Witness Name: Olive Jean Webb

Statement No.: WITN1229

Dated: 25.05.2022

ROYAL COMMISSION OF INQUIRY INTO ABUSE IN CARE

WITNESS STATEMENT OF OLIVE JEAN WEBB

I, Olive Jean Webb, will say as follows:

1. Introduction

Background

1.1. My full name is Olive Jean Webb. I was born on GRO-B 1946. I reside in GRO-C, Canterbury.

1.2. I am a Clinical Psychologist. I specialise in working with people with intellectual disabilities and people who have Autism Spectrum Disorder. I have been asked to give a statement about my time working in Sunnyside Hospital, my advocacy of the Intellectual Disability Community, as well as my role in the de-institutionalisation of psychiatric facilities in New Zealand.

Education and Work history

1.3. I started working at Sunnyside in 1970 as an Assistant Clinical Psychologist whilst finishing my master's degree and postgraduate diploma in Clinical Psychology.

1.4. From 1975 to 1988, I was the Clinician in Charge of the Mentally Handicapped Area at Sunnyside Hospital. It consisted of 2 and later 3 wards of long-term patients with intellectual disabilities, some of whom had been there for 60 years.

1.5. From 1988 to 1991, I founded and managed the Psychiatric Services for Adults with Intellectual Disabilities (PSAID) at Sunnyside Hospital.

1.6. Around a similar time, in 1973, I became a Senior Psychologist and supervised Clinical Psychologists at Templeton. They did not have a resident senior psychologist at the time. I carried out this role alongside my role at Sunnyside.

1.7. Throughout this time, I became increasingly involved with and part of IHC and involved with other community organisations as well. This was an essential strategy to smooth the pathways from hospital to community in the de-institutionalisation programs

1.8. I worked in PSAID until 1991. I then worked for two years setting up a Performance Development unit for Mental Health services. I continued my relationships with the community organisations.

1.9. At that time, Sunnyside belonged to the Crown Health Enterprises (CHE), and it was deemed that the community organisations I was involved with were competitors to the CHE. I was therefore required to severe my relationships with any community organisations as it was deemed 'a conflict of interest".

1.10. I refused to do so and was dismissed.

1.11. After this, I joined the IHC as a consultant from 1993 to 2002.

1.12. From there, I applied for a transitional board member position on the Canterbury District Health Board (CDHB). I was on the board for 13 years and stood for 3 elections from 2001 to 2013.

1.13. In 2003, I started my own consultancy business which I still operate today.

2. Sunnyside Hospital

2.1. I worked at Sunnyside Hospital for about 24 years. From the outset, I want to be clear that I seldom witnessed what might be called abuse by individuals. Most staff were fundamentally caring and wanted to do the right thing. The problem was that the 'right thing' was enmeshed in abusive systems and practices which were normal in the hospital at that time.

Day-to-day life in care

2.2. When I started in 1970 there were about 1250 to 1300 patients at Sunnyside. By 1979, there were less than 400.

2.3. One section of the hospital accommodated people with intellectual disabilities, in the language of the day they were "mentally handicapped.' In 1975 I became Clinician in Charge of the Mentally Handicapped Area.

2.4. One of the wards I was responsible for was called North House. It housed 70 men. The beds in the dormitories were so close that you had to move sideways to get in between the beds. The men were made to get up in the morning, stripped naked and then they were marched through the villa to the showers. After their showers they were dried and then marched back through this huge villa naked and dressed again in incorrectly sized hospital clothing. It was like a concentration camp.

2.5. After breakfast they were herded into the day room where they did - nothing. The days were timeless, the same thing happened, at the same time, every day. There was a complete removal of thinking, creativity, dignity, and independence. The group was further isolated by the visitor doorbell which was at the far end of the villa. Visitors had to stand outside and wait for staff to walk the length of the ward several times – finding out who they wanted to see and then going and finding them. It acted as a barrier to entering the ward – especially during winter when it was cold standing outside waiting. Often when visitors showed up, they were told to come back later.

2.6. The nursing staff had all the power in the hospital. If a patient did something wrong, they were often told to change out of their day clothes and put their nightwear on and then had to sit beside the ward office door where they could be watched by staff, and everyone could see that they had been naughty. There was no distinction between 'unwell' and 'naughty.' If, for example, you were hyper manic or erratic, you would still be disciplined for that. The discipline being put in your pyjamas and being made to sit where everybody could see you were in trouble.

