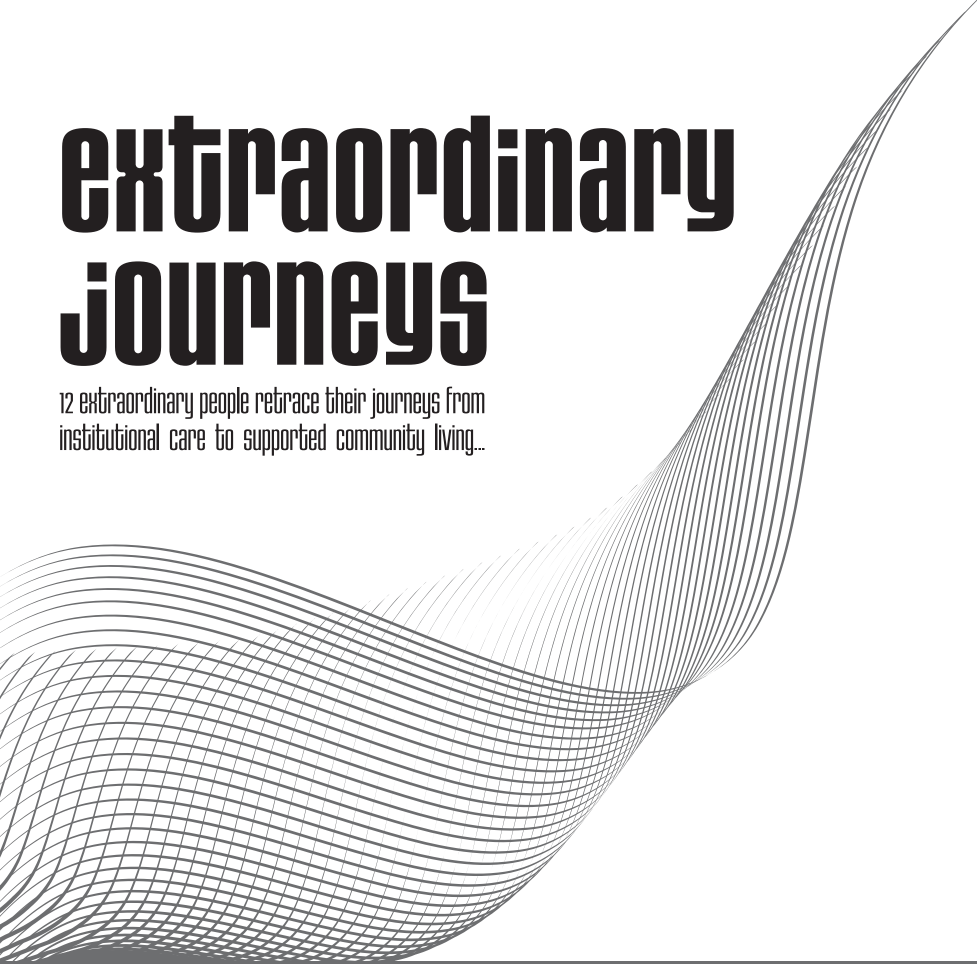
extraordinary journeys

12 extraordinary people retrace their journeys from institutional care to supported community living...



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12 extraordinary people retrace their journeys from
institutional care to supported community living...

Ko te herenga waka, he whakawhiti korero, he whakaputa whakaaro, he maramatanga.

When you see waka tied together in one place, talks are spoken, thoughts come out and then there is enlightenment.

Brian Emery
Te Roopu Taurima O Manukau Trust

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Preface

The movement from institutionalised care to supported community living and onwards to supported independent living signals a new chapter in New Zealand's disability policy. The Individualised Funding and Supported Independent Living models represent a comprehensive shift in disability support practice and it is our hope that this shift provides positive, empowering and inclusive outcomes for people with a disability in New Zealand.

Recent policy changes have empowered disabled persons with a voice in their own future and fostered a new sense of dignity and pride that for too long has been denied them.

I am acutely aware of the call from disabled persons and their families, for increased choice and control over the supports they receive and the lives they lead.

In New Zealand, as in many westernised countries, we have a history in which people with intellectual disabilities were generally institutionalised throughout much of the last century. It is only with the closure of the large hospitals over the past few decades, that people who once lived in institutions were provided with the support to live meaningful lives in the community.

The *Extraordinary Journeys* project was designed to explore the changes in the lives of people with intellectual disabilities from the time of institutionalisation, through to living in the community in the new millennium.

As expert witnesses to life in institutions and the subsequent community models of support, the aim was to hear their individual voices and stories, regardless of – and with regard for – their level of disability.

I want to commend Spectrum Care Trust Board and Te Roopu Taurima o Manukau for their dedication and commitment to supporting people with disabilities. I acknowledge, too, the proactive investment provided by the Frozen Funds Charitable Trust in considering how their funds could benefit people who use intellectual disability and mental health services.

The 12 people who feature in these stories are indeed extraordinary people living ordinary lives. The support of whanau, friends and community workers is also inspirational as we recognise the commitment of others towards supporting people with intellectual disabilities to be full participants in their own story.

Hon Tariana Turia
Minster of Disability Issues

Introduction

Little is known about how people with intellectual disabilities view themselves, their lives and their histories. Only in recent years has there been emerging literature which has focused on the needs and experiences of people with intellectual disabilities, and their individual stories.

In New Zealand, as in many westernised countries, people with intellectual disabilities were generally institutionalised throughout much of the last century. It has only been with the closure of large hospitals in the 1980s and 1990s (with the final institution, Kimberley Hospital, closed in 2006), that people with moderate to severe intellectual disabilities have been supported to live a life in the community that more closely resembles that of other New Zealanders.

The *Extraordinary Journeys* project was designed to explore the changes in the lives of people with intellectual disabilities from the time of institutionalisation, through to living in the community in the new millennium. As expert witnesses to life in institutions and the subsequent community models of support, the aim was to hear their individual voices and stories, where possible, no matter what their level of disability. Through the telling of these stories, it was anticipated analysis of common themes and patterns in people's journeys from institution to community would enable some reflection on the changes that have occurred.

The *Extraordinary Journeys* project

The drive to hear the stories of individuals who lived in the institutions came from discussions between the chief executives and senior managers of Spectrum Care Trust Board and Te Roopu Taurima O Manukau. Both organisations are charitable trusts that support people with disabilities to live in the community. Both organisations grew out of the closure of Mangere Hospital and, to this day, support many of the people who once lived in institutions.

The people who have shared their stories in this book have been generous and bold. They've told stories of being controlled, devalued, abused and separated from their families and loved ones. They've also shown resistance and resilience, and survived the beliefs and practices of a bygone era. Their stories highlight how much better their lives are in the community, but also raise other questions and insights into how services may further develop and support the individuals towards even more meaningful and productive lives.

Funding for the project was provided by the Frozen Funds Charitable Trust. This Trust was set up to administer unclaimed interest money that had accrued on patients' welfare benefits paid into psychiatric and psychopaedic hospital trust accounts in the 1970s and 1980s. The government set up the Trust so that the unclaimed balance of the funds could benefit people who used intellectual disability and mental health services.

Thanks also to the IHC Foundation, without whose contribution this project would not have been possible.

Alofa Foalima

Alofa

At a glance...

Alofa was born in Samoa in September 1959 and had a large extended family.

Alofa and her mother moved to New Zealand in 1987, when Alofa was 27 years old. Initially, they lived in Manurewa with Alofa's sister Aoga and Alofa's grandmother. Three or four years later, Alofa's mother got cancer and passed away quite suddenly, which brought a great deal of sadness into their life.

Siava, Alofa's other sister, brought Alofa and their grandmother to live with her family on the North Shore.

About a year later, Alofa moved to a rest home in Mt Eden. When that rest home closed down, Alofa moved to another in Wiri.

Phyllis Trellise met Alofa in 2007, when Phyllis took up the role of manager at the rest home in Wiri. Alofa was 46 years old at the time and living with people in their 80s.

Phyllis realised the rest home was not suitable for Alofa.

Phyllis met with Siava and talked about the possibility of Alofa living in a community home with four or five other people. The Foalima family were very interested in her moving to an ordinary home – especially if she could be supported within a Samoan environment.

At first, Alofa visited Spectrum Care's Malae Ola house on Sundays to get to know the rest of her flatmates. Everyone at the house speaks Samoan and is independent, and Alofa was soon very happy there.

When Alofa first came to Malae Ola, she didn't want to do anything. She couldn't make her bed or take a shower on her own, and didn't know how to use a knife and fork.

"Now she can do it. We just prompt her to doing things," says Lucia, Alofa's support worker. She used to want us to feed her, but now she feeds herself and even helps with the cooking and the dishes. Alofa can do her own washing and can hang it out if staff prompt her.

"But everything we do, we always ask her if she wants to do (it). She's got a choice," says Lucia.

Alofa's sister Siava and the staff at Malae Ola are very proud of Alofa. They realise she has come a long way on her journey into the community. She is able to do things for herself and help herself. She has regained much of her language.

When you don't understand, you're not happy, says Lucia. Alofa is now happy – culture and family have made her so...

Three people contributed to Alofa's story.

Alofa's sister, Siava, told of Alofa's earlier life in Samoa, of the family's move to New Zealand and of Alofa's first few years in residential care.

Phyllis Trellise, the manager of the last rest home that Alofa resided in prior to moving to Spectrum Care, shared the story of that significant transition back into the community.

Finally, Spectrum Care staff member Lucia Castella sat with Alofa during the interview and told Alofa's story since moving into supported community living.

Alofa speaks only in Samoan, though she understands some English. Despite being very nervous during the interview and unable to share much about her life, Alofa said she wanted to have her story told and to have her own name used in the book.

Introduction

Alofa was born in Samoa in September 1959, to a family with two brothers and two sisters. Following the breakdown of her parents' marriage, her father married a second time, bringing another five stepsisters and four stepbrothers to her extended family.

When Alofa was quite young, her mother also remarried and moved to Apia, though Alofa, her brothers and sisters remained on the island of Savaii. The family didn't have much to do with their father from this time onwards. He played in bands, taught music and moved about a lot.

Alofa's birth was not registered in Samoa and without a birth certificate she was unable to go to school. Siava thought this was very sad and blames her mother for this. Though Alofa did go to Sunday school, she would only stay a few minutes and would then disappear as she couldn't concentrate.

Alofa was looked after by her grandmother until she was nine or 10 years old. Around this time, Alofa's grandmother moved to New Zealand and Alofa went to live with her mother in Apia.

Life in Samoa

Alofa didn’t talk much during her childhood in Samoa, but she enjoyed working.

“In Samoa she (would) just go and do anything, like picking some firewood for making the fire at the kitchen,” says Siava. “She loved the kids very much. She helped the family with the kids and the village (with) our kids.”

Siava left Samoa for New Zealand in 1971. She doesn’t remember thinking Alofa had a disability when she was living in Samoa, saying that she was not aware that Alofa had a problem even when visiting Samoa in later years.

Alofa’s mother finally registered her daughter’s birth when she was considering a visit to New Zealand, as a birth certificate was necessary for a passport.

In around 1982, Alofa and her mother came to New Zealand to stay with Siava for a holiday. “My mum tell her to go and have a shower, she did go by herself… sometimes she don’t want a bath (and) she wants someone to do it for her.”

Siava worried about Alofa living with their mother. “My Mum was leaving her behind sometimes, and she’d go and do something off (in) the village,” says Siava. “It’s not like me and my other sister (who were more independent),” says Siava. Alofa was uncomfortable with her stepfather’s family, and Siava sometimes wonders whether her stepsisters and brothers ‘did something bad to her’.

On one occasion, Alofa got lost in Apia. “(After) about a week, they found her at the farmers – very close to the prison of Samoa,” says Siava. She’d gone into the bush to find her mother and, when she saw other people, became scared and ran away.

Life in New Zealand

Alofa and her mother moved to New Zealand in 1987, when Alofa was 27 years old. Initially, they lived in Manurewa with another sister Aoga (who now lives in Australia) and Alofa's grandmother.

Three or four years later, Alofa's mother got cancer and passed away quite suddenly, which brought a great deal of sadness into Alofa's life.

"She's not very happy," says Siava. "She always says 'I'm going to my Mum, I'm going...' I say 'Oh, Mum's gone...' and she says 'No, my Mum's there...' and I say 'Where?' 'My Mum's there with my sister...'."

It took Alofa some time to realise that her mother was gone, and she also struggled when her grandmother died several years later.

"She can't know that kind of word: 'Passed away'," says Siava.

Siava brought Alofa and their grandmother to live with her family on the North Shore. Siava still had three of her four children living at home, along with her husband.

"I had a big family," says Siava. "But I can't leave my sister with any of my other family, because my sister went to Aussie to stay."

Soon after Alofa and her grandmother moved in, Siava divorced her husband – partly because he didn't like her family staying. (Siava says the family don't know this.) Her husband yelled a lot and this created stress which didn't help Siava's health problems.

Siava's daughters helped her to look after Alofa and their great-grandmother, but they eventually moved out to have families of their own or go to work.

This left Siava doing all of the care-giving.

Siava managed this for another two or three years, but found it increasingly difficult. Their grandmother needed a lot of physical care and Alofa was unable to do more than hold her grandmother's hand while Siava bathed her and changed her nappy.

When Alofa saw Siava caring for her grandmother, she wanted Siava to do those same things for her. Siava didn't want to burden the rest of her family and, as the oldest, it fell to her to look after both Alofa and her grandmother.

At times, Siava felt angry and needed a break.

Alofa and Siava's grandmother passed away around this time. Unfortunately, Siava was not well and, at times, Alofa wouldn't listen to her. Siava got tired of having to do all the little things for Alofa, such as tying her shoelaces, and wondered at times if Alofa thought 'I don't care, she's my sister'.

Siava could tell when Alofa was angry with her.

About a year later, Siava decided it was going to kill her if she kept trying to look after Alofa. She rang the local social worker on the North Shore and asked her to try and find a place for Alofa to live. A Samoan lady came to see Siava, but nothing came of that visit. Then, one of Siava's aunties (through marriage) told her of a possible place for Alofa in a rest home in Mt Eden.

Siava was a bit concerned because their grandmother had stayed temporarily in the same home when their mother was dying, and had ended up with a big bruise (apparently because she was deaf and didn't listen properly to the nurse).

When Siava took Alofa to the rest home, she had her dressed well. However, she found the other people there were dressed "like people who walk at the road" and their clothes were not clean.

Despite some misgivings, Siava moved Alofa into the rest home in Mt Eden. Sometime later, however, a staff member came to see Siava and informed her that the rest home was to close down.

Siava said, because of her health, she couldn't look after her sister. The staff member, a Maori lady, said "Don't worry, Siava..." and said that she could take Alofa to live with her in her own home in Whangarei while she looked for somewhere else for Alofa to live.

"I'm so happy, thanks God!" says Siava of this generous offer.

The staff member, Margaret, looked after Alofa very well. "I loved that lady," Siava reflects. She had Alofa dressing "really nice... beautiful".

When Margaret came to Auckland to visit her daughter, she would ring Siava and ask her if she would like to see Alofa. Margaret would then bring Alofa to visit, dressed in nice clothes and bring food to eat with Siava. Then Margaret would pick her up later and take her back to Whangarei.

"(Margaret) found the rest home (at Wiri) in Manukau," says Siava. "They were really good. I loved the nurses." They loved Alofa and she was really good for them. Siava found it hard to leave her sister in another home. She loves her very much and often thinks about Alofa being their mother's youngest daughter. "But it's hard for me when I (am) getting sick," she says.

From rest home to supported community living

Phyllis Trellise met Alofa in 2007, when Phyllis took up the role of manager at the rest home in Wiri (following a period with disability support provider Spectrum Care). Alofa was 46 years old at the time and living with people in their 80s.

While she was able to eat her meals independently, Alofa needed help with her personal cares. Some of Alofa's behaviours in the rest home were considered 'aggressive' by staff, but Phyllis recognised that Alofa needed more interaction. Alofa didn't join in the board games or ‘housie’ that some of the residents played and, although she sat in the lounge with them, Alofa didn’t have any real friends among the residents.

Alofa would talk away in her own language, although her family said that it wasn’t Samoan. “It was as if she had made up (a language) of her own,” says Phyllis. Neither the staff nor her family understood this ‘language’.

Alofa loved music and would clap along – getting very lively in the process, says Phyllis. The staff would then get concerned that she was getting agitated. The real worry was that Alofa was living with frail elderly people and, when she became boisterous, there was the possibility she could knock one of them over.

The staff were trained to work with elderly people and had little understanding of the needs of people with intellectual disabilities.

Phyllis realised the rest home was not suitable for Alofa and was surprised to learn that when she had been reassessed, the Needs Assessment and Service Coordination agency believed that Alofa was suitably placed.

As part of her regular work, Phyllis met with Siava and talked about the possibility of Alofa living in a community home with four or five other people. The Foalima family hadn’t realised there were other options for Alofa and were very interested in her moving to an ordinary home – especially if she could be supported within a Samoan environment.

It took almost six months from the time the referral was made to when Alofa moved into a community home within Spectrum Care. The rest home staff were disappointed when Phyllis told them Alofa was moving out and really didn’t understand that Alofa could have a better life, have more independence and live with other people in a small community home.

Life in the community

Lucia says the Foalima family were very excited when Alofa moved out of the rest home and into Spectrum Care's Bridgehaven home in October 2008. Bridgehaven was the only place available at the time and catered specifically to people with serious physical disabilities, says Lucia.

This presented some difficulties as Alofa wanted to be treated the same way as the others in the home – to be fed and showered just as the others were, despite being more than capable herself. The staff realised it wasn't the best place for her and, once a space became available, she was moved to another Spectrum Care residence – Malae Ola. Although it was historically a men's house (this was the first time a lady had lived there), everyone was very happy about Alofa's arrival.

At first, Alofa visited on Sundays to get to know the rest of her flatmates. She came every week for lunch or dinner for two or three months and became familiar with everybody before moving. Everyone at Malae Ola speaks Samoan and is independent, and Alofa was soon very happy there.

Siava thinks Malae Ola is a beautiful place. "I love the place she (is) in now with the boys – just like a sister to the brothers..." She believes Alofa is doing well and is pleased she is being looked after by Samoan staff. She is also very happy Alofa is relearning and "knowing my language" – Samoan.

When Alofa first came to Malae Ola, the staff didn't know anything about her background, says Lucia. Siava would visit to help her settle in and this helped Alofa to adjust. The process was made easier as Alofa knows the Samoan culture and the language, and especially enjoys the food. Since moving, Alofa has also begun to express herself a little in English.

When asked what foods she likes, Alofa might say "Apple!" But at other times, she might say "Palusami" (taro) or "Pua'a" (pork). She likes everything.

While Alofa used to have difficulty being understood by the staff, her communication has improved over the past year. With Alofa's permission, Lucia explained how her communication has changed, saying that Alofa is now easier to understand and makes more sense. If there is something she doesn't like, it becomes clear simply by looking at her face – she'll frown if she's not happy...

The staff know when she's upset and ask her "What's wrong?" or "What's the problem?" She'll then tell you what's wrong. From time to time, she might have a sore stomach or a headache and she'll tell you, which never happened before. She also talks about her family now, "her sisters and brothers and what happened in the past..."

When Alofa first came to Malae Ola, she didn't do anything and didn't want to do anything. She couldn't make her bed or take a shower on her own, and didn't know how to use a knife and fork.

"Now she can do it. We just prompt her to doing things," says Lucia. She used to want us to feed her, but now she feeds herself and even helps with the cooking and the dishes. Alofa can do her own washing and can hang it out if staff prompt her.

"But everything we do, we always ask her if she wants to do (it). She's got a choice," says Lucia. Alofa is very helpful and will sometimes do things independently. "You don't tell her what, you don't ask... She'll just come and do it," says Lucia.

Talavou also lives at Malae Ola and is Alofa's friend. He's helped her a lot with her communication and helped her regain her Samoan language – also teaching her how to sing Samoan songs. According to Lucia, they talk in Samoan and are very happy.

Staff take Alofa to buy her clothes and toiletries, and she makes her own choices of what she likes. When Alofa came to Spectrum Care, she "dressed like old people," says Lucia. Now she has a lava-lava (traditional Polynesian skirt) and she's part of the Culture Group, where she learns Pacific Island singing and dancing every Wednesday.

Each month, the Culture Group have a special night where they have turns at doing their own traditional food and music, and wear their traditional clothes – be they Indian, Fijian or Polynesian.

Alofa dances and sings on the Samoan nights, and has been able to "evolve in her culture" in a way she was unable to before moving to Malae Ola.

Siava says Alofa loves the Samoan culture. "I'm so proud of her (and) want to go and watch her one day," when she's performing in the Culture Group.

Siava would like to see Alofa take a trip to Australia to visit her other sisters and would also like to talk to her about where she was born – and take her to Samoa to visit the village they lived in. "But I have to find my own fare for that," says Siava.

Alofa also goes out walking and is learning 'lei' (making traditional Polynesian flower wreaths). Lucia recalls the many things she is now doing – such as going bowling, to the movies or out to lunch with friends or staff.

Alofa likes to see the animals at Ambury Farm and enjoys walking around there, but she also likes to stay home.

Alofa likes celebrations and often talks about balloons because she identifies these with parties, says Lucia. Last year, she went to a restaurant to celebrate her birthday.

Alofa will be 50 years old this year but, when asked how old she is, usually says "Three!" Occasionally, she'll say "Balloons!" when she can't remember something, so staff know it's a party she's trying to tell them about. Alofa likes going out – likes dancing, parties, party music and things like that, says Lucia.

One of Alofa's goals is to visit Aoga, her sister, in Australia and often mentions her and her husband's names. Siava told staff Alofa was very close to Aoga, so staff asked the family if she could go to Australia to visit her. They then asked Alofa if she wanted to visit her sister and she said "Yes!"

When Alofa is alone with Lucia, she talks well – though “she’s always nervous when new people come around,” admits Lucia. When Alofa lived in a rest home, there were a lot of Indian staff who couldn’t communicate in Samoan. Some of the staff believe she heard them speaking in Indian and began mimicking, which may be why she sometimes talks in a way that they don’t understand.

The most important thing in Alofa’s journey is her family, says Lucia. “And the family is very happy – she’s really happy over here and she communicates in the language she’s used to. That’s very important to her...”

One of Siava’s best memories arises from Alofa’s love of Siava’s kids and the enjoyment she got from looking after them. She remembers a day when Alofa was playing ball with Siava’s grandson and he nearly fell head first. Alofa ran and caught him. “She’s a loving person,” says Siava. If Alofa was able to look after herself, Siava would have liked to have her still living with her.

Sometimes, depending on which staff are on, Alofa likes to go to church and the flatmates take turns going with her. “We ask the sister if she was allowed her to go and she said ‘Yes’.” Alofa enjoys saying a prayer in Samoan now before she eats her dinner “...and she never did that before”, says Lucia. This is called a ‘lotu’ or ‘tatalo’. Sometimes, Talavou will say a lotu for her and then she will follow him.

