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Institutionalisation in twentieth-century New Zealand

Carol Hamilton

“We see life within a family as a fundamental right for children as well as the best option. We see no place for children in institutions solely on the grounds of intellectual disability and believe that the appropriate assistance in the home will help to sustain the family. This will also be less costly to the State.”

Craig et al, 1991, 22

“*E rere ki a puawai, e tipu ki a puawai, huiā ka puawai.*”

[“As the water flows and the new buds of the forest arrive: So there is growth.”]

Catherine Colebourne and the Waikato Mental Health
History Group, 2012, 146

Introduction

This chapter focuses on the impact of processes of institutionalisation and deinstitutionalisation on the lives of people with learning/intellectual disabilities in twentieth-century New Zealand.¹ Knowledge about what happened during this period has been slow to emerge, in part due to widespread acceptance within New Zealand society of the idea of ‘out of sight, out of mind’ that surrounded the notion of (intellectual) disability at this time. Later on, the desire for families and communities to move on from institutional practices meant that talk about what had happened was not encouraged. Further, many who had been employed in institutions had signed Declarations of Fidelity that promoted a code of silence about the nature of their work. Gathering information about the experiences of the people themselves has been difficult (Catherine Colebourne and the Waikato Mental Health History Group, 2012, 227–9). However, the two decades since 2000 have seen a growth in material about this still

sensitive area of New Zealand's social history. Records about individual patients have been archived and made available to the public. Personal stories are also accessible in a variety of on-line and text formats. As Craig et al (1991) suggest, the twentieth century saw a consolidation of the right of all intellectually disabled people to live within family and community groups and to access the support needed to do so. Yet to what degree the state actively supported deinstitutionalisation as a means of defraying costs rather than upholding rights is a question that remains open. I return to this at the end of the chapter.

Beginnings: institutionalisation in pre-twentieth-century New Zealand

European settlement in New Zealand began in earnest in 1840 and the first institution was built in Karori, Wellington in 1854. Between 1860 and 1900 large numbers of migrants, the majority from the United Kingdom (UK) and Ireland, arrived, many on assisted passages. Patterns of migration affected local Māori who struggled with the twin effects of European diseases (eg diphtheria, tuberculosis, measles) and social and economic dislocation due to land confiscation (*The Ara Encyclopaedia of New Zealand*, n.d. a). The rapid building of what were called asylums is testament to how quickly European ideas about physical and social 'fitness to belong' took root. Early asylums – Sunnyside (1863), Auckland (1867), Seaview (1872) and Nelson (1876) – followed a UK Victorian-style architecture: large, austere brick buildings in which 'the disturbed, the dangerous, the unpredictable' (Campion, 2012, 12), the ill and the socially vulnerable were confined. Yet asylum use took on a distinctly New Zealand dimension. Asylums offered a workable substitute for the loss, through migration, of wider family support networks. They also provided a one-stop-shop for both migrants and Māori that best utilised the skills of the few specialist medical practitioners (Brunton, 2003). Furthermore they provided employment for local community members (Kearns et al, 2012).

Asylums were initially overseen by provincial governments as no philanthropic or religious group was big enough to take on the financial responsibility. In 1876 responsibility was transferred to the newly formed Central Government in Wellington and subsequently held alongside the general hospital system under a Ministry of Health (MOH). State control provided the basis for management of confinement, care and rehabilitation in these settings for the next 80 years. Overcrowding soon became a problem. Two further asylums

were built: Seaciffe Hall (1882), and Porirua (1887). Ashburn Hall, also built in 1882, was the first to be privately owned. It was located in Dunedin and operated alongside Seaciffe Hall, catering to the requirements of more well-to-do colonial families:

[At Ashburn Hall] there is nothing in the cheery-looking block of buildings and picturesque surroundings to suggest the idea of a home for the insane.... Inside the buildings, as outside, there is really nothing, apart from the eccentricities of the occupants of the rooms, to indicate that Ashburn Hall is a home for the insane ... (Torrance, 1890, 233)

Its opening indicated growing acceptance of institutionalisation as a means of managing the stigma involved in having a family member whose appearance and/or behaviour was deemed difficult or undesirable within the vision of New Zealand as a fit and moral society. Whether people with physical or cognitive disabilities were initially included within these euphemisms remains unclear. However, the issue of who was to be considered 'fit to belong' soon became such a pressing concern that in 1899 an Immigration Restriction Act prohibiting 'any idiot or insane person' (Office for Disability Issues, n.d.) from settling was put into place.