2.7. Restraint and seclusion were commonly used when people were very disturbed, but also as punishments.

2.8. Adult patients always had to knock at the door of the staff room before they could ask for something. They were told 'do not interrupt me' or 'do not talk to me now' because the nurses ran the show.

Patient Neglect

2.9. A few examples of how neglected these men were, come to mind. There was one guy and all he ever did was stand against the wall, which resulted in his scrotum hanging extremely low. For years, he just stood there day in and day out. When we took him swimming, we had to get special shorts to protect his dignity.

2.10. Another man was in a long bed chair. At the time, I was working alongside an amazing physio therapist who questioned why he was in the bed chair. The response from long term Sunnyside staff was: 'he just is.' The physio investigated, and it transpired that some decades ago, he had broken his hip and had been kept in the bed chair, unable to walk since. He was never reviewed and completely neglected all those years. Our physio worked closely with him and got him walking again, at this point he was in his seventies.

Initial stages of rehabilitation

2.11. It was in North House in 1974 where I started the first rehabilitation programme in the Mentally Handicapped Area of Sunnyside. I will share a few examples below of the programmes we implemented.

2.12. I started small because nothing breeds success, like success. We got six men who we were confident would succeed, and we put them around a table, and we found a job for them. Due to their prolonged institutionalisation, they had poor sensory-motor skills and therefore the jobs were simple jobs.

2.13. For example, putting sticky tape on the back of paper bibs for 45 minutes per day. We created tokens by chopping up broom handles and paid each man 6 tokens at the end of their work. The tokens could be used at the ward shop, which was run by the nurses. The men were then able to buy things they could not get anywhere else, for example, coloring books or candy. The programme was amazingly contagious, other patients started looking in and started working in another similar group, but without being paid.

2.14. Around this time the North House Villa was demolished, and we migrated into Avon Villa which was a gender mixed ward. In Avon villa, we introduced all the activities we had trialed in North House as standard activity programmes. Every morning all patients worked for tokens. Some tasks were as simple as stamping toilet rolls with a Sunnyside stamp, as toilet rolls were often stolen. Despite the simplicity of the tasks, the patients gradually became more aware and more interested in their environment. It was like a slow awakening.

2.15. The nurses in Seaforth villa, the neighboring villa had been the most oppositional towards our new programmes. But when they saw what was happening, they went to the unions, complained about favoritism, and questioned why they could not also run the programs. It was like a domino effect and suddenly Seaforth villa was following the lead. The patients across both villas thrived and they themselves developed a complex accounting system including layby and a ledger book which replaced the tokens.

2.16. Later, in the 1980's, I was asked to be involved in Ward One. Ward One had been conceptualised as a sick ward, also referred to as the 'dying ward,' and housed 30 patients. This was quite normal in a large institution, as people do get sick and require physical nursing. When I first went to Ward One there was a line of 5 patients all Cheyne stoking on the brink of death. They were being kept alive with repeated courses of antibiotics.

2.17. Some of these patients had been in the hospital forever. For example, one woman had locked hands due to sitting with her arms folded for decades and every morning they were pried open and cleaned.

2.18. We focused on getting people physically moving, because once people are physically moving, then their brains can start moving also. I am a pianist and I ended up going in with my Physiotherapist and Occupational Therapist and playing music for 45 minutes every morning to get people moving.

2.19. When the people became more active, their quality of life improved and the number of lingering deaths reduced. In essence, they lived more active lives and died more quickly – without the long lingering illnesses.

2.20. I was inspired by William Gold who used the method 'try another way.' Instead of oppressively telling people they were doing it wrong, he simply told them to "try another way." William Gold's approach remarkably resulted in severely disabled people he was working with assembling 22-step bicycle brakes. I thought I could adopt his approach and implement a safe learning environment at Sunnyside also. So, we did, and within two days an autistic deaf patient called GRO-B-1 assembled a complex construction. One of the staff members said, "I am not surprised, he used to be capable of far more than that." It infuriated me, all these decades, this staff member knew what GRO-B-1 was capable of, but made zero effort to stimulate GRO-B-1's development or improve his day-to-day care. It is yet another example of patient neglect.

2.21. We had another patient who was microcephalic and hardly spoke. She had been found living in a chook house before coming to Sunnyside. I managed to get her employment. Her job was to sit in the front of a courier van and hold the clipboard. She did it one morning a week. As time passed, her posture changed. In this car, she would sit up and she started smiling and she started talking! It was fantastic.

