keep her warm, and falsify her teaching records for those days, as no matter what physical or emotional state children came to school in, we always had to complete the teaching plans. I falsified a number of teaching records, instead choosing to read children's stories, make up funny plays, build indoor huts, sing and generally do kid stuff. I potentially may have been sacked for this if caught.

Environmental Abuse

- 2.18. A huge proportion of staff would smoke in every area of the wards before it was outlawed in the smoke-free laws, throughout all shifts. Patients were passively inhaling the fumes 24 hours a day. Staff also constantly played the music of their choice loudly, and the volume in the television room was always set to high. There was no place for people to have peace from noise chosen by others.

Neglect

Timetabling within Tokanui Hospital

- 2.19. There was a regimented culture of fixed timetables for the people who lived in these wards, which did not allow for any choice to be made, or any planning to suit an individual. There were very few meaningful activities during the day, and no activities in the day rooms where "The Days of Our Lives" television programme was largely the staff choice of activity.

Information not provided to new care providers

- 2.20. When a person was to leave the hospital, the records of what they learnt were not shared with the new providers. Accordingly, much of the person's skill acquisition was not known when they left hospital. Some years after Tokanui had closed I had the pleasure of

meeting a young boy that I taught to read and write. He cannot speak in words, but makes idiosyncratic noises and hand directions to indicate his messages. When we met, he immediately dug into my handbag to find a pen and paper and wrote down his name on the paper. It reinforced to me that the skills learned at the Training Centre had not necessarily transferred into the community setting. He learnt many skills such as writing his own name, money recognition, counting tokens to 60, colour recognition, and number recognition. My point here is that he was capable of learning many skills, and he did, but none of this information was passed on to his new provider. He was never asked to write his own name, and he never had the opportunity in a supported or prompted way to write his own name. There was little co-ordination and sharing through the discharge planning process of what people had learnt while living at Tokanui.

Relationships with students

- 2.21. We were told that we should not form relationships with our students. There were many reasons for this. However, on the annual camps we would break all the rules and give our students the best time possible, with plenty of affection and fun. The camps were great fun.
- 2.22. In the early 1980s, the positive behaviour practices such as those described by La Vigna and Donnellan, international renowned practitioners from a human rights perspective, began to be understood and adopted. A loved practitioner, John O'Brian, described interaction and intervention techniques from a quality-of-life perspective. Wolf Wolfensberger Social Role Valorisation (**SRV**) also became paramount in all intervention planning. John O'Brian's six competencies in quality of life continue to be reflected in many practices today.
- 2.23. At the Tokanui Training Centre, community presence, relationships, choice, community competence, and respect became the teaching practices and planning processes of preference derived from the six competencies in quality of life. However, management and clinical supervisors (psychologists) still required that these theories be taught from an Applied Behaviour Analysis (**ABA**) model and practice. What this means in brief is that we sought to understand the individual and their behaviour by looking at and analysing how their behaviour is affected by the environment. Positive reinforcement is one of the main strategies used in ABA. When behaviour is followed by something that is valued (a reward), a person is more likely to repeat that behaviour. Over time this encourages a positive behaviour change.
- 2.24. These teaching practices were strongly focused on examining the antecedent circumstances, what the behaviour looked like, the response, and the consequence of the behaviour. These practices and intervention strategies were effective but dictatorial, often punitive, and devoid of genuine care. These teaching relationships were completely transactional rather than relational.

Clustering

- 2.25. The wards were run down and overcrowded. As I will explain further, this had a direct impact and influence on the tolerance and patience of the direct front line support people.
- 2.26. The very way in which people were housed was abusive and led directly to negative outcomes, which I will try to explain. There were same-sex wards for thematic disabilities (autism and unknown aetiology) or people who used chairs for their mobility, and the clustering of people diagnosed as having “challenging behaviour”. This type of clustering people with similar behavioural, medical, and physical diagnoses restricted learning opportunities, restricted individualism, and increased the stress levels of the staff working with each group. The way in which people were housed directly correlated to staff’s patience and enthusiasm for their work.
- 2.27. I accept that it must have been both personally and professionally challenging to work in a ward that held 18-30 people with complex behavioural needs, and that the way in which people were housed directly impacted negatively on staffs’ empathy and desire to be of good service, however the tolerance and patience levels of staff in my opinion and from what I witnessed directly, contributed to neglect, impoverishment, and abuse. Grouping people into these thematic disability wards was an institutional decision, and the rationale was that it would keep people safer and ease the work loads of staff who were experienced in each of these disability specific wards. People had no choice where and whom they lived with, and in fact this type of grouping particularly for people who used wheelchairs for their mobility and had no expressive language, well it simply made them so much more likely to be neglected or abused.

