Witness Name: Margaret Priest

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Exhibits: [WITN0400002 – WITN0400057]

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ROYAL COMMISSION OF INQUIRY INTO ABUSE IN CARE

WITNESS STATEMENT OF MARGARET WILLIAMSON PRIEST

I, Margaret Priest, will say as follows:

1. INTRODUCTION

1.1. My full name is Margaret Williamson Priest, I am retired and living in Paraparaumu. I was born on GRO-C 1955. Before retiring, I was a teacher.

1.2. I am making this statement to the Royal Commission about my sister Irene Sutherland Priest, who has a learning disability and has been in care since she was six years old. I am Irene's welfare guardian and, due to her disability, she cannot speak for herself. Due to Irene's inability to communicate with me, I can only give evidence of things that I saw or know happened because I was either told by my parents or I have reviewed documents relating to Irene's care.

1.3. This statement is also about my own experiences with the care system and the effect Irene's time in care has had on me.

My sister, Irene Priest

1.4. My sister Irene was born thirteen months after I was born on GRO-C 1956. Our parents were Magnus and Annie Priest. My father was a pharmacist and optometrist.

1.5. I understand that Irene was a perfectly normal pregnancy. My mother told me that she wanted to have a caesarean, as I had been born by caesarean, but the obstetrician insisted that my mother give birth to Irene via natural birth.

1.6. My parents told me that the obstetrician applied forceps to Irene's head during the birth. After Irene was born, I understand that my parents thought there was something wrong with Irene. However, no explanation was provided by the many specialists she was seen by. It was not until Irene was two years old that a specialist from Austria visited and told my parents that Irene was injured at birth.

1.7. As a result, Irene has spasticity and can focus for short periods of time. She cannot speak and so it is hard to know what her mentality is. Irene communicates with me through actions, for example: she will grab my hand and direct me to what she wants; she will growl if she is unhappy; and she will smile and clap her hands if she agrees or is happy.

Early life and events leading up to admission in care

1.8. My parents were very loving and caring, and we had a relatively happy early life. Irene could not walk because of her spasticity and so I understand that my mother taught her to climb. However, once Irene started climbing, she would climb onto and jump out of windows. My parents were so worried that they had to strap Irene to her bed at night. I shared a room with Irene and I remember her fighting against the straps. I would go over and stroke her head to calm her down.

1.9. I understand that my mother found it difficult to look after Irene. My father was working and my mother had no assistance from the government or disability services to look after Irene or to give her respite. I was told that my mother was prescribed tranquilisers by our family doctor because she could not cope.

1.10. I was advised that, due to my mother's deteriorating mental wellbeing, my father investigated whether there were any care facilities that might help look after Irene. He heard about Kimberley through our family doctor. He had also heard about Hohepa but was told that Irene would not be able to go there because she needed to be of a certain ability. There was a very long waiting list for Kimberley and our family doctor pulled some strings to get Irene to the top of the waiting list.

1.11. Kimberley was promoted as a training school, and my parents were told there was nowhere else for Irene to go. I think my father was trying his best to balance looking after Irene and looking after my mother. It broke my parents' heart to send Irene away, but they thought Irene would be better off because she would at least be given proper training at Kimberley.

2. ABUSE

Kimberley

2.1. In 1962, when Irene was around six years old, she went to Kimberley. She was placed in a dormitory, which I think had ten beds in it.

2.2. Irene spent most of her life at Kimberley and was a resident until 2004.

2.3. I visited Kimberley on many occasions – either picking Irene up for a home visit or taking her back. I do not remember much about Kimberley itself, but I do remember her dormitory, the dayroom and a concrete yard.

Neglect

Family contact, love and nurture in care

2.4. When Irene was first admitted, my parents were told by the staff to leave Irene in Kimberley for at least a month, without any contact. However, during that first month, my parents were contacted by a staff member at Kimberley and told that Irene had contracted hepatitis. I understand no explanation was given for how she contracted hepatitis. Irene contracted hepatitis on at least two other occasions while at Kimberley.

2.5. I was around seven years old when Irene first contracted hepatitis. I remember going to Kimberley with my parents to pick Irene up. Irene had been placed in an isolation room, and she was alone, on her bed, rocking backwards and forwards. There was nothing else in the room, except her bed. She did not even have her teddy bear that she had taken with her to Kimberley.

2.6. My parents took Irene home every or most weekends (which would be pre-arranged), so we had a lot of contact with her. I remember at the end of every weekend, Irene would not want to return to Kimberley. Whenever my parents would start driving Irene back to Kimberley, she would start growling. As I mentioned earlier, Irene shows unhappiness through growling.

