

The Closure of the Templeton Centre

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Abstract

This M.A. thesis argues that the closure of the Templeton Centre was caused by the convergence of political, social and economic trends in psychopaedic care, occurring in other Western countries. The research paper commences with an historical exploration of the emergence of state institutions. It continues with an investigation of the role scandals played in creating the demand for the closure of psychopaedic institutions. The disability rights movements' discourse of 'normalisation', is shown as the social ideological force in the closure of state institutions, while neo-liberal ideology is seen to exploit deinstitutionalisation for economic gains. The research concludes with an assessment of parental and public reactions to the community placement of people with intellectual disabilities and an analysis of the positive outcomes and negative consequences of deinstitutionalisation.

While current research on the closure of the Templeton Centre has explored the effect of deinstitutionalisation on the intellectually disabled and their respective families, the contribution of this research to the subject is its exploration of the sociological causes and effects of the deinstitutionalisation of the Templeton Centre

The research methodology involved the collection, collation and interpretation of primary and secondary documents to construct a sociological account of the deinstitutionalisation of the Templeton Centre. The primary sources include health and social welfare documents, newsletters and letters and the secondary sources comprises books, journals and newspaper articles.

The principal argument is that the Western political, social and economic ideologies which converged at differing times to create, shape and eventually close psychopaedic institutions, also affected the Templeton Centre (1929 to 1999) in New Zealand. The research paper's conclusion is that Western political, social and economic trends will continue to shape New Zealand Governments' policies on people with intellectual disabilities. Therefore, disability research specialists must continue to study changes on the international stage, to enable them to predict the probable discourses, issues and events which will inevitably occur in New Zealand.

Introduction

On the 15th November 1994, the Intellectually Disabled Persons' Health Division of Healthlink South and the Southern Regional Health Authority (SRHA) released a discussion document calling for comment on a proposal for the deinstitutionalisation of the Templeton Centre. The Healthlink South and SRHA's proposal to close the Templeton Centre, was to act as a catalyst for widespread public debate on the effect of deinstitutionalisation on people with intellectual disabilities. While current research has investigated the impact of the closure of state institutions on people with intellectual disabilities and their families, there is an absence of research on the sociological causes and consequences of the closure of the Templeton Centre.

In part one of this M.A. thesis, the author will discuss the Western political, social and economic forces which have converged at different times to shape policies of social exclusion, incarceration, vocational training and rehabilitation of people with intellectual disabilities. The New Zealand Governments' policies towards the Templeton Centre will be shown to have followed these international trends. In addition, the Western scandals of abuse and neglect in psychopaedic institutions and the resulting criticisms of the appropriateness of those state institutions for people with intellectual disabilities, will be seen to have forced the closure of state institutions, such as the Templeton Centre.

In part two, the thesis will argue that the Western disability rights movements discourse on the civil rights of people with disabilities, expressed in the social philosophy of 'normalisation', provided the primary reason in the demand for the deinstitutionalisation of state institutions, including the Templeton Centre. However, it will also argue that Western neo-liberal governments' closure of state institutions, served a secondary purpose in reducing state expenditure on the health and disability infrastructure, including the cost of upgrading and operating the Templeton Centre.

In part three, the thesis will conclude with a comparison between the Western communities' reaction to the deinstitutionalisation of psychopaedic institutions and the parental and public reaction to the closure of the Templeton Centre. Also, Western countries' research on the positive outcomes and negative consequences of deinstitutionalisation will be compared to the life experiences of ex-Templeton residents.

Chapter One

Historical Emergence of State Institutions

The Historical Rise and Role of Institutions and the Templeton Centre

Prior to the 1800s, in Western societies, the personal care of the poor, sick and disabled populations was undertaken by unpaid care-givers such as families, relatives, neighbours and parish authorities (Felton & Shinn, 1981, Smith, 1999). Tragically, a significant number of individuals within these dependent populations were abused and neglected by their respective families and communities (Scull, 1993). It was common for people with disabilities to be forced to survive as vagrants in cities, towns and villages due to communal neglect (Scull, 1993).

By the beginning of the 1800s, Western nations began to provide limited care for these vagrant populations (Scull, 1993). In the United Kingdom, 'workhouses and madhouses', and in the United States, 'almshouses, county homes, poor houses and workhouses', were established for the care and support of individuals who lacked the resources and/or ability to care for themselves (Felton & Shinn, 1981, Dear & Wolch, 1987, Smith, 1999). These individuals included the blind, elderly,

orphans, people dying of infectious or chronic diseases, people with physical and mental disabilities, poor, unmarried mothers and widows (O'Brien & Thesing, 1999).

However, by the mid-1800s, in both the United Kingdom and the United States, the poor houses and workhouses had begun to suffer from overcrowding, caused by their attempt to cater for an increasing and diverse dependent population (O'Brien & Thesing, 1999). Therefore, the state began to build specialist institutions for specific dependent populations, such as asylums and hospitals for the psychiatrically and intellectually disabled, which helped to reduce markedly the overcrowding problem in poor houses and workhouses in both countries (Dear & Wolch, 1987, Scull, 1993, O'Brien & Thesing, 1999).

In the United Kingdom, during the mid-1800s, voluntary subscription hospitals supported by charitable subscriptions, donations and bequests, began to provide specialised institution-based care for the sick and disabled populations (Smith, 1999). The state began to incarcerate the disabled populations into these asylums and hospitals, both as a means to reduce overcrowding in its other institutions, as well as confining persons unable to conform to the norms and mores of everyday life in their families and communities (Scull, 1993, Gravestock, 1996, Smith, 1999). The St Luke's Hospital established in London in 1751, was the prototype for public asylums and hospitals, which catered specifically for people labelled as 'lunatics' (psychiatrically disabled) and 'idiots' (intellectually disabled) (Smith, 1999). By 1845, the United Kingdom Lunatic Asylum Act, made it compulsory for the state to provide specialised asylum or hospital care for people labelled as lunatics or idiots (O'Brien & Thesing, 1999).