Restraint, occupational therapy and feeding neglect

- 2.28. I witnessed one man at Tokanui Hospital and two men at Kimberley hospital be restrained in wheelchairs because of their extreme physical and behavioural challenges in the wards. They lost significant range of movement, ability to walk, and increased their aggression and pure anxiety. Thankfully, when they left hospital, with physical therapy and active support, these men regained some of their physical agility and dexterity. Very few people received the physical and occupational therapy that they required to keep and maintain their physical ranges of movement and ambulatory ability. It makes me so incredibly happy to see the children of today being assessed by multi and trans disciplinary teams to ensure that disabled children have the best possible shot at life through a raft of supportive services.
- 2.29. While I project managed the closure of Kimberley Hospital, I was incredulous at the number of people who were PEG fed. Percutaneous endoscopic gastrostomy (PEG) is a feeding tube that gives food and fluid directly into the stomach. Now I am not a medical expert, far from it, but in consultation with the multi-disciplinary team, called Explore Services, that were contracted to provide the health assessments and referrals at the time of discharge, through to overseeing the support implementation plan, I wanted to know why so many young and old, physically able and physically disabled people were PEG fed.
- 2.30. Many of these feeding tubes were assessed after discharge as not medically required for the individual and their use was slowly discontinued with regular eating instated. It was

distressing to learn that some of the people who had PEGs inserted, had this due to their complex behavioural needs and absolute dislike of meal times.

- 2.31. In my recommendations, I ask the Commission to contact Explore Services to seek the medical records held between NZCare and Explore from 2003 to 2007 regarding the number of people discharged with PEGs and how many were removed. I am sure that all the other contracted residential providers in this deinstitutionalisation project had similar experiences.

Sunburn

- 2.32. People who were unable to move were left in the sun for hours at a time, causing extreme discomfort and serious sunburn. When shade cloths were put up, people would be left for even longer. However, in the early 90s after a spate of serious sunburn incidents, the hospital instated a policy of sunburn protection, which staff could receive warnings for allowing sunburn to happen.

Eating practices

- 2.33. Staff had to support many people who could not move any part of their body and needed full support to eat. Often, they were fed cold, regurgitated food that had fallen on to the plastic bibs around their necks, with staff mechanically restraining their arms on chairs so this could happen. Charge nurses had the full authority to stop this practice, but I witnessed this daily.
- 2.34. I made it my mission to role model good eating practices, reheat food that had become cold, and check personal preferences. However, my impact and advocacy in what was meant to be one of the pleasurable parts of the day, had very little effect. I had no authority to stop this feeding/eating practice. Staff would clang a metal spoon on people's teeth and make them drink fluid from a sipper cup very fast.

Man-handling

- 2.35. Staff would regularly man-handle the people they were meant to be caring for. This might be to move them from one area or position to another. They would push other people out of the way, and yell at people to move. People who were sitting on the floor would be moved by staff pushing them with their feet. For example in Ward 16 that housed many people with physical disabilities there was a type of, well I will call it a conveyer belt, not a belt as such but a lineup of staff that had different roles in the bathing process. One staff member would wash the resident, and then that resident would be handed to another person to dry and clothe them. The staff washing people wore large plastic aprons and white gumboots. I understand the health and safety of these practices, but it made for a very cold and clinical activity that I know many people hated and resisted. It should have been a calm and pleasurable activity, that respected peoples' bodies, culture and privacy of their body parts, but it was completely transactional.
- 2.36. Even the most well intentioned and kind staff ended up engaging in these types of neglectful practices. In my opinion, this was because of the lack of "quality" time in the

regimented shifts, the lack of good staff, the lack of adequately trained staff, and also lazy and disinterested staff.

- 2.37. The residents' interaction with staff was all based on the daily care that they needed. There was no time for attention to be given to any choices or activities that the resident might have enjoyed. The relationship in its pure sense was transactional and not relational.

Lack of protection and lack of reporting or care

- 2.38. I have witnessed people with disabilities who lived together directly physically hurting each other. They would bite and scratch each other, often inflicting wounds that needed medical attention.
- 2.39. What seriously distressed me, and caused many breakdowns in my relationships with colleagues, was when people who used wheelchairs or who were restrained in chairs for meals, were bitten and scratched by others who shared the same ward environment. Defenceless young people who could not move any part of their bodies had to endure serious wounds caused by biting or scratching. This was rarely incident reported, but rather seen as: "Oh that's just so-and-so, he does that."
- 2.40. These young people had no way of verbally expressing what had happened apart from crying or making loud noises to express their pain.
- 2.41. I would often ask how a person's visible injury had occurred, or why they seemed to be in pain. Usually there was no explanation available, and no curiosity or care about the situation. Medical advice had been sought, but no solutions engineered to minimise this happening to people.
- 2.42. I am aware that a patient had unreported falls from hoists being used incorrectly. He was left with severe bruising on his legs. I observed this myself. The fall was attributed to his very rare disability that caused severe spasming.

Sexual abuse risks at Tokanui

- 2.43. There was no safeguarding of at risk adults or children in the psychopaedic wards at Tokanui hospital, particularly at night when staffing was down to a minimum and there was peripheral supervision only.
- 2.44. Disabled children were sharing living spaces with adults and pubescent young people who did not know how to direct their sexuality. Staff showed very little or no respect for sexual or intimate needs of people they supported, in fact many staff regarded people with intellectual disabilities as asexual, that they had no need for intimacy, love and sexual connection. There was no education about personal relationships, or intimacy and sexuality.