2.7. I do not think Irene was given any love while at Kimberley. I was at Kimberley a lot to pick up Irene and I never saw the staff giving any of the residents hugs or any sort of love. Every now and again there would be a lovely nurse who would treat Irene like family, but those occasions were few and far between. Most of the time, the staff I met did not see my sister as a child who needed love and care. Kimberley was just a place of people existing. When I was a teenager, I remember once walking into the anencephalic and hydrocephalic ward. What I saw was horrific. There were around twelve residents who were just lying on their beds and groaning. There was no staff with them or any kind of stimulation, like music. I think the staff did not care about the residents and saw it as just a job.

Personal items

2.8. As I mentioned earlier, when I first went to visit Irene, she did not have her teddy bear that she had taken with her to Kimberley. The loss of Irene's personal items was a consistent issue throughout her time at Kimberley. My parents would often send Irene's clothing, but I understand that Kimberley had a communal laundry and so her clothes would never make their way back to her. Anything that was good, just disappeared.

2.9. I also suspect that there was some stealing going on by the staff. I understand that each resident at Kimberley would have a fund, which included money given by the resident's family or from the state, and this fund would be used to buy necessary personal items for the resident. I was told by my parents that they would receive statements of account, which would show 24 t-shirts were bought for Irene or a very expensive jacket, but we would never see these items.

Hygiene and dental care

2.10. Irene was always clean when she came home. It seemed like she had just been washed before coming home because her hair would be wet. I am not sure about her hygiene between her home visits.

2.11. Irene did have problems with her teeth. I don't know what the oral hygiene was like at Kimberley, but Irene was frightened about going to the dentist. So, the only way she could be examined was for her to be given general anaesthetic. Because of the difficulty examining her teeth, the medical staff at Kimberley decided that it would be easier if all her teeth were removed (see letter from a staff nurse to my parents dated 27 October 1992 [WITN0400002]). I remember my parents signed a form consenting to the removal. This happened to Irene in her 30s or 40s. I desperately pleaded for implants to be put in and I am not sure why they did not because we had the money to pay for them. I just thought the removal of her teeth was the worst thing. It felt like a final indignity because she would not be able to enjoy food as much as she used to.

Education and communication

2.12. Irene did not receive any education or training that I know of at Kimberley. My family and I had heard that some of the residents at Kimberley made cardboard boxes, but we are unsure if Irene did this. It was apparent to me, though, that Irene regressed while she was at Kimberley. She was learning at home, like how to go to the toilet without a nappy, or how to use a spoon. But she was not able to do these things when she left Kimberley.

2.13. As I mentioned earlier, my sister communicates through actions. From my understanding, the staff at Kimberley never made any effort to communicate with Irene. When I was older and had more involvement in Irene's care, I asked the staff at Kimberley if they would investigate developing a specific sign language for Irene, which would allow her to point to pictures, but they did not do that.

Weight

2.14. In the 1990s, Irene started to become very thin. She weighed around 32 to 33 kilograms and was a really shocking sight. A photo of Irene, which I think was taken around this time, is annexed [WITN0400003].

2.15. The staff at Kimberley first thought it could have been an issue with her thyroid function, but her test results were normal. In letters, my father referred to Irene looking like a "bag of bones" and that our family doctor ordered her to have blood tests (see letter from my father to Dr Bennett, Medical Director, dated 4 November 1994 [WITN0400004]). I was told that our family doctor ordered those blood tests because he thought Irene might have AIDS. That is how awful she looked.

2.16. I understand that my father wanted Kimberley to refer Irene to a specialist to get a better understanding of her weight loss. This was met with resistance by the Manager and Dr Bennett. Dr Bennett said that Irene's weight was stable at 37 kilograms and that there was no point in a second opinion because they would not learn anything that they did not already know (see letters dated 17 May and 8 June 1995 from the Manager and Dr Bennett [WITN0400005] and [WITN0400006]).

2.17. Around this time, my mother also found out that Irene was being placed in a special chair, where she was strapped in and force-fed (see authorisation form for minor restraint of patient dated 6 September 1995 [WITN0400007] and recommendation by occupational therapist [WITN0400008]). My family was given a similar chair to use when Irene was home, which we refused to use. This chair now sits in my husband's workshop because I cannot bear to look at it. I acknowledge that Irene can have difficulty eating, but all that is required is patience, which my father explained to Kimberley staff in a letter dated 25 April 1993 [WITN0400009]. They didn't listen to him though.

2.18. Being force-fed had lasting effects on Irene, as for many years after this time, if myself or another person was near Irene's side to feed her, she cowered. For a while it would take around two hours to feed Irene because she was so afraid of having someone near her.

Monitoring and safety measures

2.19. Further in this statement, I set out how Irene was over-medicated during her years at Kimberley. A side effect of the medication was that Irene was quite unsteady on her feet. I have recently become aware, through the Royal Commission and reviewing Irene's files, the extent of Irene's "unsteadiness" and the failures of the Kimberley staff to prevent serious injury to Irene.