The twentieth century: the first 50 years

In the early years of the twentieth century a growing eugenics movement influenced key developments in the use of existing systems of institutionalisation in New Zealand. The science of eugenics, validated by the publication of *The Fertility of the Uygur* (Chapple, 1903), proposed that all human characteristics were heritable, with some more socially 'desirable' than others (Barker, 1983). The fertility of those with 'desirable' characteristics was to be encouraged, while the fertility of those with 'undesirable' characteristics was to be curbed. These ideas rapidly became moral imperatives, then government policies with real-time consequences for those who did not, or could not, 'fit in'. Segregation became the means of managing the behaviour of those who were considered to have the propensity to pass on undesirable traits, with 'protection, training and other benefits' available within a "well-regulated colony" (Barker, 1983, 203), said to provide the most humane means of separating members of this group from their 'fitter' peers. Many with learning/intellectual disabilities became caught up in the practices of confinement that followed.

The New Zealand Plunket Society (NZPS), set up in 1907, attempted to regulate physical and social undesirability. Truby King, founder of the NZPS, was born in New Zealand, graduated from Edinburgh Medical School in 1886 and became medical superintendent of Seacliffe Hall in 1889 (Olsen, 1981). He believed that the high rate of infant mortality and the broader issue of social degeneracy could be reversed by training girls for motherhood:

If women in general were rendered more fit for maternity, if instrumental deliveries were obviated as far as possible, if infants were nourished by their mothers, and boys and girls were given a rational education, the main supplies of population for our asylums, hospitals, benevolent institutions, gaols and slums would be cut off at the source; further, a great improvement would take place in the physical, mental, and moral condition of the whole community ... (Olsen, 1981, 6)

The NZPS instituted a medicalised assessment of the development of infants and young children. Mobile Plunket-trained nurses were to go into homes to gather information about infant development. This information was then set alongside the normative infant/young child developmental standards of the time, against which decisions about 'fitness to remain' within the family were made. By 1914 branches of the NZPS could be found in the four main cities and in many smaller towns. By 1947 85% of non-Māori babies were within the Plunket system (Olsen, 1981). However, as Brookes (2014) points out, family members also played an important part when decisions to remove sometimes very young individuals to institutional care were made. These decisions were not always easy. Mothers in particular could be caught between their feelings for their child, the responses of other family members and prevailing cultural understandings of disability as 'a problem' to be solved by committing the child to an institution. Fathers were more likely to opt for institutionalisation (Brookes, 2014). The view that 'normal' children would be affected if the disabled child remained at home was widespread. Older children could be admitted when families were no longer unable to manage the individual at home. Factors leading to institutionalisation in these cases included 'changes in family circumstances, ill health or death of a parent or a change in behaviour of the family member' (Houl, 2012, 54). In 1911 the Mental Defectives Act provided political endorsement of the eugenics movement. Asylums became mental hospitals, and

the classifying of specific degrees of 'deficiency from normal' was begun. Categorisation of defects underpinned the tightening-up of the nineteenth-century asylum system (Campion, 2012), while the indicators of deficiency – 'idiots, imbeciles, the feeble-minded and epileptics' (Campion, 2012, 16) – linked the categories to sets of personal characteristics or conditions. Idiots might have a physical disability as well as an IQ of between 20 and 50, an imbecile an IQ of between 50 and 70, possibly with no physical disability but would require care and control. The category of feeble-mindedness, or the group into which those who were 'incapable of competing on equal terms with their normal fellows' (Houl, 2012, 54) were placed, was less clearly defined and used when individuals were deemed to require more control than care. These diagnostic models enabled medical practitioners to institutionalise 'defective' individuals. The 1911 Act also provided the groundwork for the subsequent Education Act 1914 – which obliged parents, teachers and police to report all categories of 'mentally defective' children to state authorities. During the 1920s two Committees of Inquiry, into Mental Defectives (1922) and Sexual Offenders (1925), raised concerns about the reproductive capacity of 'feeble-minded' children, bolstering the link between disability, delinquency and institutionalisation. A short-lived Eugenics Board was established in 1928. The Board was charged with keeping a register of those categorised under the Act as 'mentally defective persons' and to monitor resources used to manage them. It is not clear why the Board was disbanded, but some discomfort in the community about their tasks is indicated in this poem, 'A Mother's Lament', written by a local community member:

"Oh Mother, save me from Dr Gray!²
'Cause teacher says he's coming to-day
And if I'm stupid he'll take me away."
"I cannot save you, my little child!"
His mummie said and her eyes were wild.
"You belong to the State, you're no more my child!
But Oh, my darling, don't stupid be
Or he'll say we've tainted heredity,
And must be eradicated – you and me!"
(McClure, 2017)

By the mid-1930s, legislation, medical processes and social ideas about the confinement of those classified as unfit to live in a well-regulated

society governed the operation of existing institutions. Four further institutions were built – Hokitika (1904), Tokanui (1912), Ngawhatu (1921) and Kingsseat (1929). Cherry Farm opened in 1952. They comprised smaller villa-style ward accommodation within an overall complex. This change allowed for separation and management of psychiatric patients away from those considered mentally deficient (Dowland and Mackinlay, 1985). Therapeutic programmes for psychiatric patients were set up and formal care and release plans put into place. These changes did not impact greatly on the treatment of the majority of those ‘classified’ as mentally deficient.

Tokanui Hospital, 1912–98

Tokanui was built in 1912, firstly to act as a central repository for chronic and incurable patients and to take the most challenging long-term and chronic cases from Porirua and Auckland. People with intellectual disability were more likely to become long-term residents, due to the lack of ‘cure’. After a decade Tokanui began to admit patients directly. Individuals with intellectual disability were admitted into a specific ward of the hospital. They were housed in five ward areas. These received fewer resources and staffing than other wards and little therapy. Some wards were described as bare and featureless with toilet and bathing areas offering the bare minimum of privacy. Often care involved only the basic tasks of feeding, toileting and keeping residents clean. In some cases, training programmes were run for more severely disabled residents, usually due to the enthusiasm of a particular staff member who had an interest in working with intellectually disabled people. When this person moved on, the programmes ceased.

In 1959 people with intellectual disabilities accounted for around one fifth of the residents. When Tokanui closed in 1998 they were the majority.

Source: Colebourne and the Waikato Mental Health History Group, 2012.³

Admission of those with ‘mental deficiency’ to a hospital was made on the basis of a reception order given by a magistrate after an application was lodged. Applications were to be made by a person over 21 years of age. The grounds on which the applicant was deemed mentally defective were to be stated and the application itself accompanied by two medical certificates, issued not more than three days prior to the information being put before a magistrate (Campion, 2012).

Individuals admitted under the age of 21 required an application to be made to the Inspector-General of the MOH by a parent or guardian. A statutory declaration and two medical certificates were also needed. Individuals with intellectual disabilities could be admitted straight to a ward rather than through a reception area (Dowland and Mackinlay, 1985). The form of the induction depended on the informal protocols of the ward concerned.

As part of the procedure all newcomers are given a bath or shower and put into night attire for a period of assessment ... the reason for the night attire is to make them conspicuous until staff are familiar with them. Being put into pyjamas is a practice residents are not always happy with and one of the reasons new admissions are bathed is that it helps otherwise unwilling people to get into pyjamas ... All property including clothes and valuables are taken away ... Wards differ as to whether or not all newcomers are placed in pyjamas ... The decision to come out of pyjamas often resting with the [ward] doctor (Dowland and Mackinlay, 1985, 14–15)

The management of ‘mental deficiency’ was the responsibility of the Mental Hospitals Department. Hospitals were inspected – in some cases inspection was required every three months – and an annual report produced. These documents included information about ‘patient population ... accommodation, farming operations, financial results, staff, medical superintendent’s reports’ (Campion, 2012, 17). Internal registers of admissions, boarders, discharges, escapees, restraints and seclusions, deaths and post-mortems, as well as weekly report books, case books and prescription books, were kept. Children and young people considered ‘feeble-minded’, or who had been made wards of the state, were more likely to be sent to a residential school as an alternative placement. These were established ostensibly to teach education and work skills to the young people involved. However, much depended on how the schools were run as to how much education was available. Early schools included Otekaieke (1908 – later called Campbell Park) for boys and Richmond (1916) for girls. Eventual release from the school was possible. Several psychopaedic units were also set up for more severely disabled children: Stoke Villas (1922), Templeton (1929) and, later on, Levin Training Farm and Colony (1945 – later called Kimberley Hospital). Release from psychopaedic units was far less likely.⁴