- 2.45. There were no incident reports from people with disabilities alleging any type of abuse, that I am aware of. If we review aligned research regarding the hidden sexual assault and abuse in institutional care, we can be sure that sexual assault or abuse occurred. I have questions now that include how this abuse would have contributed to challenging behaviour that young people would clearly exhibit around certain staff members. What are the indicators of abuse that we should be conversant with now? Are people with disabilities reporting abuse now, and how are they able to do this?

Self-harm, a silent neglect

- 2.46. People who self-harmed were usually ignored. People were able to cause serious harm to themselves and others. One resident had his teeth removed because of his biting, but no strategies were tried to improve the situation before this happened. From my observations, the biting happened when this man was driven to the brink of frustration by taunting from staff (often about sexual matters) and other emotional abuse by staff. I witnessed staff laughing at him when he was seriously biting his own arm in frustration. He could not speak or use expressive language.

Toileting

- 2.47. The toilets on the ward were open, so there was never any privacy. I saw people being restrained on open rows of toilets and potties until they passed bowel motions. I once saw a girl aged around 11 or 12 punished for pinching another patient, by being restrained on a toilet until she passed a bowel motion, despite it being known that she had moved her bowels that morning. She fell asleep on the toilet with her hands and waist restrained.
- 2.48. People were regularly left in their specialised seating in their wheelchairs for many hours, profusely sweating and in their own faeces. I heard staff say many times: "Let's leave him in shit for the next shift".
- 2.49. In the bathrooms in the morning there was always loud reggae or pop music played while people were being washed and dressed in cold bathrooms. The windows would be open as the staff were hot from the physical excursion of washing people. Staff would be talking to each other and taking a "production line" approach to the task of washing, drying, and dressing groups of patients. They would talk about the patients' genitals, but there was no respect or engagement with the patients while performing the most private and personal caregiving. I witnessed this as I would work in Ward 6, three mornings a week, teaching a young Māori boy to wash and dress himself.

Dental care

- 2.50. Dental care and treatment were rare for these children and young adults. In my recommendations to the Royal Commission, amongst many other aspects of life that need to be looked at, I am asking for a very deep look at how people with disabilities are supported to maintain good oral hygiene and how evidence of regular dental visits and treatment is provided. This applies in particular to those who currently live within government funded services. I know that this will provide some very disturbing results.

- 2.51. Proactive dental care was minimal. The dentist at Tokanui was regarded as a rough and impatient man, and people often had to be sedated to attend appointments. For more invasive procedures people were sent to hospital for a general anaesthetic.

Sexuality

- 2.52. The sexuality of people who both lived in Kimberley and Tokanui was seen as a topic for teasing, chastising and punishment. Nothing about sexuality was private or safeguarded. Men in particular would be taunted about sexual matters, particularly when they had erections in the ward setting. One man was taunted about his erection and given the name "Sexy Remy". The same man would masturbate in the day room, was made a public spectacle, and suffered public humiliation. He was never given any privacy. I am going to elaborate on the whole issue of sexuality in my evidence about **GRO-B-1**.
- 2.53. I witnessed the use of seclusion, time out and the use of medical prn (meaning medication as required) in attempts to calm people down.
- 2.54. The staff at Tokanui mostly lived within the Waipā district and at the many social gatherings, there were open discussions about the people they supported at Tokanui out of work hours – at social events, and in pubs et cetera. This included very negative descriptions of people's body parts, and personal information about their disabilities.

Discovery of unmarked graveyard

- 2.55. During my time at Tokanui, I lived on the Ministry of Agriculture and Fisheries (MAF) farm right behind Tokanui (on the fence line). This was a 500-acre farm, and my former partner was one of the shepherds. We had a MAF house right on the farm and I was able to enjoy a farming life. I could cycle to my place of work each day. I had a horse named Alice and a black labrador named Lucy, and we had the freedom to explore the farm.
- 2.56. In the early 1950s and 1960s the Royal Commission will be aware that Tokanui had an arrangement with this farm to provide some light farm work for people that had psychiatric disabilities such as working in the woolshed.
- 2.57. I would take my horse Alice riding over the farm, but there was this one particular paddock that my labrador Lucy would not follow us through. She would run the outside fence line and then re-join us at the other end. This paddock was often grazed with sheep, but this did not account for her apparent dislike of this paddock.
- 2.58. In early 1991 on a Sunday, I jumped Alice over the fence into this paddock and she tripped and fell, her near foreleg disappearing down a hole. I tumbled off. We were both okay except I tumbled against a hard piece of rock, or so I thought. It was actually a metal plaque that I pulled out of the grass. The plaque read "In loving memory of **GRO-B** with the dates of her life.
- 2.59. I carried this plaque back home and went immediately over to see our next-door neighbour, Corinne. Corinne lived in the cluster of the settlement houses provided for the workers of Tokanui. She was a well-known psychologist and a personal friend. Corinne

was overtly shocked and told me that this could be “the graveyard”, or what it was referred to as “the Paupers grave”, where people who lived at Tokanui were buried. After investigative work the next morning, Corinne located the plan of the graveyard buried in “the bakehouse”, the old actual bakehouse where all the records of this sort were kept.