2.22. In the late 1980's, there was a group of senior nurses lead by Valda Kelly and Madeline Dungraft who led a movement for patients to have their own clothing instead of just hospital issues. This meant that residents had their own wardrobes and could wear clothes they had chosen and that fitted. This was fundamental to their future moves into community settings. They could look and feel like other people.

Māori Patients in care

2.23. There were very few Māori at Sunnyside. I recall one Māori man with intellectual disabilities who became a resident in Avon Villa when Les Ding was Superintendent. This was at the time we were all learning about biculturalism. Les and Ngai Tahu, the local iwi convened a Hui in the Sunnyside Hall. It became a wharenui for the purposes of the Hui and people slept there overnight. This Māori patient was required by the iwi to be there, and he slept on the elevated mattress at the top because he was Rangatira. The Hui was for staff rather than patients. It was an interesting challenge to the perceptions of people involved who had to turn upside down the power relationship with a patient. His status with Māori put him above the staff in this situation.

2.24. This is in stark contrast to the early days at Tokanui where I had nurse-aided during university holidays. In Tokanui, Pākehā officials took Māori children from the East Cape and placed them in Tokanui for 'better' care. This is where children became very cut off from their families. Similarly, Porirua and Kimberly took Māori children from Hawkes Bay and the Wellington area.

2.25. When NZ started the de-institutionalisation programs, Ngāti Porou in Gisborne and Ngāti Kahungunu in Hawkes Bay became highly active in establishing homes and services to bring their children home. Some of their children were in their 60's by then. There was a service for intellectually disabled people, specifically set up out of Tokanui and Māngere which is now called Te Roopu Taurima O Manukau. They do not provide services exclusively for Māori, but they have a Māori Kaupapa that guide their service delivery.

3. Templeton Hospital

3.1. I never worked at Templeton Hospital but supervised other psychologists there, frequently spent time at the Riding for Disabled unit where a friend and RDA colleague worked and often visited the wards and other facilities. I also visited there when I was working for IHC.

3.2. The wards were large and some housed 40 or 50 people. Early on in my experience, some of the wards did not have toilet paper and I know of one occasion when a behaviour support specialist went to a ward to put in place an intervention because a resident was wiping her bottom on the ward curtains. When the specialist discovered there was no toilet paper this was introduced, and the problem behaviour disappeared. Many of the bathrooms had 6-8 toilet pans all in the one room with no partitions in between so people all went to the toilet together. In one ward this was called the 'milking session' when 6-8 men sat side by side on the toilets. It was common to see individual residents walking around the wards naked.

3.3. As the de-institutionalisation movement started things started to improve. Eventually residents got their own clothes.

3.4. Templeton had a preparation or 'snakes and ladders' system for training people for community placements. As residents learned new skills and behaved themselves, they were placed in 'higher functioning' wards. They often got very excited because it meant they were going to be placed in a community home. But often, nothing then happened, and they got frustrated and could become angry and challenging. This often led to them being demoted to a 'lower functioning' ward and they had to start again.

3.5. Tony Ryder has told me about male staff who hit and abused residents in their care.

3.6. I understand restraint and seclusion was often used.

4. De-institutionalisation Movement

4.1. Imagine living in a place for decades and the people in charge tell you that they are responsible for your entire life. You have to knock on the office door to get their attention, you have to ask to go to the toilet. If you are either unwell or 'naughty' you have to get into your pajamas and dressing gown and sit outside the office door where you can be closely supervised, and everyone can see that you are unwell and/or you have been punished.

4.2. When de-institutionalisation hit in the 1980's, I was very involved nationally as well as at Sunnyside. I was seconded for 50 percent of my time to then Department of Health. The person who was in charge was Margaret Guthrie. I worked with a person called John Grey and the director of nursing, Anne Warner. My job was to do research for the department but also to lead a roadshow, which went around New Zealand, promoting community care and de-institutionalisation.

4.3. At Sunnyside, we adopted the philosophical view that people who are in hospital should be 'actively mentally sick.' 'Actively sick' did not include people just taking pills. We reasoned that many people in the community take pills and that kept them well. We also realised we had to re-define mental health. Physical health is measured by how we stay well and do not go to hospital, whereas with mental health you could measure your success by the number of discharges from hospital and the number of people we discharged who stayed out.