2.20. There are a large number of incident reports and events registers that show Irene falling or tripping up, and hurting herself. Because these are so extensive, I have described

each incident that I have seen below. What is most alarming is that there are at least 17 head injuries:

a) An incident report dated 19 February 1981 describes Irene throwing herself to the floor and knocking her head on the corner of the bench, which resulted in a superficial cut on the crown of her head [WITN0400010].

b) An incident report dated 14 July 1981 describes Irene running and tripping over another patient. She fell and knocked the back of her head against a wall, sustaining a cut to the back of her head [WITN0400011].

c) An incident report dated 11 October 1981 describes Irene sustaining a gash to her chin when she tripped over another patient and fell against the play pen [WITN0400012].

d) An incident report dated 12 June 1991 describes finding Irene in a corridor with a bleeding grazed nose. Prior to this she had been on a swing in the courtyard and had fallen [WITN0400013].

e) An incident report dated 4 June 1994 described Irene being hyperactive and colliding/falling over people. During hair grooming, staff found a ¾ inch cut to the rear of her head, which required 3 sutures. The requirement for sutures was identified by the doctor two days after the incident when he or she was notified, which seems to be negligent to me [WITN0400014].

f) An incident report dated 15 November 1995 described Irene slipping in her own urine and hitting her head on the heater, which caused an indentation and slight bleeding on her head [WITN0400015].

g) An incident report dated 3 December 1995 described staff hearing a crash and finding Irene under a stack of chairs [WITN0400016].

h) An event register with an entry dated 21 July 1996 described Irene running around and staff hearing a thump, finding her lying on the floor with a puddle of urine nearby [WITN0400017].

i) An event register with an entry dated 1 October 1996, and a corresponding incident report, described Irene running and tripping over, causing her to fall onto the corner of a heater. She had a 3.5cm laceration down the length of her nose and grazes. There were superficial lacerations on her forehead, a mild underlying haematoma and blood running from her ears/nose. She was given stitches. [WITN0400017 WITN0400018].

j) An event register with an entry dated 16 April 1997 described Irene banging into a furniture and receiving a small "nick" to her eyebrow [WITN0400017].

k) An event register with an entry dated 27 August 1997 described Irene running out of the day room and catching her pinkie finger on the edge of the door, causing it to rip open [WITN0400019].

l) An event register with an entry dated 23 October 1997 described Irene falling over and knocking her face on a heater, causing a gash to her nose [WITN0400019].

m) Nursing notes with an entry dated 21 November 1997 describes Irene jumping around and hitting her head on the corner of a table, causing a laceration to her forehead [WITN0400020]. Another incident report on the same date refers to Irene being purposefully tripped up by another patient. [WITN0400021].

n) An incident report dated 2 May 1998 described staff finding Irene on the floor with her head against the corner of a cupboard [WITN0400022].

o) An event register with an entry dated 30 August 1998 described Irene pushing herself sideways and falling over a wheelchair. She hit her head on the bottom of the chair, causing a lump to form [WITN0400023].

p) An event register with an entry dated 6 December 1998 described Irene throwing herself on the floor and hitting the side of her head against a door frame. This caused a 1 and ½ inch laceration [WITN0400023].

q) An event register with an entry dated 24 December 1998 described Irene falling outside of the office and landing on the floor, hitting her head. This caused a slight laceration to the back of her head [WITN0400023].

r) An event register with an entry dated 22 February 1999 described Irene falling while running to the toilet, and hitting her head on the toilet seat. This caused a bleeding nose and bruising on her forehead [WITN0400023].

s) An event register with an entry dated 19 May 1999 described Irene falling in the shower, causing a minor cut to the front right of her scalp [WITN0400023].

t) An event register with an entry dated 4 July 1999 described Irene throwing herself off the toilet and falling face first. This caused a graze to her right arm [WITN0400023].

u) An event register with an entry dated 25 June 2000 described Irene tripping on the way to the dining room, causing a cut above her left eyebrow, which required steri-strips [WITN0400024].

v) An incident report dated 7 August 2002 describes Irene losing her balance and falling backwards and hitting her head against the metal strip on the toilet door. This caused a small cut to the back of her head [WITN0400025].

w) An incident report dated 18 August 2002 describes Irene tumbling and falling forward onto the floor, causing a blood nose [WITN0400026].

x) An event register with an entry dated 26 February 2003 describes Irene falling heavily on her back and hitting her head on the floor [WITN0400027].

y) An event register with an entry dated 19 April 2003 describes Irene falling and bumping her nose and grazing her chin [WITN0400027].

z) An event register with an entry dated 8 February 2004 describes Irene falling and causing a gash to her head [WITN0400027].

2.21. From what I can see, there appears to be little attempt by Kimberley staff to protect Irene from hurting herself, other than eventually getting Irene a rugby headgear to protect her head. However, there did not seem to be any other protective measures, like changing the furniture so that it was more friendly to unsteady residents like Irene. I remember a lot of the furniture was quite hard, with sharp edges.