- 2.60. To our shock, it showed that just under 500 people were buried in that unmarked paddock. They were divided up into religious denominations such as Catholics, Protestants etc. A lengthy process endured, with the right authorities and iwi, to resurrect the respect of these lives. More recently a large, beautiful memorial has replaced the very small, insignificant one which was instated not long after Alice and I fell into this paddock. My partner at the time was responsible for re-fencing the paddock to ensure that all these lives were respected by imposing a boundary and that no stock would graze on the land. I often wondered what people who lived in Tokanui thought and experienced during those days when they were working on the farm. The dead being taken to the graveyard would have been transported past the working woolshed. I have wondered how it must have felt to know that there was a high likelihood that you might end up in an unmarked grave, if you had no family involvement.

Complaints

No place for advocacy

- 2.61. I did question some of the practices at the time, but I was very young myself. There was no place for advocacy for the children. The staffing was hierarchical, and dictatorial. If questions were asked about the ethics of the treatment, we would be told that other people could be employed to do our jobs. A senior Training Officer explained this to me and he has since passed away. I recall an incident where I was asked to put a young Māori boy aged about 4 years old into time out for incorrect responses during a picture recognition session, and I refused to do this. This boy had an impoverished and unloving home environment and needed love and affection. Instead, he was placed into an institution that was equally devoid of what he needed.

No ability for residents to complain

- 2.62. The people with disabilities living on these wards either had no personal ability to make a complaint, or they had a very real fear of retaliation if they made a complaint. It must have been hell living in the enforced domestic abuse situations that had become a normalised part of life in these wards. A complaints system existed but people in care did not know how to file a complaint, or lacked the expressive content in explaining what they experienced, and staff were afraid of complaining as they feared repercussions.

Reporting incidents

- 2.63. Tokanui was an institution in a true sense. The very act of challenging authority was considered illegitimate, rendering advocacy impossible. Incident reporting was taken seriously when staff members were hurt, but not when people with disabilities were witnessed being neglected or abused.

- 2.64. I was ostracised and threatened by other staff when I reported, or tried to report, what I saw at Tokanui. This occurred on two occasions, once when the tyres on my VW were slashed and not reparable. I took these covert threats very seriously. I did not want to leave but I had to become more compliant myself in my overt camaraderie with colleagues to ensure not only the safety of myself, but the safety of people with disabilities who were relying on me and other gate keepers, to try and keep them safe.
- 2.65. I became well known for reporting concerning incidents or practices, and eventually I learnt that this in fact had a negative impact on the very people I was trying to keep safe. I remember worrying about whether the children that I was concerned about would get dinner because I had reported that their hair was being pulled by a staff member who had a vindictive voice when I was not around, as evidenced by GRO-B-1 telling me so. I learnt, like other disempowered staff, that it was better to keep quiet and work on making the best of the situation as I possibly could.
- 2.66. Sometimes I would hear staff call out to one another that "the Gestapo's here" when I arrived on the ward, as a warning that I would report any abuse or neglect that I saw. These were my peers, and they just made life more difficult for me in my work role. They would describe me in derogatory ways in front of people I supported, I was left out of staff parties, social and outside events. The people I supported would report to me that they were thankful that the behaviour of other staff was "better" when I was around. Often the updated communication devices that I had implemented for people, went missing or couldn't be found. I could never prove this but I know it was the very staff that saw me as an adversary and a snitch.
- 2.67. I would talk to other Training Officers about what happened at the Children's Training Centre, and the Head Nurse about the injuries and other things I saw on the wards. Sometimes I would be told that there would be an independent investigation about matters I complained of, but I never saw any positive outcomes or changes as a result.
- 2.68. There were some staff who tried to complain. But only issues to do with the health and safety of staff were listened to and acted on. Staff who tried to complain about the care of the residents were rendered powerless, and their relationships with other staff would be impacted.
- 2.69. A recent experience on Facebook when I tried to engage with people who were illegally entering the Tokanui Hospital grounds to take "spooky photos" demonstrated to me that these same old Tokanui staff adversaries, still view the lived experience of survivors at this hospital as humane, caring and compassionate. And for some, I am sure this is the case.
- 2.70. On Facebook, there is an "Abandoned Places" page. On this page, I explained to the person who posted the "spooky photos" that what they were doing was illegal, disrespectful and that I was compelled to report them. I then sought support from a Tokanui "old staff" Facebook page of which I am a member, in reporting the people who were breaking into Tokanui. The overwhelming majority of the comments from former Tokanui staff were that there was nothing wrong with this: "Good on them for breaking in" and "Get of your high horse".