The United States of America, during the late-1800s followed the changing international trend towards the care and confinement of the disabled population. The United States Government increasingly placed large numbers of people with psychiatric and/or intellectual disabilities into specialist asylums and mental hospitals (Dear & Wolch, 1987). However, in the United States there was a convergence of social and economic factors which caused the state to follow the international trend towards the incarceration of the intellectually disabled into asylums and mental hospitals. The United States Government's encouragement of rapid capitalist economic growth, had resulted in the production of a large range of private and public goods and services for the consumer (O'Brien & Thesing, 1999). These public goods and services included new medical products and practices for the treatment of the disabled (Curtis, 1986). New medical products and procedures enabled infants born with severe physical and intellectual disabilities to have an increased survival rate after birth (Curtis, 1986). Also, the average life expectancy of people with disabilities increased due to improved public housing, health and welfare services (Curtis, 1986).

However, the United States' capitalist economic growth also led to an increasingly modernised and urbanised population, resulting in the disruption and displacement of extended family networks, which led to the development of the socially isolated nuclear family. Unfortunately, the new emerging nuclear family often lacked the willingness and/or resources to provide full-time care for their disabled relative in the family environment (Curtis, 1986). Therefore, the growth of the capitalist mode of production, improved health products and services, the increased disabled population and the social decline of care-giving in nuclear families, created pressure on the United States' Government to build specialised state hospitals and institutions for the care of the intellectually disabled (Curtis, 1986).

By the 1900s, in both the United Kingdom and the United States, state institutions had developed a dual role in the care of the intellectually disabled. This dual role included 'vocational training' as well as 'moral treatment' for the intellectually disabled (Curtis, 1986). The capitalist mode of production required vocational training for people with intellectual disabilities, to equip them with new skills which would facilitate their ability to contribute to factory-based production (Curtis, 1986, O'Brien & Thesing, 1999). Also, the state rehabilitation of the intellectually disabled included 'moral treatment' for patients, in order to teach individuals to adopt 'socially appropriate behavioural norms', which would allow them to return to their families and the community (Dear & Wolch, 1987 p.29).

However, by the 1970s, Western Governments had begun to revise the role of state institutions as providers of vocational training and social rehabilitation for the intellectually disabled. Instead, the state began to adopt the philosophical discourse of normalisation, which argued that people with disabilities would have a better 'quality of life' within a community environment (Bennie, 1993). The social discourse of normalisation challenged the appropriateness of state institutions in the long-term care of the disabled population. This led to the promotion of an anti-institutionalisation discourse within state health and disability policies and practices (Bennie, 1993, O'Brien & Thesing, 1999). The principles of normalisation argued that people with disabilities needed to live in a normal environment to enable them to develop socially valued roles and competencies, which would allow them to live a more normal life. This change in social philosophy in the care of the disabled was to set the scene for the large scale closure of state institutions in all Western countries.

The Templeton Farm Colony (New Zealand)

In New Zealand, the historical evolution of its state institutions has paralleled developments in the United Kingdom and the United States (O'Brien & Thesing, 1999). Prior to the mid-1850s, the personal care of the intellectually disabled was undertaken by families and/or relatives (Thomson, 1995). This placed a huge care-burden on families, especially women who were the primary unpaid care-givers (O'Brien & Thesing, 1999). However, in 1853, the Government began to build 'lunatic asylums' for the care and confinement of people with psychiatric disabilities (O'Brien & Thesing, 1999). Also, in the 1860s, a limited number of 'benevolent institutions' were established to care for the disabled, destitute elderly, orphans and unmarried mothers (Thomson, 1995). In 1911, the Mental Defectives Act enabled state 'lunatic asylums' to accept people with intellectual disabilities as patients (Shephard, 1995).

In 1928, Dr. T. G. Gray, Director of Mental Health, travelled to the United Kingdom, United States and Europe to study international trends in the care and treatment of the intellectually disabled (Shephard, 1979). Dr Gray's research showed that the placement of people with intellectual disabilities into lunatic asylums (mental hospitals) meant that they were often inappropriately labelled and treated as 'sick' persons (O'Brien & Thesing, 1999). Dr. Gray's submission to the New Zealand Parliament in 1928, sought an amendment to the 1911 Mental Deficiency Act (Shephard, 1979). The amendment permitted some institutions to be set aside specifically for the care, control and vocational training of intellectually disabled children, who had been previously accommodated in mental hospitals (Shephard, 1979, Hill, 1987). The New Zealand Parliament passed the amendment, which meant that children with intellectual disabilities would no longer be incarcerated in state mental hospitals, or be endured as a care burden on their respective families.

In 1929, the Templeton Farm Colony, which had been built as a replacement for Sunnyside Hospital, (a provider of care for psychiatric and psychogeriatric patients), was set aside for the care and control of children with intellectual disabilities (Somerville, et al. 1976, Shephard, 1979, Shephard, 1995, Hill, 1987). The Templeton Farm Colony, under the provisions within the amendment to the 1911 Mental Deficiency Act, became a specialised state institution, for the care, control and vocational training of children with intellectual disabilities (Shephard, 1995, Healthlink South, 1994). The Templeton Farm School was also established to provide special education classes for the intellectually disabled children (Shephard, 1979). On the 19th August 1929, eight male children were admitted to the Templeton Farm Colony as residents (Shephard, 1979). The male 'children's' ages ranged from five years to twenty years of age (the term 'children' tended to be associated with an alleged mental age, rather than their actual biological age) (Shephard, 1979).

The Templeton Farm Colony, located thirteen kilometres south of Christchurch, provided a rural location, which was geographically isolated from the able-bodied society (Shephard, 1979, Healthlink South & SRHA, 1994). The geographical location socially excluded children with intellectual disabilities, as a means to protect the able-bodied population from the alleged dangers of the disabled (Shephard, 1979). Also, the state sought to protect children with intellectual disabilities from the suspicion and hostility of the able-bodied society (SRHA & Healthlink South, 1994).