Drug abuse

2.22. I think the worst thing that happened to Irene at Kimberley was the indiscriminate drugging. Between at least 1968 to 2003, Irene was placed on a concoction of drugs, like Mellerill, Carbamazepine, Cisapride, Cogentin (Benztropine), Fergen, Clonazepam and Doxepin. These drugs would have all sorts of side effects, like drowsiness, nausea, fatigue and coordination disturbance (see undated handwritten note [WITN0400028]). I also understand that Irene was given a drug or injection to stop her periods, which I found horrific.

2.23. The effects and side-effects of the drugs that Irene suffered were of real concern to my parents and myself. The worst drug was Mellerill. Irene was like a zombie on Mellerill, and my father, who was a pharmacist, was especially at pains to try to get Irene off this drug. He told Dr Taylor, the Medical Superintendent, when Irene was on Mellerill she acted like a "zombie", walked backwards instead of forwards, had cold extremities and was completely disorientated (See Letter from my father to Dr Taylor dated 25 January 1988 [WITN0400029]).

2.24. My father tried to work with the medical staff at Kimberley to ensure Irene was given the appropriate drugs and asked, on multiple occasions, that her medication be changed. In one letter, dated 25 April 1993 [WITN0400009], my father said that he thought Irene was "over-medicated" and asked that "Irene's medication and its effects be looked at". In this letter my father explained that they had withdrawn much of her medication while she was on home leave and she had given my parents little trouble.

2.25. Sometimes, Irene was taken off Melleril (see individual support plan dated 26 October 1993 [WITN0400030], which says Irene "should not take Melleril at all"). However, despite the consistent discussions between my father and Dr Bennett (see letter dated 4 November 1994 written by my father to the Medical Director [WITN0400004]) and although Dr Bennett agreed that the drugs were unhelpful and poorly tolerated by Irene, he considered the use of them justified because there were no alternatives to controlling Irene's hyperactive behaviour (see letter dated 8 June 1995 from Dr Bennett to my father [WITN0400006]).

2.26. There were of course alternatives to drugging Irene if she was hyperactive, and my father raised these with the medical staff at Kimberley (see letter dated 25 April 1993 [WITN0400009]). However, I think the reason Irene was consistently given drugs was because: the staff were constantly changing (so there was no institutional knowledge of how to care for Irene); Kimberley was understaffed; and drugs were an easy way to subdue the residents. I think that because Irene was in Kimberley's care, the staff did not think that the parents should have much say in the matter.

2.27. Irene was weaned off drugs in the late 2000s. I had started looking into the side effects of some of her drugs and found that one of the side effects was something called "Sudden Drop Syndrome", which sounded familiar to Irene's falls. After reducing the drugs, she stopped falling over and her Parkinsons went away. I am also convinced that her weight loss in the 1990s was related to the drugs she was on. Now that Irene is off the drugs, she is very perky, and her appetite has returned.

Physical abuse

2.28. I was not personally aware that Irene was physically abused (or abused in any other way) while at Kimberley. I remember that sometimes, Irene would come home from Kimberley with injuries such as scarring, stitches or bad grazes on her hands or cheeks. She also had an eye injury at one point. I am not aware of any explanation being given to my parents about the causes of the injuries. As I mentioned above, she did fall a lot, so I thought that was definitely part of it.

2.29. However, I now know, from seeing documents in Irene's file, that Irene was physically assaulted on a number of occasions by other residents. I remember that Irene was moved into a female villa called Hawea and some of the residents in this villa were violent. The documents show that Irene was assaulted by other residents. For example:

a) On 10 October 1976, Irene was scratched under the left eye by another patient [Incident report, WITN0400031].

b) On 18 November 1985, Irene was kicked by another patient on her nose, causing it to bleed [Incident report WITN0400032].

c) On 30 June 1988, another patient pulled Irene's hair and banged her head against the wall, causing her nose to bleed [Incident report WITN0400033].

d) In February 1992, another patient pulled Irene's hair on two occasions (one attack caused some hair to come out) and pulled Irene head first to the ground and punching her on the face continuously, causing grazing to Irene's forehead [Incident report WITN0400034].

e) On 19 May 1995, she was found with a split eye lid, which was an injury known to be caused by another patient [Incident report WITN0400035]. On 16 July 1995, Irene was attacked by a patient and had a cut lip as result [Event register, WITN0400015] Later in the year, she was also hit by another patient on the head,

which caused a small cut on the top of her head [Event register, entry dated 28 December 1995 [WITN0400016].

f) On 2 March 1996, Irene was attacked by another resident and again required sutures, however this was deferred for two days. This seems negligent to me and would not happen to a non-disabled person [Incident report [WITN0400036]

g) On 15 April 1997, she was bitten on the nose by another resident, which caused small lacerations and abrasions to her nose and a deeper laceration to the tip of her nose [Incident report [WITN0400037].

h) In February and March 1998, she was bitten on the chin by another patient (Event register, entry dated 21 February 1998 [WITN0400019]) and later bitten on the nose (Event register, entry dated 15 March 1998 [WITN0400038]).