Augmentative communication systems

- 2.71. Prior to Tokanui closing, I worked with [GRO-B-1] (who I will later talk about) and about 20 to 30 other "young" people in Tokanui hospital to assess and provide augmentative communication devices.
- 2.72. Augmentative and Alternative Communication (AAC) interventions use the individual's communication capabilities and then build systems around that person to increase the ability of a person to better communicate. This might include pictorial symbols, aids and strategies with the intention to enhance their individual ability to better communicate. This can include the use of gestures, sign language, the use of photographic albums and memory albums, printed words, objects and yes and no cards. Eye gaze displays, better reading of an individual's postures, and the better recognition of an individuals in idiosyncratic noises so that their communicative ability was enhanced formed a large part of my work. Stephen Hawking uses a computer to communicate, this is an AAC method.
- 2.73. In 1990, the Waikato District Health Board supported me to attend Nebraska University for a six-month intensive course in Augmentative and Alternative Communication. I developed expertise in working with people with intellectual disabilities in developing personalised communication systems.
- 2.74. I also worked with people who were described as having extreme behavioural repertoires, to transform their behaviour into a communicative context. I know that "challenging behaviour", as it was called, was overwhelmingly caused by emotional and physical neglect, as well as stimuli impoverishment.
- 2.75. Often, I believe they (as demonstrated in their behaviour) were also responding to a wide variety of abuse. I believe that they were behaving in perfectly understandable ways in very abnormal environments.
- 2.76. My intent and practice was to provide the most impoverished people with ways in which to communicate and be able to better indicate their stressors. On some occasions their increased ability to tell me what was going on provided more risk for them. I can exemplify this in one story that [GRO-B-1] told me about a staff member who was allegedly sexually abusing young children who could not communicate or move any part of their bodies. [GRO-B-1]'s testimony in this situation was not believed and the alleged perpetrator threatened [GRO-B-1]'s life. The staff member continued to work there.
- [GRO-B-1]
- 2.77. I would like to talk to you now about Mr [GRO-B-1] [GRO-B-1] and I are the same age, and although I am completely relying on memory now, he came to live in Tokanui Hospital when he was between 5 and 8 years old. I met [GRO-B-1] when I was 19, at Tokanui Hospital, so he had already lived there for 13 to 15 years. [GRO-B-1] unfortunately has passed away, but I would like to share our story with you.
- 2.78. To get to the Children's Training Centre I would walk past Ward 16 which housed approximately 32 people with what were considered to have severe physical and

intellectual disabilities. They all used wheelchairs for their mobility and were dependent on the staff to support them in all aspects of their life. Very few, perhaps five, children from this ward came to the Training Centre.

- 2.79. On the Tokanui site there was also an education department school. **GRO-B-2** was the principal and there were teachers as well as teacher aides. I will further address **GRO-B-2** in the latter part of my statement - he has since been convicted of sexual offending in **GRO-B**.
- 2.80. Approximately eight children from Ward 16 went to the Education School instead of the Training Centre. There was very little connection between the two schools. I would go into Ward 16 each day to collect a young man who was attending the Training Centre. During these brief visits to Ward 16 there was a young man about my age (turns out we were both born in the same year) who always caught my attention because I felt his eyes showed a need to communicate. This man was **GRO-B-1** who was born with cerebral palsy. **GRO-B-1** as we now know, did not have a cognitive disability, but his physical disabilities meant he was unable to communicate via speech or movement when I met him.
- 2.81. He could not move his very thin arms or legs, he could not propel his own wheelchair, and he spent most of his days in the day room of Ward 16 in his specialised wedge. He hung over the wedge and could raise his head to watch or listen to whatever was going on in the ward. Every time I walked past him to collect another boy, he would raise his head and give the widest smile. **GRO-B-1** had the most expressive communicative eyes, and I was drawn to him. I was always in a hurry and would walk past him and say things like "hey ya **GRO-B-1** how are you doing, are you having a good day" and he would open his mouth wide and give his famous cackle. One day I walked past him and gave the usual banter but noticed that he had pursed his lips tightly in answering me, instead of his wide-open mouth. This stopped me in my tracks, and I walked back to him able to communicate via speech or movement when I met him.
- 2.82. I asked **GRO-B-1** if he could say yes and no. He opened his mouth wide. I asked him what his no response was, and he tightly pursed his lips. It was immediate, it was purposeful, and immediately I knew that **GRO-B-1** had an incredible receptive world, but no expressive way to talk. I went back to the Training Centre and told the psychologist that **GRO-B-1** had to start coming to the Training Centre the next day, and that he would be in my class, plus I would give him one to one time. Reluctantly this was agreed and **GRO-B-1** and I started our 20-year friendship and working history.
- 2.83. The first day, I pulled together a very perfunctory eye gaze display and asked him to identify letters with his eyes. I had to have another way, so I designed a frame (see photograph of this frame **WITN0601002**)).
- 2.84. To cut a very long story short, **GRO-B-1** was able to spell, albeit phonetically on occasions. For example, he spelt out my name "Karo-lion", a name that in later years we would laugh about and still use. I cannot describe the day that we set up the eye gaze frame and started asking him to spell things out. I called one of my fellow training officers to come and watch what I found hard to believe. How had this man learnt to read and spell? As he would tell me later, he spent years on the floor of the dayroom watching playschool and

other children's programmes that allowed him, to a degree, to learn. Over the course of the next five years, GRO-B-1 and I designed a number of overlays in his eye gaze system that amounted to a vocabulary of five and a half thousand words. This was transferred when he left hospital to a book that was a duplicate of the system, but one that could be carried, and contained all the vocabulary he needed.