The twentieth century – the second 50 years

The second half of the twentieth century saw an increasing questioning of the efficacy of keeping disabled people in institutional settings. Knowledge of what had happened in Germany in the 1930s and 1940s when disabled and non-disabled people were subject to mass incarceration and execution, and New Zealand's commitment to the United Nations Universal Declaration of Human Rights in 1948 led to calls for the development of community care. In 1949 the Intellectually Handicapped Children's Parents Association (later IHC) was founded by Margaret and Hal Anyon, parents of a son with Down's Syndrome who wanted to see their disabled child educated, employed and living in the community. In the beginning IHC was concerned with securing community living for their members' young relatives with intellectual disability, who would live in hostel-style accommodation run by IHC-trained staff. This vision also provided a template for how community-based support could be provided for intellectually disabled adults who were resident in long-stay hospitals. However, as the process of deinstitutionalisation of physically and psychiatrically disabled people began, influential groups sought to retain the option of continued institutional placement for people with intellectual disabilities.

In 1952 a Government Consultative Committee was set up to consider the role of psychopaedic institutions. In 1953 the Aitken Report, named after the doctor who chaired the committee, was published (Stace, 2014). This recommended that intellectually disabled people continue to be housed in large 'mental deficiency colonies' and that the capacity of psychopaedic institutions, such as those at Levin (Kimberley) and Templeton, be increased. It further recommended that parents be encouraged to leave their disabled children in these institutions from about the age of five. Its influence was significant, as indicated in a report about residential capacity at Tokanui Hospital at the end of the 1960s.

There is a constant demand for psychopaedic beds and a particularly heavy demand for the admission of children in the 5–15 age range ... demand has remained high in recent years notwithstanding a very considerable build-up of subsidiary services such as occupation centres, hostels and sheltered workshops in local communities. (Department of Health, 1969, 100)

Case studies of admittance, 1950s–1970s

Robert – admitted to Kimberley in 1959, age 18 months. Left Campbell Park residential school in 1966, age 15:

"I came [to Kimberley] when I was just a baby... I don't remember this time really well except that there was a lot of us and that even though I was small I know I had a mum and a dad and a sister. I cried for them but no-one came and eventually I stopped crying ... I know of stories of parents dropping their child off for the first time and then changing their minds on the way back home or after a week or two apart. Those parents couldn't just go back and pick up their baby. They had to battle the system and prove that they could look after their child before he or she could be released to them ..." (McRae, 2014, 14–23)

Alice – admitted to Kingseat Hospital in 1950, age 8. Left Carrington Hospital, age 48:

"I saw Mum packing a suitcase in the dining room and I was just standing there watching. I said, what are you packing that suitcase for? Those look like my clothes, where am I going? And she said you're going to your Auntie Pats for a week's holiday. And the next morning Dad carried out the suitcase and put it on the back seat of the car ... When Dad had finished signing the papers they gave me a bath. I said I want to go home I don't like this place. They said, if you can behave yourself for a fortnight you can go home. And I was six months locked up in that observation ward." (Production SCDigital, 2015)

Norman – deemed low-grade feeble-minded. Admitted to Templeton, age 6. Went to work on a farm, age 18. Declared 'fit to live in normal society' in 1960, age 21:

"It was a place where kids went to. Most had disabilities of some sort. They told me I would go to school there. I never got to go to school. Instead I worked on the farm. I had to look after the less abled, clean them up." (Smyth, n.d.)

Bev – as a ward of the state was admitted to Porirua Psychiatric Hospital in the 1960s, age 15. Left at an unknown date:

"They'd put children locked up with these people in this ward ... we were attacked, was worse than that, I remember, I was in the kitchen and I was ..."

electric shock treatment] ... I couldn't remember who I was and I couldn't remember why I was here ... when I woke up from it my throat was ... like I had something shoved down my throat." (Kearns et al, 2012)

Brent – admitted to Kimberley in 1972, age 2. Left when Kimberley closed in 1996.

"Mum and Dad say goodbye to me and they'll come back another day. I started to get a bit scared then. I didn't understand much. I was just a little boy then ... that's all I remember. 1972." (Stuff, 2014)

While demand for placements remained high, oversight of the living conditions of those with intellectual disabilities, never as rigorous as for those with other disabling conditions, became less and less thorough. Abuse and neglect, including 'physical, sexual, emotional, spiritual abuse, neglect and issues of control and restraint' (Mirfin-Veritch and Conder, 2017, 6) in the hospitals, units and residential schools were commonplace. Those who avoided abuse themselves had to witness the abuse and neglect of those they lived with. Some staff did what they could to keep residents safe in the hospitals and schools, and concerns about maltreatment were raised from the 1950s onwards. However, far too little was done to remedy the situation (DBI, 2008).