Lucia says sometimes you can see Alofa is thinking. “She’s quiet and then suddenly she starts to talk about the family. She’ll say their names and, when we ask her sister about what she has said about her cousin, her stepfather or the village, her sister says she is remembering those things. Sometimes she’s told us the names of the kids that were being looked after or the names of other villages and families, and the people who looked after her in Samoa.”

These things had been lost, but have been coming back to Alofa recently. She remembers more now that she is happy and can talk in her own language, says Lucia. “But she never talked about the hospital (rest home)...”

Conclusion

Alofa’s sister Siava and the staff at Malae Ola are very proud of Alofa. They realise she has come a long way on her journey into the community. She is able to do things for herself and help herself. She has regained much of her language. “When you don’t understand, you’re not happy,” says Lucia.

Alofa is now happy – culture and family have made her so...

Brian Box

Brian

At a glance...

Brian was born in 1947 and was one of 23 children. At three years old, he developed meningitis and became very ill.

Brian was admitted to Kingseat Hospital at aged six and was later transferred to Kimberley when he was 11 years old.

Despite being in a dormitory and sharing with other patients, Brian had a lonely existence at Kimberley. He had no one there that he related well to.

Brian lost touch with his family and it wasn't until 1982 that Brian's sister, Debbie, found out about him. Debbie had been fostered when she was six years old.

It took another 20 years for Brian to finally be released from Kimberley Hospital and placed in a supported community environment.

When Brian first got out of Kimberley, he went to a powhiri (Maori welcoming ceremony) with Te Roopu Taurima O Manukau in Mangere Hospital. The powhiri was his welcome back to the whanau.

Many of the whanau were there to welcome back their brother, nephew, uncle and koro ('grandfather').

Later that day, Brian went to his new home in Porchester Road and entered his home in the customary way, being welcomed by a powhiri.

After Brian moved into Porchester Road, things began to change. He loved where he was living. His room was beautiful and he was happy.

Later, Brian moved to a beautiful home in Penrose with another man. He's been in good homes ever since he left Kimberley.

Brian understands everything. He's living a good life and his future is looking good. He's enjoying life. He knows what life is about and Debbie knows that he's happy and can tell people what he wants.

Debbie's children and mokopuna say their uncle is happy and are glad to have him back.

There were no positive things about Brian's time in Kimberley.

Debbie wishes her family had got to know Brian better because Brian's a very special person.

Debbie's sure, if their Mum and Dad were alive today, they'd be happy to know that there's still a lot of aroha (love) out there.

Debbie and her husband are now the proud grandparents of 33 grandchildren and great grandparents of two great-granddaughters, with another one of the way. They share all of them with their koro, Brian.

Ko tanui toku waka,

Ko wiakato toku awa

Ko maungatautari toku maunga,

Ko maungatauitari me pohara oku marae,

Ko Waikato toku iwi,

Ko ngati koroki kahu kura toku hapu,

Ko Brian Box toku ingoa.

Brian's Box's story is one of aroha and belonging between a brother and sister. This story was told by Brian's younger sister, Debbie Taehuri Taufa. Debbie's korero (language) resonates with the sense that Brian belongs to her and she to him.

Some information was also provided by Te Roopu Taurima staff member Lorraine Bailey.

Introduction

Brian was born in 1947 and was one of 23 children. I didn't know about Brian until the 1980s, when one of my brothers told me about him and showed me a photograph. Brian was then living in Kimberley Hospital.

Brian had lived with our parents but, at three years old, he developed meningitis. He was admitted to Kingseat Hospital at aged six and was later transferred to Kimberley when he was 11 years old.

I was a year younger than Brian and don't remember him as a young boy. At the age of six, I was made a Ward of the State and put into a foster home for girls. Later, I was fostered by a Pakeha woman who I grew to love and I called my 'Mum'.

Years later, my Mum told Social Welfare staff that she wanted to meet with my natural parents. My mother and father came to see me at our home in Papatoetoe. I had thought my older sister was my mother and these people were my grandparents.

I was hurt to learn the truth. When I was between 16 and 20 years old, I went to stay with my parents.

In 1969, I got married and had three sons and one daughter, but this ended in divorce. I remarried in 1985 to a Tongan man named Holomesi Taufa. My husband and I went to live in Gisborne to work on a farm as scrub cutters.

On July 17th 1982, I got a phone call from my family in Auckland to say that our father was very sick so I went home. Sadly, he passed away two days later. This is when my brother Jack Pouaka (who has now also passed away) told me about Brian.

Life in institutions

Not long after finding out about Brian, I was in Palmerston North for a Jehovah's Witness conference. I asked where Kimberley Hospital was and took my husband and two children to visit Brian. When I arrived, I explained to the staff that I was Brian's sister, but had never met him.

When we went to the ward, I saw this man and called out his name – Brian. The staff member asked me how I knew it was him if I had never met him and I said he was the spitting image of our Dad. My sons Duane, Jason and Teina said "Look, there's Koro!" (which means granddad in Maori).

When I first met Brian he didn't recognise me, but he held my hand. I grabbed him and said "Sister". He looked like he would take my hand off, the way he held it so tight. He was ready for family contact. I think he must have known that I was something to do with him. I felt sorry for my bro...

After this, I went back to my mother and said "Look, I got the family together and I want to bring Brian here." My mother lived in Mangere in Auckland and hadn't had any contact with Brian for a long time. She said "He's over here..." meaning Kingseat and hadn't been told that he'd gone out of the district. I said "I'm going to bring him back."

We had six children to care for, as my Tongan stepdaughters Lautaimi, Melevai and Ofa had come to live with us from Tonga. So I moved my whole family to Palmerston North so that we could live near Uncle Brian and look after him. I kept going to see him and started working out how to get him back up north.

When I went to visit Brian, I would sometimes pat his hand and he would have an odd look on his face. I asked a staff member what they thought was wrong and they said “Brian thinks you’re disciplining or hurting him.”

It made me cry because I was just patting his hand and he was showing fear. He must have thought I was disciplining him and that really hurt me. I cuddled him. He had tears and I had tears. Brian didn’t understand that patting his hand was a good thing, not a bad thing.

Brian used to bang on the windows, but he couldn’t break them. When we visited, the staff would lock us in a small room with Brian. I asked the staff “Why do you lock the doors?”

I used to feel cold because it took me back to my time in the girls’ home when there was a woman police officer there at all times. Staff said being locked in was for our own safety as some of the patients can get a bit aggressive, but I didn’t see that.

I asked if I could take Brian out instead of me coming in, but they said Brian can get a bit aggressive, but I never saw that. I looked at my bro and all these patients, and all I could see was fear and lots of hurt and pain.

All Brian and the other patients needed was someone to love them and to treat them with respect and kindness. They all needed people they could trust.

There was no improvement to the focus on safety over the years, although I did get to take Brian to my sister-in-law’s sometimes, or we’d take him to McDonalds for kai (food). When he’d been to visit us and I’d drive him back to Kimberley Hospital, he’d sit in my car happy. As soon as we went over a certain road, he knew he was going back. His head would hang down and his face would change, and I'd think 'Here we go, Brian' – I knew it would be hurting time.

He wouldn't want to get out of our van. I wanted to run away with him and never take him back to that horrible hospital, but I would've probably had the police after me, which would've destroyed my chance of getting Brian out of Kimberley Hospital for good.

I'd take him out for lunch, but he wasn't allowed to stay overnight – I'd have to bring him back, even though I didn't want to. Then, when he got back to Kimberley Hospital, he'd bang on the windows and call out to me, and my children would say "He's crying, Mum!". I'd be sitting in the van doing the same.

A hospital is supposed to be a safe place. You see this kind of thing in an Alfred Hitchcock movie, not realising it's happening in our society today. He didn't want me to leave him there. It was locked doors everywhere – banging doors and locking keys. These people aren't dangerous. All they do is sit there and rock, and they were locking them up. It was really hurtful to see that. And every time I went to pick him up on the weekend, my son would say "I want him out of there..." I cried a lot of tears for Brian in those days.

Brian always suffers in the cold weather. He's like my Mum. She used to feel the cold. The other patients would have missing blankets as Brian would go around and pinch them all. The clothes Brian wore at Kimberley Hospital weren't fit to wash the floor with and didn't keep him warm. You could see that he was cold, as he'd be shaking. The shorts would be pulled right up above his waist. I would've bought him some clothes if I had the money. But he was getting a benefit, so what were the hospital staff spending his money on?

They wanted me to sign or agree to Brian paying for a new bed, but I asked "Why?" when the hospital already provided beds.

I told them they needed to buy him and the other patients some warm clothes.

Despite being in a dormitory and sharing with other patients, Brian had a lonely existence. He had no one there that he related well to. When I would take him back to Kimberley, they'd be sitting in their own corners. It was horrible to see.

Brian used to stick objects in his ears and he's damaged them. In his notes, it says that he had a congenital defect that made him prone to ear infections. There must have been something wrong to make someone do that, but he hasn't done this for many years now. The staff at Kimberley said he used to scream, too. But when I took him out he would be calm. He hasn't stuck things in his ears or screamed since he left Kimberley Hospital.

There were elderly adoptive parents that used to take Brian out but, by the early 1980s, they'd passed away and that was when I said I wanted to be Brian's legal guardian. Anything to do with him I wanted to be included. I became Brian's legal guardian and was determined to get him out of hospital, but it wasn't easy.

There were problems because I didn't know that the guardianship had expired, so I had to write letters to lawyers and the hospital to get legal guardianship reinstated. The hospital eventually said Brian could come and live in Auckland, but then they said he'd missed out on coming up to Mangere Hospital because it was closing, so they again said he couldn't leave Kimberley.

I asked my sister Wairopa (Ropa) to write a letter on behalf of all the whanau (family) in support of our brother Brian being transferred back to live in Auckland. All of the family members signed the letter and she posted it to Kimberley Hospital. I don't know what happened to that letter.

My sister Ropa and I spoke with Lorraine Bailey in 1996 or 1997, when she was working for Spectrum Care. We wanted Brian to be moved up to Auckland in time for my Mum's big birthday celebration. Lorraine and I then visited Kimberley Hospital together. Lorraine's impression at the time was that Brian was dressed in hospital clothing and had all the mannerisms and idiosyncrasies of someone in institutional care.

He could be quite aggressive, but it was survival of the fittest in that environment. After the visit, Lorraine wrote a service proposal to Life Unlimited (Needs Assessment and Service Coordination agency) to help get Brian moved to Auckland. Spectrum Care had a place for Brian to move into permanently in their Maori Service and it should have been easy.

We waited. I moved the family back up from Palmerston North to Auckland and we continued to wait for Brian to come. I wrote to Kimberley when I knew they wanted to go to Court to stop him leaving and asked what the holdup was. They said they were stopping him moving out due to his health. It was just another thing to stop me getting control – I don't think it had anything to do with his health. They didn't want to let him go. It was very hard for my children, my husband and me. I wanted the best for my brother.

At one stage, we met with a lawyer and Conny Shalten (from Life Unlimited) – a woman who was going to become an important link in getting Brian out of hospital. My brother Lewis Pouaka came with me because he was worried that I would get angry – and I did! Lawyers didn't know what I felt. They don't have the same taki as me, the same feeling as I have for my brother.

Brian never got to Mum's birthday. We tried hard to get Brian up to Auckland before Mum passed away but, in the end, she died before he got to see her.

When we finally got a reply back about the service proposal for Brian, the hospital had got an injunction so that no clients could leave, irrespective of family wishes. This was at the time when Kimberley was starting to go through the process of being closed. Lorraine then wrote a second proposal to the lawyers who were involved. The reply that came back was awful.

The lawyer said they didn't see it as appropriate given the family had not had anything to do with Brian and, as a result, Brian would not be getting out of Kimberley Hospital. This was very distressing for Brian, me and my family. So we moved back to Palmerston North to be near Brian and I decided I wouldn't leave until I knew that Brian would be free to move to Auckland.

In 2001, Lorraine made another approach and Conny worked with us to get Brian out of Kimberley. I thought that even if I have to take him back into my own home, I'd do it. My kids were prepared to take him – they said that hospital is not the place for him.

The last line in the Needs Assessment that was done at this time said, "It is strongly recommended that the process to place Brian begin as soon as possible, to enable Brian and his whanau to enjoy the reunion they have been denied for so long."

Brian finally got out of Kimberley Hospital in 2002. We waited until he was living in Auckland and then we moved up, following him.

Life in the community

When Brian first got out of Kimberley, he went to a powhiri (Maori welcoming ceremony) with Te Roopu Taurima O Manukau in Mangere Hospital. The powhiri was his welcome back to the whanau.

Many of the whanau were there to welcome our brother, nephew, uncle and koro. Later that day, Brian went to his new home in Porchester Road and entered his home in the customary way, being welcomed by a powhiri.

This home was a mansion! I said to Brian "Look at your room. Look at your double bed!" and I teased him saying "You better give me the bed, as you haven't got a partner!" He just threw himself onto his bed and smiled. I knew he was happy.

The windows were open and I said “No more locked windows, bro” – I had tears of happiness for him. He went to the door and didn’t know if he was allowed to go out. I said “You can come outside, Brian…” He was touching the trees and it made me cry as he could do the things he wasn’t allowed to do (at Kimberley). He could feel the fresh air on his face. He was free. He was smiling. He could feel that he was free.

After Brian moved into Porchester Road, things began to change. When I went to leave, I’d say to Brian “Come and see your sister off…” When he was at Kimberley and I went to leave, he’d go and hop in my van, but at Porchester Road he held onto one of the whaeas (meaning mother or care giver) that worked at the house and hid behind her. He was saying, in his way, “I don’t want to come with you.”

I said “What’s wrong?” and then realised and said “No you’re not going with your sister…” He didn’t want to come with me. It made me feel really happy. He loved where he was living. His room was beautiful and he was happy.

Later, Brian moved to a home in Penrose with another man. That was a beautiful place, too. He’s been in good homes ever since he left Kimberley.

I can have a good sleep, now that I don’t have to worry about him. I know he’s happy. As long as he’s happy, then I’m happy. Brian shows me he’s happy, too – if I go to leave and he doesn’t want to come with me, he’s happy…

One Sunday in Manukau, the mokopuna (service users) living in the various Spectrum Care homes and the staff got together for a powhiri where they introduced themselves to everyone else. There was a Maori woman there and she was quite upset about how the staff were looking after her daughter. I was quite angry about what she was saying and, when it came to my turn to introduce Brian and myself, I said “Whaea, if you only knew where my brother and some of these mokopuna came from (meaning Kingseat and Kimberley Hospitals) you would kiss the floor that these staff are walking on. Look at my brother today. He's the bomb! He's the man and he smells clean. Look at his clean clothes and he's got shoes, and he's even wearing sunglasses. Whaea arohamai, give them a chance!"

The next meeting came around and this woman apologised to the staff and to me. She said "You're right, whaea. My girl is in good hands. I was worrying about nothing."

My children and all of our mokopuna have a good relationship with their koro and uncle, Brian. Sadly, the rest of my family (after my brother Jack's death) don't visit him. I don't know why. A couple of years ago, Brian moved to live in Hamilton. We were already living here and he came over to our house for the day. The mokopuna Lesieli and Pita got out their colouring books and gave them to their koro, Brian. Lesieli and Pita were so pleased that their koro was trying to colour in a picture. Brian was good with them. I was worried the grandchildren might make fun of him, but no. I was really happy when they said "This is our koro, eh Nan." They were happy that they got to spend a whole day with him in their own house. They just loved him to bits.

Last year, the Te Roopu Taurima staff took Brian over to the Pohara Marae. This is where we come from in the Waikato. Lorraine told us it was the first time he'd been there. He's now in touch with his whanau and his marae. I took Brian to our youngest sister Maryanne's funeral. She was only 45 years old when she died, the youngest of the 23 of us brothers and sisters.

Brian likes singing and music. He goes to an activity centre each day and likes the staff, but doesn't appear to have any special friends. We had his 60th birthday recently and Te Roopu Taurima put on a massive, beautiful birthday for him at Valentines. All the family were there – aunties, nieces, cousins, our tuakana (our older brother Button) and me. And he had this beautiful big (I mean 'BIG') chocolate cake. Brian's eyes were so big! I knew he couldn't wait to taste his cake.

Brian definitely has a sweet tooth. When he goes out shopping, he pushes the trolley and he knows the aisle where the chocolate is. When he sees it, he'll always stop. The staff encourage him to keep going, but he stands his ground, saying "No! Lollies!" He'll stand there until they give him a bar of chocolate.

Brian understands everything. He's living a good life and his future is looking good. He's enjoying life. He knows what life is about and I know that he's happy and can tell people what he wants.

Finding Brian and being part of his life has been awesome for me. I would do it all over again if I had to, just for him. I'm just happy that I found him and could do something for him.

I have a really special whanau bond with Brian. I was brought up by the social welfare system, but I always wanted to belong to something, to someone, and the closest I ever got to belonging to someone was my own kids and my husband.

It took me a while to get to know my brothers and sisters. One of my sisters has passed away and, though she knew I was her sister, she stayed away and kept me at a distance.

This one here (Brian), I don't have to keep my distance – he's mine. He's not going to push me away. I talk to Brian because, like me, he's been by himself and I know that he wants a bit of love. I'm so close to Brian.

When I walk in that door he jumps up and gives me a cuddle. If he could talk, he'd say 'Thank you, sister.'

My children and mokopuna say their uncle is happy and they're glad I got him out of the hospital. I thought it was a good place – a hospital – but the banging doors and the keys, oh man... It made me think back to when I was in the girls' home. I could relate to being locked up. I used to freak out with slammed and locked doors. Brian was only a kid of 11 when he, too, had doors slammed behind him all the time and was locked in.

Conclusion

There were no positive things about Brian's time in Kimberley – I wouldn't like anybody to be there. The worst time for me in our journey was when Kimberley Hospital would not let Brian go and I had to stay down there nearby him.

I think Brian would tell us, if he could, the worst now would be the thought of returning to the hospital. It would really hurt him if I had to take him back to Kimberley, if it was still open. It's never going to happen as long as I'm alive. He'll never enter another institution. He'll be staying around by me.

I only got to know about 11 of my brothers and sisters, and now there are only five of us left. I wish my family had seen Brian. Brian is now the second eldest brother still alive. He's a very special person. For me, the best thing has been that feeling of belonging – he belongs to me, he's mine.

I know that if I was in the same situation, he would've done the same for me. I know that if I was there sitting in his shoes and he was in mine, I know he'd do exactly the same thing for me.

If Brian could talk, I think he'd say the best thing was that he's free – "Thank you, sis. I'm free at last..." And I'm sure, if our Mum and Dad were alive today, they'd be happy to know that there's still a lot of aroha (love) out there.

My husband and I are the proud grandparents of 33 grandchildren and great grandparents of two great-granddaughters, with another one of the way. We share all of them with their koro, Brian.

Acknowledgements

Debbie wishes to thank the two beautiful women who helped her and made it possible for Brian to leave Kimberley Hospital – whaeas Conny Schalten and Lorraine Bailey. Debbie also wishes to thank the staff of Te Roopu Taurima for giving the mokopuna their lives back and enabling them to live freely.

David Blackett

David

At a glance...

I was born in 1960 at the old Cornwall Hospital and lived with Mum and Dad in Panorama Road, Mt Wellington.

I was three years old when I went to Sunrise Home in Manurewa and I lived there until I was eight. Then I went to live at Homai College – it was for all the blind people.

I went to Mangere Hospital when I was around 14 years of age. I used to go from Mangere Hospital to Mt Richmond School in a taxi. I had to go to dances and the pictures when I was living there.

The worst thing for me at Mangere Hospital was that I used to get pushed over by other patients. One of them broke my elbow once.

I use a fold-up cane to help me get around these days, but when I was at Mangere Hospital I didn't have anything to help me – I had to hold onto someone's arm to move around. If there was no one to hold onto, I'd have to wait.

At 19 years old, I went to St John's to live. When I was over in St John's, I wasn't able to get up until I was told. That wasn't good. Staff came and told us all when to get up and have a shower and shave and have breakfast... We only had a little bit of choice – not much. You weren't allowed to go into the dining room unless you were told.

Now at Mangere Road it's different. We just get up when we choose.

I used to stay in the wing all day and the doors used to get locked. I didn't like that. We were locked in at night, too. I just had to leave it, that's all. I just moved out. I was happy to leave St John's.

I went to Mangere Road in 1991. At Mangere Road, I like to listen to music on the radio – rock'n'roll. I won a certificate once when I danced to the music 'Brown girl in the rain'.

I like to go out and the Foundation of the Blind is my favourite place. They have talking scales there and talking phones!

I'm more confident and don't need people to help me as much. I find it easier because it's nice and quiet, and easier to find my way around.

Every year, I have an 'Outcomes' meeting and they bring up goals. I like the Outcomes meeting. That'll be in November, I think. I was asked what goals I might bring up. That mystery trip! I've talked to Cilla (Service Coordinator) about the mystery trip.

I miss working and, while I can't do lots of things, I do like to help out. I've helped out in the institutions and now at Mangere Road.

I'm happy where I'm living. The best thing is being with the men at my house.

I've done very well.

David Blackett told his own story, with help from Spectrum Care staff member Paula Lauese.

Introduction

I am 49 years old and was born on 18 April 1960 at the old Cornwall Hospital, not far from Greenlane Hospital. I've got five sisters. Linda, Marlene, Diane, Sharon and Gail, and I'm the youngest in the family. Mum passed away in 2002. Two of my sisters and my Dad live in New Lynn.

I've lived in several institutions in my life. This is my story.

Growing up in Auckland

As a child, I lived with Mum and Dad in Panorama Road, Mt Wellington. Dad used to work at Samuel Parkers and he also worked at the show grounds. I used to live there at night, when the show was on. I couldn't sleep at night with all the noise. They had a caretaker's house there. They used to stay up there, Dad was the caretaker.

Dad used to take me out to places. And Mum, to get the blackberries. Mum and Dad would take me to the beach for a swim, like down the cliff. I fell down the cliff and hurt my leg – I was only about six years old. I cut my leg and ended up in hospital.

I went to Mt Richmond School from age five to 16. I used to play a trick on Mum and tell Mr Bentley (the teacher) I wasn't coming to school. He would tell the taxi not to pick me up tomorrow. Paula adds the next day Mum would be wondering why the taxi hadn't come and she would phone them. They'd say that I'd cancelled it and I'd get punished. “No watching TV for a month,” she'd say.

Life in institutions

I was three years old when I went to Sunrise Home in Manurewa and I lived there until I was eight years old. Then I went to live at Homai College – it was for all the blind people.

I went to Mangere Hospital when I was around 14 years of age. I had to go to there for the school holidays first (Paula says this was probably to try it out and to have a break from home) and then I went there permanently.

I used to go from Mangere Hospital to Mt Richmond School in a taxi. I had to go to dances and the pictures when I was living there. I used to go up to the pictures on a Friday night.

I used to work at Mountain Industries, Mangere, packing head phones. I used to put them into bags and pack them – I enjoyed that. We also packed ice cream spoons. I also went to APET (a vocational programme) and got paid there.