From 1929 to 1942 the Templeton Farm Colony began to expand, with the majority of the accommodation being built, including large dormitory style villas for the increasing male and female resident population (Healthlink South, 1994). In 1930 Maple Villa was built, followed in 1931 by Briar Villa, then in 1932 Kauri Villa, 1934 Hinau Villa, 1935 Rimu Villa, 1937 Totara Villa and Manuka Villa, and in 1942 Cedar Villa (Shephard, 1995). By 1936, a occupational block was built to provide trade related training for male residents in the production and/or repair of furniture, venetian blinds, livestock covers, wooden toys, foot-wear and leather-craft accessories (Shephard, 1979, Shephard, 1975, Hill, 1987). By 1937, eight villas had been opened and in 1939 the laundry was also opened (Shephard, 1979). In 1947, the villas were separated into female and male villas (Shephard, 1995).

The Templeton Farm Colony provided both vocational training and employment for its more able-bodied residents (Shephard, 1979, Hill, 1987). The Templeton Farm comprised nine hundred and eighty acres, of which seven hundred acres was used for livestock (cows, pigs and sheep) and mixed cropping activities (Shephard, 1979, Shephard, 1995). The Templeton Farm produced farm produce for both the needs of its own hospital as well as other institutions in the North Canterbury region (Shephard, 1979, Shephard, 1995). The Templeton Farm Colony also included a large garden area, which provided vocational training for male residents in lawn cutting and maintenance, hedge trimming, gorse grubbing, weed control, moulding and digging of potatoes and the cleaning of water races (Shephard, 1979). While male residents were trained in farm and gardening skills, female residents were restricted to domestic related labour in the kitchens, laundry and other domestic situations (Shephard, 1979). However, the vocational and employment skills were appropriate only to the more able-bodied male and female Templeton residents (Shephard, 1979).

In 1939, the outbreak of World War Two saw a lull in the development of the Templeton Farm Colony, as limited finance and resources were re-directed to the war effort (Shephard, 1979).

In 1955, the Nurse's Home was opened for female staff members, separating the staff accommodation from the patients villas (Shephard, 1979). In 1959, the Male Staff Hostel opened, which completed the separation of staff from patient accommodation (Shephard, 1979).

In 1960, Kowhai Villa, Pine Villa, Tawa Villa, a community hall and a store and office were added to the Templeton complex (Hill, 1987, Shephard, 1995). By 1966, the Templeton Farm Colony's facilities further expanded to include a chapel, called 'The Chapel of the Holy Family' (Shephard, 1979, Shephard, 1995). However, in 1967, the Templeton Farm Colony was dis-established with the transfer of eight hundred acres to the Agriculture Department, to be used as a crown agriculture research station (Shephard, 1979). The Templeton Farm Colony's loss of the farm acreage and its related farming activities, (which left the hospital and school as its major assets) meant that it increasingly became referred to as the Templeton Hospital and Training School. The demise of the Templeton Farm Colony also heralded a social change from vocational training and employment for the intellectually disabled to an increased emphasis on social rehabilitation, which would enable the more able-bodied to learn skills enabling them to return to the community.

In 1968, the Templeton Hospital and Training School opened a new administration block (Shephard, 1979). In 1973 Puriri Villa was opened, followed in 1974 by Poplar Villa and Rata Villa and in 1975 Nikau Villa, Miro Villa and Beech Villa were also opened (Shephard, 1995) By 1975, a gymnasium and indoor heated swimming pool were also completed (Singh, et al. 1985, Shephard, 1995). By 1976, the Templeton Hospital and Training School established three homes in the community for more able residents, who were supported by social workers, as well as one half-way house located at the Templeton Hospital (Somerville, et al. 1976). In 1977 the Industrial Training Complex was opened which included an industrial block, printing department, pre-industry block, pre-school and school (Somerville, et al. 1976, Shephard, 1979) In 1978, the cricket pavilion was completed (Shephard, 1979, Hill, 1987, Healthlink South, 1994). In 1989, the old villas, Hinau and Cedar were closed as the population decreased and by 1992 Maple Villa had also closed (Shephard, 1995). In 1988, the Templeton Hospital and Training School was re-titled the Templeton Centre (Shephard, 1995).

While the Templeton Centre was a state institution, it had, over the years, developed a sense of community identity and provided limited participation in normal everyday activities for most of its residents, such as improved residential care, vocational training, social rehabilitation employment, sport, recreation and various other types of entertainment (Shephard, 1979). The Templeton Centre residential care normally meant the placement of residents in dormitories of approximately twelve beds in fifty bed villas, with residents of similar age and level of disability placed in the same villa (Somerville, et al. 1976, Singh, et al. 1985). However, Templeton residents who were more independent were placed into smaller groups (5-6 persons) in supervised flats, to resemble a more normal residential environment (Singh, et al. 1985). Those Templeton residents who were more able-bodied, were engaged in a wide range of vocational training, social skill development and employment activities (Somerville, et al. 1976, Shephard, 1979). Templeton residents were also involved in a large number of sports, which included basketball, cricket, rugby and softball (Shephard, 1979). Templeton residents were also involved in the Templeton Band and often attended dances in the recreation centre (Shephard, 1979). The Riding for the Disabled, lawn bowls, tennis courts, a pond adjoining

a bush track, an aviary and a small zoo were also sources of recreational activity for residents (CAHB, 1991, Shephard, 1995). Some Templeton residents attended classes at the Christchurch Polytechnic to learn basic life skills and engage in special needs educational courses (CAHB, 1991, CAHB, 1993). The Templeton School, which employed full-time teachers also provided life skills and educational classes for special needs children (CAHB, 1993).

Templeton Residents

The Templeton resident population was to change over the years in both numbers and type of intellectual disability. On the 19th August 1929, the Templeton Farm Colony admitted eight intellectually disabled male children, who were deemed sufficiently able-bodied to engage in agricultural and horticultural vocational training and employment (Shephard, 1979). On the 12th March 1930, the Templeton Farm Colony accepted four intellectually disabled females, who were able to be trained in domestic skills (Shephard, 1979). As the Templeton Farm Colony villas were built, the number of residents steadily increased (Somerville, et al. 1976). The Templeton Farm Colony began to accept as residents, older intellectually disabled male and female residents (Shephard, 1979).