4.4. The de-institutionalisation movement changed the way we did things on the ground. We closed Cherry Farm, Braemar, Ngawhatu, Māngere, Raventhorp, Tokanui and finally, Kimberly. Sunnyside did not actually close, it morphed into becoming Hillmorton. We moved about 150 people with intellectual disabilities out of Hillmorton and PSAID was established, which is an active psychiatric treatment unit that still exists today

Early stages of de-institutionalisation at Sunnyside

4.5. During the initial stages of de-institutionalisation, Templeton and a lot of other institutions held provocative public hearings about their de-institutionalisation and moving certain individuals into the community. I disagreed with this, for example, when a child with autism and Down Syndrome was born across the road from me, his parents did not ask me whether it was okay if he resided there. Similarly, if he was 30 years old, my opinion did not need to be sought if he wanted to be in the community. He has the same citizenship as me. Morally, we did not have to consult the public and get permission for people from the hospitals to live in their streets

4.6. I therefore just operated under the radar when I moved people out of Sunnyside. I did not need it to be public information. I did not need my patients labelled and stigmatised before even moving out.

4.7. Our first attempt in the late 1980s at de-institutionalisation involved us selecting 4-6 patients who seemed compatible together. We placed them from 9-5pm in a house on Sunnyside where they lived and ate together. We ensured that the groups consisted of people with varying levels of abilities. As part of my doctoral research, I found that if you have someone of certain abilities and put them in a group that has different abilities, they will gravitate towards the mean of the group. If you put them in a group that is less able, they will lose skills. On the contrary, if you put them in a group that is more able, they will gain skills.

4.8. For example, we had an elderly man with down syndrome called GRO-B-2 and he could do nothing due to a lack of muscle tone. However, he could talk, and he was funny. We moved him out in the first groups and if GRO-B-2 was there, everyone else was happy. In turn, the more able patients supported GRO-B-2 with his day-to-day tasks. We knew certain people would do well in the community, but we ensured less able people were placed alongside them.

4.9. It was remarkably successful and because they were discharged, they automatically qualified for an invalid benefit. But we broke the rules and at the same time they were receiving welfare benefits, we staffed the community homes with hospital staff and used the hospital budget to fund this. This was double-dipping, but we did it. A portion of their benefits supplied the rent and food, and we supplied the staff.

4.10. With each group their families were engaged and were part of the process. We then linked in with neighbours so that natural support was encouraged. If some neighbours were anxious about them, we would invite the neighbours in for tea and break down any misconceived perceptions about the residency of disabled people in their community.

4.11. We also moved some elderly into carefully screened rest homes. We made sure they provided high quality community-focussed care. Henderson rest home was great because they were set up specifically for post-institution elderly people.

4.12. Only a handful of people returned from the community homes, mainly for medical reasons, for which we would treat them and then return them to the community.

4.13. Our team at Sunnyside worked with IHC, but we ran our own service, and the Psychiatric Service for Adult with Intellectual Disability (PSAID) still runs a community service. PSAID therefore became a backup for all sorts of services throughout the community. The only criterion we had for accepting someone to our service was that somebody was asking for help. This was a kinder approach which bypassed the more rigid, box ticking approach adopted by most of the disability sector.

Resistance to the De-Institutionalisation Movement

Templeton Parents Association

4.14. The most independent and aggressive anti de-institutionalisation group was the Templeton Parents Association (TPA). There was a belief that the system wanted to send their children home to them, which they opposed.

4.15. The TPA was so well organised that they infiltrated the Canterbury Western branch of the National Party. Jenny Shipley was Health Minister and then Prime Minister. It was the work of this group that led to the creation of Brackenridge village.

4.16. Brackenridge was built on the grounds of Templeton. It was a secure facility, with a high barbed fence along the perimeter so that patients could move freely within the property. 80 patients from Templeton were placed there not necessarily because of the patients' needs, but more so because of the parents' wishes.

4.17. There were two famous families, the Adams family, and the GRO-B-3 Family. GRO-B-3's son, GRO-B-3 was very autistic, disturbed, and violent. She initially fought to have him kept at Templeton Hospital, but after he was injured at Templeton, she fought to have an intensely staffed community placement for him.

4.18. The Adams' family had two autistic adult sons. They did not want them out of Templeton, and they went to live in the Brackenridge Village. Years later they bought a house that Brackenridge agreed to staff. Due to the fact that Mrs. Adams fought the system, she was considered a 'difficult mother' and therefore challenged at times by the system.