Robert

"... we were taken care of, fed and changed. But I don't remember being touched or cuddled like other kids are ... it was a lonely life. We grew up with hundreds of people around us but as a little boy I didn't know another human being. Not properly." (McRae, 2014, 15)

"Sometimes when you were in real trouble they'd take you to Villa 5 ... it was a nightmare and they would take you there as a warning that this was where you would end up if you didn't conform. I still remember being taken there and seeing this completely naked person who had an accident, being washed down with a fire-hose. He was screaming for them to stop... I was a small child back then." (McRae, 2014, 33–4)

Alice

"I used to get dragged down the corridor by staff by the feet and hair and they throw me into a seclusion room there ... and I screamed and screamed and screamed at them, pleaded with them to let me out ... the nurses used to look into you to see what you were up to. If they saw you were

up to no good they'd get reinforcements and unlock the door and come in with a couple of hypodermic needles." (Production SCDigital, 2015)

Norman

"I was abused at Templeton. I was beaten by staff and patients. Life there was hell ... sexually abused, ahn, sodomised, you know. I suppose you could say that it continued on – not just only me but I think a lot of other people too.... You don't forget, doesn't matter how much counselling you have ..." (Smyth, n.d.)

Robert

"Don't get me wrong. There was some good staff ... they gave me books and toy animals from cereal packets and sometimes they took me home to their places at the weekend. I used to cling to those staff but always, in the end, they'd walk out of my life ..." (McRae, 2014, 32)

Alice

"I had a lot of nurse friends that stuck up for me ..." (Production SCDigital, 2015)

While debates for and against institutional care continued, wider societal views about the capacity of young people with intellectual disabilities to learn were changing. Media, including locally produced films, were instrumental in raising public awareness about the capacity of children with intellectual disabilities to learn if given the chance. Commentary from a 1960s film documentary about training offered to intellectually disabled young people in three psychopaedic institutions – Templeton, Ngawhatu and Kimberley – indicates how community views about ability and members of this group were beginning to alter. This documentary included the follow statement alongside footage of intellectually disabled children learning in a new on-site training centre:

[these institutions] ... are caring for 1,500 patients, most of them children ... yet the patients are not necessarily physically ill. The children here are sick, yes, but the sickness is locked away inside their heads ... these are inspiring places, where the close mysterious horizons of the mentally retarded's world are slowly clearing. (New Zealand National Film Unit, 1964)

Further questions about the efficacy of institutional placement for intellectually disabled people saw the movement to reintegrate individuals from institutions gain more momentum from the early 1970s (Houlst, 2012). Having developed a strong information and advocacy role for families and at government level, IHC applied for government funding to purchase and manage family homes in suburban towns. By the late 1970s it had become a powerful, nationwide organisational network that was almost sole provider of residential services for people with intellectual disabilities. IHC was an enthusiastic adopter of the principles of normalisation, 'letting the retarded obtain an existence as close to normal as possible' (Nirje, 1969, 3). This idea became a cornerstone belief for IHC service delivery (Craig et al, 1991). Yet by the end of the 1980s, deinstitutionalisation processes across the country remained slow. The lack of a national plan for the reduction of numbers living in institutions coupled with the lack of community-based placements for those leaving presented particular barriers, as this excerpt from an IHC report shows.

The 550 houses at present owned by the Society will be insufficient if there is a substantial number of transfers of residents from psychopaedic institutions to IHC services. (Craig et al, 1991)

Other limiting factors included transition costs and the fiscal implications of supporting a diminishing number of people left in the institutions (Craig et al, 1991). At the time, a long-stay supplement of \$88.44 (NZ\$158.00 in 2017) per day was paid to local area health boards who held contracts to support individuals in long-stay accommodation. Shifting individuals out of institutional care represented a considerable loss to these providers. Supporting people to leave was further complicated by a government proposal to shift responsibility for all funding and coordination of services from the MOH to the Ministry of Social Welfare. This proposal took a number of years to action (PSA, 1990, 3). Further, the strong belief of some parents/guardians of the benefits of institutional care made it difficult for some residents to leave (Craig et al, 1991). Finally, some institutions were significant local employers, leading to local pressure to keep them. Waiting left some staff in limbo; one staff member reported remembering a discussion about the closure of Kimberley at her interview 17 years earlier (DBI, 2008). Institutional staff were seen as not having the right philosophy and skills to work in community services, and advertised community-based positions were not open

to them (DBI, 2008). As a response, the MOH set up guidelines for ensuring how full community support for deinstitutionalised intellectually disabled people was to be actioned. These included that people be accommodated in 'homes ... that look like others in the neighbourhood, and for locations [to be] close to a wider range of community resources' (Harnett et al, 1988, 3).