2.30. These are just the incidences that are recorded, but there are also a few documents referring to unexplained injuries, which could be related to physical assaults or Irene falling over (see Incident reports dated 24 May 1968 [WITN0400039]; 16 September 1981 [WITN0400040]; 17 December 1981 [WITN0400041]; 30 September 1995 [WITN0400042]; 28 December 1997 [WITN0400043]; Event register, entry dated 4 May 1995, 19 May 1995, 27 June 1995 [WITN0400015]; 3 February 1996 [WITN0400016]; October 1997 [WITN0400019]; 29 July 1998, 20 November 1998, 12 February 1999, 6 March 1999 [WITN0400023]; 31 March 2004, 11 April 2004 [WITN0400027]).

2.31. I also witnessed another resident at Kimberley being physically abused. I remember, when I was around sixteen or seventeen, I went to Kimberley to pick Irene up for the weekend. I arrived early and found the front door was already unlocked. I went into the day room and I saw a naked woman on the ground, being kicked in the stomach, at full force, by a male nurse. The woman was moaning and was not getting off the floor. I found it really shocking and so I collected Irene and took her home. I wanted mother and father to make a complaint, but they refused because they thought it would make things worse for Irene. That is when I learned about the climate of fear amongst families of Kimberley residents, and that my parents feared that there would be some sort of repercussion against Irene if they complained.

Seclusion

2.32. I am also aware, from Irene's files, that Irene was put into seclusion as a punishment for her behaviour. Between 12 June 1990 and 25 August 1990, Irene was placed in seclusion over 18 days total, sometimes a few days in a row (Seclusion registers dated 12 June 1990 to 23 June 1990 [WITN0400044]; 1 July 1990 to 10 July 1990 [WITN0400045]; 1 August 1990 to 25 August 1990 [WITN0400046]). The seclusion period was usually for a short time, with the longest time being 2 hours, however I can only imagine how distressing this would have been for her. Further, in 1998, there is a note that she was placed in seclusion for 8 hours [Seclusion order [WITN0400047]). On another occasion, she came out of the seclusion room with a cut under her chin (Event register, entry dated 10 August 1999 [WITN0400023]), which just adds to the consistent lack of any monitoring by Kimberley staff.

De-institutionalisation

2.33. Kimberley was, in my opinion, a hellhole. I would say that Irene regressed in Kimberley due to neglect. I can only describe Irene as having existed in Kimberley. I have attached a photo of Irene [WITN0400048], which I believe was taken near the end of her time at Kimberley, and it shows the physical effect Kimberley had on her.

2.34. It did get better for Irene near the end. In the early years I never saw any of the residents engaging in fun activities at Kimberley. By the late 1990s and early 2000s, Irene was taken in van rides to beaches and they had BBQs and there were events planned for the residents like concerts, swimming and discos. I also recall there were lots of activities around Christmas time and it was sometimes so exciting for Irene that we would not take Irene home for Christmas.

2.35. Irene was one of the last to leave Kimberley once the de-institutionalisation process had begun. My family and I were first made aware of the government's decision to shut down Kimberley in or around 2001 (see letter from Ministry of Health dated 3 September 2001 [WITN0400049]). Although my parents knew that de-institutionalisation would be better for Irene, they were also quite scared as Kimberley was all they had known.

2.36. Overall, my family and I found the de-institutionalisation process very confusing. We would be dealing with one government agency or a service provider, which suddenly would be renamed or somebody else would take over. It was never the same person walking you through the process. I was going to every meeting and taking notes, but I still found it very confusing.

New Zealand Care – GRO-C House

2.37. As a result of the de-institutionalisation process, in 2004, Irene was placed into a New Zealand Care (**NZ Care**) house in Paraparaumu called GRO-C House.

2.38. At the start, I really thought the facility was great. It felt like Irene's home and the staff were nice.

Physical abuse

The injuries

2.39. From March 2006 onwards, Irene had a range of visible injuries. In March 2006, I was told by a caregiver to lift up Irene's jersey as I was taking her out for a home visit. I lifted up Irene's jersey and saw carpet burns all over her stomach and back. I then looked at her wrists and ankles and saw bruises. I thought that it looked like Irene had been dragged along the floor.

2.40. On 2 April 2006, Irene had a fall hitting her right cheek; on 9 May 2006, Irene had abrasions on her right thigh; on 17 May 2006, Irene had grazes under her right forearm; and on 5 June 2006, Irene suffered a head injury, a cracked chin and bruised eye, which

she had to go to hospital for. On this occasion, I was told Irene had fallen in the night on her dresser (see incident report dated 5 June 2006 [WITN0400050]).