4.19. I recall Mrs. Adams had a meeting with the Ministry of Health and invited me. The Ministry's contracts manager at the time opened the meeting by saying that the purpose of the meeting was to make sure the Adams family *only* got their share of available funds. There was this notion of 'they should not get more than they deserve.' He said if they got more than they deserve, other people would miss out. I found this extremely manipulative and unethical because the Adams' boys required special care.

4.20. Mrs. Adams and I became mutually respecting friends.

Hospital Board Chairs Meeting

4.21. As part of the de-institutionalisation drive, I spoke at a meeting of the hospital chairs in Wellington in the 1980s. The Templeton Parents Association at the time was chaired by Mr.

GRO-C-1 who was also the chair of the Hospital Boards Association. As part of the drive, we wanted to achieve two things. One, support people the right way as institutions were not doing that. They were collective, abusive, and secretive. Secondly, to free up the money that was tied up in capital and work maintenance and convert it into support staff in community services.

4.22. I shared at the meeting that it was costing $70,000 a year to mow the grass at Templeton, the equivalent of two support staff's salaries. Mr. GRO-C-1 made some disparaging comments about the de-institutionalisation movement stating that people at the institutions were so happy that they had a playground and everything they could wish for.

4.23. He then wrote to George Salmon, the Director General of Health, to express his concerns about how I, an employee of the then Canterbury Area Health Board, attacked the way business was done by the boards. He suggested they revise my employment conditions if I was going to be that outspoken. Mr. Salmon wrote back, copying me in, and stated that he was happy with my work and that Mr GRO-C-1 should be more concerned with what I had to say.

5. Staff attitudes

Us versus them

5.1. During my career I witnessed few instances of direct abuse by individuals, but the bigger issue was that the system was abusive. To understand the system, you need to understand that what you have is a group of people who are vulnerable and who need developing, strengthening and support. The people who are meant to be enabling all of that are the people who actually control where they live, how much money they have, where they spend it, who they are friends with and what they do. Thus, the first problem that arises from this model is an imbalance of power.

5.2. You can implement changes to combat this power issue but changing attitudes is the more challenging task. It is like having a software system that defaults. The default culture in the institutions is that staff and the 'system' see people with disabilities as being *ipso facto*, incompetent, in-educable, or 'naughty' and therefore, are seen as somehow not responsible for their behavior.

5.3. Therefore, whatever changes and improvements are achieved, as soon as difficulties occur the default culture recurs, and the person becomes the problem again. There is a belief that whatever ails them, this is part of their incompetence, and we cannot do anything about it. There is this common theme that someone with an intellectual disability is unchangeable.

5.4. This is different from other psychological practices. For example, if you take someone with an anxiety order and treat them, you are giving them the tools to live with and manage their anxiety.

5.5. This defaulting culture recurs in some community settings. There are some so-called community homes that house a dozen or so people that have staff rooms and staff toilets and the residents are ordered about and commanded to do things. The residents are excluded from decision-making and have to ask permission to do things.

5.6. The culture is built on certain values and concepts which become self-reinforcing. That is why you will see nursing staff who are amazing people, yet still refer to patients as 'them,' they still see their patients as people who are somehow enduringly different from, and inferior to, other people. Some people suggest there is some sort of test that should be used to see if people are good enough to be in the community, I recall Dr GRO-C-2 (then Templeton Medical Superintendent) made a statement to The Listener once, stating that some people at Templeton were too ugly to be placed in the community.

Abuse of staff power due to lack of support and training

5.7. If you have good people who make up the staff, and put them into a situation where they are untrained, frightened, uninformed, and unsupported then the staff will default to the 'us' and 'them' culture that sets the scene for power-based management and systemised disempowerment and abuse

5.8. Currently in disability services, there is a lack of oversight. You will find that the Ministry does not know when people with an intellectual disability are restrained or secluded in government services. For example, Hillmorton sends its seclusion and restraint statistics to the Ministry of health, but there is no focused report on what is happening with intellectually disabled service users in that hospital.

5.9. In December 2021, I heard someone in a service was locking residents up at night with a big padlock. They manhandled residents and placed them in headlocks and smashed them onto the ground. It was weeks before senior staff found out about it. The easy solution is to say get rid of the corrupt staff. The longer analysis is that the staff are frightened and do not know what to do and they are often managed too remotely.