Some areas made more resettlement progress than others. In the Waikato region 40 residents of Tokanui Hospital had left by the end of the 1980s, while in Otago 'only 12 of the 140 people identified at Cherry Farm as having an intellectual disability have been transferred' (Craig et al, 1991, 3). For those able to leave, life was, in some ways, very different. Yet some indicators suggest that the people themselves had little option about who they lived with and how they chose to live their lives.

Tokanui Hospital Group, Community Home Evaluation, 1988

A Community Home Evaluation team visited two community-based residence initiative pilot projects in the Waikato region. After an extensive review of the physical environment, support structures and the programmes available to the people from Tokanui living in the residences, the evaluation team concluded that the transition process from the institution had been largely successful.

5.1 Routines

In general the daily routines of the homes followed patterns typical of most New Zealanders. Bed times, waking up, mealtimes, showers and household chores were completed at times in keeping with average New Zealand families. Rigid hospital routines have not been transferred to the community setting as evidenced one Friday night when the evaluators went shopping and banking with the ____ Road residents and sat down to a greatly appreciated meal of fish and chips at around 8.15pm.

5.6 Personal Wellbeing of Clients

Individual health needs were closely attended to at both community homes, medication reviews were carried out regularly by appropriately qualified people. The standard of dress of the residents was particularly pleasing. This is important if the residents' presentation in the community is to enhance their dignity as adults. The staff of both houses are to be congratulated for the high standards they have achieved in this area.

There is no question that community involvement had improved the lives of people released from long-stay hospital care, yet questions remained. Hospital routines were not transferred but, in their place, dominant ideas about how the average New Zealander spent their day came to govern significant aspects of their lives. These could be equally restricting. This statement was made at an early conference about the rights and needs of disabled people:

“... their rights to normal living are offered on the one hand and taken away with the other e.g. one of the conditions of semi-independent flatting, which is a good step in the right direction, for women at one branch, is that they must either have a tubal ligation or a hysterectomy. In another case a woman who was forced to undergo these measures now wants to marry and have children. No one is prepared to tell her she can't have children, but she is encouraged to get married and try anyway.” (“The Handicapped: Rights, Needs, Services’ seminar, 1979, 35)

Health and well-being were more closely attended to than they had been previously, but how much emotional support for trauma experienced while living in institutional care was needed or offered remains an open question:

She conveyed how she re-lived the trauma of her feelings and experiences while in State care through her dreams: “Sometimes I dream about the hospitals I have been in. It can happen any time. When I dream about those places the dreams always wake me up. They are bad dreams. I wake up scared that I am still there.” (Hunter, 1997, 12)

By the last decade of the twentieth century over 11,000 people were receiving community-based residential support (PSA, 1990). Community groups began grappling with how to manage the support requirements of two distinct cohorts – younger people who had never experienced institutional care, and older people who had been through this system. IHC had been at the forefront of the deinstitutionalisation movement, but was increasingly seen as an organisation that could not support both groups effectively.

By the end of the twentieth century how intellectually disabled people were to be supported to live in their local community had become an issue of national priority. In 2000, a National Advisory

Committee on Health and Disability was set up under sections 11 and 13 of the New Zealand Public Health and Disability Act 2000 to provide independent advice to the Minister of Health on a range of issues. The committee led a nationwide consultation process prior to publication in 2003 of the first comprehensive vision for community-based support for intellectually disabled people, the *To Have An ‘Ordinary’ Life – Kia Whai Oranga ‘Noa’* policy document (Ministry of Health, 2003). The process included 10 facilitated focus groups of up to 10 intellectually disabled people who spent two days discussing issues that were important to them (Ministry of Health, 2003). Family/Whānau and service sector focus groups were also held. *To Have An Ordinary Life* recognised that ‘all people, whatever their level of impairment, have the same fundamental human needs and expectations’ (Ministry of Health, 2003, 2) as their non-disabled peers. Its 23 recommendations outlined changes needed including: needs assessment, service coordination, service purchasing, and service delivery. To deliver on people’s aspirations about where, how and with whom they live, publication was followed by closure of the last psychopaedic institution, Kimberley Hospital, in 2006.