2.41. On another occasion, Irene had a suspected broken arm by it being twisted up behind her back. Irene was also overdosed on drugs requiring her stomach to be pumped. I am also aware of another resident in the NZ Care home who died from choking on a scone.

Complaint to NZ Care

2.42. I was so upset about what was happening to Irene. The carpet burns shocked me the most and I just could not believe this was happening, after everything we went through with Kimberley. I wanted to find out what was going on and so I requested Irene's records from NZ Care, but they would not give them to me.

2.43. I tried to discuss the situation with Irene's doctor, but because Irene was an adult and I was not her welfare guardian at the time, her doctor could not talk to me about her health. He also advised me not to take on NZ Care because it would make things worse for Irene. I did eventually get welfare guardianship of Irene, although this was a difficult process, which I will explain later in this statement.

2.44. I did write to NZ Care because I started to have real concerns about a support worker, who was the sole person on night duty the night Irene had her head injury. I had a few interactions with this support worker, which always left me with a sense of unease. When I would pick Irene up for a home visit, the support worker at issue would say things like "you cannot take Irene today", and when I would say that I would be taking her out, the support worker would say, angrily, "well don't bring her back to me if she gets sick!". The support worker would also refer to Irene being "naughty" because she would get up in the night. I told her that Irene was probably just hungry, but the support worker didn't seem to think this was a reasonable suggestion.

2.45. On one occasion, I was at GRO-C and heard another resident crying and found them on the floor, bleeding. I called for help and the support worker at issue came, but she broke down and said she had requested stress leave. She also said that other support workers were blaming her for Irene's head injury. This whole incident was very concerning, not only because it was evident the support worker was in no position to look after the visibly distressed resident but also because it seemed like she had some involvement in Irene's injuries.

2.46. When I first raised my concerns about the support worker, I think the Group General Manager underestimated me. He initially delegated my complaint to a newly appointed Regional Manager. Although she was nice and offered to meet with me (see email from the Regional Manager to me dated 14 August 2006 [WITN0400051]), I thought the delegation was quite disrespectful and it suggested that he did not take my concerns seriously.

2.47. I eventually had a meeting with the Group General Manager, where he offered to move Irene into a safe house. But I refused because I thought about the five other people who were living in this house. I told him that he had to fix this care home.

Police involvement

2.48. In or around August 2006, Irene's doctor contacted NZ Care about Irene's injuries. He said that either NZ Care would need to contact the Police, or he would himself. So, NZ Care contacted the Police, with my permission. Once the Police became involved (and the media became interested), I felt that NZ Care started to take my concerns more seriously and were more receptive to my concerns.

2.49. The Police were fabulous. The Officer in Charge took the complaint seriously and showed humanity towards Irene. He met Irene at GRO-C , and she took a liking to him because she grabbed his hand and guided him towards his car so that she could have a ride in his Police car. I got the impression that the Officer in Charge was dedicated to keeping Irene safe.

2.50. The Police placed a hidden camera in Irene's room, but I have never seen the footage recorded. They also interviewed all the staff members, including the support worker at issue, but I understand they had difficulty getting any information from them. Throughout the process, the Police kept me updated on the progress of the investigation.

2.51. Unfortunately, because the Police could not find any corroborating evidence to support what had happened to Irene, the Police had to close the case (see letter from the Officer in Charge on 15 January 2007 [WITN0400052]). Although this was a disappointing outcome, I believe the Police had done all they could.

NZ Care response and incidences now

2.52. I understand that as a result of NZ Care's internal investigation, three staff members lost their jobs at GRO-C , including the support worker at issue. However, I believe some or all of the staff members were moved sideways to other NZ Care facilities.

2.53. After the incidents in 2006, Irene suffered a further injury in or around June 2013. I was advised by a caregiver that Irene's nose was bruised and swollen. The caregiver said that Irene went to bed with no injury but had a broken nose in the morning, which I did not believe. What I found most distressing was that Irene had a broken nose for at least a few days, with no painkillers given. I again brought this to NZ Care's attention and I decided not to take it any further because I felt that NZ Care took it seriously. However, it did leave me with a feeling of unease.

2.54. I also received an anonymous letter from a staff member at Irene's house on 29 October 2014 (dated 21 October 2014, [WITN0400053]). In this letter, the staff member raised concerns with the employment of a new caregiver who was removed from another NZ Care home due to complaints by staff of her abusing a resident. The anonymous staffer wanted to let me know because they had major concerns for the safety of the residents in Irene's house.

2.55. After I received this letter, I spoke in confidence to a caregiver, whom I trusted. This caregiver told me that the contents of the letter were true but that the new caregiver of concern was working in a monitored situation and was never alone with the residents. The

caregiver promised to advise me if there were any incidents. I also spoke to the Manager of the three NZ Care houses, and I thought she trivialised it by saying that other people had received the letter and the writer had a personal issue with the caregiver. However, I decided to defer any complaints until there was a reason to complain.