When I was asked what I remember about Mangere Hospital, the first thing I said was “Yeah, I got chucked in the swimming pool once by a staff member.” I was thrown in at the deep end – for no reason – and, while I could paddle, I’ve been scared of the pools ever since then. Paula adds that David will not go swimming even now.

The worst thing for me at Mangere Hospital is that I used to get pushed over by other patients. One of them broke my elbow once. I had to go to Middlemore Hospital and stayed in for one night. I had a plaster cast on.

I use a fold-up cane to help me get around these days, but when I was at Mangere Hospital I didn’t have anything to help me – I had to hold onto someone’s arm to move around. If there was no one to hold onto, I’d have to wait. I didn’t have anything to do with the Blind Foundation when I was living at Mangere Hospital.

Paula reminded me of how the clothes were all kept in one big room and it was ‘first up, best dressed’. They used to get something out and see if it would fit me. I thought it was horrible.

I have my own room now. At Mangere, I had to share a room. They had the school boys’ side and the big boys’ side. There were 30 of them in one dormitory. I used to go to Mangere Hospital dentist and I had a heart operation once – a long time ago.

At 19 years old, I went to St John's to live. When I was over in St John's (Villa Three) I wasn't able to get up until I was told. That wasn't good. Staff came and told us all when to get up and have a shower and shave and have breakfast... We only had a little bit of choice – not much. You weren't allowed to go into the dining room unless you were told. Now at Mangere Road it's different. We just get up when we choose.

At St John's, I was in Wing Three. I used to sleep in the big dormitory with 50 other people. For my birthday, I used to go out with my family for the day. I used to go to the beach house from St John's and that was good.

We used to get all sorts of food at St John's. I liked the ice cream and jelly best. We used to go to the dances on Tuesday nights. They used to have an organ. I liked to have a dance around.

I used to help Ron Trellise. He was the charge nurse at Wing Three. I used to answer the phones and help look after all the sick people. We used to have a canteen. I used to go up to (Mountain) Industries, too, and do lacing. We used to make boxes. We had to put them together and then they'd get counted. They used to tie them up and put them on the pallet. I liked that job. I also used to work in the canteen club and count all the lollies and stuff. I was asked if I sneaked any of the lollies. "No way!" (laughing).

When I went to bed at St John's, the other people in the dormitory used to make noise. They used to run up and down the dormitory. It was a noisy place.

I used to help the staff at St John's to look after all the guys, showering them and bathing them. Scrub their backs and all that for them. Take them over to the dining room for their meals. I used to stay in the wing all day and the doors used to get locked. I didn't like that. We were locked in at night, too.

I just had to leave it, that's all. I just moved out. I was happy to leave St John's.

Life in the community

I went to Mangere Road in 1991. At Mangere Road, I like to listen to music on the radio – yeah, rock'n'roll. Paula adds that David goes out to talent quests and to sing, and came second in the contest on one occasion.

I did dancing. I danced to the music 'Brown girl in the rain'. I chose the music and got a certificate.

I used to like country and western – quite a few years ago now. I used to go to country and western dances from Mangere Road – John and I used to go to dinner. Paula says this happened at the church, but it is not on anymore.

I also go to Makatoa. This is a day programme with activities like drawing, cooking and music, and they also practice for the talent quests, says Paula. I go on Tuesdays and that's enough.

I like to go out and the Foundation of the Blind is my favourite place. They have talking scales there and talking phones! Yeah, I'm going to get one – and scales! I have a talking watch at home. A couple of years ago, I went with the Foundation on a camp and stayed in cabins at Tauranga. I climbed the rocks. I enjoy going out.

Paula adds that David goes out for lunch regularly and to Papakura on the train or into town to Britomart. She says David has also been on the ferry quite often.

I've also gone with one of my flatmates to the St John's Spa at Mangere. I used to go to the one down by the plaza to sit in it. I used to go to 10-pin bowling, too, but I've not done it for a long time.

Paula says that David used to go when he was at the day programme, but when that stopped he didn't want to go bowling by himself. I like rugby and listen to it on the radio or TV, and played cricket once at Mangere Hospital.

Sometimes I help staff to bake. I like to help with making banana cakes. Paula says David also puts his own washing away. I like to help out, but I have no eyesight at all, so boiling the jug is a bit hard. The hardest thing about my sight is that I can't see anything.

Staff help me to make my breakfast. I usually have Weet-bix and Milo. I get choices at Mangere Road. I get to choose to go out to places and that. When it comes to meals, we just have what we have – potatoes and whatever...

I get to help plan the meals sometimes. I was asked what my favourite meals are – sometimes we have mince, sausages and potatoes. Both mince and sausages are my favourites, and Paula reminded me I like silver beet and cabbage together. For my birthday, I had a party this year and a lot of cake. Yes, lots of goodies... I decided to have my party at Mangere Road.

My friends are John, Rodney, Peter and David McCoin. They're also my flatmates. I've known John from Mangere Hospital. I met Rodney at St John's. I met Peter Johnson at Mt Richmond School.

I had a friend called Andre. I met Andre at Unit Six at Mangere Hospital, but he passed away last week. Paula adds his funeral was yesterday, but David didn't want to go. There might have been a lot of people and that put me off. I was asked when I had last seen Andre – it was when we were still in Unit Six. I haven't seen him since then.

I've got lots of friends – got five at our house now. The best thing about living where I am now is the fact I'm away with all the men. I don't get pushed over at Mangere Road. I enjoy it. I'm happy there.

My Dad is still alive. I went to his birthday. I talk to him. Dad is a great man. I am, too. I visit my family sometimes and spend long weekends, holidays and Christmas with them. At Christmas, the family has a roast dinner and presents. When staying with them, I watch a bit of TV and sometimes go out to a café with my sisters for lunch. We also go together to visit another sister who lives in Huntly.

I went down to Linda's place to see the pets. She's got lambs, dogs – two dogs – a cat, cows, horses, sheep and pigs. I go down at Christmas time to see her. I like the animals. I pat them and Linda feeds them. We don't have any pets where I live, but I'd like to have one of my own – a cat. I'd call it Timothy because it's a nice name. We used to have a cat called Timothy before at Mum and Dad's.

I was asked was there anything I'd like to see change or improve at Mangere Road. I don't go to work anymore now. They don't have a job for me to go to. I got made redundant from Onehunga Work Options. Paula adds this happened when they put people onto salaries.

I miss work. I still get money out of the banks (laughing). I used to work from one o'clock to three, one day a week. I'd like to work again. I'd like to do it from nine to three.

Paula says that when David first came to the house, he used to be scared and would sit in one place and not move. She says David is starting to find his way around the house now and is doing more for himself.

I'm more confident and don't need people to help me as much. I find it easier because it's nice and quiet, and easier to find my way around.

We're booked to go to the beach house next year, says Paula. Next year, I'd like to go on a mystery trip. I'd like to go on the train to Hamilton again, like I did last time with Diane, my sister. I went down to Hamilton on the train and enjoyed it. I had morning tea on the train on the way down – scones. I had a cup of tea on the train and I enjoyed it. I stayed in a motel down there and Alan went down with me, and we went on the boat for dinner.

I hope I have a really good teacher. Every year, I have an 'Outcomes' meeting and they bring up goals. I like the Outcomes meeting. That'll be in November, I think. I was asked what goals I might bring up. That mystery trip! I've talked to Cilla (Service Coordinator) about the mystery trip.

Conclusion

I miss working and, while I can’t do lots of things, I do like to help out. I’ve helped out in the institutions and now at Mangere Road.

I’m happy where I’m living. The best thing is being with the men at my house.

I’ve done very well.

Dawn Campbell

Dawn

At a glance...

Dawn was born at Bethany Hospital in Grey Lynn in 1936. It's likely she was born with a disability, but her family don't know for sure. Dawn was adopted as a baby by a Northland family. Her brother, Paul, went to Kokopu School, but there are no school records for Dawn so she probably didn't go to school.

Dawn was about 16 when her adoptive parents had to put her into care because she got to the stage where they couldn't handle her. Her Mum had been ill and could no longer manage Dawn because she had many problems and was quite strong. At first, she went to Oakley Hospital. Later, she was transferred to Kingseat Hospital and, from there on, no one's really sure where she went before moving into a supported community home with Spectrum Care.

Dawn arrived at Spectrum Care with a 'Kleensak' full of dirty clothes and nothing else.

She has now lived with Spectrum Care for over 13 years and has been at Grotto Street, Onehunga, with four other women for around four years.

Dawn has a lovely personality. She is a beautiful person inside and is very caring and happy to share her belongings with her fellow flatmates. She likes talking to people, especially children, and she loves babies. Dawn likes travelling and loves going in the car.

She prefers to go out every day, if she can, and doesn't like staying at home for too long. She likes to interact and roam around, and also loves going on holiday.

Almost three years ago, Dawn was contacted by her 74-year-old sister Aloma Lockwood. Dawn had not known about Aloma and Aloma had not known about Dawn. They've got to know each other over the past three years and their story is a heart-warming one.

Both Dawn and her sister Aloma were adopted as babies, though by different families.

When Aloma started her own family, some elderly aunties let slip one day that she'd been adopted at birth. This was a big shock. Some years before, Aloma's adopted mother had told her that she had a sister – Dawn – who was up north, but wouldn't tell her anything else. Once Aloma's mother had passed away, Aloma and her daughter Janene decided that it was time they started looking for Dawn and their biological mother.

It's been wonderful for both Dawn and Aloma to have found each other. If Aloma had not been determined to find her, Dawn may never have known she had a sister and wouldn't have the family contact she's had since they were reunited.

Dawn's story was told by Spectrum Care staff member Lorraine Herewini and her sister Aloma Lockwood. Dawn came and went from the interview with Lorraine, adding comments to the conversation. Dawn also agreed with Lorraine about what she liked and shared her photographs as we talked.

Aloma was interviewed separately a few weeks later.

The information they have shared has been combined in the telling of Dawn's story.

Introduction

Dawn has lived with Spectrum Care for over 13 years and has been at Grotto Street, Onehunga, with four other women for around four years.

Dawn came from a home called 'Avondale', although no one is sure whether it was a part of Mangere Hospital or a home for the elderly, says Lorraine. Before that, she'd been in several other homes, including Oakley and Kingseat hospitals.

Lorraine says Dawn arrived at Spectrum Care with a 'Kleensak' full of dirty clothes and nothing else.

Dawn has been in the system since she was 16 years of age and she will be 73 this year.

Almost three years ago, Dawn was contacted by her 74-year-old biological sister Aloma Lockwood. Prior to this, neither had known of each other's existence and they've spent the past three years getting to know each other. Their story is a heart-warming one.

Life in institutions

Little is known about Dawn's life in institutions. Most of those who knew her during this lengthy period have either moved on or passed on and can no longer assist us in understanding what her life was like. Dawn has told Lorraine quite a lot about her past, including her time in one of the institutions where she "looked after all the babies".

Dawn agreed saying “Yeah, I love babies...” Dawn also used to help the people who were in wheelchairs and, at one stage, she helped out on a farm, probably within an institution. She would’ve been quite capable in those days.

She didn’t like the boys because some of them were rude. When checking this with her, Dawn confirmed that she was not fond of “the boys”.

Life in the communinty

Dawn has a lovely personality. She is a beautiful person inside and is very caring and happy to share her belongings with her fellow flatmates. She likes talking to people, especially children, and she loves babies. She loves telling people about her bedroom and showing them her things, including her many photographs. Dawn can also be quite humorous, with a wicked, fun-loving sense of humour. “You can have a good laugh with her,” says Lorraine.

When Dawn first came to live with Spectrum Care, she also attended a workshop in Papatoetoe and has kept in touch with her friends there. She used to put washers on nails, did arts and crafts, and rolled wool into balls. Dawn likes magazines, which her sister brings when she comes to visit each fortnight.

Dawn likes travelling and loves going in the car. She prefers to go out every day, if she can, and doesn’t like staying at home for too long. She likes to interact and roam around, and also loves going on holiday.

Because Dawn didn’t have a lot of contact with her adopted family in later years, she’s spent a lot of time with Lorraine’s family. They’ve accepted her and taken her for budget holidays.

Dawn goes out quite a lot and tends to spend a lot of money, so she doesn’t have much money for holidays. But when she’s with Lorraine’s family, they treat her very much as part of the family and have a lot of respect for her.

As the family is Maori, Lorraine was a bit concerned about whether Dawn would cope when they first took her onto a marae, but she loved it.

"I think because she's older, no matter whether she had a disability, she was treated as an elder, so she got the special treatment," says Lorraine. She gets quite spoilt when she goes there. She just mingled with everyone and the true Dawn came out – a confident person with whanau around her, not just 'a client'.

In asking Dawn what she thought of going on holiday with Lorraine, she said "Northland – Dad!" Dawn likes visiting Lorraine's Dad and she laughed when telling the interviewer she likes him and he calls her 'Dawnie'. Dawn also talked about Lorraine's brother and all the mokopuna (grandchildren).

Dawn is quite motherly with them and knows how to cuddle and handle them. It got a bit hard for Lorraine taking her up to visit family, because Dawn never wanted to come home, which Lorraine found really sad.

Dawn's father is buried up north and she's been to visit the grave. During the interview, Dawn showed a picture of his headstone. She also said "My baby girl up there..." referring to her stepsister Jan who is also buried in Northland.

Dawn has also been on holiday to Cape Reinga, with another lady from Grotto Street and a staff member, and had a great time.

Dawn is one of those people where everything has to be done to a routine and be in its place. She likes her home to be tidy and organised, particularly her bedroom. Dawn doesn't like anything in her room being touched and if staff need to clean or change anything, they need to let her know. If an item is broken and needs to be thrown out, staff need to explain it to Dawn. As long as she knows exactly what's happening, she's happy, says Lorraine.

Dawn is getting older and there have been a lot of changes in her. She used to be very independent, but she has a hip problem now and needs a lot more support these days. She has a very high tolerance of pain and, if you asked her how her hip is, she'll just say it's alright. The surgeon said that she wouldn't be able to handle a hip operation and told Aloma (and her husband Graham) that it would be best to do nothing until her hip gets really bad.

Despite her bad hip, Dawn loves dancing. If Graham starts dancing, Dawn is always keen to join in – "Her arms are going and her legs are going," says Aloma. She also likes getting dressed up and going to the Spectrum Care ball.

Clothes are important to Dawn. She loves clothes and enjoys going to shops like Millers and Farmers, or any boutique clothes shops. She loves looking at clothes. If she had her way, everything would be blue, says Lorraine. But she doesn't like spending all her money on clothes. Dawn has a beautiful wardrobe and she's very particular about how she puts her clothes in her drawers.

Lorraine thinks that while Dawn seems quite happy with Spectrum Care, she'd like to live with her and her family. From time to time, Lorraine does have to remind Dawn that she works in her house. Had Dawn lived in a family environment, life would have been a lot different. Lorraine admits that it's great Dawn now has her real sister.

Staff have to be careful with Dawn. For example, Aloma gave her knitting needles, but Dawn lashes out sometimes and staff were worried she might injure somebody with them.

Dawn likes going to the hairdressers, but occasionally her hairdresser comes to her home and gives her that personal attention. At times, Dawn becomes very agitated and requires time out, so she rearranges her drawers and wardrobe – taking everything out and putting it back in again until she's happy and satisfied.

Dawn loves going out in the car, but sometimes needs to be reminded the other ladies have to have their turn in going out as well.

“Dawn’s story reminds me of these ‘lost children’,” says Lorraine.

Aloma and Graham Lockwood

Both Dawn and her biological sister Aloma were adopted as babies, though by different families. Aloma tells the story of how she came to find Dawn.

When Aloma started her own family, some elderly aunties let slip one day that she’d been adopted at birth. This was a big shock. Some years before, Aloma’s adopted mother had told her that she had a sister – Dawn – who was up north, but wouldn’t tell her anything else. Once Aloma’s mother had passed away, Aloma and her daughter Janene decided that it was time they started looking for Dawn and their biological mother.

Finding Mum

Aloma had been named Betty Nita on her birth certificate, but her adoptive mother called her Aloma. Her father’s name was not recorded.

Aloma found her biological mother, Joyce, through the electoral roll and rung her up one night in 1987. Her mother said that what had happened was 50 years ago and it’d been a long, long time and was a horrible experience she really didn’t want to remember, says Aloma. A week or two later, Joyce wrote to Aloma on her birthday. Her mother had thought it over, but after talking to her sister decided that she’d like to meet Aloma. Nothing was said, however, about meeting up with Dawn.

Joyce said she didn’t want her family to know about Aloma because she’d kept it quiet all these years. Aloma went to see her one evening because Joyce didn’t want her to come on the weekend as this was when her family visited her.

"I bought a new dress, got myself all dressed up so she'd be so proud of me," says Aloma. "I wanted her to be proud...

"Well, I can tell you, by the time I got to the door and knocked, the left leg started shaking – just nerves – but I couldn't control it. Anyhow, when she opened up the door, it was just like looking at me, 15 years older. I mean, even my 21st photo is just like her," says Aloma.

Dawn and Aloma's mother Joyce was a lovely person. "She had me at the age of 15 and then she had Dawn – and it was by the stepfather. That is how it came about – it was incest and he got jailed for five years."

Joyce had later married Stan Jackson and they had three children. So Dawn and Aloma had two stepbrothers – Cliff and Ron – and a stepsister, Marion.

Finding Dawn

Finding Dawn was a challenge. It took over 18 months to get all the information that enabled Aloma and her family to find Dawn. "It would've been nice had my adopted Mum told me more about it," says Aloma. "I mean, she was a lovely lady, but she never told us much. The day she told me about Dawn, she started to cry and that was the end of it – she never said another word..."

Aloma and Graham had to apply to the courts for birth certificates and adoption records, which took quite a while to be provided.

"We've got all sorts of things," says Aloma. "We've got her mother's certificate, her birth certificate and her father's birth certificate."

They visited different people to see if they could provide them with information. Aloma put an advertisement in the *Woman's Day* and the *New Zealand Women's Weekly* asking if anyone knew Dawn, giving details of where she was born and where she'd lived. Aloma and Graham also went to the Whangarei

Library and the local cemetery where they found the graves of Dawn's adoptive parents, and discovered that Dawn had a stepbrother, Paul. They also checked school records. After returning from Whangarei, they looked up the electoral roll and this was how they found Dawn.

There was great excitement when Janene made the first contact and they all went to visit Dawn at Grotto Street – taking a birthday cake with two candles on it.

"The staff were absolutely wonderful and they put on an afternoon tea," says Aloma. "It was just an absolutely fabulous day."

"It was a very good experience and we were just so thrilled when we found her. But I was thinking in my own mind, 'Oh, she'll be married with children, she'll have kiddies and we'll all get together…' But it was lovely meeting her, it was really, really lovely."

Dawn's history

Dawn was born at Bethany Hospital in Grey Lynn in September 1936. It's likely she was born with a disability, but her family don't know for sure. Dawn was adopted as a baby by a Northland family. Her brother Paul went to Kokopu School, but there are no school records for Dawn so it's likely she received no education.

Dawn was about 16 when her adoptive parents had to put her into care because she got to the stage where they couldn't handle her. Her Mum had been ill and could no longer manage Dawn because she had many problems and was quite strong. Initially, she was placed in Oakley Hospital at Point Chevalier. Later, she was transferred to Kingseat Hospital and, from there on, there's little information about where she went before moving into a supported community environment with Spectrum Care.

When Dawn's adoptive mother passed away, her father remarried and had another daughter, Jan Gillespie. Dawn was very fond of Jan and her father. Jan visited Dawn many times over the years. Her father used to visit her in the various places she lived and, when Dawn came to Spectrum Care, she used to ask about him. He'd passed away, but Jan hadn't wanted to tell her. Staff decided it was better for Dawn to know and so they told her.

Sadly, Jan was killed in an accident in 2007. Dawn is very fond of her photographs and points out her family to visitors and staff at every opportunity.

Dawn accepts that Aloma is her sister, but it's unclear whether she really understands the circumstances with her biological mother. She talked about her saying "That's my Aunty..." But everybody has become her 'aunty'.

She tells people that the woman (in the photograph) is Aloma's Mum. When Aloma and Lorraine took Dawn to meet her elderly mother, Joyce, Dawn said to her "Poor lady, poor lady..."

When Joyce passed away, Dawn took it very hard. She'd only met her twice, but she must have understood to some degree that this person had been important in her life. Dawn looks very like Joyce and there are photographs that show this likeness.

Lorraine thinks Dawn is very similar in personality to her sister Aloma. It's wonderful and yet so sad that they've only got to know each other so recently. Aloma's grandson Kurt also lives in a Spectrum Care home and Dawn was invited to his 21st birthday last year.

Aloma tries hard to understand Dawn, but there are a lot of things she doesn't quite get. "Unfortunately, she doesn't have teeth and I think if she had some teeth she'd be better – that we could understand her a little bit more. She does gabble a little bit, but there are words we can pick up."

Sometimes when Aloma visits, Dawn is in a real paddy, but other times she's very happy to see her. They look through the photo albums together, with Aloma and Graham pointing out the different people in the family. They've named all the photographs to make it easier for staff to help Dawn know who's who.

"She can't say our names, but she will say to me 'How's my little girl?' which is my granddaughter Jade, and 'How's my sister?' which is actually my daughter Janine she's talking about," says Aloma.

"Dawn loved it when she came over to my home one day and my granddaughter Jade – she's disabled and she's lovely – gave her a beautiful doll. Well, she just loved it! She just loved this doll! And if I take magazines over, she's got to look for the babies," says Aloma. She also likes the pictures of food and will often point recipes out to the staff.

Meeting the extended family

Aloma had kept her existence secret for many years, out of respect for her mother's wishes. But her mother's health had deteriorated – she now had Alzheimer's disease and was living in a rest home – and Aloma felt that making contact with her biological family couldn't hurt her elderly mother now.

Aloma was reading the garage sales in the local paper one day and something about an address caught her eye. She looked it up in her address book and realised it was her half-sister Marion's daughter's address. The next day Aloma, Graham and Janine got dressed up and went to the garage sale. They heard a man telling a customer that they were selling their mother's things, because she'd gone into a nursing home.

Aloma said to Janine "Look, these are your grandmother's things, so buy up as much as you want!" She then went and introduced herself to Marion saying "Look, I'm not sure of how to say this, but I'm Aloma and I'm your mother's daughter. Your mother had me at the age of 15 and adopted me to a family in Birkenhead."

They welcomed Aloma and her family with open arms, and various other family were phoned and came down to meet them. It was a lovely gathering.

“They were very surprised,” says Aloma. While there have been some parties and contact since then, Marion and her family have shown no interest in meeting Dawn. “Poor old Dawn… It’s not much of a life for her really, is it?” says Aloma. “I mean, you know, when you think of all the things that we do…” But she is looked after very well within Spectrum Care.

Conclusion

Dawn has spent much of her life in institutions. While she did have contact with her adoptive family in later years, there had been no one left to maintain that contact and interest.

It’s been wonderful for both Dawn and Aloma to have found each other. Their story is one of secrecy and stigma in a bygone era. Had Aloma not been determined to find her, Dawn may still have been unaware she had a sister and wouldn’t have the family contact she’s had since they were reunited.

Dick Old

Dick

At a glance...