5.10. There is a whole lot of research that exists that talks about the impact of staff training. Evidence suggests that if you train people in a classroom, the knowledge does not transfer to practice. Imagine if every agency had someone who was simply employed as a behavior clinical specialist. Their only job would be to go around the homes and find out what is happening, correct mistakes and train the staff on-the-job. It is a luxury that seldom happens, although there are some services that are doing just this.

5.11. Patients or residents need to be treated and talked to by staff with respect. People who are deemed 'challenging' are more than likely not challenging but just not listened to. Tony R. has been categorised as 'challenging' but his attitude to life is hugely normal. You could make him fly off the handle by telling him: 'you will do what I say.' You would not say that to any other 60-year-old man. This type of language is an abuse of power.

5.12. 10 years ago, Tony was residing in a community home, and he loved pigs, he would cuddle them and kiss them goodbye, and he stank. One night, he went into the kitchen to make a cup of coffee and the staff member said: 'You are not going into the kitchen until you have had a shower.' Tony was incredibly upset by this use of authority to order him about.

5.13. I went around to the house and asked the staff member whether he would speak like that to his own mother. The staff member said: ‘Of course not, but it is impossible to get Tony to shower.’ I explained that when Tony comes to my place, he showers twice a day. The staff member could not believe it, he asked how we achieved that. I explained that we do not tell him to do it like a 5-year-old. We would just say, let's go to the pub tonight, I will go and clean this whilst you have a shower and then we can go. It is really simple stuff once you stop viewing patients as ‘them.’

Staffing standard

5.14. When you go to a posh retail store, the measure of the service is the degree to which the customer is satisfied and the degree to which the shop is concerned about the customer satisfaction. The exact same standard should apply to support services. We need individuals as support people who measure the goodness of their job by the happiness and contentment of the person they are supporting.

5.15. For example, in central Otago there is a service called ‘Living Options’ and it is one of the most person-centered services in the country. They support 40 people, and the person being supported is at the pinnacle of all decision-making.

5.16. Living Options asked me to see a disturbed 9-year-old Māori girl with Down Syndrome who had been a victim of CYFS. When I first met her, I thought she had autism. When Living Options took her in, the CEO of Living Options, Alison Wildey, (ex-psych nurse at Templeton) briefed the staff and said the girl wanted to be a princess.

5.17. She instructed the staff that if they were unsure about what to do with her, to just treat her like a princess because that is what she required. She stayed at Living Options during the week and attended Dunstan High School. At the end of her final year, she went to a school ball in a beautiful gown with her boyfriend and had the best night of her life.

5.18. The other students gave her the live microphone and asked the band to play ‘her song.’ The Living Options values and respect for her had rubbed off on the school. That is what it is all about. She will always need support as she is severely disabled, but that does not mean she needs to be objectified. She needs to be respected, valued, and made to feel worthy.

Community placement abuse

5.19. A service-user I met had lived in Kimberley where she was able to roam free around the grounds. She had been severely sexually abused as well as other forms of abuse through seclusion and restraints etc. whilst at Kimberly. She was considered ‘challenging’ because she argued with people and often resisted their attempts to make her do things. For this reason, when she moved out of Kimberley she was put in a secure house in Palmerston North, which she hated.

5.20. She was transferred to multiple different houses due to her becoming more irritable as her frustrations built up. Her file stated that the warning signs for her becoming unwell again would include her talking about Kimberley and becoming quite sinister.

5.21. Whilst in a community home this sort of talk had been going on for 10 days and no one had done anything. They had not picked up the known signs of her distress. Subsequently, she attacked someone with a pair of scissors. As a direct result of that, she is now in a secure unit in Auckland.

5.22. When we de-briefed the case, we discovered that one of her support people had been sleeping with her. The support person was using drugs and alcohol on the job and would sleep with her arms over her torso, so that if she moved, the support person would wake up. This had been going on for weeks and intensified over time, we do not know whether any sexual abuse also occurred. The support person was dismissed from the service.

5.23. The behaviour of the support person was clearly upsetting the service user.

5.24. This resident is unfit to stand trial and there was no court trial and so no-where where this potentially mitigating information could be heard. She has therefore received what could be a life sentence locked up in a secure unit detained under the Intellectual Disability (Compulsory Care and Rehabilitation) Act [IDCC&R]. If she was given a trial, the mitigating factors could have been put forward, but she had no opportunity to do this or have counsel do this for her. I am aware the IDCC&R Act has regular reviews, but in practice many people continue to be detained beyond the time periods set out in the Act.