- 2.85. Over time the system developed into the version that can be seen on the People First video: GRO-B-1. There is also a video called GRO-B-1 a video we produced about his sexual abuse and his deinstitutionalising experience, which is available from the IHC Library.
- 2.86. As GRO-B-1 gained a voice through this system, he told me about many aspects of his life at Tokanui, and what both himself and others there were subjected to.
- 2.87. GRO-B-1 knew about staff taking patients' belongings (for example hand knitted jerseys and CDs) as well as TVs and VCRs from the wards. He told me about relationships between staff, including who was having affairs with who at work.
- 2.88. This was a dangerous time for GRO-B-1 because of course other staff had never considered him to be a person who could speak of what he saw and heard. Things took place around him which the perpetrators had assumed could not be spoken of. He heard staff speaking about things that they assumed he could not repeat.
- 2.89. GRO-B-1 and I talked a great deal about the system that he was subjected to, and the things he missed out on through being kept in an institution and denied communication for so many years. He wanted to take legal action against the education department about the education he never received, and on behalf of the many Tokanui residents who had been denied any training or education because of the perception that they were "untrainable".
- 2.90. GRO-B-1 mourned his years of being unable to communicate with his family, or to engage in social and sexual relationships with others. He had many battles to be able to take some of the steps he wanted to take, when he gained his voice. While he remained in Tokanui he feared further physical and sexual assaults himself. I feared for GRO-B-1 during this time because some of the staff he was telling me about were responsible for supporting him to eat and preventing him from choking. He also knew about the risk.
- 2.91. GRO-B-1 spoke to me about the sexual abuse that he endured from staff, and about the sexual and physical abuse of others that he saw or was aware of. One incident that distressed me so much that I confronted the cleaner who was the perpetrator of this abuse. I immediately reported this to the charge nurse of Ward 16 after GRO-B-1 had told me. The cleaner on Ward 16 thought it was hilarious to suck GRO-B-1's penis into a high-powered vacuum cleaner and laugh with other members of the staffing team. Other staff had seen it, and they thought it was funny, but the practice was stopped immediately when I reported it.
- 2.92. GRO-B-1 was able to make disclosures about another staff member who engaged in abusive behaviour towards his peers, which led to an unsuccessful prosecution. This alleged

perpetrator threatened [GRO-B-1]'s life, before he was fired as part of the investigation. This was a terrifying time for [GRO-B-1].

- 2.93. It is fair to say that I adored [GRO-B-1]. We experienced so many things together, far too many to add into this evidence. He taught me a great deal about humanity and being of genuine service to people with disabilities. He taught me a great deal about never making assumptions about what people are trying to communicate, and always to seek authentically to understand what people are trying to communicate.
- 2.94. When he was learning to communicate, I asked him what he wanted in life. His reply to me on this day was that he wanted to have sex. His world view of "sex" was in part based on what he had watched on "Days of our Lives" and other soaps, lying in the day room on his wedge in Ward 16. I asked him if he knew what sex was and he answered no. I dutifully got a "birds and the bees" movie and showed this to him, which shocked him and he became extremely emotional, mouthing very strong "no's" to me. What he was trying to tell me, as we discovered after hours of enquiry after showing the video to him, was that he wanted to see his body naked. He wanted to be handled in a soft and caressing way. He wanted to feel love and close intimacy rather than being on a conveyor belt of being washed, roughly handled and changed with people commenting on his body negatively. The only way he had to try and communicate these needs to me was by the use of the word sex. In later years when I was his case manager and helped him leave Tokanui, he privately procured the services of a sex worker to explore his sexuality. This was a ten-year paid relationship that [GRO-B-1] wished was so much more.
- 2.95. In 1992, I decided the only way to safeguard [GRO-B-1] and many others was to apply for the position of case manager at Waikato Community Living Trust. I became the case manager for the young men whom I suspected [GRO-B-2] was abusing (I later detail what I found out about [GRO-B-2]). I was also the case manager for many others and moved them as part of the closure of Tokanui Hospital.
- 2.96. I was [GRO-B-1]'s case manager when he left Tokanui to live in the community when he was about 30 years old. He would speak at polytechnic courses about caring for disabled people, sexuality, and institutional living. His goals included going to university and writing the story of his life living with cerebral palsy.
- 2.97. [GRO-B-1] passed away in 2012.
- 2.98. As an aside, my mother was a social worker for IHC in the late 1960s early 1970s, and she had supported [GRO-B-1]'s family to place him in Tokanui, as she did for many families, and her daughter became hell bent on getting them out. Our philosophical discussions regarding how ironic this was, were and remain challenging and compelling.

[GRO-B-2] – principal of the Education Department School at Tokanui

- 2.99. [GRO-B-1] also raised a serious allegation regarding the then principal of the Education Department School based at Tokanui, whose name is [GRO-B-2]. [GRO-B-2] took his disabled students (young boys) to his house in Kihikihi every weekend on a rotational fashion (two to three boys each weekend). This was allegedly with the sanction from the

wards in which they lived. [GRO-B-2] had his own specialised wheelchair van that he used to take the young men home.