The Templeton Farm Colony and re-titled Templeton Hospital and Training School tended to cater for people with mild to moderate intellectual disabilities, which enabled vocational rehabilitation programmes to be more effective in preparing people for an eventual return to community living (Shephard, 1979). However, a limited number of intellectually disabled residents had more severe and/or multi-disabilities, which severely limited their ability to benefit from vocational and social rehabilitation programmes.

The Templeton residents included both day patients for respite care, short-term patients for medical assessments and specific training programmes, as well as long-term stay patients (Shephard, 1979). The Templeton Hospital also provided medical assessment, dentistry, doctors, domiciliary nursing, occupational and physiotherapy, physical education, psychological services, speech therapy, vocational training and social workers (Somerville, et al. 1976, CAHB, 1991, CAHB 1992).

The Templeton villas were organised into four main villa areas, which included the multi-disability area, habitation area, pre-community area and an extended care area (CAHB, 1991a). The multi-disability area (Briar, Nikau, Kauri & Rowan villas) provided beds for people with physical and intellectual disability (CAHB, 1991b). The habilitation area (Pine, Kowhai, Rata & Puriri villas) provided beds for people engaged in habilitation and training programmes (CAHB, 1992). The pre-community area (Beech, Hinau, Miro & Polar villas) provided beds for people receiving life skills training prior to discharge into the community, while the extended care area (Totara, Manuka, Maple, Matai & Rimu villas) provided beds for people receiving long-term extended care (CAHB, 1993).

However, as the vocational training and social rehabilitation programmes transferred the more able-bodied into the community, the Templeton population began to shift towards a more severely and multi-disabled population (Shephard, 1979, Shephard, 1995). Templeton residents ranged from the moderately intellectually disabled, requiring continuous supervision, to profoundly intellectually and physically disabled with challenging behaviours, who required intensive nursing care twenty four hours a day, seven days a week (Shephard, 1979). Urgent admissions were usually of multi-disabled children who could not be managed in the family home, older male children who had behavioural problems

at home and school, and those intellectually disabled adults with ageing parents who could not cope, who sought a permanent settled environment for their dependent family member (Somerville, et al. 1976).

From its original admission of eight, the Templeton resident population changed over the years, peaking at six hundred and fifty four in 1974 (Singh, et al. 1985). By 1994 the numbers had fallen to four hundred and eighty (Singh, et al. 1985, Healthlink South 1994). The 1929 to 1974 increase in Templeton residents, was due to the growth of state incarceration of people with mild intellectual disabilities for vocational training and social rehabilitation as well as long term confinement of the more severely intellectually disabled. The New Zealand Government's policies followed international trends of incarceration, social exclusion and limited vocational training and social rehabilitation. However, the 1974 to 1994 decline in Templeton residents was due to the transfer of elderly intellectually disabled to nursing homes and rest homes, as well as natural death (Healthlink South & SRHA, 1994). Also, the state health authorities' decision to place people with intellectual disabilities into community-based care, rather than into the Templeton Centre, meant that the decline in Templeton residents would not be reversed (Healthlink South & SRHA, 1994).

At the 1st of January 1994, 450 Templeton Centre residents were aged over 17 years of age and 30 were under 17 years of age (Healthlink South & SRHA, 1994). The residents age groups were, children 0-10 years (8), youth 11-20 (39), young adults 21-30 (116), middle aged adults 31-60 (313) and older adults 61+ (4) (Healthlink South, 1994). The gender ratio of Templeton residents was 306 males and 174 females (Healthlink South & SRHA, 1994). The range of ethnic groups included 461 European, 16 Maori, 2 Pacific Island and 1 'other' (Healthlink South & SRHA, 1994). The range of disabilities included; 48 minimal needs with nil to moderate challenging behaviour, 66 minimal needs and severe challenging behaviour, 96 moderate needs with nil to moderate challenging behaviour, 142 moderate needs with severe challenging behaviour, 81 intensive needs with nil to moderate challenging behaviour, and 47 intensive needs with severe challenging behaviour (Healthlink South & SRHA, 1994) The level of intellectual disability was classified as 19 people with mild intellectual disability, 167 people with moderate intellectual disability, 158 people with severe intellectual disability and 136 people with profound intellectual disability (Healthlink South & SRHA, 1994).

The demographic trends show that the Templeton Centre's resident population was steadily decreasing in number, caused by a raised entrance age, reduced admissions due to alternative community options (except for people with multi-disability and/or severe intellectual disability), increased community placements, transfer of elderly disabled to retirement and nursing homes as well as natural death (Healthlink South & SRHA, 1994). There was a greater number of males to females which reflected the higher incidence of intellectual disability among males and the tendency for males to be placed in institutions rather than being cared for in the family environment (Healthlink South & SRHA, 1994). The average age of Templeton Centre residents was steadily increasing, with an increasing number of middle-aged residents (Healthlink South & SRHA, 1994). The Templeton population also had an increasing number of people with moderate to severe intellectual disabilities as well as multi-disabilities, due to the transfer of higher functioning residents into the community (Healthlink South, 1994).

However, the Templeton Centre's role in vocational training and social rehabilitation was to be undermined by both its changing demographics and the

shift from vocational and social rehabilitation to normalisation. The Templeton Centre's increasing ageing and severely disabled resident population, had learnt all the vocational training and social rehabilitation skills their disability enabled, therefore, the Templeton Centre's role as a service provider of vocational training and social rehabilitation skills was no longer relevant. Also, state institutions, such as the Templeton Centre, were seen as incompatible with the emerging international trend towards normalisation. The Templeton Centre's large institutional setting and large dormitory villas were seen as creating a culture which encouraged institutional behaviour among its residents (Healthlink South & SRHA, 1994). The emphasis on the disabling effects of the personal disability had shifted to the alleged disabling effect of the institution on the individual (Wolfensberger, 1983, Wolfensberger, 1987). While the institutional setting did not cause the disability, it was seen as contributing and compounding the effect of disability on the life of the individual (Wolfensberger, 1983). Therefore, the solution to the disabling effect of an institution-based environment was to shift the disabled person to a 'normal' environment such as a (5-6 person) group home in the community (Wolfensberger, 1983, Wolfensberger, 1987).