6. Overmedicalisation

6.1. People were medicated to keep them calm and to control aggression. They were not medicated to keep them dribbling in the corner, although that was the result.

Punitive medicating

6.2. I saw a lot of punitive medicating. One resident in Avon villa (Sunnyside) was sore and the then ward Doctor said to me: ‘I know if you or I had it, it would be sore, but do you think these people feel pain?’ He later said something to her which upset her and so in retaliation she broke the antenna on his car. He was furious when he found it and stormed back into the ward and put her medication up as punishment.

6.3. In the institutions, drugs were prescribed to stop the fighting between patients. Male patients often received Mellaril which had the additional ‘advantage’ of producing erectile disfunction. It was seen as a way of controlling the men’s sexual behaviour. This thinking is a carryover from the eugenic beliefs of people like Truby King who set up the psychopaedic hospitals in order to segregate inferior breeding stock.

6.4. When Mellaril was removed from the market it was initially replaced with other major tranquillisers.

Uniformed GP prescriptions

6.5. Research that I undertook when working for IHC indicated that prior to people leaving Templeton, the Canterbury Area Health Board was spending about $3000 per person on medication. The medical care at Templeton was provided by local GP's who were contracted in, and occasionally a psychiatrist assisted. I do not think the GP's had a good understanding of what the medication requirements for disabled people were.

6.6. For example, there is an anti-convulsive drug called – Dilantin (phenytoin) which has a side effect of the swelling of gums. A GP would leave a patient who had not had seizures for ten years on Dilantin, despite the side effects, because that was considered to be an easier way to manage it. GPs have told me that if seizures were not occurring then there would be no way they would interfere and change medication. One GP told me he did not know enough about it to do that.

Over medication in community care

6.7. When I was working at IHC in 1999, I undertook research into the use of medications in community settings. I took every fourth house of IHC over the country and did a snapshot of what medication was being used.

6.8. Shockingly, the pattern of medication was the same as in the institutions. Normally the goal is to have a person taking as few psychotropic medications as possible. Ideally one if they need it, two if they must. Yet I found that there were some people who were prescribed 7-8 psychotropic medications concurrently with massive sedating side effects.

6.9. Several years later, in 2007, I did a follow up with a smaller group in Christchurch and Hamilton IHC residences. Although there was still over-medication, there had been a shift towards more modern medicine, and I saw a rise in anti-depressant drugs.

6.10. It is my opinion that in community settings overmedication continued because there were under-staffing issues and staff were often frightened. For example, if there is one staff member with six residents and one resident becomes aggressive, medication will be used to control them, thereby ignoring the message the challenged person is trying to send. By doing so, the system closes ranks above the person and does not respond to their needs because it can shortcut it with medication.

6.11. Often it is the support people who request the medication. The reason support staff opt for medication as a first response is because there may be a 12 month wait to get the resident into a treatment program with a behaviour support specialist.

6.12. I do not agree with medicating people for anger issues, anger is not a disease. How do you justify the medication? I do think some medications have their place but if you want to respond to a specific need then giving a pill is not providing the appropriate treatment.

7. Health

7.1. The health status of people with an intellectual disability is generally worse than that of Māori and Pasifika.

7.2. When I was working for IHC I introduced annual Health checks in 1999. After the first health checks were done, we gathered all the data about what had been identified during this first comprehensive health check.

7.3. The data showed that 73% of people required significant health interventions, ranging from cataract operations to cancer screens, dental work, pain management and more.

7.4. My results were identical to those found by colleagues in Wales (Dr Mike Kerr) and Australia (Dr Nick Lennox).

7.5. Annual Health checks are now commonly sought in all disability services. It is important however to ensure the checks are done thoroughly and not just copied from year to year by a reluctant Doctor.

8. Funding

Pre-2000s

8.1. Pre-1970s and 80s funding was obtained based on what was spent the year prior. This resulted in inappropriate use of funds. For example, someone would intentionally break something to receive a newer version of the item, staff would steal items from the inventory store, or rapidly increase spending prior to the closure of the fiscal year.

8.2. In the 1980's hospitals received bulk funding. However, community services were more progressive in their funding processes. They were funded in accordance with the number of people they supported, taking into account their level of dependency.