- 2.100. [GRO-B-1] had described to me that one of the boys, [GRO-B-2] took home was able to communicate with [GRO-B-1] through an eye gaze communication that they had worked out together. This system was not overt, but [GRO-B-1] assured me that the boy was describing a type of terror, in his facial expressions, at going home to [GRO-B-2]s in the weekends when he was scheduled to go. Now, this anecdotal narrative cannot be verified, nor can I describe any credible evidence that this communication between [GRO-B-1] and the boy occurred. I am convinced now, however, that these young boys were the victims of a serious paedophile. I learnt in April 2021 that [GRO-B-2] had been convicted of sexual assault and abuse of two young men at a criminal trial in [GRO-B-1] from [GRO-B-1] when he was the headmaster of the primary school, prior to being the headmaster at the Tokanui education school. Two men came forward who went to [GRO-B-1] primary school and told their stories. [GRO-B-2] was found guilty and sentenced for a term in Waikeria prison.
- 2.101. [GRO-B-2] would take home these boys from Tokanui on the weekends. They could not speak, yet they could make verbalisations which indicated their moods and emotional status. They could not move or control any part of their bodies and were totally dependent on their support team for all their eating, and all activities of daily living. They wore incontinence products and again were totally dependent on support.
- 2.102. Once I became aware of [GRO-B-2] taking these young boys' home, this was possibly around 1990-1991, I immediately spoke with Dr [GRO-C] from Waikato Community Trust, who felt that we needed to investigate this further. She contacted the Medical Officer from Tokanui at the time, Dr [GRO-C]. She arranged for some of the men to be taken for forensic sexual abuse testing at Waikato hospital on the Monday morning after [GRO-B-2] returned them from a weekend stay. This was done very covertly. No one from the ward knew except for the senior nursing management. I supported the men to go, rode in the ambulance with them, and supported them through a very invasive forensic sexual assault examination which was extremely traumatic for them.
- 2.103. The outcome of the forensic testing was that no physical evidence could be found. Because these young men were all subjected to daily enemas for bowel evacuation, there were the "usual" signs of the high and long-term use of enemas on their rectums, but that was all that could be found. However, based on this highly suspicious situation, [GRO-C] contacted [GRO-B-2] and told him that she remained concerned about this highly unusual and odd relationship with all the young boys. She told him that he was no longer able to take the men home. He complied with this. However, he still had these young boys at the school all day. I am aware of other evidence from a teacher aide at the school. I know that she has described the way in which [GRO-B-2] would clean the young men's penises, and that [GRO-B-2] made it clear to his teacher aides that he was the only person to deal with their incontinence issues. As mentioned, I raised my concerns with Dr [GRO-C]. I am unaware whether any complaint was made to the Police at this time.
- 2.104. When I found out in 2021 that [GRO-B-2] had spent time in prison in [GRO-B-2] for sexually abusing young boys, this was catastrophic for me. I find it difficult to describe how I feel about this. Although never proved, I absolutely believe that these young boys at

Tokanui endured the abuse of a serious paedophile. No one recognised or responded to the extremely suspicious behaviour from this disgusting monster whom I understand is still alive. I could not protect them then. No one protected them. This is a disgusting indictment on institutional life and demonstrates the complete lack of value placed on the humanity and rights of these young men. This will probably haunt me for the rest of my life.

3. Barriers to disclosure of abuse

- 3.1. It is well documented that people with disabilities, particularly people with intellectual disabilities, experience significant barriers to making complaints about their service. What I witnessed in Tokanui and Kimberley Hospitals was that people with intellectual disabilities faced the following barriers:
 - a. The inability to communicate;
 - b. Fear of retribution or not being believed;
 - c. The acceptance of the status quo, in that this was life and they couldn't do anything about making it better;
 - d. Many changes of staff, who brought with them different attitudes and value to their lives; and
 - e. The lack of clear and well-defined policies and protocols around reporting abuse, and what constituted neglect and abuse.
- 3.2. The people who lived at these hospitals were not aware of their rights in receipt of service, they were not educated or informed of what constituted neglect and abuse, or the process for getting support and reporting it. They did not understand what exploitation was, they knew what was happening to them was wrong, but could not articulate and report because of these many barriers.
- 3.3. In my recommendations, I have asked the Royal Commission to take a closer look at how the reporting and responding to neglect and abuse is instated and monitored in service provision.

4. My involvement with the closure of Kimberley Hospital

- 4.1. Between 2002 and late 2006, I project-managed the closure of Kimberley Hospital for NZ Care. 312 people were to move into NZ Care residential services. This contract involved the relocation of those people who had intellectual disabilities and varied in age from 28 to 78. What I witnessed in terms of environmental, physical, emotional and psychological neglect is known by many (and recorded in the Donald Beasley Institute publications that the Commission has received).
- 4.2. However, I would like to share my thoughts and experiences around the themes of neglect and abuse for specific individuals.

- 4.3. As part of the process of moving people from Kimberley to the community I needed to assemble the record of each person's life, before life, and during life, at Kimberley. For many people this could only be partially completed. The poor record keeping meant there were many missing documents about people's family life, histories and contacts. There were many emotional journeys as we strived to reconnect families at this time. Families were reconnecting because people were leaving the institution.
- 4.4. The needs assessments at discharge were inadequate. The focus was on transactional support needs, rather than relational learning needs and the support people needed to maintain a level of independence in their own lives. So, the new care staff learned about how to move or feed a person but not what they liked to do or see, or how to communicate with them. This is still a relevant issue in the needs assessments completed today.
- 4.5. The lack of information that was not known about each person and provided in their needs assessment was in my view a form of neglect. Information about people's lives focused on deficits and not adaptive behaviour, or what people could achieve. The representation of people and descriptors of people, particularly with complex behaviour, gave them very little chance of broadening positive life experiences.