When I was a little boy, I lived with my Mum and Dad, but when Dad got sick I went into Carrington Hospital. Dad passed away when I was in Carrington.

I lived in Carrington a long time ago – years and years, till I worked my way out.

My Mum's in a rest home now. I had a brother, but he died. I've also got an older sister.

I lived in Ward 10 at Carrington Hospital, which was up past the chapel. I liked to go to church on Sunday and used to tape the church service, as I had my own tape recorder. I kept the tapes and would listen to them again.

I could hardly hear anybody talking to me in Carrington – I didn't have hearing aids then and I was deaf.

I got belted up in Carrington Hospital by a patient. She kicked me in the leg till it bled. It took a long time to heal. I also used to get doped up in Carrington Hospital.

I didn't like living at Carrington. I always got belted up by the other patients because I was small. I slept in a bed in the ward with everybody.

When I left Carrington Hospital I was in a boarding house out at Swanson. I also lived in a block of flats by the ambulance station. From there, I went into a rest home at Te Atatu. I didn't like that one. I was in a place called

Adriatic rest home. I moved from there over to Burnsall. Burnsall was a home for people who were deaf. I didn't like Burnsall because the boys were belting me up. One of them was always hitting me and every time I made a cup of coffee, he pulled me backwards and kicked me in the ribs. I didn't stay there long.

Then I moved to Portage Road and I'm in the flat out in the community on my own. I like having my own space. There is a house with five flatmates in front of my flat and the staff give me rides everywhere when they go out. Staff make my meals and do the housekeeping, and they pay for all my telephone calls.

I like living in the community because I'm free. I like living in the flat because it's nice and quiet. I can watch telly when I want to and I decide what I watch – I control the remote. I like sleeping in my flat – it's better than sleeping in a ward.

I was asked what the worst thing was about living in the community and I couldn't think of anything – I like living in my flat.

My sister lives in Auckland and I see her a lot. She comes to see me on my birthday. I go home at Christmas time and see my sister and have dinner with her. And Mum comes, too.

I like living by myself. I'm much better now I'm out of Carrington.

Dick Old tells his story, with Spectrum Care staff member Vijay Kumar present for some of the interview. Dick has a very strong work ethic and his story emphasises the importance of having a valued role and being paid for the work that's done.

Introduction

When I was a little boy, I lived with my Mum and Dad. I lived with Mum and Dad for a long time, but when Dad got sick I went into Carrington Hospital. Dad passed away when I was in Carrington. I went to his funeral – it was a big one, a great big one.

I lived in Carrington a long time ago – years and years, till I worked my way out.

My Mum's in a rest home now. I had a brother, but he died. He had emphysema and I've got it, too. It's caused by smoking and I still smoke. I've also got an older sister.

Life in institutions

I lived in Ward 10 at Carrington Hospital, which was up past the chapel. I liked to go to church on Sunday and used to tape the church service, as I had my own tape recorder. I kept the tapes and would listen to them again. I haven't got that tape recorder any more.

I could hardly hear anybody talking to me in Carrington – I didn't have hearing aids then and I was deaf. I couldn't hear (my friend) Ken Downey talking to me.

I got belted up in Carrington Hospital by a patient. She kicked me in the leg till it bled. She took great big hunks off my leg and I had to go to physio everyday to get it put under the lamp. It took a long time to heal. I got belted up by her and she wouldn't leave me alone. I also used to get doped up in Carrington Hospital.

I didn't like living at Carrington. I always got belted up by the other patients because I was small. I slept in a bed in the ward with everybody.

There was another little bloke there – Ken Downey – but I used to look after him. If I had any small change, I'd say "There you are!" and he'd give me free cigarettes for it. I used to go and get his cup of tea for him.

I worked in the paint shop, painting the legs on the tables, and then I worked in the woodwork centre doing rails for the bathrooms – countersinking the screw holes.

I used to go over to the industrial workshop and pick my pay up. I can't remember what I got paid, but it was a lot of money. I liked the paint shop job the best. I liked painting the edges of the tables. I was pretty good with the paintbrush and made straight lines.

I used to do the lawn mowing at Carrington and mow the paddocks. The electric mower had a wide frame and was called a Hayter lawnmower. I used to go way up through the hostels and mow the lawns. And I worked in a store helping Malcolm pack stuff in boxes. He used to give me a book of papers for nothing. I got paid for these jobs.

When I was in Carrington, I got run over by a motorbike. It was down by the lights and he revved up and kept on going. I was run over and hit. I ended up in Middlemore Hospital and they had to put stitches in my leg. I was there for a long time.

I had to buy a packet of tobacco in hospital because I couldn't get across the road to buy it (laughs). I was badly injured. They were going to cut my leg off. Yeah, that's how bad it was. But my Dad made them put it in plaster and it went right up to my hip. It healed, but I walk with a limp from the accident. I had four bones sticking out.

Then I went from Middlemore back to Carrington and, after I came out of plaster, they used to put me on the walking frames to teach me to walk. I used to work everyday in the therapy room. I used to take their milk to them and run errands for them – I'd go over the road to get the newspaper for them and they'd give me a tip. I'd do it every morning. I used to take the milk and the newspaper in a big basket down to my school and up to the home visitors and down to therapy. The milkman gave me the milk.

I made a picture when I was in Carrington of a Maori person holding a fish by its tail. I carved it all out and they sold it. One of the staff bought it and I got money for it.

Malcolm used to save me the little tissue packets of tobacco if I answered the phone for him. He was my boss. He used to make picture frames with the silver paper. Terry made me a carving of a mother and child, and a lovely carving of kiwis. I gave it to Helen, the boss.

I used to go to the canteen and get my clothes for nothing. They had a pile of them and I didn't mind getting them from there.

When I was at Carrington, I'd have my birthday in the ward and they'd make me a great big cake that I'd share with the patients. When I was in the hostel, I celebrated my birthday. They'd make me a cake and give me a packet of cigarettes. Now on my birthday, I go over to the house. They make me a cake with candles on it and give me a packet of cigarettes, from all the patients. For my next birthday, I want to go to Valentines.

Life in the community

When I left Carrington Hospital I was in a boarding house out at Swanson and Uncle Joe came one day and said "I'll buy you a packet of tobacco..." and he did, he bought me a packet of tobacco.

I also lived in a block of flats by the ambulance station. From there, I went into a rest home at Te Atatu. I didn't like that one. I was in a place called Adriatic rest home (a Spectrum Care home). And I moved from there over to Burnsall. Burnsall was a home for people who were deaf. I didn't like that one. I didn't like Burnsall because the boys were belting me up. One of them was always hitting me and every time I made a cup of coffee, he pulled me backwards and kicked me in the ribs. I didn't stay there long. Vijay adds that Dick wanted to move into a flat on his own.

Then I moved to Portage Road and I'm in the flat out in the community on my own. I like having my own space. There is a house with five flatmates in front of my flat and the staff give me rides everywhere when they go out. Staff make my meals and do the housekeeping, and they pay for all my telephone calls.

I used to work for Work Options, putting screws and nails in the trays. I worked there for a long time. The work was a bit like what I used to do at Carrington. I did some packing and got paid for some of it. Then I got made redundant and left. I got made redundant when the place started to pay the workforce and I didn't get called up any more for the workforce. They made me leave. I am 64 years old and still on the pension.

After I left Work Options, I went gardening. I like gardening, but I don't get paid for it. I go up to Little Orchard at Kumeu (Activity Centre) on Thursdays. I don't get paid for it, but I'd like to be paid for it. On Mondays, I go gardening at Seabrook in Kumeu and I don't get paid up there. When I'm gardening, I'm putting plants in the pot, like little cabbages and lettuces. Then they're put outside on the ground until they grow. Then, later, they put them in pots and sell them. Yesterday at Seabrook, we were planting maidenhair ferns.

I used to work in the industrial unit at Carrington Hospital, putting dishcloths in a plastic bag and sealing them. We also did cellotape, folding cellotape, putting them in a box and then wrapping them up and put them in another box.

They had this machine that was used to make little cloths for the first aid kit. I used to sew down and then across, making bandages and slings. We got paid for the jobs and the money was good.

I go to Communicare on Wednesdays and I'm making a mat, weaving it by hand in pink and red. I didn't choose the colours, the bosses choose. I get it when it's finished. I was asked "How come I didn't get to choose the colours then?!" I just laughed and said "Reds and pinks!" We used to make scrapbooks for the hospitals.

I like living in the community because I'm free. I like living in the flat because it's nice and quiet. I can watch telly when I want to and I decide what I watch – I control the remote. I like sleeping in my flat – it's better than sleeping in a ward. Susie's the house leader and she takes me to buy my clothes. She bought me this new pair of shoes and she's taking me to get a pair of trousers and another skivvy. She chooses them for me because I can't figure out the colours.

I was asked what the worst thing was about living in the community and I couldn't think of anything – I like living in my flat.

When David goes out in the afternoons I go for a ride in the van. The meals are good. Takeaway pizza is my favourite. The staff decide on the meals and I take my meals up to my flat and eat them on my little table. Sometimes I'll stay at the house for tea when David's cooking.

I have friends. Tony and Wayne from the house in front pop in to see me and Wayne comes out and has a cup of coffee with me. I also go and see them. I'm quite happy and there's nothing else that I want. I've got Alison, but she's up at the Jadewyn Cottage in the flat. I met her at Communicare, but I went to the handicapped school with her in Symonds Street. She was in Carrington, too. She used to get belted up, too, by another girl who also did the same to me.

Alison lives in a flat on her own and the staff take me to see her once a fortnight. They leave me there and I have my cup of coffee with her.

We go for holidays out to the beach house at Maraetai and I'm going again in September. We have to do some planning. Vijay added that Dick goes with one of the people from the house and the staff.

I like going to the beach. When I went last time we went fishing and didn't catch a fish (laughs). That night I had a glass of beer. At night, we play cards: 'Last card' – David won. We go for walks up the beach, collect shells and mussels and bring them back. When I'm at the beach house, I help with the cooking. I like to load and empty the dishwasher.

I went to Houghton's Bush Camp at Murewai and spent the night there. I went on a bush walk competition and got a certificate for it. It was a long walk. I go out 10-pin bowling with Tony and Stevie. I like it and always win. I roll the ball up and it knocks the whole lot out.

My sister lives in Auckland and I see her a lot. She comes to see me the day of my birthday. I go home at Christmas time and see my sister and have dinner with her. And Mum comes, too. My mother and sister don't smoke. Mum has given up. She used to smoke, but she doesn't now. I gave up and now I've started again. I'm going home this Christmas because my nephew is going to Australia at Christmas time.

My Mum is very sick. She used to live in a rest home. Vijay says she now lives in a hospital. He says she had a birthday in early May and turned 94. We visited her sometime in late April. She lives in bed...

When I visit, Mum gives me little containers of jam and butter, and she gives me some lollies, too. She gave me chocolate when I went and saw her on Mother's Day. I took her some fudge, flowers and oranges and bananas. The staff helped me decide what to take.

I've always volunteered for jobs. I have my little veggie garden where I am now. I've got silver beet coming up about that high (showing the interviewer). I'm letting the other silver beets grow bigger.

Susie bought me some potting soil and I'm going to spread it all over my garden and dig it in. I grow a few spuds and lettuces.

Conclusion

I lived in Carrington Hospital a long time ago – years and years – till I worked my way out. I didn't like Carrington. I like living by myself. I'm much better now I'm out of Carrington.

Wherever Dick has lived, he's found ways of working for money or as a volunteer. His drive to be helpful and to work is fundamental to his being.

Gair Thompson

Gair

At a glance...

Gair is 50 years old and lives on Auckland's North Shore, near Long Bay.

Gair was a very active child. He used to climb the fence and wander off, and he'd usually head towards the beach. This was a problem because there were so many beaches near home.

There were vacancies at Mangere Hospital at the time and Gair was offered a vacancy, though Gair's mother didn't accept it for quite a few years.

Gair went to Mangere in 1961 at around 11 years of age.

It took Gair a while to settle at Mangere Hospital. When his father picked him up and brought him home for a long weekend, he didn't want to leave. I used to send Gair's Mum a cake back with him and that was one thing that persuaded him to go.

After a few years at Mangere, where he'd been quite settled, Gair was transferred to St John's.

Unfortunately, the staff at Mangere and St John's didn't take the time to teach Gair much. He didn't make friends in those places. While at St John's, however, Gair went to a National Special Olympics competition in New Plymouth and got a gold medal.

In 1991 or 1992, after two or three years at St John's, Gair went to live at Relko – a community home within Spectrum Care. He lives there with four flatmates.

Relko was one of the first houses in the community for people with disabilities. It was a big change and it helped Gair so much.

Relko is close to Gair's family home – he and the staff often walk there. Sometimes he and his flatmates (and a staff member) would walk to Gair's mother's house, which is nearby for morning tea and then walk to Long Bay.

Gair is much more independent now. He wasn't particularly tidy when he lived at home, but he's more grown up now. He can do most things and he's a lot happier. Gair has all these old records and tapes he plays when he comes home on a Monday and now he's got a CD (player) and he's happy to play that when he's home.

At Relko, they all have their own individual birthday parties and make it special. Gair also has a lady friend that he meets down at 'Move and Groove' – a disco on a Wednesday morning, put on by the Kumeu Church.

Gair is happy living in the community and that makes his mother's life easier. He has a great personality and gets on well with his flatmates. He has his routines and makes his own choices, and it is good that he lives so close to his Mum. They keep in contact each week and she feels that Gair has a good lifestyle and is well supported by the staff.

Gair Thompson's story was told by his mother, Mrs Thompson, with help from Spectrum Care staff member Mike Smith.

The interview took place at Mrs Thompson's home. Gair was present for the interview and helped out by showing his photographs, pictures and trinkets.

Introduction

Gair is 50 years old and has an older brother. The family home has always been on Auckland's North Shore, near Long Bay.

As a baby, he was very normal-looking, though he didn't go to school until he was about seven or eight. Gair went to the school in Northcote, which was really just a play school, but it was very good. They picked him up with others in the Bays and took him there so many days a week.

Gair was a very active child. He used to climb the fence and wander off, and he'd usually head towards the beach. This was a problem because there were so many beaches near home. There was no one else at that time that could help me search, so I was running here and there and, you know... not the best for the nerves.

There were vacancies at Mangere Hospital at the time and I was offered a vacancy, but I didn't accept for quite a few years. But then it was just too much for me – my husband was working, of course...

Gair went to Mangere in 1961 at around 11 years of age. He transferred to St John's around 1989 or 1990 and then he went to live at Relko – a community home within Spectrum Care – in 1991 or 1992. He lives there with four flatmates.

Life in institutions

It took Gair a while to settle at Mangere Hospital. When his father picked him up and brought him home for a long weekend, he didn't want to leave. I used to send a cake back with him and that was one thing that persuaded him to go.

After a few years at Mangere, where he'd been quite settled, he was transferred to St John's. It was in Papatoetoe and was the old Anglican home for the children. There was a workshop there and they considered Gair could work. Well, he could work, but he didn't settle there. Most of the people were older than he was and he didn't fit in so well.

Unfortunately, the staff at Mangere and St John's didn't take the time to teach Gair much. I always remember looking in at the dormitory – the different rows of beds and so on – and I still didn't want him there, but I realised I couldn't carry on. He didn't make friends in those places.

He would always come home for his birthday, Christmas and all the holidays – I could manage it then. It was a long way from here away down to Mangere to collect him. My husband would drive down and pick him up and then we'd both take him back, which was quite a job sometimes. Once the car door wasn't locked and he took off in Browns Bay at the shopping centre. It was a nightmare. He really didn't want to go back.

At Mangere, I can remember one little instance – the worker in his unit saying to me, "That's one thing: Gair's always very clean and fresh, and smells nicely when he comes back."

I thought 'Oh well, these poor workers...' Some people were not getting good care from their families if they went home. Some of them didn't even get to go home.

Gair took part in the athletics for the Special Olympics when he was at Mangere and then St John's, and this was a good thing. He went to a National Special Olympics competition in New Plymouth and got a gold medal.

This same year, my husband and I were asked if we would like Gair transferred to a home in the community, called Relko. There were four people living there then and Gair fitted in very well and, really, I think it's since then that he's gained so much, learned so much and developed so much.

Life in the community

Relko was one of the first houses in the community for people with disabilities. It was a big change and it helped Gair so much. It was so good once he got into the house. It changed his life and mine. It was a load off my mind because I used to think of him in there (at Mangere and St John's) and think 'Oh dear, how's he doing today?' I used to worry about him.

Relko is close to my home – he and the staff often walk here. He's streetwise and can walk here on his own, says Mike. Sometimes he and his flatmates (and a staff member) would come for morning tea and then walk to Long Bay.

"They'd be walking maybe up to 10 kilometres by the time they got home and the leader was always Gair," says Mike. Gair also goes on bush walks with Gwen (a staff member) near Relko.

Gair is much more independent now. "He's interested in keeping the house just so," says Mike. "He's very competent in that way – everything's got to be just so at Relko."

He wasn't particularly tidy when he lived at home, but he's more grown up now. He can do most things and is a lot happier. He plays all these old records and tapes when he comes home on a Monday, and now he's got a CD player he also plays when he's home.

"Gair goes home on a Monday at 10am and comes back to Relko at about 2.30pm and that time is special," says Mike.

Gair comes and stays for long weekends in his own room and everything has to be done right. It's nice that Gair's brother and family live right behind me, too.

Gair likes to put his feet in the water when they go to the beach and he can hear the waves. He likes the shells, too. He also wants to look at the *TV Guide* to see what's on. Having an interview in our home isn't part of his routine. Over the years, he's got even more into a routine.

Camping has been a favourite activity with Gair. "He's gone camping every year for the past eight or nine years," says Mike. "He loves seeing the dolphins and his favourite place is Russell, in the Bay of Islands." (Gair brought out a large photograph of a dolphin he saw on his last trip on the boat and showed the interviewer.)

"He learnt to say 'dolphin' a while ago," says Mike. "He's never forgotten it."

Gair has been on lots of camping holidays with Mike and has his own tent and sleeping bag. He likes to put the tent up and pull it down.

He used to go camping with two other service users, but Gair likes his space and prefers to go on his own. He made a whole meal by himself while he and Mike were camping.

Gair has the choice of going other places, but usually wants to go to Russell. He likes going on the ferry and it's all familiar to him.

"We met the All Blacks coach, Graham Henry, up there while he was fishing," says Gair, pointing out the photograph of himself congratulating Graeme Henry on his catch. It does him so much good and he just tells you all about it when he comes home. (Gair has lots of photographs of his camping trips and proudly shows them to those present.)

Horse riding was another pastime that Gair enjoyed. He used to go to 'Riding for the Disabled' at Silverdale, but unfortunately the horse, Toto, passed away and Gair wasn't interested in going on any other horses. There was also a big demand for the service and there was no guarantee he would always get to go on a horse.

Every other Sunday, Gair goes to the gym for a workout with his support worker. "Gair's routine is very important to him," says Mike. "When he gets up in the morning, he strips the staff bed and makes it up with clean sheets for the next night. Then he tidies up his bedroom. He might put his knick knacks in different places, but the chairs have got to be a certain way.

“Switches are another thing. He likes all the switches a certain way and we’ve got another service user at Relko who likes them another way, so they play games all day long. So the lights are going on and off.

“Gair’s routine includes his meals,” says Mike “He likes his yoghurt first thing in the morning, followed by his bread and spreads. But now he does it all himself – he’s very capable in that area.

“Next, Gair gets the Hoover out and he moves all the chairs out to vacuum the floor. He empties the dishwasher two or three times a day and always wears gloves – we don’t have to prompt him on that,” says Mike.

Gair likes to be busy and, if he’s bored, he looks for things to do. “He’s got a terrific character and sometimes he gets up to mischief,” says Mike.

“There was one time that we had a phone call from the old people’s home opposite Relko – the nurse phoned up asking if we’d lost one of our clients. The staff said ‘No…’, but Gair had closed his bedroom door (as he does if he wants some time on his own) and actually gone across to the old people’s home. On the way through, he’d picked this old lady’s dress off one of the washing lines, put that on and, when the staff member went across to find him, there he was – sat in the lounge by the television in this dress with a big smile on his face! That just shows his character,” says Mike.

“He’s a lot of fun. He knew he was being a clown and will play up to the crowd. He’ll have you on and say he has tooth ache for example, even though he doesn’t have any teeth. Staff will say, ‘Oh well, you won’t be able to have ice cream tonight…’ and he’ll say ‘All better now, all better now!’ You play these games and he’s got a cheeky grin on his face…”

Gair has a very good memory, too, says Mrs Thompson. He even told me when his Dad took him for a walk to the waterfall in Albany, and here and there and everywhere. He also remembers special sandwiches that his Dad made for him – and it's been 17 years since he passed away.

Also, there was a little cottage that an elderly lady lived in just a way up the road there and I had an old picture of it. Well, she's gone 25 years and he picked it up and said 'Oh, auntie's house, auntie's house!' He knows she passed away many years ago.

Gair has a strong personality and can be stubborn, but there's no malice or anything like that – a very loveable sort of personality, but devilish to say the least! I get exhausted these days and so don't have Gair to stay as much as I used to.

Mike takes Gair shopping for clothing and other personal items – Gair takes a lot of pride in his clothes and appearance. When he comes home to me on Mondays, he wants to change his clothes, so I keep a set here for him to change into. He likes to be clean. When he was in the institutions, these things didn't matter – being one of many, I suppose.

Gair does like to throw things. He's done this since he was a little boy, when he used to go up on the roof. Often he throws things he shouldn't. Mike says he never does this in anger, but possibly out of boredom or not having the attention he likes.

"All of the clothes get thrown," says Mike. "We had an issue next door just recently because he used to have little model cars and he started throwing them all over the wall... The neighbour had just bought a new BMW so that was not appreciated. At one stage, I went into the bush and picked up 19 toy cars and a bar of soap stuck up in a tree!"

One of the best things for me has been seeing Gair develop.

"He listens," says Mike. "When he first went to Relko he'd pick up the vacuum cleaner, but now he mops all the kitchen floors. He's got his routine – he'll go down in the morning and get the buckets and mops up for us. The dustpan and brush are in a certain place and he'll go 'You get out, you get out' so it means he wants to do the floors."

At Relko, they all have their own individual birthday parties and make it special, says Mrs Thompson. They usually come up to visit me and Gair gets another wee birthday here. Gair has got a lady friend that he meets down at ‘Move and Groove’ – a disco on a Wednesday morning, put on by the Kumeu Church. They supply biscuits and tea afterwards. (Gair shows the interviewer a photograph of Rachel and him dancing.)

“Rachel is supported by Mount Tabor Trust,” says Mike. “Gair and his flatmates socialise with the people from this Trust – we go across there for barbecues and they come across to us...”

Over the past two or three years, Gair has been choosing not to go out as much as he used to.

“He’s got his own space, it’s his choice,” says Mike. “He gets on well with his flatmates and has a special friendship with John. Gair likes his privacy and he’ll go to his bedroom to read his magazines or watch a DVD or television. He manages all the controls himself.”