2.56. Today, Irene is still in her NZ Care home and has a very happy life in her care home. I would say her care home is a shining example of what care for disabled people like Irene can be. She has a caregiver who treats her like family. There is now a more collaborative relationship between NZ Care and the families of the residents. I have been included in the governance of the home and I have been on some interviewing committees.

Access to justice and the welfare guardianship system

2.57. In 1995, my parents were appointed as Irene's welfare guardians and in 2002, my mother and I were appointed as Irene's property managers. In 2006, when I was first made aware of Irene's injuries in NZ Care, my mother was old and ill with cancer and my father was dead. My mother was in no state to be able to represent or speak for Irene and because I was not Irene's welfare guardian at this time, it was very difficult to get her the help she needed. When I contacted the Court, I was advised that a lawyer would not be appointed unless Irene's situation changed.

2.58. Eventually I petitioned the Court to get a joint welfare guardianship. We had to show there were special circumstances that required a joint welfare guardianship, including that we believed abuse was happening. The Court appointed Irene a lawyer, whom I really did not like and he was not in our District. I understand he was part of a firm that acted for residents from Kimberley, but I did not think he was doing a good job because he would visit Irene and two other people in her home, and barely pay them any attention. He would just talk to the caregivers and charge for a report, and applications for Welfare Guardianships or Protection of Personal and Property Rights orders, that simply regurgitated what the caregivers said. Irene should have had the right to choose her own lawyer.

2.59. It took over two months before I was appointed as a joint welfare guardian. I found this whole process quite distressing, and it showed a real flaw in the system. The most vulnerable people, like Irene, need to have a trusted advocate available quickly. In a situation like Irene's, where she was being abused at that point in time and her welfare guardian was seriously ill and unable to provide representation, then she should have had a lawyer immediately available.

Discrimination in the medical sector

2.60. In May 2020, Irene's appetite had reduced again, and her doctor was worried that it could be caused by cancer. Irene was referred by her doctor for a GI Endoscopy due to an unexplained iron deficiency. Irene's doctor assured me that Irene would be seen almost immediately because of the urgency of her case. In the referral, Irene's doctor explained that Irene was severely mentally handicapped and that she would have no understanding of hospital procedures. On 19 May 2020, the Gastroenterology department declined the referral and said [redacted]:

> You have not provided a good reason to further investigate this finding in this patient and provided no indication how this might humanely be achieved. We have limited clinic space and it is not a good use of that space to be assessing patients for suitability for endoscopic exams. If there is a physician more familiar with her care then you might wish to consult that person.

2.61. I was very hurt and angered by this response. I cried for at least two months (and I am not a crier), thinking about how Irene was being discriminated against because of her disability, in a situation where she could have a life-threatening disease.

2.62. In early July 2020, Irene's condition became acute and she was taken to Wellington Hospital. Irene was cared for and the doctor showed compassion and understanding of her disability. This doctor thought the original comment from the gastroenterology department was very harsh.

2.63. I received apologies from doctors in the gastroenterology department – I was able to speak to the head of the department and the doctor who declined the referral. I talked to them for a considerable period of time, and the doctor involved provided a genuine apology. He assured me he had not intended to discriminate against Irene because of her disability. I was assured that the protocols had changed so that it was no longer one person in charge of decision-making regarding treatment in the department. I found these conversations with the doctors from the department very restorative.

3. IMPACTS

Impacts on Irene

3.1. Irene is very resilient and she doesn't know anything other than what she has experienced. I think the physical abuse at Kimberley and NZ Care might be easier for her to recover from because she might not remember it, but I cannot be sure of that. Ultimately, she lost around 20 years of her life due to the drugging she suffered in Kimberley. There was no quality of life for her at this time.

3.2. The neglect and lack of love in Kimberley has made Irene less trusting of people. It took away a lot of her loving and warm nature. In the past she would have been really happy to cuddle or give me a kiss, but now that does not really happen. There has been a part of that warmth that has gone from her life.

3.3. Today, Irene lives a happy and fulfilled life. I have attached a photo of her from January 2021 [**WITN0400055**], which shows her looking healthy and happy. Her caregiver takes Irene on drives, which she loves. Irene gets taken to the supermarket and she can push the trolley, which she finds very exciting. I make money available to Irene so that she can treat her caregiver to a coffee on an outing. We also funded Irene to go for a weekend trip to Hawkes Bay and to Kapiti Island. Every day, Irene goes to an activities place called MASH, where they have music and dancing. She also goes once a month to a place in Levin where there is a dance. Irene's caregiver has identified that Irene loves music and that she is artistic, so she takes her to Art Galleries, concerts and the museum, which

calms her down. Overall, Irene has a brilliant existence and is treated with huge respect by her caregiver.