8.3. Unfortunately, bulk funding got out of control with the appointment of the CHE who used a commercial model to obtain the maximum amount of funding.

8.4. The environment became increasingly competitive, and funds were essentially funneled away from the community services and the people. The funding provided was not adequate for the support needs disabled people required.

8.5. When de-institutionalisation commenced in the late 1980s, the Government became concerned about the lack of competition in community settings and so there was an influx in providers all over New Zealand.

8.6. With the formation of the District Health Boards, Healthcare of the elderly was devolved to the DHBs, meaning that at a regional level there were local people who knew exactly what was happening. For example, currently in Christchurch there is a central resource that shows what rest homes have beds available. So, there is some coordination there.

8.7. But the Ministry of Health retained intellectual and physical disability and brain injury people for direct funding. The separation meant that when the disabled people funded directly from the ministry turned 65, the ministry would no longer fund any of their support needs as the elderly were then funded by the DHBs. Often this has meant they have had to leave their Ministry/disability-funded home and move to a DHB funded home. This led to discontinuity of care. This has been discriminatory.

8.8. It gets even worse if someone has an intellectual disability because they are 4-5 times more likely to have health and psychiatric challenges. However, frequently the DHB's claim they do not have to provide those services for them because they are funded directly from the Ministry of Health. There are some DHB psychiatric services for people with an intellectual disability – like PSAID and others, but it is very difficult to get into them.

8.9. The gap of untreated conditions in the disability sector is enormous. In physical health, we have a health system that is so reactive, if you get sick, you go to the doctor, and a treatment plan is put in place. But people with intellectual disabilities do not complain because they often do not have the body awareness or the conceptual ability to complain, and the Doctors are not trained to assess people with limited language and cognitive abilities.

8.10. It was for this reason that IHC introduced annual health checks in 1999. After the first general health check of every person that IHC supported we discovered that 73% had undiagnosed treatable conditions. This is in addition to the over-medication.

Post 2000s

8.11. The current issue we face is funding. The disability sector is mainly focused on rationing and funding. There are individual support staff and services who are fantastic, but the system is not equipped to adequately support them.

8.12. In November 2021, I was at a DHB Community Public Health and Disability Advisory Committee Meeting. There was a comment made about a task relating to people with disabilities that had not been carried out. The argument from the finance member was that times were tough and therefore they could not afford to do the right thing for people with disabilities. I erupted, I said nothing has changed, why pick on one group of customers and say you cannot afford to treat them. It reflects that this person does not place the same amount of value on disabled customers versus non-disabled customers.

8.13. One hundred years ago, disability services used to be managed by the old Department of Social Welfare. This meant that the same people that were managing the budget for everyone else were also managing the disability budget, it did not work.

8.14. It is going to be very interesting to see what changes will be implemented by the new Ministry of Disability. However, I think there is a risk that once again Disability services will be competing with other community support services. The new ministry has the same minister as MSD and thus will be closely allied to MSD. Potentially, nothing has changed.

Policy changes

8.15. De-institutionalisation was fantastic but once the hospitals and units were closed, there were still inequities and there still are. It would make sense for the policy makers to further this process.

8.16. When a health board position was advertised by the Canterbury District Health Board, I thought I would have a crack to get in at policy level. I think in my time on the board, people would argue differently, but I do not believe that I made one iota of difference to the lives of people with intellectual disabilities. I constantly brought disabled people to the table when they were missed of the agenda, but they were overlooked anyway.

8.17. However, in the last three years the CDHB has been increasingly incorporating considerations of Disability Issues in their policy development and it has set up an employment programme, which trains disabled people for a year to become service support people. But they are the biggest employer in the South Island and could be employing people with disabilities all over the all over the place.

8.18. Over the last 20 years NZ has had a number of employment programs that have supported people with intellectual disabilities in paid work, but this initiative has significantly waned in many parts of the country. In many parts of the country, people with intellectual disabilities who could be in paid work are languishing in 'activity centers,' being entertained or engaged in interminable training programs and unpaid work experience.

8.19. It is noteworthy that at the last meeting of the Community Public Health and Disability Support Advisory Committee of the CDHB, a 'disability lens' was being applied to all items on the agenda. Hopefully, this will continue in the new health structures. Unless this happens deliberately, they will again default to being ignored or 'siloed' away from mainstream considerations.

8.20. The lead agencies could be much more involved in personal advocacy to ensure that any new initiatives reach the person who has a disability.

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: 25th May 2022