When we go to Relko with Gair’s brother and family for any celebration, it’s a delight and of course he just enjoys having us there in his home. I feel comfortable and happy that Gair is there – he’ll ring me three or four times a week to tell me what he’s doing.

Conclusion

Gair is happy living in the community and that makes my life easier. He has a great personality and gets on well with his flatmates. He has his routines and makes his own choices, and it’s good that he lives so close to me. We keep in contact each week and I feel that Gair has a good lifestyle and is well supported by the staff at Relko.

John Mana

John

At a glance...

John was born in New Zealand in 1959, though John's parents came from Manahiki Island, which is one of the Cook Islands.

John lived in Grey Lynn with his family until he was five years old.

Around this time, John had an accident and hospital staff placed him in a special children's home at Birkenhead, where he remained until he was 15.

John then returned to his whanau. John's sister, Takihei, says that by that time John could speak and do many things for himself. There had been a lot of improvement.

John then started going to the Ranfurly Home (and workshop) in Parnell during the day.

After John's Mum got sick and passed away, Takihei says he was beaten by his father. When he passed away, the family home had to be sold and Takihei had to fight hard for John to get his share. Then Takihei says another member of their family started beating John.

Takihei was very angry and got some help from a member of her church. They wrote a letter to start the process of finding somewhere else for John to live.

In 1995, at the age of 36, John moved to Mangere Road with Spectrum Care.

John now does his own washing and ironing, and also helps with cooking meals – he's very independent.

John has a full-time job at the Auckland University of Technology, where he works doing the lawns, weed-eating, cleaning windows, mopping the floors, and washing and drying the dishes.

On the weekends, John goes busking, with his bucket, flute and Cook Island regalia. John's very well known and makes a lot of money. Everyone at the town centre knows John and they call out to him as they pass, "Hi John... Hey John..."

John has lived a life with his whanau, in an institution and now in a group home. He has experienced abuse from some family members, but also great love and support from his sister, Takihei.

John is ready to live on his own. He wants his own home. He has friends in the community, a job, and his own interests. John is his own man, making his own money and decisions about what he does from day to day. He has a number of routines that enable him to look after himself and he wants the opportunity to do just that – to be free.

John Mana and Spectrum Care staff member Jasmine Kire told John's story together. John brought an album of photographs to the interview and these helped him to tell some of his story.

John's sister, Takihei Kairua, was also interviewed by phone and helped with some of the information pertaining to John's early life, family and time in an institution.

Introduction

I was born in New Zealand in 1959. Jasmine says my parents came from Manahiki Island, which is one of the Cook Islands and that I still have family on Manahiki Island, as well as on the main island of Rarotonga.

My sister, Takihei, says my Dad was an engineer on a cargo boat. As a seaman, he travelled about six months of the year, often to America. "Dad and my Mum died," says John.

I have two sisters and one brother. Takihei says I have three sisters. Two of my sisters and their families live in Manurewa and my brother "Joe live long way" in Taranaki. Jasmine adds that I see my older sister, Takihei, a lot and visit her once or twice a month. I phone them. "You got to ring them." Takihei says she and her daughter also visit me at home in Mountain Road, Mangere.

Holidaying in Rarotonga

I had a wonderful trip to Rarotonga in April 2008 and this was the first thing I wanted to share about my life. Jasmine says we went for two weeks, but this was not my first trip to Rarotonga. She says I'd also gone to Rarotonga a few years ago with some of my flatmates.

The photographs of my recent trip included pictures of me enjoying a nice cold beer, and some of me with cousins and nephews that live in Rarotonga. I recognised a cousin on the flight to Rarotonga and Jasmine says I enjoyed catching up with him when I got there. She adds I also met up with another cousin from Aitutaki and went out to dinner with my nephew, Noa. Noa and Babbie live in a village called Taketumu, says Jasmine.

“Went the plane. Food and everything. Put the headphones. Look at the movie. Everybody sleeping, they put the blind down. You got to push the button. Turn the light on...” I liked the plane trip and looking “all the way down” when the plane was up in the air.

There were lots of photographs of the day-to-day details of the trip. Jasmine says we stayed at a house “and after that get up in the morning and I had fresh fruit and cornflakes. They were small cornflakes...” (describing the packaging). I liked drinking the juice out of the coconut.

“Been that one, the bar and they got a pool. Relax by the pool.” The water was warm. We also went swimming in a pool below a waterfall. “I love the water.” We hired a car, too, and Jasmine says we were able to put the top down.

On their last night in Rarotonga, Jasmine says Mama, one of the ladies at the local shop, came to see us and she sang some love songs and we had a beautiful night together.

While in Rarotonga, I decided to get a moko (a tattoo) on my shoulder. I had a photograph taken to record the event. It’s a gecko. It didn’t hurt, although Jasmine says “Course it did!”

“Won’t come off now... He’s eating the spider.”

“Those are some of my friends...” (pointing to another photograph). Jasmine says when I was in Rarotonga, I met up with Johno, an ex-Spectrum Care worker I bumped into one day at the flea market. “Johno, he doesn’t live here. It is a long way from there. Yeah, this is his home...” (meaning Rarotonga). Jasmine says Johno asked if he could come around and take me for a motorbike ride, so we spent a whole day out together touring and relaxing.

John's early life

"I lived at Grey Lynn," with my family... Takihei says I lived there until I was five years old. I used to share a bedroom with Dad. "Dad sleep in the top and I sleep in the bottom" of the bunk bed. My sister says I was a normal boy.

No one was looking after me and one day I was told "to get out of the house, goodbye... My Dad, he's angry. I had to get out the house."

My Dad told me that there would be no more food for me. I was really scared, so I left and went to the park where I had an accident and hurt my head. An ambulance came. Takihei says I had an accident on the swings at the park where I dropped and fell. She says the family thought that I had something wrong with my ear and I was taken to hospital and had an operation on my ear drum.

She says I was disabled from around this time onwards. Takihei says the hospital staff placed me in a special children's home at Birkenhead and I remained there until I was 15 years of age. She says there were six or seven other children living "in this little hospital," all very young with special needs.

Takihei recalls that my speech had been normal before I went into hospital for my operation. Afterwards, however, I couldn't speak properly, made funny noises and couldn't hear. She says the staff at Birkenhead worked with me on my speech. I had to wear a hearing aid and had to learn how to walk again because, when I walked, one leg was not working properly.

When I lived in the children's home, Takihei says she and Mum visited every weekend and had to catch three buses to get there and three to get back. Takihei was only 12 years old when I first went to the home. She remembers I was always in pyjamas when she visited – always... She never saw me dressed in clothes and thought it was a bit lazy of the staff. This was the worst thing about being in this place, from Takihei's point of view.

She says I always wanted to come home with them when they visited, and they'd say they'd come and see me again next weekend. Takihei doesn't recall anyone else from the whanau visiting me.

Takihei says that I did get to play games at the home, but she and Mum never got to see this as they didn't happen in the weekends. Takihei couldn't visit during the week because she had to go to school. She says I slept in a room with all the other children – all together. There were always staff on duty.

I returned to the whanau at 15 years of age. Takihei says that, by that time, I could speak and could do many things for myself. There had been a lot of improvement.

From then on I started going to the Ranfurly Home in Parnell during the day. Takihei says I'd catch the bus from near the family home in Ponsonby and go to Parnell to work in the workshop.

The Ranfurly Home workshop made all sorts of crafty things. "My aunty, she's got an old car" and lived in a "dingy old house" in Ponsonby. Takihei recalls my aunty Tiare used to go and visit me when I was at the workshop and says aunty used to drive so slowly, but looked after that old car. Aunty Tiare would pick me up and take me home to her place for the day. She always called me 'Hopini'.

After Mum got sick and passed away, Takihei says I was beaten by my father. She says she too had been abused by our father when she was younger. When he passed away, the family home had to be sold and Takihei says she had to fight hard for me to get my share. Then Takihei says another member of my family started beating me.

One weekend, I came to see Takihei and she saw my back was black with bruises. She says it looked like I had been hit several times with an island broom. Takihei was very angry. She got some help from a member of her church and she showed them my bruises. They then wrote a letter to start the process of finding somewhere else for me to live.

Takihei says she had been asked by our mother to look after me, so she approached the IHC and asked that arrangements were made for me to go and live somewhere where I could be cared for. Takihei also arranged through the courts for me to have a property manager to protect my assets from anyone who may wish to take advantage of me. I moved to Spectrum Care in 1995.

Life in the community

At aged 36, I moved to Mangere Road with Spectrum Care. Jasmine says I do my own washing and ironing, and I also help with cooking meals – I'm very independent. "Pumpkin, cauli, cabbage and onion," and my favourite vegetable is carrots. Jasmine says that I like to cook eggs and French toast. I also like luncheon ham and used to cook at the old family home. Jasmine says if I'm hungry when I get home from work, I'll cook myself something.

I have a full-time job at a school. Jasmine adds that it is at the Auckland University of Technology. I work doing the lawns, weed-eating, cleaning windows, mopping the floors "and after that I wash the dishes and dry them. After that, I wipe the bench down and then the cooking... I cook the pumpkin, potato and I do the broccoli and cauli. After that, I put it in the pot and make the soup."

I make the soup on my own. Jasmine says I have a person who helps to organise what I need to do each day. I catch a bus to and from work.

Jasmine says that on the weekends I go busking, taking my bucket and flute, and my Cook Island regalia. She adds that the staff drop me off and I set myself up with my record player and Cook Island music. Jasmine says I'm very well known and make a lot of money. She says everyone at the town centre knows me and they call out to me when they pass me, "Hi John... Hey John..."

I go busking at the Mangere Shopping Mall. I used to go busking to Otara, but there were too many people there. I catch the bus home.

I have a photograph of Heather, an old flame of mine, says Jasmine. “She doesn’t live here anymore, she’s moved.” Jasmine adds that I’ve lost contact since Heather moved to be supported by another organisation.

I’ve made friends with the local laundromat lady and I often go and help her. Jasmine adds that sometimes I’ll come home from work and then go down to the laundromat. She says my friend always flicks me $5 or $10. That’s my sideliner, she says.

I had a birthday party at Valentine’s Restaurant. Takihei adds that I turned 50 in the middle of the year and that I invited 50 people to my party. Takihei says I had a lot of family come who I hadn’t seen for many years. My brother came from Taranaki. I was very excited. I had a big cake made by my aunty. Takihei also said that I had three ‘Tevavae’ on display at my party. She says a Tevavae is a very special handmade bedcover and we had two of these on the walls and one on the chair that I was sitting in.

Staff haven’t set goals with me for two years now, says Jasmine. This is because I make my own decisions about what I do and I have a full life. Not only do I work and busk, but I’ve done lots of other things. For example, Jasmine says I’ve done many types of pottery and horse riding. I used to ride a horse called ‘Manly’. One day he got spooked and reared up and I fell off and hurt my head. We had to go to the Emergency Department, but I was okay. “Scared me off…” I didn’t go for a few weeks, then went back.

Jasmine says I really enjoy typing out verses from the bible and I like to go to the movies. “And after that Santa…”

At Christmas, I dress up as Father Christmas and I like doing this. Jasmine says I take on the role of Santa for the Advocacy Christmas celebrations, and I’m getting out and living my life.

She says they don't put me into this little square box anymore. If staff say they're taking everyone somewhere, I'll often say "No, I don't want to go..." and when staff ask me what I'm going to do, Jasmine says I will tell you. I might say "Well, I'm going to catch a bus here to the pictures..." or "I need to go and see somebody..." and that is what I do. Off I go. Jasmine says I don't like to be herded into the van. No, I've broken out from that. "I'm ready to live on my own. I like to live my own place."

I was asked what else I'd like to do in future. I'd like to go out and have a good time at Rainbow's End. I like the little dodgem cars and have gone on these before. I also like to play "the game – the hammer. Go up and hits the bell..." but I haven't won a prize yet.

For the past three years, I've wanted to live on my own. "My own home..." Jasmine says I'm sick of living with flatmates. I can do my "cleaning on my own, cooking, washing, dry clothes..."

I'd like "watching TV on my own." Jasmine adds that I get frustrated because my wish to live alone hasn't come to fruition yet. She says I need to be set free.

Conclusion

John Mana has lived a life with his whanau, in an institution and now in a group home. He has experienced abuse from some family members, but also great love and support from his sister, Takihei.

John is ready to live on his own. He wants his own home. He has friends in the community a job and his own interests. John is his own man, making his own money and decisions about what he does from day to day. He has a number of routines that enable him to look after himself and he wants the opportunity to do just that – to be free.

John Te Kiri

John

At a glance...

John is 54 years old and lives at Mangere Road, Otahuhu, with five flatmates. John lived at Homai College, Kingseat Hospital, Mangere Hospital and St John's, and came to Mangere Road from St John's in 1991.

John was about 12 when he first went to Kingseat Hospital. It was 1965.

John was born in the Cook Islands, but was brought to New Zealand by an auntie to have an eye operation – he's been here ever since.

John is totally blind and has been all his life.

John says that Kingseat Hospital was "a solid metal place where you couldn't get out". On some occasions, people would be locked in for up to four days of the week.

There were no sports or games at Kingseat Hospital, but there was a recreation hall where John used to go to the pictures.

John also lived in Unit Five, a maximum security unit at Mangere Hospital where he was locked up "the whole time".

One of John's worst memories was getting thrown in the deep end of a swimming pool by staff.

At Mangere Hospital, it was ‘first up, best dressed’. The clothes were all in one big room and the staff would just get anything out for people to wear on the day.

The worst thing about being in the institutions was when parents used to take their family member out for the holidays – John had no one to take him out and was very lonely. It isn’t such a problem now that he lives in the community, because he can go out with staff.

John’s been living at Mangere Road for 18 years now and likes it a lot.

He says the best thing about living at Mangere Road is that he gets on well with his flatmates and enjoys talking to them. John enjoys the company and freedom there.

John’s lived most of his life in institutions. When asked what the best thing about them was, he couldn’t think of anything. The best thing about living where he lives now is that he gets on well with his flatmates and one of them is his best mate.

“I enjoy the company and my freedom… I do everything that I want to do.”

John has no known family and has lived all of his life either in institutions or community support homes. He tells his story with a little help from Spectrum Care staff member Paula Lauese.

Introduction

I'm 54 years old and live at Mangere Road, Otahuhu, with five flatmates. I've lived at Homai College, Kingseat Hospital, Mangere Hospital and St John's. I came to Mangere Road from St John's in 1991.

I was about 12 when I first went to Kingseat Hospital. It was 1965. "I don't have any family at all." I'm looking into a possible family connection in the Cook Islands. Paula added that there are people by the name of Te Kiri on Manaia Island and they may be related to me.

I don't remember where I was before Kingseat. "I had a mother and father, but my father was over in the Cook Islands." Paula says I was born in the Cook Islands and my auntie brought me over here to have an eye operation, and I've been here ever since. I'm totally blind and have been all my life.

Life in institutions

I was at Homai College for the Blind before I went to Kingseat. It was good there. "I couldn't do anything by myself out there because they had the blind lady that was out there, Miss Penmace – she was the big boss."

I went to school and lived at Homai.

"Kingseat Hospital was a solid metal place where you couldn't get out. Some locations, you used to get locked up. They (other patients) were so mental, they used to throw things at you and chuck things at you all the time, and sometimes they used to get stroppy and things like that… One of the staff came along and said 'Hey come on, cut that out! You don't need to chuck that around, that's not very nice!' Then one of the other staff members caught one of them and locked him in his room for about four days of the week.

“Kingseat Hospital was a place where patients used to run away, used to take off, used to run outside the villa at night. They used to take off down the streets and down the other side of the trees and that sort of thing. One of them took off from Villa Three one night – I was in Villa Three. This young patient had just run away and took off and the police couldn’t find them and he was gone… They never found him. He had a lucky escape. The poor guy used to get locked up and they used to throw away the keys...”

There were no sports or games at Kingseat Hospital, but there was a “recreation hall where we used to go to the pictures. So I used to go to the pictures on a Thursday night.” I remember one of them was a cowboy one. We also had dances. “They were good. They were not too bad. People used to dance in the hall. I used to sing when I was listening to the radio in the dayroom at Kingseat Hospital.”

I also lived in Unit Five, a maximum security unit at Mangere Hospital.

“I used to get locked up in a side room, down the bottom. You weren’t allowed to go anywhere. You weren’t allowed to go to the pictures or anywhere. I couldn’t celebrate when I was in (Unit) Five at all. I was locked up for the whole time.”

There was no birthday cake on your birthday and no celebration. I don’t know why I was angry when I was at Kingseat, but I didn’t have sight. “I was just so frightened, I couldn’t see what was coming to me, you know?

“I had friends out in Kingseat. I had a nice friend called George Dutton. He was a staff member. He used to come and talk to me and tell me what it was like, what it was before. He was one of the staff members out there.” He was kind to me. “I haven’t been in touch with George for a long time, not since then...”

Mangere Hospital was an institution. “We never used to go out at night, we used to get locked up in Villas and Wards and, all of sudden, that place was like a security thing and we weren’t allowed out anywhere. I could never, never ever get out of it. It was very hard."

One of my worst memories of the place was "I used to get chucked in swimming pools and things like that. I couldn't even swim from what happened," and it was staff that used to throw me in. The pool was very deep at one end. "I felt so scared after it. You know, I didn't like it..." It was frightening.

St John's was off Puhinui Road. "People used to throw tables and chairs. I was in Room Three. It wasn't locked" so people could go out at night. Staff would take people out shopping. "We had the movies over at St John's. They had a church there."

Paula says there were three big wings, each with about 30 people in them. "30-odd people there... Some of them used to go to work – you know, catch their own buses and that. I used to go on the bus every day to Aspirations Services (Spectrum Care's Activity Centre) in Papatoetoe, from 9am to 3pm. We used to put washers on nails and caps on things, but we didn't do any packing.

"I was once scared when I was over there at St John's. Some guy came down and said 'Oh, has anybody seen the staff member?' I said 'No, I haven't seen one of them...' I said 'Well, I'll go and look for one of them if you want me to.' They looked around and said they saw the staff member walking around down towards (Room) Three. It was about two people in (Room) Three one night. I don't know who they were, but there was one of them walking around looking for a staff member and they couldn't find anybody!"

I used to sleep in the dormitory at St John's. There were about 50 of us sleeping the dormitory. "I used to go to bed at 7pm... I still go to bed at 7pm". Paula suggests it's a bit later now and it's getting later and later.

We used to have meals in the dining room. "It was a big dining room, too. Yeah, lots of noise and lots of people – noisy! When we used to sit down, we had a nurse who used to come around with a spoon behind his back. He was just telling them to be quiet: 'I don't want to hear a pin drop!' he'd say."

He'd bang the spoon on the table if someone talked. We had to eat every meal in silence. We weren't allowed to talk. If anyone talked, they'd be put outside and "they'd miss out on their dinner. It doesn't happen to me now."

The meals were okay, but other people didn't like the way they were cooked. I prefer the food we get now. There was a good smell coming out of the kitchen one day and the cook "pulled out a spoon and said 'You want something to eat?' I said 'Yeah!' and I ate what she gave me."

The wards were "pretty smelly and you can smell what's in the shower and what's in the bathroom. We had a big bathroom and we used to have 30-odd residents in one bathroom." They would all have to shower at the same time. There wasn't much privacy, though there were doors on the showers and on the bathroom.

At Mangere Hospital, it was 'first up, best dressed'. The clothes were all in one big room and the staff would just get anything out for people to wear on the day, says Paula. "It was terrible..."

The worst thing about being in the institutions was when parents used to take their family member out for the holidays and I had no one to take me out. It was very lonely. It isn't such a problem now I live in the community, because I go out with the staff.

Life in the community

I've been living at Mangere Road for 18 years. "It's alright, it's good, you know? The guys (flatmates) are good. They're okay... We usually have about two (staff) on during the day and two in the afternoon."

On Tuesday and Thursday we generally go to the Aspirations Services' Activities Centre in Makatoa. "But that hasn't been happening lately." Paula adds that I usually say I don't want to go, so we do other things. "Yeah, I tell her that I don't feel like it and just say 'No' – that's all."

When I do go, I sit and watch them dance. I don't dance myself. Paula says I'm a great singer and I sing for the people while they dance. “I like ’60s and ’70s rock and roll, that sort of thing... Yeah, I enjoy singing.”

Our house has “two lounges – one up the top, one down the bottom – two showers, one loo for the staff and one for the clients.” I haven't noticed any smells in the house that I'm living in now, but Paula reminded me that I often say ‘That smells nice!’ when the staff have done the cleaning.

“I like the place tidy. I keep my room tidy. I put my things where I want them, you know?” Paula says I need a bit of help, but I make my own bed. I've got my own clothes now and I like that. I choose them and I put on what I want. I go shopping, but don't like going when the shops are busy because someone might bump into me.

I don't do a lot. I listen to Solid Gold radio. “We go for train rides, to cafes, holidays and things like that, you know? They're the only things we go to. Well this year, we've just been down to the beach house. We just wandered down there for a week. That was good. This is towards Maraetai Beach.”

Paula reminded me I also go to meetings with the Foundation of the Blind, and they have helped me get a talking watch and audio tapes which I listen to.

When Paula first got to know me, I was frightened and was quite scared about going out in the community. I'd hear all these things on the radio. But now Paula says I'll go out with the staff all day and in the evening. I can go to the letterbox and front gate on my own, and around the yard. I can be on my own for “a couple of hours, that's all...” And the week at the beach house was “a really big deal”. It used to be two days and I'd have to get back, but I managed a whole week on holiday away from home, says Paula.

Paula says there's been a big change in me over the past five or six years. She says I used to have to be first – like the first person to have a shower – but I've learned to share now. "I offer to help. Like 'Would you like a hand with the baking today?' and 'Would you like me to put the washing away?'."

She says I'll come and say, 'I'll vacuum for you!" She says I've come a long way. I help bake cakes. I like banana and "the odd chocolate cake".

"I put my clothes in my room. Yeah, that's what I do." I can also answer the phone and take messages. If I needed help in an emergency "I'd just dial 111".

I get up at around 6am these days. We sleep in on the weekends. Paula says that at the weekends, I used to go to bed not a minute before or a minute after 10pm. It was always 10pm at the weekends, but now I take myself off at anytime.

David is my best mate. He lived with me at St John's and now he lives with me at Mangere Road. We moved there together. We're friends and flatmates. I was asked what we do together. "Oh, we just talk, that's all. Listen to my radio. We just chat about some of the things like (what) we used to do."

We used to play tricks on staff. There was this one trick where I put a rubber crawly thing in the office "and one of the staff members called out and said 'What's that doing in there?'." I told Paula that the staff would make my bed, then I'd go along and pull it to bits and they'd have to come and make it again. I liked to have fun with the staff.

"I had my birthday with my flatmates." I had it at home because this is what I wanted. I had pork and special things – I don't have a favourite meal.

The best thing about living where I live now is "I get on well with the guys and I talk to them, you know? I like it there. I enjoy the company and my freedom there, you know? I do everything that I want to do..." I can't think of a 'worst thing'.