Impacts on me

3.4. I love and care for my sister very much and what has happened to her has really affected me. I have always felt responsible for her and she is my weak spot. You cannot live your life happily if your loved one is not happy.

3.5. I was so upset when she went to Kimberley and I hated going there. The whole experience for my mother and father was also dreadful. I think my mother was depressed from the time Irene was born until about 2004, when we had the brief respite with Irene moving into GRO-C .

3.6. When Irene's teeth were removed, I cried for a long time and tried to fight against it. I feel like I have been fighting my whole life. Every time I think that something is going smoothly, there is just something else that comes up. It is so exhausting and has had physical consequences. My skin started peeling from stress during the NZ Care investigation. I also feel sorry for my children and my husband because I have been always fighting, which means my energy has not always been with them.

3.7. The distrust of the care system is always present for me. I felt so let down that after finally getting Irene out of Kimberley, she was abused in GRO-C which we thought would be our new hope. To find out that she was being dragged and dehumanized was just so awful. The lack of openness from NZ Care was the last straw and I just kept on thinking when was it going to stop. I now always feel like I have to be on high alert and distrustful, even though NZ Care is doing a really good job now.

3.8. I am also angry. The people who were cruel to Irene and other disabled people never seem to pay. It is like this big white hole of anger that you cannot describe. I have cried a lot and it is just this deep-seated upset that these carers could treat other human beings in this way. Irene has no way of protecting herself and she has no voice to speak up. It is not just Irene that I fight for, but I fight for change so that these things do not happen to other vulnerable people. Disabled and vulnerable people deserve the very best. My anger will not go until I am able to forgive. I will not be able to forgive until there is an acknowledgement of the inhumanity towards Irene and others in her situation.

4. REDRESS

4.1. My family and I have never made any claims to the state, ACC or otherwise on Irene's behalf in relation to the original injury at birth that caused her disability; the abuse and neglect she suffered in Kimberley or the abuse she suffered in NZ Care. We did not think that money would make her situation any better.

5. LOOKING FORWARD

5.1. All that my family and I care about is acknowledgement that the State has done wrong by Irene. Kimberley was a hellhole and there were inadequate checks on the staff in these

places. If the government were to apologise, that would cover a lot, but it still allows these people who have done wrong by Irene to get away with it. What I wish from the Inquiry is restorative justice sessions with the people who have mistreated Irene and other vulnerable residents, so that they can understand why what they did was wrong and the effect it has had on those residents.

5.2. I think the best we can do now is draw a line in the sand and ensure that from now on, care for disabled people, like Irene, is as good as it can possibly be.

Training of staff

5.3. What happened to Irene in GRO-C could have been avoided if the caregivers had been trained better, the team was more stable and the government had more oversight of the facility. I believe there should be a nationally recognized caregiver qualification and a career structure to encourage caregivers to stay in the disability sector. I have attached a submission I provided to the Inquiry into the Quality and Care of Services Provision for Disabled People [WITN0400056]. In this submission I outline the recommendations I have for training and keeping good caregivers. These recommendations apply to this Commission.

De-institutionalisation process

5.4. I also think there were a number of issues with the de-institutionalisation process, which should be considered if a similar process was to occur in the future. Firstly, I think the reason why some of the abuse that occurred to Irene in GRO-C was due to the home not being set up properly. Despite having years to set up the new care homes, it all felt like it was too quick.

5.5. Secondly, there were (and are) not enough checks on the new care homes. Although the Ministry of Health does complete audits, these are routine, allowing the care homes to spruce the place up in preparation for the audit. The first audit by the Ministry of Health for GRO-C was not until two years after GRO-C was established. The audit, which happened between 11 and 15 September 2006 (Ministry of Health Audit Report 11 to 15 September 2006 [WITN0400057]), seemed to only happen because of the police investigation into Irene's abuse. Despite this, the audit did not even consider the issues that caused the police investigation.

5.6. Finally, during the de-institutionalisation process, there should only be one person assigned to each family to guide them through the process. As I said earlier, my family and I found the whole de-institutionalisation process very confusing because we never knew who the main contact person was.

Disability funding

5.7. I also think that disabled people in care need to receive a higher disability allowance from the government. Irene lives a very happy and fulfilled life now because she is very lucky. My family has enough money to fund her to do the kinds of activities I described earlier. Irene does get an allowance from the state, but this is only $68 per week. This can cover

the little joys, like getting her hair done once a month or a pedicure, but it is not enough to give her the life she deserves. Other residents in these care facilities may rely solely on the allowance.

Conclusion

5.8. Irene never deserved to be hurt or frightened. She deserved to have the best life that was available to her, but this has not happened for most of her life.

5.9. I have spent my life fighting for Irene and I am tired. I can only hope that this Royal Commission will lead to change in the disability care system.

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: 28 January, 2022

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