However, the shift of emphasis from the disability to the environment, ignored the powerful disabling effect a severe or profound intellectual disability has on the individual, irrespective of changes to the physical environment. Also, the advocates of normalisation seemingly ignored the fact that the Templeton Centre's population had a high number of people with severe and profound disabilities.

A Summary of the Rise of State Institutions and the Templeton Centre

This historical overview of the gradual emergence and steady decline of Western state asylums and institutions has shown that the Templeton Centre followed international trends. Historically, the rise of state institutions, including the Templeton Centre, was caused by the unwillingness and/or inability of families and communities to adequately care for people with intellectual disabilities. In Western societies, the state incarceration of people labelled as 'lunatics' and 'idiots' into asylums and institutions was a form of social control and exclusion, primarily aimed at maintaining civil and moral order as well as protecting the able-bodied population. In New Zealand, the 1911 Mental Defective Act led to the social exclusion and incarceration of the intellectually disabled into state mental asylums and hospitals. The Western nations' incarceration of the intellectually disabled often exposed them to inappropriate moral and medical treatment. Prior to Dr Gray's 1928 submission on the 1911 Mental Defective Act, New Zealanders with intellectual disabilities were also placed under medical confinement and control.

As Western states changed their perceptions of the value of the disabled, the role of state institutions also changed. The capitalist society sought to use state institutions to re-educate people with disabilities to enable them to contribute to the capitalist mode of production. In New Zealand, the 1928 amendment to the Mental Defectives Act, enabled the Government to shift people with intellectual disabilities from the care of mental institutions, to state institutions which provided vocational training and limited social rehabilitation of people with intellectual disabilities to make them socially and economically productive citizens. The Templeton Farm Colony successfully integrated the intellectually disabled into primary and secondary modes of production. The Western states' revision of the appropriateness of institutional-based care as a site for social rehabilitation, led to the advocacy of the application of the principles of normalisation in a community environment. The Templeton Centre, as a state institution, was now incompatible

with the new social goals of normalisation embedded within this new and broader form of social rehabilitation discourse. Therefore, the historical international trends which had shaped the rise of state institutions such as the Templeton Centre now demanded its immediate closure. The Western states' usage of state institutions had turned full circle and the intellectually disabled, including Templeton Centre residents, would return to the same community environment, which had formerly shown such a lack of care and compassion.

Chapter Two

Scandals in State Institutions

The role of Scandals in the Development of Government Policies on State Institutions

The decline of state institutions, caused by the emergence of anti-institutionalisation discourse, supported by the philosophy of normalisation, was accelerated by scandals related to the care of people with intellectual disabilities in state institutions. Since the 1960s, the United Kingdom, United States, Australia and New Zealand began to adopt the philosophy of normalisation, as a solution to scandals related to patient over-crowding, patient abuse and neglect as well as the development of abnormal behavioural patterns among the intellectually disabled in state institutions (Bachrach, 1978).

In the late 1960s, in the United Kingdom, 'The Report of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency', advocated the transfer of people with disabilities from state institutions to community-based residential care (O'Brien & Thesing, 1999). The Royal Commission's report argued that the transfer of people with intellectual disabilities into community-based residential care, would alleviate the problems related to patient overcrowding in state hospitals and institutions (O'Brien & Thesing, 1999).

The 1970s Campaign for the Mentally Handicapped also supported the call of deinstitutionalisation of people with intellectual disabilities into full residential care in the community (O'Brien & Thesing, 1999). The public support of deinstitutionalisation increased as several Royal Commissions of Enquiry revealed scandals involving the abuse and neglect of patients in state institutions (O'Brien & Thesing, 1999). In 1971, the Department of Health and Social Security published a white paper entitled 'Better Services for the Mentally Handicapped' which provided a comprehensive guide for health and local authorities to provide community-based services for people with intellectual disabilities (Hudson, 1991, O'Brien & Thesing, 1999). The major strategy of community-based services, was to change the inappropriate behavioural patterns among the intellectually disabled, which were caused by their incarceration in state institutions. In 1975, the 'Better Services for the Mentally Handicapped III' paper, also promoted the strategy of community-based services for the intellectually disabled (Thornicroft & Bebbington, 1989).

In 1983, the policy of deinstitutionalisation was firmly embedded in the 'Health and Social Services and Social Security Adjudication Act' (Hudson, 1991). This legislation required District Health Authorities (DHA's) to fund local authorities and voluntary agencies to shift people from state hospitals into

community-based care (Hudson, 1991). This led to the implementation of pilot programmes for deinstitutionalisation in the United Kingdom (Hudson, 1991).

In the United States, the linkage between scandal in institutional care and policy development followed international trends. Prior to World War Two, institutionalisation was seen as a progressive mental health strategy for people with psychiatric and intellectual disabilities (Grob, 1995). However, since World War Two, institutionalisation became increasingly seen as merely a form of warehousing of people with psychiatric and intellectual disabilities (Grob, 1995). The United States' institutions were criticised for several reasons including; abuse and neglect of patients, inadequate staff-patient ratios, inappropriate treatment and punishment methods for unacceptable behaviour, practices which encouraged dehumanisation, negative staff attitudes, and the overly routinised institutional life of patients (Biklen, 1979, Dear & Wolch, 1987, Grob, 1995).

The public criticisms of institutions were advanced by civil liberties lawyers in both federal and state courts as class action lawsuits were filed at both the federal and state level against specific institutions accused of abuse and neglect (Curtis, 1986, Johnson, 1989). For example, in the class action against Willowbrook State School, civil liberties lawyers adopted the strategy of targeting a state institution that had been publicly criticised for its poor conditions and treatment of people with disabilities (Curtis, 1986). The civil liberties lawyers identified relatives of people with disabilities, as well as former disgruntled employees, who were willing to testify against the institution in a class action (Curtis, 1986). The lawyers then filed a law suit against the state institution for violation of the disabled person's constitutional rights and used the court proceedings to release documents, photographs and testimonies to the print media to distribute to the public across the country (Curtis, 1986).