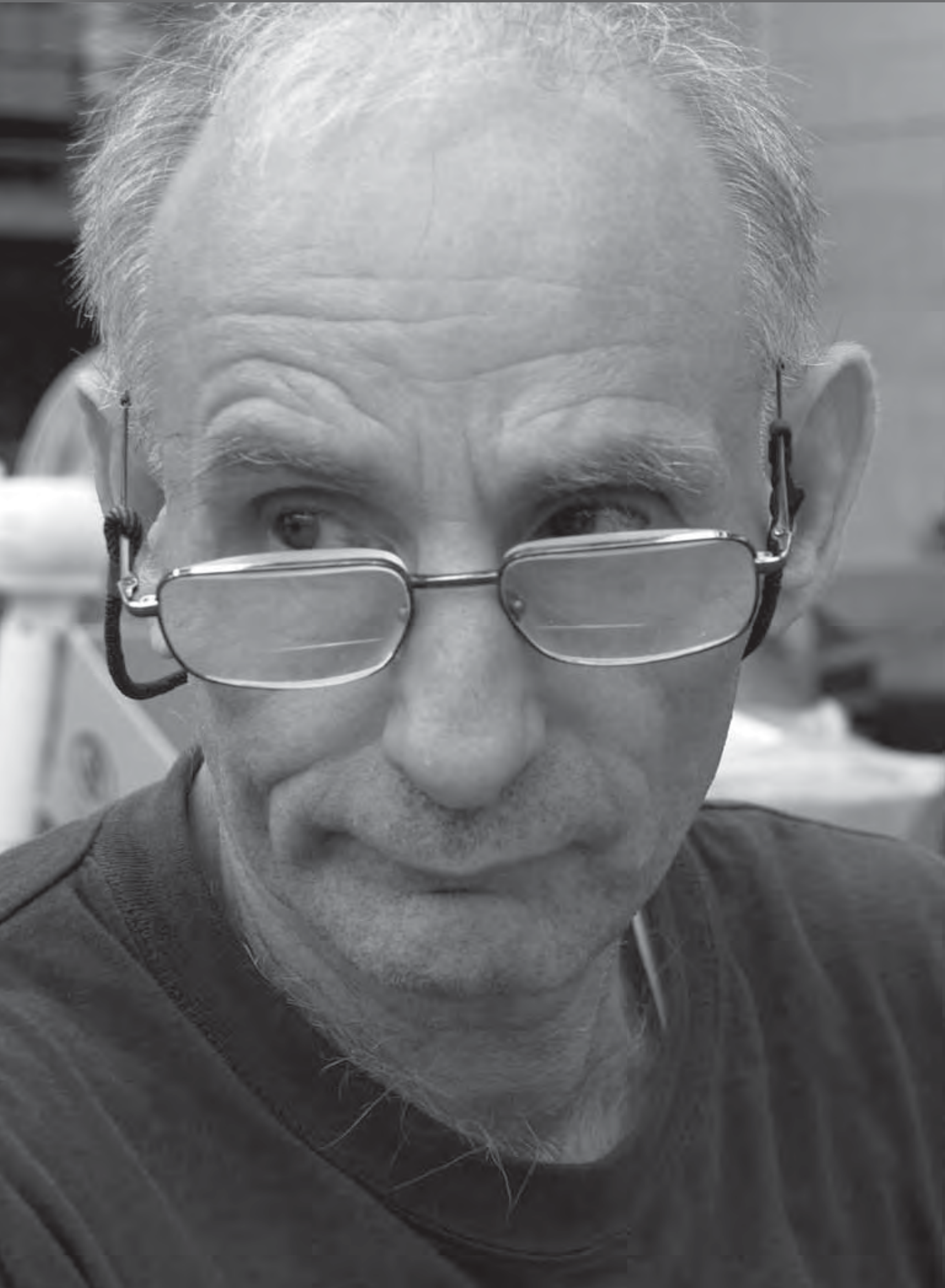
I’d like a new stereo “with a microphone on it. I’d talk on it” and sing. Yeah, I won the talent quest. I sang ‘Dream Dream Dream’. I’m thinking about going in the next talent contest, too.

Conclusion

I’ve lived most of my life in institutions. When asked what the best thing about them was, I couldn’t think of anything. The best thing about living where I live now is I get on well with my flatmates and one of them is my best mate.

“I enjoy the company and my freedom… I do everything that I want to do.”

Kevin Webster



Kevin

At a glance...

Kevin is 56 years old and has lived in Fairview Road, Papatoetoe, since 1994. Before that, Kevin lived at St John's.

Kevin grew up in Northland and lived with his Mum until he was 14 or 15, then he went to St John's.

Kevin has a brother, Charlie, and a sister, Lynn, who are both in Auckland. Charlie's also in a supported residential home (though with another support organisation), while Lynn is married with children.

Kevin worked when he was at St John's, packing boxes, mowing the lawns, gardening, watering and planting the garden. In fact, he helped to do all the work with his friends – "Making the tea, doing the dishes, cleaning the sink..."

When he was at St John's, Kevin's clothes would get washed for him, though sometimes they went missing. "It was something I didn't like – my clothes going," says Kevin. "Now all my things stay together and I like that."

When Kevin came out of St John's in 1991, he went to Kotamu Road – the first Spectrum home he lived in. Then, in 1994, he moved to Fairview Road.

Kevin lives with his flatmate and friend Kenny in a two-bedroom self-contained flat, and there are four other people who live in the house on the same section.

Kevin helps clean the house up and clean the kitchen, and even pulls the fridge and freezer out to clean behind them! He's very particular and likes the place to be tidy.

Kevin works at one of Spectrum Care's Activity Centres from Monday to Thursday, putting white rubber washers on roofing bolts.

Kevin likes to keep his pay slips in his room and only uses the money he earns on special occasions.

The worst thing about where Kevin lives now, he says, is that some of the cups and bread plates are cracked.

He likes having his own room and his privacy, but sometimes people still come barging in... "You haven't knocked, dummy!" he reminds them. "Knock first and respect my privacy!"

Once a month, Kevin goes to a cafe with his friend Charlie. Last month, they went to MOTAT and then to Manukau before returning home.

Kevin likes his home at Fairview Road because there's no fighting with his flatmates. He says it's much better than being at St John's for that reason.

Kevin likes things tidy and he helps a lot with the cleaning. He likes where he lives and his bedroom is his own space.

"It's far better than being at St John's. I've got friends and there are no fights."

Kevin was interviewed with Spectrum Care staff member Brenda Siaosi.

Introduction

I'm 56 going on 57 years old and I live in a flat in Fairview Road, Papatoetoe. Brenda says I've lived there since 1994.

Before that, I lived at St John's. I grew up in Northland and lived with my Mum until I was 14 or 15. Then I went to St John's. I have a brother, Charlie, and a sister, Lynn. They both live in Auckland – "Charlie's just around the corner." He's also in a residential home, but it's under another trust, says Brenda. Lynn is married with children.

Life at home and boarding in Tuakau

When I was little and growing up in Northland, "I was at Bernard Street". It had "concrete stairs that Dad make years ago…" I went to a special school in Whangarei, says Brenda. I "used to play car, racing car things. With a marble – hits the cars down. Whack! And one was complete falls and one where he wears glasses, and Hungry Hippo. Me and Charlie had, it was broken, too. Yeah, there was a golf set – had a golf set at home – and I used to play toys like light shines on my lap. Signs, truck and a matching one..."

My Dad "used to make concrete. Claymore Concrete, he worked at Claymore Concrete." I'd go with him to his work and help him "with the tractor. Load it with hay. The loading – me and Charlie did the loading." The hay was for the horses.

Dad had a Mercedes car. "The other one was an old green Austin... and the Special, before the Kingswood… and after the Kingswood, it was the Hunter…" Mum "used to clean the school. She'd make scones, cakes, biscuits – only made for visitors. Yeah, we got some of the baking. But we let the guests go first!" She would bake for us when we went on picnics to "the beach at McKenzie Bay".

I used to listen "to music on the gramophone" and I also helped "with the cleaning and the dishes and putting it all away."

Life in institutions

"I was happy to go there (St John's). Yeah, was in a room with all the other old flatmates of mine – Terry Hoppings, Tommy Myers, Douglas Shaw and Robin Singster."

Meals at St John's were "good – share amongst other people. There is 20 other people beside me. Like for breakfast, cornflakes or porridge..." We didn't have many choices, "no, so I ate it".

I worked when I was at St John's. I did "high-grade boxes up the top, they used to go together, lacing, and silver cloth and stains, printing." I also did "mowing the lawns, gardening, watering the garden, watering it. Put peas in, put seeds in..." The gardening job I liked the most was "growing pumpkins". I helped to do all the work with my friends. "Make the tea, do dishes, clean the sink..."

Sid was the gardening man and I loved working with Sid. "I had a good friend called Sid, yeah." I used to go and visit him for a cup of tea when I moved to Papatoetoe, but he's "gone back up north" now to live.

I remember "going to the pictures – used to have pictures through the hall on these old wooden seats. Steel seats, plywood seats, and some of them were coming to pieces. That was some of the seats I saw outside the old hall – the old hall for the island dance. Yeah, and little small seats made of plywood, too. Plastic ones – they have plastic ones with legs with breaks. We had a couple of white chairs, like these – steel. We had these round tables, with four (people) on them – yeah, four or five. I would move around and sit anywhere..."

Mr Greer was walking around and he'd say "You could sit anywhere you wished, Kevin, without being bossed around by anyone."

I "had my own bed". There were 20 others in the dormitory. "I shared a room with Steven Chaplin, Scott, Gordon and myself."

“The plumber used to fix the toilet seat every time – gets broken and somebody sits on it like that. It was a wooden toilet seat. Got broken... Yeah, they’d come and fix it...”

My brother Charlie was also at St John’s. We went home for the holidays “with Mum and Dad, they were good and Charlie stayed with us, too. Charlie was in Ward One and I was in Room Three. Everything was shared at St John’s. I chose my own clothes and “I go out with staff to buy my clothes”.

At St John’s, I liked to “help clean up bits and pieces. Wardrobe was broken – mirror. We had this broken mirror from somewhere. The boy came along and Carrie got hit on the head when the mirror came down – smashed to smithereens. His head was okay. Didn’t get cut – lucky he wasn’t cut, should have moved away. This boy was wild and threw the cushion. The mirror came down off the mantelpiece. Yeah, off the mantelpiece in the lounge. I was there at the time, I was looking at the TV...”

I felt “sad when it broke, because we used that for the shaver – for shaving mirror. Don’t ask what happened to the mirror, it got broken and they (two other patients) smashed it, turned and got into the cushion thrown, came down...”

The staff punished the boys responsible. “They got made to pay for the broken mirror. The staff said the mirror was used for shaving, not for throwing cushions and come down on the floor and SMASH! No good...”

“Really didn’t like them throwing pillows around... and the other one was hairbrushes. Yeah, and combs... Combs!” I got hit. “They didn’t like me. I threw one of them back, but I wasn’t allowed to do it.” I got into trouble with my boss. He stopped us from throwing things around. I was a bit scared when we had fights.

When I was at St John’s, my things would get washed: undies, towels and sheets. My clothes got lost. It was quite sad. “It was something I didn’t like, my clothes going...” Now “all my things stay together” and I like that.

Life in the community

When I came out of St John’s in 1991, I went to Kotamu Road – that was the first Spectrum home I lived in. Then, in 1994, I moved to Fairview Road.

“I got a little flat.” I live with Kenny in a two-bedroom self-contained flat, and there are four other guys who live in the house on the same section.

I help clean the house up and clean the kitchen. Brenda says I even pull the fridge and freezer out to clean behind them, and I am very particular. I “like the place to be tidy”. I used to mow the lawns. “Yeah, I enjoyed that. Mowed my own bit of the flat… Me and Kenny mowed the strip.” ‘

We used to have a garden, but “not anymore – they mowed over it”. When asked if I would like a garden again, I said “Yeah, we haven’t got a garden bag either – it’s gone. Garden bag we used to hang…” Brenda tells me the garden bag has gone back now because I stopped mowing the lawns. I got sick of it. The boys do it now (the lawn mowing guys).

I stay home on Saturday morning, when my flatmates go to their sports. Brenda says I sleep in, then have breakfast and clean the house up. She says I am very kind hearted and will help my flatmates if they need a hand. “I wants to help Ian with his washing…”

I go to Aspirations Services for work. “Monday, Tuesday, Wednesday, Thursday. Four days a week” and I put “rubber, white washers on the nuts”. I like it there. If I’m sick, I stay home in bed. “Quite happy to stay, get rid of the ’flu first. Yeah, sneeze and cough. They got it – have to wash your hands. Otherwise, I would have the swine flu. Clean the fingers…”

I have “a job that you get pay slips, I keep them in my room.” I give the money to the staff. They put it in my wallet. “I use it on special occasions!”

I make myself a cup of tea. The staff help with the cooking at our place. “I’m not fussy, I don’t look at it – I go ahead and eat and eat and eat!” I like “mince, if its mince. Fish and chips and Burger King are my favourites, and the other one is McDonalds. That’s a good one!”

“I’m not fussy. I eat it. I was at golf, this lady comes along and we all have the same food here. We all had the same food as 20 other people...” I thought it was “pretty good, sharing it with other people”. For breakfast I can have “Weet-bix, Cornflakes, Ricies, but I choose the Weet-bix and the next morning I will go for Cornflakes.” I can change what I want, “I do that – same as everybody!”

I like “having my own bedroom, with the TV and the radio – just the radio!” I also have a bookshelf. This is much better than being in a dormitory. I go with my key worker to buy my clothes. I choose them – “I chose this jersey!”

“Staff help me to “get rid of all the broken stuff”. We put it in the carport. “That’s the stuff we’ve got in the shed – all broken.” Brenda helped me explain this. She said, “If its looks broken to Kevin, he’ll just throw it out. So you turn around and all of a sudden something has disappeared and Kevin has gone and thrown it out, put it on the side of the road. Anyone driving past stops and picks it up, and it’s gone. But Kevin is a great one for doing things like that – a clean out!”

If something is broken, I also “try and fix it so it blows up – fix things and they go ‘Bang!’ Like if it’s a heater that’s broken and I can’t repair it anymore, and here’s me fiddling with it, trying to make it go...”

Brenda says I’m helpful around the house and will do things like replace a broken toilet seat. The tool box belongs to the house now – “It’s not my tool box...”

The worst thing about where I live now is that some of the cups and bread plates are cracked. I’ll “replace them, if I see any chips. I know which one is chipped; it’s the breakfast or bread plates." Brenda asked me to let the staff know before I throw them out. "I'm going to help buy some new ones. The other thing is the vacuum cleaner hose. It keeps coming out" and it annoys me. Brenda says today we're going to price a new vacuum cleaner for my flat and see if it can be replaced.

I like having my own room and my privacy. "Because, otherwise, they go barging in... 'You haven't knocked, dummy!' I remind them. 'Knock first and respect my privacy!' I say."

"Some of my CDs went missing. I only got three of them back. I don't know where they went. I had quite a few of them. Some of them, I've written in my... What's it called? Inventory!" I have an inventory of my music, so I can keep track of them. "I have how many, Brenda? 1, 2, 3, 4, 5, 6, 7, 8, 9, 10... But I can't find them."

I go to the church around the corner. I walk with Gordon to St George's Anglican Church. My brother Charlie goes to the same church, says Brenda. Millie picks me up and takes me to the church home group at Puhinui Trust or to Dawn's house. We do "a lot of singing from the church, from the home group..."

I go out once a month with Charlie to a café for a light lunch or a coffee. Brenda reminded me we went to MOTAT (Museum of Transport and Technology) together last month. "And from there we went to Manukau and we came home."

I like to go to the pictures and have lunch – one-on-ones. I like to go to McDonalds, KFC... "I'm into that. Doesn't matter what it is. Good food, yeah! KFC – Ben's work" (Ben is Kevin's friend).

"It's a good place, though, and there's a café there and a lady does the cooking, cooking the chicken and chips. Get back and just watch TV, already finished dinner..." On my birthday I "go to a big restaurant with lots of my flatmates and my brother."

I've got friends at work. "I've got Leanne and Tua – Tua works with me and Leanne. There's Neil, Gordon and Paul..." I see them when I'm at work.

There's no fighting with my flatmates. Where I live now is far better than being at St John's. It's better "because of the no fights..." not like at St John's.

Conclusion

I like things tidy and I help a lot with the cleaning. I don't like things being broken. I like where I live and my bedroom is my own space. It's far better than being at St John's. I've got friends and there are no fights.

Leng Cheng

Leng

At a glance...

Leng was born in Cambodia in 1966, where he grew up with his four sisters and two brothers. Their parents were originally from China.

Leng's father died during the war in Cambodia and Leng also saw someone take his brother away.

After the war, the family moved to Vietnam and lived in a refugee camp for 10 years.

Life was hard in the camp. Leng's brother had to sell empty cans to earn money to pay for food for the whole family and rice was rationed to nine kilograms per person per month.

The family waited 10 years for the immigration documents that would allow them to move to New Zealand.

Leng became unwell and got very angry. His behaviour was much worse in New Zealand than it'd ever been in the Vietnamese camp and he was eventually taken to a mental health hospital.

Leng remained quite aggressive towards other patients and also harmed himself while in the institutions.

Leng has lived in Spectrum Care's Pallant House for about six years. He's a very cheerful person, who always has a smile on his face and can be jovial at times.

From 10am to midday every second Sunday, Leng goes to the Buddhist temple. Leng is a very spiritual man and is very keen on his own culture. Staff bought Leng a black gown and he wears this when he goes to the temple to pray.

When he visits his mother and his sister, Leng will pause and pray in the prayer corner, and join his hands together before greeting his family.

Leng goes to Aspirations Services Monday to Friday from 10am to 2pm and takes part in gym, music, computer skills, singing, sports and literacy. He likes to write the alphabet, and is a very neat and tidy person. He also really enjoys going to tai chi on Thursdays at the Manurewa Recreational Centre.

Over the past three years, Leng has become calmer and less aggressive. Leng's life has improved and some of this may be attributed to his religion.

Leng has witnessed some very distressing events in his life and these have affected him deeply.

In the past, he's been alienated from his culture and has had to learn to communicate in a country that is very different to Cambodia. Though he still has serious health issues, his sister and staff believe he is now happy and settled.

Leng's story is told by his sister, Jessica Cheng, with the assistance of Spectrum Care's Asian Services adviser, Ian Chan.

Jessica tells of Leng's life in Cambodia, Vietnam, Thailand and, lastly, New Zealand.

Spectrum Care staff member Asish Narayan has worked with Leng for three years and shares Leng's story since living at Pallant House.

Leng has given his consent for both Jessica and Asish to tell his story.

Introduction

Leng was born in Cambodia in 1966, where he grew up with his four sisters and two brothers. Their parents were originally from Chaozhou in the southern province of Guangdong, China.

Jessica says Leng was a normal boy – possibly a little bit naughty – and didn't have a disability when he was younger. When he was about eight years old (before the war), however, he fell and hit his head on some concrete. He was taken to hospital, but wasn't x-rayed at the time.

Leng's father died during the war in Cambodia and Leng also saw someone take his brother away. He was about 18 years old when he became mentally unwell and Jessica thinks Leng's condition may be the result of the war and what he saw.

After the war, the family moved to Vietnam and lived in a refugee camp for 10 years. When he first went to the camp, Leng would study and go to the school library for an hour a day to learn some Chinese words. However, Leng's health forced him to stop after only three years.

He wasn't 'normal' when he lived in Vietnam, says Jessica, and he used to lose his temper with others from time to time. The family were unable to get any help for him in the refugee camp.

Life was hard in the camp. Leng's brother had to sell empty cans to earn money to pay for food for the whole family and rice was rationed to nine kilograms per person per month. The family are Buddhist and, while they followed their religion in Cambodia, there was no opportunity to do so when they were in the Vietnamese camp.

The family waited 10 years for the immigration documents which would allow them to move to New Zealand. During this time, they lived in a small room in a mud-brick shanty house and slept on hard wooden beds. Each house had about 16 families living in it, with each separated by a partition. Water was collected from a nearby well.

The Cheng family eventually moved from the Vietnamese camp to a refugee camp in Thailand, before moving to New Zealand in 1989.

Leng's health problems made the move to New Zealand more complicated. At the airport, Leng stopped talking, and became very tense and rigid. The authorities in Thailand decided that Leng needed to undergo a thorough medical examination prior to moving to New Zealand, so Leng's eldest brother stayed with him for a month while he had the tests. When they were finally allowed to leave, they had to be accompanied by a medical doctor.

Initially, Leng and his family settled in Nelson, where their sponsor (arranged by a distant relation) lived. The whole family lived in a house the distant relative rented for them. Leng and his Mum stayed home sometimes, while the rest of the family went to the local polytechnic college to study English.

Leng had again become unwell and got very angry. His behaviour was much worse in New Zealand than it'd ever been in the Vietnamese camp. Leng banged his fists on the wall and threw things around, and was eventually taken to a mental health hospital for assessment and treatment.

He stayed in hospital for a few months, but within one or two weeks of returning home he became aggressive to his sisters and had to be returned to hospital.

Jessica doesn't know why Leng's behaviour worsened, but mentions that Leng had to take a lot of medication at the start of the treatment. He tried many different medications, some of which made him worse. The family didn't have much time with Leng then, because he was in hospital so much.

After four years in Nelson, Leng's mother got Parkinson's disease. The family decided to move up to Auckland, so she could get acupuncture treatment. Mum moved up first as the eldest brother was already living in Auckland. The rest of the family moved up after Mum and then, about a year later, Leng moved up to be close to the family.

At first, he lived in the hospital. The family don't know the names of the hospitals he lived in because Leng would usually come and visit them at home – they only went to see him in the hospital a few times. Also, once they had their own families, they visited Leng less often. One place Jessica remembers was in Papakura and another was on State Highway 16 near Henderson, Waitakere.

Jessica says that, according to the staff, Leng remained quite aggressive towards other patients in the hospitals and also harmed himself. He showed little improvement while in the institutions.

Life in the community

Leng has lived in Spectrum Care's Pallant House for five or six years, says Asish. Leng is a very cheerful person, who always has a smile on his face and can be jovial at times. Leng understands all English spoken to him, but staff sometimes struggle to understand Leng's verbal responses. Asish is learning some Chinese words and teaching the rest of the staff to help make communicating with Leng easier. Leng will write in Chinese – which Ian sometimes translates to English – and also uses body language and pictures to communicate.

Leng speaks Mandarin when he visits his sister, says Asish, but Jessica finds him difficult to understand as he doesn't have any teeth – although he can usually get his point across.

When Leng's upset, he goes to the front gate and wants to get out, but he's not safe out on his own because he doesn't have any road sense. He can be pointing and saying he wants to get over the fence, but he can't say why.

Leng used to make faces and "do actions" and, when no one else was near, would swear and hit his head, says Asish.

Leng remembers a traumatic incident from his past and he imitates trying to hit or shoot someone. It could be to do with his Dad, who went away and never returned, or his brother. Leng tries to show staff what happened – he says 'Hit!' and shoots or points a make-believe gun, then he makes his body go all loose and closes his eyes as if he's going to fall.

He's seems to be telling us he's observed someone being shot, says Asish.