5. Other matters

- 5.1. Now, thinking back about all the terrible indictments that I witnessed in the institutions, I am concerned about how much attitudinal traction we have made in addressing the rights and living conditions of people with disabilities. Of course, there have been many positive changes, with legislation, commissioned reports such as "An Ordinary Life" etc. In fact, there have been a multitude of reports and legislation.
- 5.2. I believe it is how we now authentically review if institutional neglect in current service provision is still relevant and pervasive today, but the subtlety is more covert. In September 2021, IDEA Services Chief Executive confirmed via a media statement that they prohibited the use of baths in all of their residential services. They have also disallowed the use of any spa pools in residential homes and other facilities owned or leased by IDEA Services. The reason cited was that there have been significant investigations and due diligence into the risk of using baths in services, and a recent court ruling stated that their duty to minimise the risk of baths was greater than people's rights to choose to have one. Perhaps a controversial example, but one which many recipients of service are very unhappy with, however they have very few ways of being able to express this from a self-advocacy perspective or from an informed decision-making premise.
- 5.3. Over the years, the changing philosophies that providers have strongly believed in have been derived from a humanistic perspective and approach. The strongest common statement that providers share is their values statement, and what underpins this as a service approach. What I see today in service provision is that values and principles are rarely self-evident, even when they appear in written form, as they always require interpretation and application to specific instances, and this requires the constant action of human judgement. Human judgement is always fallible and influenced by factors that often remain unconscious and implicit.

- 5.4. Values, assumptions and beliefs often masquerade as being “self-evident”, or as “givens” when in reality they are usually more contestable than is recognised.

6. Some final thoughts and recommendations

- 6.1. My first recommendation is that a Ministry of Vulnerable Adults (this would need another name) be created, dedicated to an increasing population of people with pan-disability. As part of this ministry’s function, a model of case management could be instated whereby every vulnerable adult is given a case manager who provides individual surveillance and monitoring of that person, from a person-centered approach – not an audited, contractual approach. This model of case management would be one closely replicated by the case management model used in the closure of Tokanui Hospital.
- 6.2. The announcement of a dedicated Ministry for Disabilities has now occurred, which is long overdue. I therefore ask the Royal Commission to ensure that one of the new Ministry’s mandates is to explore the professional resilience and training of its staff aligned to the quality of life, human rights and core values as exalted by residential service providers.
- 6.3. I recommend that a conversation / exploration occurs into how the values and principles of an organisation / service provider are authentically evidenced in the Ministry of Health contractual audits. How is the reporting of abuse and neglect evidenced in the audits?
- 6.4. I recommend a conversation with Explore which is the National Behaviour Support Services about what they witness today. Are they a reactive service provider, or could they provide an “expert” stream of service from a more proactive approach? People only get referred to this service when things are going drastically wrong in their lives.
- 6.5. I recommend that the Royal Commission consults with NZCare and Explore to determine how many people discharged from Kimberley Hospital from 2003 through until October 2006 who were fed by percutaneous endoscopic gastrostomy (PEG), determine why these were inserted, and why they were removed when the individual was discharged from Kimberley Hospital.
- 6.6. I recommend a conversation on values “training “in organisations. How are values practically demonstrated within a service provider? How are providers demonstrating the UNCRPD in action? For example in September 2021, IDEA’s prohibition of the use of baths in all residential services, an outcome of pleading guilty to failing its health and safety duties resulting in the bathing death of a woman in Waitara. A service issue and Ministry of Health issue at the core, but very definitely a human rights issue that has a resonance with past institutional indictments.
- 6.7. Every person with an intellectual disability should have a communications system, or alternative mode, and be able to contribute to their own lives. Checks should ensure that the system is being used, and used to help the disabled person. It is incredibly difficult to get expertise, funding or even basic communicative support if you are a person with an intellectual disability in service provision.

- 6.8. How do people with learning disabilities currently make a complaint, and realistically how many complaints are received, particularly from people with no expressive language?
- 6.9. I recommend a discussion and review of how many people with disabilities live with undiagnosed depression in New Zealand as a result of their abuse and neglect in institutional care.

7. Conclusion

- 7.1. Thank you for allowing me to give my evidence. Even though it is 30 years late, and many people have passed on, it feels good that you are listening and that there will be some meaningful and purposeful changes and redress for this very marginalised population of people.

Apology

- 7.2. Finally, I would like to make a call out to the children I have cared for. I want to reach out and make an apology to these people and go and visit them in person to give that apology, return photos that I have of them in storage, have a cup of tea with them and see that their adult life has been good for them. I have spoken to the General Manager Service Development and Strategy at IHC and explained that I want to do this and seeking contact details for the people concerned. However, she said she couldn't provide me with these details due to the Privacy Act. So I am unsure of my next steps in being able to do this, and I sincerely hope that the children I was responsible for a short time in their lives have indeed had a better life than the one they endured in State care.

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.

Signed:

GRO-C

Dated: 21 March 2022