In the United States, the print media has had a powerful influence over politicians, judges and the public in debates about deinstitutionalisation (Biklen, 1979). This was demonstrated in 1966, when Dr. Burton published 'Christmas in Purgatory', which exposed in graphic detail, using both text and photographs, accounts of patients being constrained in straight-jackets, locked in isolation cells, tied to chairs and benches, washed with fire hoses and instances where children were locked in alleged 'therapeutic cages' (Blatt & Kaplan, 1966, Biklen, 1979).

The combination of civil liberties lawyers' class actions against US institutions and media reportage of scandals in institutions, helped to create a public perception that all institutions were inappropriate care-givers for people with disabilities, which in turn reinforced the public demand for deinstitutionalisation (Booth, et al. 1989, O'Brien & Thesing, 1999). In 1963, President Kennedy announced the policy of deinstitutionalisation, which advocated the shift of people from federal and state institutions into community-based care programmes (Shinn & Felton, 1981, Howell, 1991).

In Australia, the convergence of scandals and commissions of enquiry have shaped the demand for deinstitutionalisation of state institutions. Since the 1970s, disability rights movements have advocated the dismantling of congregated and segregated state institutions and the transfer of patients to community-based residential care, which promised to enhance the quality of life of ex-patients (O'Brien & Thesing, 1999). The disability rights movement received support for deinstitutionalisation from judicial enquires into allegations of abuse in state

institutions (O'Brien & Thesing, 1999). In 1995, the Queensland Advocacy Incorporated (advocacy service) wrote in its submission on alleged abuses at the Basil Stafford Centre in Brisbane, that "institutions and institutionalised living in themselves, are causal factors in the presence and perpetuation of ... forms of abuse and neglect of persons who are devalued and vulnerable" (O'Brien & Thesing, 1999 p. 9)

The Australian Government, in response to the political advocacy of the disability movement and public scandals revealed in commissions of enquiry, responded with the policy shift towards the closure of hospitals and state institutions (O'Brien & Thesing, 1999). However, critics of the Australian Government's role in deinstitutionalisation have argued that its policy of hospital closure has been driven by the 'new right' ideology of economic rationality and service downscaling, instead of concerns about the quality of life of people with intellectual disabilities (O'Brien & Thesing, 1999).

New Zealand Review of Institutions and Alleged Scandals at the Templeton Centre

In New Zealand, the Government has followed international trends in the review of the care and treatment of people with intellectual disabilities (O'Brien & Thesing, 1999). The New Zealand Government's review of state institutions has also been affected by alleged scandals in the care and management of people with disabilities.

In 1985, John McGee, an American expert in behaviour intervention, came to New Zealand, to study a number of institutions caring for the intellectually disabled (O'Brien, 1996) McGee's visits were to raise concerns related to the welfare of the intellectually disabled in New Zealand state institutions. McGee reported in the publication 'Mental Handicap in New Zealand' that patients displayed institutional behavioural patterns which were signs of inappropriate care and institutional neglect (O'Brien, 1996). McGee described patients whose faces showed masks of emptiness, with eyes motionless as fingers flicked and with bodies which aimlessly rocked back and forth (O'Brien, 1996).

The Fourth Labour Government (1984-1990) responded to public concerns raised about the quality of care in psychiatric hospitals and institutions for people with intellectual disabilities, by engaging in a review of institutional care (Department of Health, 1986). In 1986, the Department of Health conducted a major review of institutions for the psychiatrically and intellectually disabled (Department of Health, 1986). The review's report expressed major concerns with the usage of state facilities for the social exclusion, seclusion and restraint of patients (Department of Health, 1986). The report described state institutions as 'Dickensian' environments in which 'low stimulus' rooms had barren walls, an absence of furniture, no toilet facilities, with mattresses lying on the floor of the cell for bedding and with light, heating and ventilation controlled exclusively by the medical personnel (Department of Health, 1986). In state institutions for the intellectually disabled, a major concern was the usage of 'time-out' boxes and cupboards which were used as a punitive measure to suppress unacceptable behaviour patterns (Department of Health, 1986). The report described scenes of under-noticed patients being left under-stimulated and under-occupied, standing, sitting or walking aimlessly in stark, crowded, smoke-filled day rooms (Department of Health, 1986). The report described hospital wards as bare, unattractive and depressing environments, which were inappropriate for the care of long-term residents (Department of Health, 1986). Also, hospital dormitories were criticised for their lack of regard for residents' individual privacy and dignity (Department of Health, 1986). The loss of privacy and dignity included the lack of sleeping cubicles,

absence of curtaining in dormitories, the lack of space for personal possessions, communal showers, the lack of doors on toilets cubicles and bathrooms, and in some institutions the siting of bench type toilets in open corridors (Department of Health, 1986). The report also stated that the large number of residents in dormitories created mental health and behavioural problems among patients (Department of Health, 1986).

The Department of Health's review of rehabilitation programmes summarised that some of the programmes were ad hoc, with minimal treatment planning and lack of multi-disciplinary input or set patient care objectives (Department of Health, 1986). The review team argued that good rehabilitation programmes, combined with quality community care, would benefit a large number of people with psychiatric and intellectual disabilities (Department of Health, 1986). The review team also argued that the rural isolation of many institutions (Templeton Centre included) was a barrier to closer community contacts, which was seen as crucial to the successful re-integration of the disabled into the community (Department of Health, 1986).

In 1985, the Fourth Labour Government announced the adoption of the "policy of community living for people in long-term institutional care" (O'Brien & Thesing, 1999 p. 6). The Labour Government's policy announcement was followed by the closure of several major psychiatric hospitals and specialised institutions for people with intellectual disabilities (O'Brien & Thesing, 1999). The Government policy caused widespread hospital and ward closures which displaced hundreds of people with psychiatric and intellectual disabilities from hospitals and institutions such as Carrington, Cherry Farm, Kingseat, Lake Alice, Mangere, Ngawhatu, Ravensthorpe and Seacliff (O'Brien & Thesing, 1999). The Government also developed transition programmes for ex-patients to shift into community-based care (O'Brien & Thesing, 1999).