Leng used to do this quite often, especially when he was mentally unwell, but he hasn't done this for about six months.

From 10am to midday every second Sunday, Leng goes to the Buddhist temple, says Asish. Leng is a very spiritual man and he's very keen on his own culture. Staff bought Leng a black gown and he wears this when he goes to the temple to pray.

Asish says Leng has been going to the temple over the past year and this has contributed greatly to his wellbeing. Ian adds that Leng has become very familiar with the people at the temple.

Asish also thinks that Leng's involvement in his religion has been significant in some of the changes in Leng. When Leng visits his mother and his sister, he'll pause and pray in the prayer corner, and join his hands together before greeting his family.

Leng visits his family once a month with Asish. He also phones his sister once a fortnight – his sister talks and Leng listens. Leng would like to have contact with his older brother in Auckland and younger sister in Sydney, and Asish is working on this with Leng.

The most distressing thing for Leng is that he can't express himself or participate in conversation. It's really hard for the family to understand. Jessica says that sometimes Leng seems to want to respond to the family. He seems to be thinking and wants to reply, but can't get what he wants to say out.

Leng likes to listen to Mandarin songs and music, and he can write his own name in Chinese characters. Leng does talk, but Ian and Jessica can't understand him. He can say the family members' names and he'll answer 'Yes!' or 'No!' to make himself understood.

Leng really likes Chinese food, so he enjoys visiting the family home or getting Chinese takeaways at Pallant House. He also likes chicken, which he asks for on New Year's Eve. But he has to have soft foods like chow mien, as he doesn't have any teeth, says Asish.

The staff buy Leng's clothes and help him to look good.

When Leng visits his family, he'll watch TV and have a cup of coffee. Jessica says that, since leaving hospital, he "is a better person and has a better temperament." The best thing in Leng's life now, according to Jessica, is that he can go out into the community with support and is happy.

Ian describes Leng as "a good man and a good worker" and says he's improved a lot – probably as a result of being on the right medication now.

Jessica says that Leng is calm and well behaved when he comes to visit his family these days. He'll listen to them.

Leng is quite independent and only needs a little help with wearing the right clothes for the weather. Leng doesn't help with cooking meals because he's not allowed in the kitchen because of safety concerns.

Some of Leng's flatmates tend to throw things like knives or anything loose. Leng's aim is very good, so he uses plastic plates, says Asish, as he'll throw a plate at a staff member or another person from time to time. Sometimes, though, he throws items playfully.

When he's unwell or has to wait too long for something and someone upsets him, he gets irritated and throws things. Staff need to be quite skilled to work with Leng. He'll also hit or punch staff or residents if he's unhappy.

Staff know when Leng is unwell and avoid taking him out during these times.

Asish says Leng goes to Aspirations Services' Activity Centre Monday to Friday from 10am to 2pm and takes part in gym, music, computer skills, singing, sports and literacy. He likes to write the alphabet, and is a very neat and tidy person. He really enjoys going to tai chi on Thursdays at Manurewa Recreational Centre.

He's in a class with some older ladies and gentlemen and is well liked – he likes being there. He also likes taking part in gym and swing ball, and enjoys the sporty side of things. Asish says Leng was learning the guitar and does a Maori cultural class and painting.

"Leng doesn't actually do the work, but he enjoys watching people," says Asish. Leng entered the Spectrum Care talent contest and sang, which was a real achievement, says Asish.

Leng doesn't have many friends. Stacey, the tai chi instructor, and Kath Page, a participant at the tai chi class, are his friends and they come to parties at Pallant House. They always ask after Leng and have a drink with him after class, says Asish. Ian states that the people at the temple ask after Leng. He gets on okay with other staff at Aspirations Services and at the house, says Asish.

Leng enjoys time on his own in his room. He goes out more in the community than he used to and it's now safe to take him out with the other service users and one staff member (he used to require two). Leng doesn't need as much medication now – perhaps only a couple of times a month – and this is a big improvement.

Leng likes to celebrate the Chinese New Year, says Ian. Jessica adds that, in their family, their mother is the most important person and her birthday is celebrated together with a lunch or dinner. During the war in Cambodia, people were too busy and it was too difficult a time to celebrate birthdays. As a result, some people don't know when their birthdays are.

Asish has noticed some major changes in Leng since working with him. Over the past three years, Leng has become calmer and less aggressive. When he first started working with Leng, the thought of taking him out of the house was horrifying, says Asish, but now he can take him anywhere.

Asish has taken Leng to a Chinese Cultural Art & Dance show (three-hours long), then dinner out. He really enjoyed it and was smiling and clapping at the show. They played old songs that Leng knew and he sang along with them.

Conclusion

Over the past couple of years, Leng's life has improved and some of this may be attributed to having his spiritual needs met. Leng has witnessed some very distressing events in his life and these have affected him deeply.

In the past, he's been alienated from his culture and has had to learn to communicate in a country that's very different to Cambodia. He still has serious health issues, but his sister and staff believe he's now happy and settled.

Rodney Daken

Rodney

At a glance...

I was born in Te Kuiti and have three brothers – Warren, Colin and Murray – and three sister-in-laws – Wendy, Linda and Anne.

My family moved to Auckland and I went to Sunnydean School until I was 11, when I moved to Levin Farm (Kimberley Hospital).

I moved to Levin Farm in 1960. The worst thing about being at Levin Farm was "they were trying to have me on that I couldn't come up to Mangere", that I might never be allowed out of Levin Farm. The best thing was being "shifted up on the Thursday morning to Mangere and St John's." Levin Farm was "too far from my family to go down and it cost petrol every time they went down – it cost them too much money for petrol..."

I was moved out of Levin Farm and came up to St John's in Papatoetoe in 1966, when I was 17 years old. This was when they opened up Mangere and I wanted to move, but I thought "it wasn't the suitabilist place for me." I lived at St John's from 1966 to 1991.

The food at St John's "wasn't very nice – no gravy on it". Living in the community, I have gravy.

I always wanted to go to Waikaraka Park – to the stock cars – on my own. My Dad was a stock car driver. "I always wanted to go on my own and one of the

Kingseat staff said ‘No’ because he thought it was too late at night. I didn’t think it was too late!”

But I did get to go at St John’s because “Trudy would drop me over” and “one of the towies (tow truck drivers) would ring the taxi company and they’d take me back. Yeah, that worked out...”

I was “a lot happier” when I moved up to St John’s. My best memories of St John’s were “Mr Manning (head nurse) was always there when Mum and Dad came, because him and Dad would talk about the fishing.

I moved into Mangere Road with Spectrum care in 1991. “Where I’m living now is much better, Paula’s a good cook and I do a lot of things on my own like MOTAT and museums, speedway and stock cars… also the airfield at MOTAT, too.”

I go on my own and get there early and wait for them to open. “I get the minders to take me and pick me up again...” I go to the Easter Show, too.

I like doing things on my own. I’ve got a lot of friends in the community and I go to church on Sundays. I look after my own money and bank account, and I have a cell phone.

I have lots of friends in the community. I go to MOTAT, dodgems and stock car racing. I go to work three days a week. Life is much better since leaving St John’s and it’s good now I can do things on my own...

Rodney Daken lives in Otahuhu and tells the story of his life in institutions and in the community.

Rodney's passion for stock car racing has stayed with him throughout his life. He's always wanted to follow his interests on his own in the community and, since moving to Otahuhu in 1991, has achieved this aim.

Spectrum Care staff member Paula Lauese was present during most of Rodney's interview.

Introduction

I was born in Te Kuiti and I have three brothers – Warren, Colin and Murray – and three sister-in-laws – Wendy, Linda and Anne.

My family moved to Auckland and I went to Sunnydean School until I was 11, when I moved to Levin Farm (Kimberley Hospital).

Later, I was moved out of Levin Farm and came up to St John's in Papatoetoe. I then went to Newton Central School. I lived at St John's for 25 years and then, in 1991, I went to live in the Spectrum Care house at Mangere Road in Otahuhu.

My Dad was a stock car driver – he was a good driver. "Yeah, he got spun into the fence and a nose bleed!" I used to go when my father raced at Te Rapa in Epsom and Western Springs.

"I quite liked going to watch. I'd like to go back to the speedway and stock cars again, and I'd get back to Waikaraka (Park) when I could…

"The man would cut my hair and the man that had the bag shop. That was old Slater Hays (racing driver). He rode the bikes and he rode the big stockies… And the big noises! I liked it when they used to flip the car (laughing)… Rev them up and tip them over!

“I was there the night Desmond Cullen was killed at Epsom. The funeral was on a Wednesday morning. I felt sorry for him.” I didn’t go to the funeral, but others went – people from Greenlane who raced and people on ambulance duty.

“Pity I couldn’t have gone. They thought it would be only for family. It was school holidays and Christmas time. Yeah, and they’d have to go away to a funeral… I didn’t see the death notice...”

I was a petrol head... “Yeah, I was a petrol head when I was seven!”

Life in institutions

Levin Farm

I moved to Levin Farm in 1960, when I was 11. My uncle and aunty, Bob and Adele Sorensen, would come and visit me at Levin Farm. “They get the kids in the car and go down and see me...” I went to Courtly Fells School there and then they closed it down.

“There was a nice headmaster called Peter Graham.” Then there was Sister Morris and she was the charge of Manawai. “I’d like to go back and see how much it’s changed.

“They wouldn’t let us go out to the stock cars at Palmy (Palmerston North). I was going to get a chance to go and they’d have to get a five o’clock man to drop me over...” We did go – “Yes, it did happen in the end.” We went every Saturday night. “I used to like it for the big crashes!”

I went to school and to workshop. “We had a man that gave us the strap in front of Greenlane Hospital” at Levin Farm. “I didn’t like him. That was down in Kimberly… He was running the three industries.” I got the strap for something I never did. “And I had a right to go to social welfare about it.” So “Mr Adams and Mr Donks took me along. They said they’d sue if it happened again and I’d be shifted out.” It didn’t happen again because “they were watching”. I knew what my rights were.

“Richard Brown was telling me about the hills at the back of the villas. He said one night ‘You and I and Michael are going up there…’ and I said ‘What do you do if they ask who you are?’ He said ‘Tell them you’re Owen Smith or tell them you’re Busby or Lawrence or Loui or Sam or Laurie or Alan Lough (who was at my other workshop). Tell them you’re Peter McNeal or Dave Robinson…’

“‘No!’ I told them all, ‘No! I’m not going up there, get caught by the cops. I’m scared!’ I was going to get grabbed by a big policeman (laughing).”

They decided not to run away. “Best way to do it is to stop and think before you run away. If they ran away from there, they’d either go to Kingseat or Oakley. Locked up there, where the staff can knock you out with tablets… Yes, and I don’t want to get put in there – I’m scared (laughs).

“We had a big dormitory and sometimes, if they were very naughty, the doctors would put them on punishment – no canteen, bed at five o’clock, no pictures, no church, no TV…”

The Levin municipal person, Mr Jenton, got me into brass band training. “They put me on a trombone. I practised all the time. Yes, and I was practising one time during my lunch break. Mr Hoskings played the tenor horn.”

I enjoyed music and “in the summer, we’d go out on the paddock in the summer nights. When the winter nights come ahead, we’d go into the recreation hall.”

We went to an event at the James Smith Theatre in Wellington “and I always sat next to Mr Hoskings in the bus, where we’d be talking about what we fear and what we didn’t fear, which was lovely.

“Should’ve seen the smiles of the kids’ faces when the bands came by” and I was in it! “Yes, got my first chance and I was only 15 at the time!

"The staff let us have a shower before tea. We had a shower with other people – five others." At the end of the day, the staff would say 'Good night. See you tomorrow, same time...'

I had a nice old friend called Mr Roy Barr. He was a staff member and "he was in the villas with all the other staff." He was younger than me.

"I suppose he'd be in one of the houses wouldn't he? Yes, I'd love to see him again one day." I'd tell him all about Spectrum Care. I don't know where he could be. He'd "get a shock to see I'm doing things on my own!"

We used to talk about the naughty boys and what punishment they should get. Peter Graham was a nice person. He was a staff member.

"I don't know what he's doing now, old Peter..."

The worst thing about being at Levin Farm was "they were trying to have me on that I couldn't come up to Mangere", that I might never be allowed out of Levin Farm. The best thing was being "shifted up on the Thursday morning to Mangere and St John's." Levin Farm was "too far from my family to go down and it cost petrol every time they went down – it cost them too much money for petrol..."

I did have cousins and an aunty and uncle down there, and "I'd always go back to see them."

St John's

I was moved out of Levin Farm and came up to St John's in Papatoetoe in 1966, when I was 17 years old. This was when they opened up Mangere and I wanted to move, but I thought "it wasn't the suitabilist place for me." I lived at St John's from 1966 to 1991.

I went to Newton Central School in Winroff Street, "which was a much better school. Then they went and tried to close it and the hospital down…

“The headmaster, when I got to Newton, was Mr Strong… If he could look down and see me now, he’d get a shock wouldn’t he?” He’d be shocked about “me getting a job… and getting all that money!”

“When I came to St John’s, the head nurse was Mr Manning – who was a good friend of my Dad. He had Carrington and Kingseat staff working with him.

“We weren’t allowed to go anywhere on our own. Came along Fergie and got me out doing things on my own – going to soccer on my own, to the banks and walks on my own… And I thought one time I’d like to do MOTAT on my own and Mr Manning and another man thought that would be too much, which it wasn’t for me...”

Now I’m doing it on my own. “Yes, I showed them!”

The food at St John’s “wasn’t very nice – no gravy on it”. Living in the community, I have gravy. “Yeah, I make one up.”

I always wanted to go to Waikaraka Park – to the stock cars – on my own.

“I always wanted to go on my own and one of the Kingseat staff said ‘No’ because he thought it was too late at night. I didn’t think it was too late!”

But I did get to go at St John’s because “Trudy would drop me over” and “one of the towies (tow truck drivers) would ring the taxi company and they’d take me back. Yeah, that worked out...”

At St John’s, we wore “longs in the winter and shorts in the summer”. The staff would buy our clothes and “take six of us at a time to buy it. And they’d pay – the staff would pay it off.”

When I buy clothes now, “I get the staff to go with me”. I’d rather buy the clothes on my own, but they come to make sure it’s the right fit. If I bought them on my own, I “might go a bit overboard. I did when I was little and it was Christmas, I’d go a bit overboard” with presents. “Yeah, and Dad couldn’t afford most of them.”

When I was at St John's, I was put under specialists. I think it was because of my behaviour. I used to try to wander off when I got upset about not being allowed out in the community. I was asked if I ever tried to hurt myself or break anything like windows. "No! Mr Manning might take it out of my pocket (laughs)!"

Paula says I'm too sensible for that! One of the staff gave me an injection. "He thought I was going to report somebody to Dr Dam, which I wouldn't."

I didn't like the way the place was run. "Not letting me go out to speedway and stock cars and the Easter show on my own… Trying to say 'Nobody goes anywhere!" and I didn't like that."

I got given the injection "for trying to argue the toss and I wasn't, I had my rights." The injection was punishment and it made me feel all drowsy. "I didn't think that was fair at all. So we went along and saw Dr Dam. Dr Dam thought that I had rights" about when and where I went. He was the psychiatrist – "a little Indian doctor there... I had quite a number of doctors then – Dr Savage and Dr Honeyman... We had a lady doctor called Dr Manders and Dr Vaness and Narelle and Dr Jefferies and Ian. We had a big group of psychiatrists all the time and they changed time to time..."

Dr Dam and Dr Manders and Dr Vaness "understood my meanings".

During the day, "I'd go to the workshop there" with a staff member I didn't like. We did the boxes up for packing. "We did the stocking boxes for the Lane's hosiery and the sock boxes." We made up the boxes to pack Hager's white shirts. We also packed shirts for Adamhoff and Vance Vivian shirt manufacturers.

There was an IHC home on Waiheke Island, overlooking Rocky Bay. I went there for a holiday. "And there was a guy called Mr Claybid. When I went to go back, Dr Matthews didn't think it was a very good idea. I don't think he was right. "No. I think I was right!"

I was “a lot happier” when I moved up to St John’s. My best memories of St John’s were “Mr Manning (head nurse) was always there when Mum and Dad came, because him and Dad would talk about the fishing. And I said to Mr Firth ‘I reckon we should catch the big one!’ He said ‘You’re right there, I think we should!” Mr Manning and Dad went fishing together. I didn’t go because they were “too frightened of me catching a kingie or kahawhai. Yeah, ’cause I loved the old kingies and kahawhai – always wanted to smoke them...”

I’d been fishing in the holidays. “Only when Dad was going to the RSA or Cossie Club at Christmas and New Year, we’d always put something on – like a bit of a trip to wherever they were having their picnics. They’d take us to their thing, do the fishing and then Dad’s mates put me with somebody that I didn’t know from St John’s. And I didn’t know anybody from St John’s church and I had a good friend called Alan Alistair there and Gerald Keys. And they just asked me to come and have a beer with them.

“Yeah, I did and I thought that was the best thing in my life. Yeah, it was always Dad and Dr Matthews and Dr Ladbrook and Blackie would go and have one (a beer). Yeah, and Mr Manning was a bit iffy on me having it. But they said ‘No, he’s a champion that boy of yours!’”

Life in the community

I moved into Mangere Road with Spectrum care in 1991. “Where I’m living now is much better, she’s a good cook (Paula) and I do a lot of things on my own like MOTAT and museums, speedway and stock cars… also the airfield at MOTAT, too.”

I go on my own and get there early and wait for them to open. “I get the minders to take me and pick me up again...” I go to the Easter Show, too.

“When I went to MOTAT the first time on my own, somebody thought it wasn’t a good idea and Kylie started me off with it.” Kylie used to work in the house.

My favourite place is the dodgems and I go on my own. I'm a good driver. "Yes, I'm bashing other people around… Yeah, I do a George Philips on them." I was asked 'What's a George Philips?' "They go and get me in the rear, so I just sneak up behind them slowly and nudge them in the rear..." (laughs).

I go on the ghost train at the Easter Show. "Yeah, there's not many shows around now the Easter Show's finished. You think they'd have the big winter one wouldn't you? I don't know what happened to the winter show."

I like doing things on my own. I've been on the ghost train "a couple of times at night with another man I didn't know… Just a friend, a man I never knew and he just took me through… and he paid for us..."

I've "got a lot of friends in the community and Harold is one of them – you know what he does? He owns a big shop – a second-hand shop. I always call down and see him." We have a good chat and talk about "his work and my work. We talk also about the next coming of the Lord."

I go to church on Sundays. I got baptised a few months ago in the Baptist Church on Carol Lambie Drive. "They put in the pool, put me under and bought me up again. Yes, it was a bit scary, but I took it!" On Good Friday, I go with some of my friends to look at Easter egg exhibitions "and they have the crosses and the paintings..."

I go to the White Cross in Otahuhu, which is the Medical Centre. My dentist is here, too.

At home, I help out in the kitchen and with the cooking. I cook different meals. My favourite is sausages and, if I was cooking, I might do chips with them – just put all the chips around it so to make it look like it's a meal." I like roast vegetables if we're having a roast.

I have my own room and I keep it clean. "I tidy up before I go out..."

I work Tuesday to Thursday from 9am to 2pm. “We do different jobs – we do nails, New Zealand Nails, Dave’s Nails. We pack a lot of interesting things like grimmicks.” The interviewer asked ‘What are grimmicks?’ “Grimmicks are the benzene caps – caps for petrol cars...”

I find it easy work. But I’d rather change jobs and come and work here (at Spectrum Care’s office).” I’d like to be working with computers and answering telephones.

Paula collapsed one day at the house and “I rang the ambulance. Yes, and I’ll never forget that night I rang 111 and dialled them.” I knew what to do. I got help for Paula. “It was my godfather who answered the telephone (the 111 call) – Mike. Yeah, and he came whizzing down.

If the house catches fire, get out quickly, get the phone. Ring Bob Sorensen. Put their fire engines down and horns, fire trucks down – soon as they could!”

Kylie taught me “when to do it and when not to do it… She was one of the students there.” I’ve had first aid training at APET (Auckland Protected Employment Trust), too. “Because I saved Stephanie Beasley’s life by ringing 111 and letting them know. She was rushed off up to Greenlane. I found her lying on the floor at APET and I knew what to do.” APET was my workplace “for a while, till I was taken out of there.”

“It’s good now I can do things on my own.” I enjoy having a beer with my mates now and again. One Anzac Day, I had a beer with the band at the Otahuhu RSA. “They used to come and shouted me. I sometimes go to the Cossie Club in Papatoetoe or Otahuhu. I often stop and have a beer on a Sunday with Kelly and Mr Speights, and Beverly shouts me a coffee. They’re in an old house which is very elderly. Kelly taught me some naughty jokes. Him and his wife Dolly put me up to it, and my brother wasn’t very impressed about it!”

My brother lives in Australia and he comes over sometimes to see me. I’ve gone over to Australia “when my Mum was there and my Dad. I went to stay with my Mum in her other flat in Goolla. My Dad's gone and my Mum is in a home. But her granddaughter Michelle's looking at bringing her out and getting her a granny flat built on "and I'd like to go over there again sometime..."

I used to fly on my own and "Mum and Dad met me at the airport. Coming back, the staff at St John's would meet me."

I've gone to Australia only once or twice since living in the community. "I went with Gary Rogers – he was a minder, staff. He's gone to IHC. My brother won't let me go over at the moment. Because they're coming over and they'll see me when they come over..."

Paula clarified that, "It's because he doesn't want Rodney seeing his Mum the way she is now because she won't remember him. But I said that, well, it's not fair on Rodney. He'd like to see his Mum even so, and Rodney understands..."

I feel it's a bit upsetting (that I can't go over), but I can take it. I've got the money in the bank to go over. I'm also "saving for my 60th – yeah, September the 24th – which I'll do an hour at MOTAT till four that day, come back and have a party after! Looking at a restaurant – one in Royal Oak there, Pizza Hut..."

The interviewer asked whether there was anything else I'd like to tell her about my life and story. "I'd like to put it all on a big book. Yeah, I'd love to do that!" I like the idea of having my story told with other peoples stories.

I was asked whether I'd ever thought about living on my own. "Quite comfortable where I am..." Life is "much better" since leaving St John's. Life would be even better if I could go walking "around the (Western) Springs a bit at night." I don't do this "because they don't have many staff in the evening.

I remember where the zoo was and I could remember where the airfield is..." I used to do this, but my father didn't think it was safe. "Sometimes they used to have the carnival over at

Western Springs when I was little. I'd go there the first night of opening – me and a few of my little friends at Sunnydean. Me, David Curry and a few others would go and have a crack at the dodgems. We all were laughing at each other, thinking right we're going to win this one!" (laughing).

Paula added that I can remember things happening way back, and people's names. She also said I like walking. "Yeah, you could put me a spot somewhere in Auckland and I could walk for miles from there."

She says it relaxes me, especially if for some reason I can't go and do what I want to. I catch the ARA bus to work every day. My brother was against it, but he's quite happy now. Paula says if I miss the first bus, I know how to catch the next one. I know the number of the buses.