Conclusion

The success of the deinstitutionalisation movement in New Zealand was largely due to the persistent advocacy of groups of family members and support personnel who wanted to see a move away from regimes of custodial care, and the establishment of high-quality and respectful community-based service systems. There was much to be optimistic about the goal of full community membership in the early years of the twenty-first century. *To Have An Ordinary Life* (Ministry of Health, 2003) captured the aspirations of parent and advocacy groups. It also provided a vision for people to tell their stories and to record what they want in their lives. However, the late twentieth-century difficulties associated with management and funding of the support needed to achieve these goals persisted into the twenty-first century. As Joseph and Kearns (1997) remarked soon after the closure of Tokanui Hospital, ‘institutions have been easily closed, but less easily replaced’ (p 187). This statement is reflected in the contemporary educational, social and health problems that remain embedded in the support systems on which intellectually disabled people and their family members must rely. These include ongoing difficulties with assessment and funding of individual educational and social needs, the difficulties some people have in exercising choice and control over aspects of their lives, and

the lack of real choice among a number of service providers for those leaving home as young adults. Competition for social welfare funding is fierce and community-based services are particularly vulnerable in periods of fiscal austerity. New support service initiatives such as the Enabling Good Lives Demonstration⁵ are a welcome move to improve both support and funding options. However, funding for projects connected to this Demonstration are allocated on year-by-year cycles, thus long-term funding is not guaranteed. What happens when funding is withdrawn and why the full inclusion of intellectually disabled people is so hard to achieve are questions that have no ready answers. What is important is that we do not forget what happened in the past and that the lessons that can be taken from what went on then can be used to inform what needs to happen in the future.

Postscript: Email from Dr Carol Hamilton to The Royal Commission of Inquiry into Historical Abuse in State Care, 26 April 2018

Carol:

... do the terms of enquiry include State Care in residential facilities? Reason for asking is that I'm writing a book chapter about institutionalisation processes – it's an international publication – and would like to include that this enquiry is taking into consideration past practices of ID [intellectually disabled] people's care in institutional settings.

Gordon [for the Royal Commission]:

... the Royal Commission of Inquiry into Historical Abuse in State Care will include consideration of care provided to people with Intellectual Disabilities in residential facilities such as Kimberley and Tokanui. I hope this clarifies the matter for you.

Appendix

Approximate number of people in New Zealand with an intellectual disability in 1991

South Island	
Braemar/Ngawhātu	208
Cherry Farm	169
Gore Hospital	9
Seaview	69
Templeton	550
North Island	
Kimberley	492
Lake Alice	3
Mangere	342
New Plymouth	24
Porirua	139
Tokanui	350
Total	2,439
With families or in their own homes	5,300
In IHC homes	3,000
In Hohepa Homes	150
Mr Tabor Trust Homes	41
Other	309
Total current estimate	11,000 (approx.)

Psychiatric hospitals

Carrington, Kingsseat, Raventhorpe, Tokanui, Lake Alice, Porirua, Ngawhātu, Seaview, Sunnyside, Cherry Farm

Source: Craig et al (1991), 32.

Notes

- 1 The Treaty of Waitangi was signed in 1840 when NZ became a British colony.
- 2 Dr Gray, originally from Scotland, proposed severe eugenics-inspired measures for the registration and isolation of 'mental defectives' in New Zealand. He became head of New Zealand's mental hospitals in 1927.
- 3 The Waikato Mental Health History Group was set up by Associate Professor Catharine Colebourne from the University of Waikato as part of an oral history project into mental health in the Waikato region of New Zealand. Tokanui Hospital was the fourth-biggest long-stay psychiatric and intellectual disability institution in the country and was situated outside of Te Awamutu. Many local people were connected over time with the hospital, which was one of the biggest employers in the region.
- 4 New Zealand was unique in offering a three-year qualification in psychopaedic nursing. This was an allied mental health qualification for people wishing to work with people with intellectual disabilities. The qualification was completed 'on the job' and was disestablished in 1989.
- 5 Information about the Enabling Good Lives Project can be found at www.enablinggoodlives.co.nz

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