In the 1990's, the National Government continued the policy of deinstitutionalisation of state institutions for both the psychiatrically and intellectually disabled. The National Government's policy was supported by data collected by its Health Authorities, based on international and local research on the affects of deinstitutionalisation on the life experiences of people with intellectual disabilities. In 1993, the Central Regional Health Authority released a literature review on issues related to critical factors for the successful implementation of deinstitutionalisation (Bennie, 1993). The literature review included studies on the St Nicholas Hospital (Australia) Project, the Richmond NSW Programme (Australia), the Penhurst Longitudinal Study (USA), the Northampton State Hospital (USA), the Worcester Development Project (UK), and the Tranquille Hospital (Canada) (Bennie, 1993). These international studies promoted deinstitutionalisation as a quality of life issue for people with intellectual disabilities (Bennie, 1993).

The National Government's health authorities began to formulate proposals for the deinstitutionalisation of state institutions based on the international experience of normalisation and social role valourisation, which were seen as improving the quality of life of people with disabilities (Healthlink South & SRHA, 1994). The Government's health authorities, including the Ministry of Health, Canterbury Area Health Board, its successor the Southern Regional Health Authority and Healthlink South; promoted deinsitutionalisation as a human rights issue for the intellectually disabled in institutions such as the Templeton Centre (Healthlink South & SRHA, 1994). However, the public was sceptical of the National Government's and its state health authorities' view that institutional life was harmful for the intellectually disabled. However, the state argument

against institutional care was supported by ex-Templeton residents who entered the public debate with allegations of abuse and neglect at the Templeton Centre.

A major allegation of abuse and neglect related to the Templeton Centre involved Norman Madden, known in the media as one of the 'lost boys', who was mistakenly labelled as mentally deficient, and was sent to the Templeton Hospital and Training Centre in 1935 at the age of six, where he remained as a resident until 1949 (Gilling, 1997, Martin, 1999). Madden alleged that from the age of twelve he had suffered sexual and mental abuse from both care-givers and other residents (Tyler, 1998, Waikato Times, 1998). He also claimed to have been subjected to repeated acts of violence, severe intimidation, different forms of deprivation and punishment as well as being tricked into being sterilised against his will (McNeil, 1995, Taylor, 1998). Madden gave graphic descriptions of being locked for several months, on a daily basis, in a dog kennel as punishment for being a nuisance to care-givers (Sunday News, 1997). He stated in an interview "Templeton had not been a hospital, ... it was more like a penal colony", he added "My life was taken from me. I was denied the right to go to school; never given any teaching in the 14 years at Templeton" (Tyler, 1998, p.2). Madden declared "We were just animals really"... "The only thing I got was the fist and the boot" (Tyler, 1998 p.4).

While Madden described in graphic detail, the abuse and neglect he had endured, he actually supported the development of the Templeton Centre as a sheltered village, as he felt that the intellectually disabled residents would be unable to successfully adapt to community life (McNeil, 1995). While Madden's argument that the Templeton Centre should be retained as a sheltered village did not assist the state authorities' intention to close the institution, his stories of abuse and neglect fuelled public concerns for the welfare of the intellectually disabled in state institutions.

De Hart, the former head of the training department at the Templeton Centre, cast doubts on the alleged abuse of Madden (Tyler, 1999). Hart declared "I can honestly say the staff at the Templeton Hospital I experienced would never in a thousand years have tolerated the inhumanity Norm Madden claims he experienced" and "Templeton was not the 'place of horrors' described in recent articles...at least not in my time there...It was a place of compassion, caring and love...a happy place for patients and staff" (Tyler, 1999, p.7).

Madden sought a Government investigation and compensation into his wrongful placement and mistreatment at the Templeton Centre (Sunday News, 1997a). However, the Government refused to investigate the allegations due to the events occurring 40 years ago and the alleged abusers being no longer employed at the Templeton Centre (Sunday News, 1997a). While Madden's allegations of abuse related to events forty to fifty years ago, the 1990's media coverage of this and other stories of historical abuse at the Templeton Centre, led to increased support among health bureaucrats, service providers and the community for the closure of the Templeton Centre.

In summary, Western state policies on deinstitutionalisation have developed in response to a range of social and legal pressures including; Government reviews, Royal Commissions of Enquiry, legal action and media reportage on scandals involving patient overcrowding, abuse and neglect in state institutions. The New Zealand Government's decision to adopt deinstitutionalisation can be seen to have followed international trends in concerns for the care of the disabled. The New Zealand Government used overseas research on the adverse effects of institutional life, to shape its policies on its state institutions. While the

New Zealand Government did not have a commission of enquiry, its Department of Health review of psychiatric and intellectually disabled institutions played the same role in raising concerns about the appropriateness of institutional care for the disabled. The Fourth Labour Government's legal action in the form of the introduction of the "policy of community living for people in long-term institution care" followed the United States' trend to use the legal system to affect change in the lives of the disabled (O'Brien & Thesing, 1999 p. 6), The National Government's pursuit of the policy of deinstitutionalisation, which gained some legitimacy through allegations of institutional abuse by former residents, followed the international trend of institutional scandals being used to support the deinstitutionalisation discourse. Therefore, it can be argued that the New Zealand Government's policy towards the closure of state institutions, such as the Templeton Centre, was once more shaped by international trends, which promoted normalisation to solve alleged scandals in institutional based care.

Chapter Three

The Disability Rights Movement

The Deinstitutionalisation Movement

Advocacy for Disability Rights

Since the 1970s, the United Kingdom, United States and Australia have received powerful support from the disability rights and deinstitutionalisation movements for their policies of deinstitutionalisation of state institutions (Oliver & Barnes, 1993, Shannon & Hovell, 1993). The Western disability rights and deinstitutionalisation movements' advocacy for the closure of state institutions was to affect the New Zealand Government's decision to close the Templeton Centre.

In Western countries, since the beginning of the 1960s, human and civil rights movements have protested against discrimination suffered by people on the basis of ethnicity, gender and sexual orientation (Levy & Rubenstein, 1996, Johnson, 1998, O'Brien & Thesing, 1999). The human and civil rights movements' political philosophy was based on issues such as citizenship rights and equal rights (Johnson, 1998, O'Brien & Thesing, 1999). As the human and civil rights movements achieved success in dismantling some of the barriers faced by people on gender, ethnicity and sexual orientation issues, people with disabilities began to advocate for their own political and civil rights (Levy & Rubenstein, 1996, O'Brien & Thesing, 1999).