"You know what I should do, I should try getting a bus over to MOTAT. Catch the 334 to Onehunga and I'll have to probably catch a Pt Chevalier or Greenlane out wouldn't I?" Paula confirmed I'm right. "I caught the bus to Manukau, Sylvia Park..." then I just "nosed around the shops." When I'm learning a new route, Paula goes in the car behind the bus.

I look after my own money and bank account, and I have a cell phone. "Yeah, it's good fun! I ring if I see something suspicious. I get the police or fire engine if there's a fire, and if I see an accident I stop by and just dial 111 and tell them."

I ring the staff "if I've got a thing on at the Speights' (friends). Sometimes my god-brother might ring up and say 'Speedway is cancelled tonight in Waikaraka' and they'd race again on Sunday. He drives a stock car himself..."

I want to go on holiday again to the Beach House at Maraetai. Paula said this is a ResCare holiday home. I went fishing with Graham when I was there, but there was "nothing out there to be had..."

I went to Maraetai by myself before, but last time I went with my flatmates. If I had my choice, I would live with John and David and Peter (three of my current flatmates).

“I’d like to go down to the beach house again sometime.” I was asked whether I’d like to go to the South Island. “I’ve been there and done that...” They stopped there to get fuel and then took off again when I was flying to Australia. “I have an uncle and aunty in Christchurch...”

Conclusion

I have lots of friends in the community. I go to MOTAT, dodgems and stock car racing. I go to work three days a week. Life is “much better” since leaving St John’s. “And it’s good now I can do things on my own...”

Wichmond Tavioni

Wichmond

At a glance...

My name is Wichmond Tavioni and I live at Mangere Bridge. I come from Rarotonga, but I was born here. I have five brothers and three sisters.

My younger sister is living in Tauranga. My Dad has passed on. My Mum and my niece live together now, and I keep in contact with my Mum.

I grew up with my family, but didn't get along with my brothers and sisters and got up to lots of mischief. I used to take off and couldn't settle at home, so I lived on the street and would get brought home by police. I'd take off again and got into small crimes.

My family didn't know how to deal with me, so they put me into an institution.

I was locked up in Mt Eden prison before going to Kingseat. At Kingseat, I didn't have any freedom – being locked in all the time – and this was the worst thing for me. It's not living in a house, a house is different. It's open and you can walk out of the house when you feel like it...

At Kingseat, you had to go to bed at a certain time. I had a room with a bed on the floor and they used a key to get in. They always locked it at night. I was locked in a bedroom.

I used to run away from Kingseat. Kingseat was horrible for me. I used to sleep out in the community and it was scary. Then I'd get into trouble with the Police. I was in a bad way, locked in all the time. That's why I ran away. Kingseat wasn't the right place for me.

I've been through a lot of institutions. After Kingseat, my mother put me in St John's in Papatoetoe. We slept in dormitories with lots of beds. I also lived at Carrington and Oakley Hospitals, locked in all the time. You didn't have freedom in the institutions

After I left the institutions, I went to live in a house in Manukau and now Mangere Bridge. There are five of us flatmates living together at Mangere Bridge. We're all from the Pacific Islands. I like my flatmates.

There's more freedom living in a house in the community. I decide when I get up in the morning. I don't like anyone to stop me going out. I go out every day.

I go gallivanting around... Normally I go out quite a lot on my own. I go to Manukau City and look around the shops and go out for coffees. I also go to church in the weekends...

I go to Faith City church in Manukau – sometimes I go at night. I do all sorts and take the bus home.

I set my own goals and I decide who comes to meetings about my goals. I choose what I'll tell people and what I won't.

The best thing about living where I live now is I can go out anytime I want. I have freedom. I'd like more privacy and more friends, but it's much better than living in an institution. Lucky I'm in Spectrum (Care) now... I'm quite happy where I am.

Wichmond told most of his story himself, with a little support from Spectrum Care staff member Nga Alofa.

Introduction

My name is Wichmond Tavioni and I live at Mangere Bridge. I come from Rarotonga, although I was born here. Mum and Dad are Cook Islanders and I'm the youngest of eight children. I have five brothers and three sisters. My younger sister is living in Tauranga. My Dad has passed on. My Mum and my niece live together now, and I keep in contact with my Mum.

I grew up with my family, but didn't get along with my brothers and sisters and got up to lots of mischief. I used to take off and couldn't settle at home, so I lived on the street and would get brought home by police. I'd take off again and got into small crimes. My family were concerned about how they were raising me and didn't know how to deal with me, so they put me into an institution.

Life in institutions

I was locked up in Mt Eden prison before going to Kingseat. At Kingseat, I didn't have any freedom – being locked in all the time – and this was the worst thing for me. "It's not living in a house, a house is different. It's open and you can walk out of the house when you feel like it..."

At Kingseat, you had to go to bed at a certain time. They used to have a room with a bed on the floor. It had a cupboard and an open window, and a door below the window, and they used a key to get in. They always locked it at night. I was locked in a bedroom.

I used to run away from Kingseat. Kingseat was horrible for me. I used to catch a bus up the road and ask the bus driver to drop me off at Manukau City. I used to sleep out in the community and it was scary. Then I'd get into trouble with the police. I was in a bad way, locked in all the time. That's why I ran away. "Kingseat wasn't the right place for me."

"They used to put you in pyjamas. That was a horrible thing. They used to have a square table by the kitchen that was the real bad table. If you run away, they put you in pyjamas and on the bad table." You had to stay in pyjamas all day while the others had their clothes on. You had to sit in one corner by yourself and you don't have your friends around you.

We used to have soup every day in the cold season, when it was raining and miserable. The soup was good. There was a Catholic church in the grounds and I used to go along to the church on a Sunday. Birthdays weren't celebrated at Kingseat, but I do remember the discos and dances – these were the best things about Kingseat. I used to socialise with people, we used to have people from out in the community coming to the discos at Kingseat. We used to go to Karaka by bus for dances and there was a hall there. You don't have to be locked in all the time.

I've been through a lot of institutions. After Kingseat, my mother put me in St John's in Papatoetoe. We slept in dormitories with lots of beds. I also lived at Carrington and Oakley Hospitals, locked in all the time. You didn't have freedom in the institutions. When you live in a house it's different. "Kingseat wasn't a suitable place... It wasn't the right place."

Life in the community

After I left the institutions, I went to live in a house in Manukau and now Mangere Bridge. There are five of us flatmates living together at Mangere Bridge. We're all from the Pacific Islands. I like my flatmates. There's more freedom living in a house in the community. I decide when I get up in the morning. I don't like anyone to stop me going out. I go out every day. "I go gallivanting around... Normally I go out quite a lot on my own. I go to Manukau City and look around the shops, and go out for coffees. I also go to church in the weekends..."

Sometimes the staff are concerned that I stay out very late and worry that I might not be safe. But I have to go out there in the city. I've heard a lot of bad things happening out there. That's why I have to stay around people when I'm out in the community. I can also tell someone if I'm worried – I know my rights. The staff ask me to return by a certain time and say I have to have my medication at 9pm. But I say I'll take my medication with me and go out. All I have to do is ask for my money and sign for it.

I go to Faith City church in Manukau – sometimes I go at night. I do all sorts and take the bus home. I am glad Nga is here to fill in a few gaps for me. She says staff let the on-call staff know what I'm doing and that I work with the Behaviour Support team and we talk about keeping myself safe. "Lucky I'm in Spectrum (Care) now... I'm quite happy where I am."

At home, I spend most of my time in my room listening to my radio. I like real music – Pacific Island music and Radio PI (Pacific Islands). I like privacy in my room. Our house only has one lounge. You need a place like the garage, where you and friends can listen to the stereo. I don't bring friends home because there's no privacy. I like to arrange everything with the people from church. They pick me up, meet me at church and bring me home. That's the way I like to do it. I don't like to bring people over.

I call my family once a week and I visit them on Mother's Day and birthdays (and other times, too). My Mum's quite busy with church. I choose my own gifts for Mum, but a lady in my house normally helps me out. If I don't like it, I tell the staff and I don't buy it. Last Sunday, I took Mum a present and she really appreciated it.

I go out on my birthday. I normally choose a restaurant and I really like seafood. I like going out to restaurants and go a lot.

The meals here are nice. Normally, I do my own breakfast. I fry myself some eggs and toast. I prefer the staff to cook the evening meal. After church, staff make a nice roast lunch. One week, we have taro and roast pork, then the next week it could be green bananas and raw fish. The menu is on the cupboard. I ask ‘What’s for dinner?’ I decide if I want what is on the menu. If I don’t want that, I can make my own dinner. I like to have sausages – my favourite – and cook mashed potatoes. Another of my favourites is pineapple pie.

When in Carrington, there was a hairdresser who came in to do the haircuts. I prefer to go down to the salon and get it cut and that’s what I do. You get more freedom in Spectrum Care to get your haircut down there.

I set my own goals and I decide who comes to meetings about my goals. I choose what I’ll tell people and what I won’t. I’m trying to save to go to Rarotonga, if I have the finances. I’ve been before in 2004, with two staff, and met my cousin. He saw me in the van and he came and shook my hand – he recognised me when I first got to Rarotonga!

I went to the last Spectrum Care ball as Count Dracula with a cape and I was the main speaker, greeting everyone at the hall. I go to lots of Spectrum Care parties and celebrations. I’m the Pacific Islands representative for Spectrum Care and everyone knows me. I’m the main speaker when we have guests at Te Akapunga.

I work at Aspirations Services at the Mall three day a week. People go and do nails for buildings and put the washers on. It’s more like a training place, where they find jobs for people out in the community. I come home with my payslip every second Thursday. I like my job in a way. I like to mingle with people (at work), but I really love my smokes and can smoke any time I want.

I went to Rotorua on a church camp, with one Maori person from out in the church community supporting me. We went swimming in a pool. Rotorua was so different to me. We had to share a room together. I wasn’t happy with that and I wanted to go back home. I like to take my time and it was all very rushed – I had a few clashes with a few church members, but I learnt a lot from it.

I used to have lots of friends in the institutions, but I don't know where they are at the moment. When I moved to Mangere Bridge, I had a friend who used to live down the road. I'd have a coffee with him. He was a good friend to me. Now I'm alone by myself. My friend passed on – he was quite young. I used to socialise with him and he lived in a boarding house. He used to be an orderly at Kingseat Hospital and when I went to Carrington Hospital he met me there and we became friends. Now I only have one friend who lives in Otahuhu. I keep in contact with him over the phone. His mum passed away and I used to go home to his house with him after church, but that's not happening now.

I'd like to have a friend I could go out to the movies and mingle with. I'm not interested in dating or having a girlfriend. Some of the guys in my house aren't suitable to go out with. They have staff with them. With me, I don't need staff. All they need to do is to drop me off.

I want to be more social. I want to be more independent and go out with a friend to the movies or the city and look around the shops.

Conclusion

The best thing about living where I live now is I can go out anytime I want. I have freedom. I'd like more privacy and more friends, but it's much better than living in an institution. "Lucky I'm in Spectrum (Care) now... I'm quite happy where I am."

Appendix one

Research process – Outline

The study aimed to provide the views and stories of 12 people who had, at some stage, lived in a hospital or rest home, but were now being supported in the community by Spectrum Care Trust Board and Te Roopu Taurima O Manukau. The project had been approved by the Northern Regional Ethics Committee. Advice to and oversight of the project was provided by consumer and technical advisory panels.

Technical Advisory Committee members were Brigit Mirfin-Veitch (Director – Donald Beasley Institute), Brigit Sneddon (Centre Director – Parent and Family Resource Centre), Lorraine Bailey (Special Projects Manager – Te Roopu Taurima O Manukau Trust), John Stacey (General Manager – EQS), Philip Patston (Director – Diversity New Zealand and Diversityworks Trust) and Chris Harris (Chief Executive – Spectrum Care Trust Board). The committee was advised by Cathy Coleborne (Associate Professor, History Department – University of Waikato).

To be selected for the study, the person had to have an intellectual disability and have lived in an institution previously. They had to be currently receiving support in the community within the Hamilton or Auckland regions, from either Spectrum Care or Te Roopu Taurima O Manukau. They also had to want to have their story told.

The assistance of staff in both organisations was necessary to support people with intellectual disabilities to learn about the project. Staff also had an understanding of who may have had a story to tell – and they were proactive in encouraging those people to consider taking part in the project. There were three presentations arranged, with potential participants, staff and family invited to attend. Those who attended the presentations learned about the study and how to get involved, as well as informed consent procedures and the rights of those who would take part.

Once expressions of interest had been received, the potential participants were each visited and given specific information about the study. They were asked whether they wanted help to tell their story and who they wanted that help from. If they wanted to take part, they were supported to complete the Informed Consent Form. Interviews were then scheduled with the participants and the people they'd identified to support them. Where a person wanted their story told, but was unable to tell it themselves, family and staff worked together to tell their story.

Appendix two

Oral history

This project was designed to capture the stories and words of people living with an intellectual disability. An oral history approach to this study was chosen as the most suitable, given it enables the voices of ordinary people to be heard. It can provide insights into aspects of people's lives that otherwise may be unattainable. Oral histories aim to capture histories of the more recent past, where other evidence does not exist (Goodley, 1996).

This idea of telling stories is a respected academic form in the discipline of history and, through oral interviews, documenting of histories of the more recent past (and particularly the mid-to-late 20th century) have been possible. Most significantly, as an academic field, it has emerged in relationship with public history work conducted within specific communities. Informal, anecdotal and personalised accounts of history can provide a direct route to social understanding (Goodley, 1996).

Historians also suggest that oral history can assist understanding of how others make sense of their past, how their own experiences relate to the social context of the time, and how the past is incorporated into the present. Oral history assists with exploring how people construct meaning (in Green & Hutching, 2004), particularly people whose social lives and experiences have been marginalised in the past, such as the intellectually disabled. Oral history can empower people with intellectual disabilities by enabling them to own and control the stories of their lives (Jack, 1995, in Atkinson 2004).

Telling stories is a normal part of life. It helps people to explore, explain and understand themselves, and what's important to them. People who've lived an institutional life have generally had little opportunity for storytelling. They've lived apart from their families, often from a very early age. They have limited contact with friends and very little memorabilia such as photographs, with which to prompt shared experiences. Offering people the opportunity to tell their own story can be affirming and empowering (Gillman et al 1997, in Atkinson, 2004). It also enables the linking of the "public and private worlds, and gives substance to the social worlds" of those who are telling the story (Goodley, 1996, p337).

Appendix three

Interview process

People with intellectual disabilities often have difficulty communicating. Some have limited use of words, while others have problems remembering details. However, to rely only on those people who are articulate would mean that the experiences and perspectives of those often with more severe disabilities would be lost.

The interview was semi-structured. In other words, it was conversational and flexible, but provided some questions and prompts where individuals needed help to talk about their lives in the institutions and their subsequent years in the community.

While many of the interviews took place in a central office location, some were conducted in either the person's family home or their residence, depending on where they felt most comfortable. In some instances, a second or third interview was arranged – either with the person or members of their family – to further expand the information provided.

Under normal research conditions, the researcher would ask open questions, being careful not to ask leading questions. However, when working with people with intellectual disabilities, these techniques limit rather than support good communication. To overcome potential communication challenges, the interviewer asked questions about people, activities and topics separately.

Repetition and honesty were important to prevent misunderstanding. Participants were encouraged to bring pictures and items that would assist them to tell their story. Where the participant agreed to a family or staff member being included in the interview, their knowledge of the person's communication assisted the researcher to hear the person's voice and story. In these situations, however, it was important to avoid the support person influencing what the person said, or did not say, given overlapping roles and conflicts. It was also crucial to capture the values, thoughts and feelings of the person with the disability, rather than those of their family, staff or, indeed, the researcher (Goodley, 1996).

Each interview was audio-taped, transcribed and then written up as a story. The draft stories were then forwarded to the participants to check for accuracy. Once the story had been critiqued and changes made, it was then forwarded to the Advisory Panel for their feedback and consideration for inclusion in the publication. Once the selection had been made, all of the participants were informed of the outcome and, once published, all were provided with a copy of the book.

Appendix four

Project participants

Approximately 60 people attended the initial project presentations. From this, 14 expressions of interest were received and 13 people agreed to take part in the project. On beginning the interview process, one person withdrew, leaving 12 participants. The age range included three people in their 40s, five in their 50s, three in their 60s and one in their early 70s.

Those who took part represented diverse cultural backgrounds, with six New Zealand-born Europeans, two Cook Island Maori, one Maori, one Samoan and one Cambodian. The remaining participant was exploring the possibility they may also be Cook Island Maori.

Ten men and two women shared their stories, with four people telling their stories with little or no input from families and staff. Five of the stories were told by the participants' family members and four of these were also supplemented by staff. In all but one of the interviews, the person with the story to tell was present and actively took part in information sharing. A further three participants told their stories without help from families, but with assistance from staff. All 12 stories were accepted for publication and are included in this book.

All participants chose to use their own names in the book. Where stories revealed information that had the potential to distress other individuals, identifying materials were removed.

Appendix five

Findings

Experiences of institutions

The participants' stories of the institutions had many similarities. All indicated some form of alienation or separation from their families, often from childhood or early teenage years and, in one man's case, total loss of contact and knowledge (to this day) of his family. Families also felt this alienation and struggled to visit the hospitals which were generally located in out-of-the-way places.

Those institutionalised had little choice in the basic day-to-day activities in their lives – they ate their meals at the institutional meal times, showered often en masse and at specified times, slept in dormitories and socialised in controlled environments – usually segregated from the wider community. Special interests outside the institutions were considered too risky by staff and were often discouraged. Transport and supervision were also issues in attending such events.

In some instances, people didn't have their own clothes, but wore whatever was taken from a 'clean laundry pile'. John Te Kiri is blind and told of having no access to equipment and being totally reliant on others to help him move around when he lived at Mangere Hospital. Alofa, through being institutionalised, lost many of her abilities and had to learn them again when she went to live in the community. Each of these facets add to a view of people with no freedom, afforded little or no individuality, of having been depersonalised and devalued.

People cannot be separated from their culture or background without being alienated. One's culture is the foundation to who they are, where they are from and how they view the world. Customs, traditions, roles and responsibilities help people to order and understand their lives.

Leng Cheng's story is one of poverty and refugee status, having fled Cambodia for the safe camps of Vietnam. The family's eventual move to New Zealand, however, didn't improve Leng's health and one can only imagine the desperation he must have felt being unwell in hospital and separated from his family, while also having to learn a new language, customs and religion.

The references to the staff of the institutions generally fell into two distinct groups. Some staff were referred to as friends – people who'd been kind and supportive to those interned. Others were referred to negatively and it was clear that these individuals used their power in ways that limited or controlled these same people.

In many ways, that was their job. Two people, both of who had very limited or no vision, told stories of being thrown into the deep end of a swimming pool by a staff member and left to sink or swim. These experiences were horrific for these then young individuals and the impact of these cruel acts affects both of them to this day. Sometimes patients also abused each other. Dick Old recounted in his story an incident where he was seriously injured and had to have treatment for some time afterwards.

Some of the stories were about escaping the institutions or running away. One man shared his frequent despair at seeing others go on leave for Christmas and holidays, when he had no family and nowhere else to go. A family member told of hating taking her brother, Brian, back to hospital and for many years being denied the opportunity to bring him to live closer to her and the whanau because those in charge did not believe that the family were interested in him.

Dawn's story tells of the stigma and secrecy of a bygone era, and the reconnection with a biological sister of whom, for most of her life, she was unaware. Unable to tell her own story, much of her institutional history has been lost.

There were some positive reflections shared about institutional life, across the storytellers. Work and the institutional workshops were portrayed in a positive light by some of the participants. Some individuals developed their own roles and responsibilities in the institutions, and this gave them a sense of purpose and value. Dances and socials were also remembered with fondness. There were stories told of friends in the institutions, but sadly many of these relationships have been lost since individuals have moved into the community.

Life in the community

All of the individuals interviewed, and their families, conveyed a sense that they (or their loved one) were much happier living in the community than when they lived in an institution. The stories told of a greater sense of choice and independence, and of access to more community activities and events than ever before. There was a sense of people being supported to take some risks, having understood what these risks were. There were also comments made about feeling 'safe' in the community – John Te Kiri said he could find his way around his home and environment, and didn't get knocked over any more. Dick Old was pleased that he was living with flatmates that didn't fight with each other.

Cultural support was important to the people now being supported in the community. While those telling their stories didn't state that they were receiving such support, their stories told of celebrations, favourite foods prepared in traditional styles, learning or being encouraged to talk in their native tongue and staff working to improve their own understandings of language other than English. Through support, several of the participants had been helped to reconnect with their culture, language, customs and practices, and religion. There were several people who were involved with and supported by their local churches. For Leng, the reconnection with his religion was very important to the improvements in his health and wellbeing.

Family contact has also been easier and more regular than when these individuals lived in an institution. Many families were actively involved in the person's life in the community.

In telling their stories, people shared aspects of their day-to-day lives in the community. Each person told of having more responsibility for themselves – cooking some of their own meals and choosing where they went on holiday, some with one-to-one support. Alofa, for example, had learnt to eat with a knife and fork, and to take a shower on her own. But for some individuals, there were still limitations to their living situations.

Friendship was an issue for some of the participants. While some referred to having friends through church activities, others indicated that this was an area of their lives that was lacking. Several people had also lost contact with friends from the past.

Another issue commented on by some, was the desire to work and the loss of work opportunities in the community. The ability to make choices, and have the freedom to decide who you live with and what you do, was also an issue evident within some of the stories.

Conclusion

This project was about people with intellectual disabilities telling their stories of institutional and community living. There is no doubt that each individual (or the family member telling their story) believed they were leading a far better life in the community than they ever did in the institutions of the past.

The 12 stories had many themes in common. The importance of family/whanau and connectedness resonated throughout. Relationships with family had, in most cases, endured despite often difficult circumstances. Friendships had been harder to maintain in the community setting and, for some, this remained an unmet need. Culture and, in some cases, religion, were vital components of support that enabled individuals to experience better lives in the community. Work (and the opportunity to work) was something that was important to some, but less available to individuals than when they lived in the institutions.

Finally, the importance of freedom to choose one's own path could not be overstated. Institutional living had taken away this basic human need. Community living, to an extent, has given it back.

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The *Extraordinary Journeys* project is about people with intellectual disabilities telling their stories of institutional and community living.

The 12 stories within have many common themes. The importance of family/whanau and connectedness resonates throughout. Relationships with family have, in most cases, endured despite often difficult circumstances. Friendships, on the other hand, have been harder to maintain in the community setting and, for some, this remains an unmet need. Culture and, in some cases, religion, are vital components of support that have enabled individuals to experience better lives in the community. Work (and the opportunity to work) was important to some, despite being generally less available to individuals in the community than in the institutions.

Finally, the importance of freedom to choose one's own path cannot be overstated. Institutional living took away this basic human need. Community living, to an extent, gave it back.

Research for the *Extraordinary Journeys* project was conducted by Wendy Becker. Over the past 30 years, Wendy has worked as a health professional, educator and manager in both government and non-government sectors. Wendy's qualifications include a Master of Public Health, an Advanced Diploma in Occupational Therapy and a Certificate in Adult Teaching.