Disability rights groups argued that people with disabilities should have citizenship rights equal to able-bodied citizens, which included the right to fully participate in mainstream society (La Greca, 1983, Oliver & Barnes, 1993, Johnson, 1998). Disability rights groups' advocacy of equal citizenship rights and community inclusion led to the demand for deinstitutionalisation and the establishment of a humanistic community care alternative (Shannon & Hovell, 1993, McCubbin, 1994, O'Brien & Thesing, 1999). The disability rights groups' demand for deinstitutionalisation was based on the dual arguments that institutions restricted people's right to choice and prevented them enjoying a quality of life shared by other citizens (Oliver & Barnes, 1993, Shannon & Hovell, 1993). At the same time, community-based care was seen to enhance the civil rights and social inclusion of the disabled in the able-bodied community (Oliver & Barnes, 1993, Shannon & Hovell, 1993).

In Western nations, a large amount of protest and litigation on deinstitutionalisation revolved around people's right to egalitarianism and protection of their civil rights (Levy & Rubenstein, 1996, O'Brien & Thesing, 1999). These Western protests and court cases led to an improvement of the conditions in state institutions, as well as prompting the state to explore long-term alternatives to institutionalisation, consider hospital closures and investigate the establishment of community care programs (O'Brien & Thesing, 1999).

While the disability rights movement received support from human and civil rights movements at the local and national level, it also received recognition at an international level (Johnson, 1998, O'Brien & Thesing, 1999). This recognition came in the form of the United Nations Declaration on the Rights of Mentally Retarded Persons, 1971 and the Declarations on the Rights of Disabled Persons, 1975 (Johnson, 1998). In the United Nations' declarations, the disability rights discourse emphasised civil rights, human dignity and the right to a full, enjoyable and normal life as enabled by the person's disability (Johnson, 1998, O'Brien & Thesing, 1999). The United Nations' declarations also included the right of people with disabilities to access services which enabled the development of people's capacities and skills which would increase their ability to successfully reintegrate into society (O'Brien & Thesing, 1999). In 1993, the United Nations, adopted the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, which bound signatory countries to adopt policies that guaranteed people with disabilities the same life chances as the able-bodied in society (O'Brien & Thesing, 1999). These life chances included participation in areas such as personal relationships, family life, education, employment, culture and sport (O'Brien & Thesing, 1999).

New Zealand Disability Rights Advocates

In New Zealand, the major political advocates of disability rights and the deinstitutionalisation of the Templeton Centre, have been the state health bureaucracies, community care service providers and the People First movement. The state health bureaucracies which advocated for the rights of people with intellectual disabilities to be shifted from the Templeton Centre into the community, included the Canterbury Area Health Board, the Southern Regional Health Authority and Healthlink South.

In 1993, the Canterbury Area Health Board (CAHB), in its 'Report : Development of a Strategic Plan for the Board's Intellectual Disability Services', argued that the intellectually disabled person's right to personal growth and development was central to the development of services for ex-Templeton Centre

residents (CAHB, 1993a). The CAHB's report stated that its aim was "assisting each client to achieve a life style as close as possible to normal in all respects" (CAHB, 1993a, p.10). The CAHB report's statement that a normal life was a civil right for the intellectually disabled, raised the issue of whether or not state institutions were appropriate in facilitating the development of a normal life for the intellectually disabled. Therefore, the CAHB's report raised doubts on the appropriateness of the continued role of the Templeton Centre as a long-term care-giver for the intellectually disabled.

On the 15th November 1994, the Southern Regional Health Authority (SRHA) and the Intellectually Disabled Person's Health Division of Healthlink South released 'A Proposal for the Deinstitutionalisation of the Templeton Centre' (Healthlink South & SRHA). The proposal advocated that "People with intellectual disability are entitled to living accommodation and lifestyles which are as close as possible to the normal pattern of living enjoyed by the general population" (Healthlink South & SHRA, 1994, p.3). These principles were to be applied irrespective of the type or level of the person's disability (Healthlink South & SHRA, 1994). The SRHA and Healthlink South's proposal advocated the disability rights discourse that a normal life for the intellectually disabled had to be developed in a community environment. Therefore, the Templeton Centre was no longer an appropriate environment for any person with an intellectual disability.

While state health bureaucracies advocated for the right of Templeton Centre residents to live a normal life in the community, at the policy level, its key health managers engaged in the advocacy of disability rights in the public arena. The Healthlink South chairman, Bert Bullen, advocated that the Templeton Centre, as a state institution, provided outdated and poor quality services for the intellectually disabled (Gilling, 1994). Bullen argued that overseas research had shown that community-based care would provide better quality care for people with intellectual disabilities (Gilling, 1994). Bullen's political discourse of the rights of the intellectually disabled to a better life in the community, served to show that the forced closure of the Templeton Centre was being conducted for humanitarian reasons.

The General manager of Disability Support Services in the SRHA, Jean O'Callaghan, strongly advocated for disability rights as the reason for the deinstitutionalisation of the Templeton Centre (O'Callaghan, 1995, O'Callaghan, 1995a,). O'Callaghan argued that the intellectually disabled had a right to return to the community, to enable them to live a normal life (O'Callaghan, 1995b, O'Callaghan, 1995c). O'Callaghan argued that ex-Templeton Centre residents would enjoy a better quality of life, with the minimum of state intervention in their everyday lives (O'Callaghan, 1995b, O'Callaghan, 1995c).

The Manager of the Physical, Sensory and Intellectual Services Disability Support Services of the SRHA, Suzanne Win, who had studied the success of community services overseas, argued that deinstitutionalisation added to the quality of life of all people with intellectual disabilities by enabling them to experience a normal life (Win, 1995, Win, 1995a). Win advocated that people with intellectual disabilities were entitled to, and were capable of, enjoying a normal life in the community (Win, 1995b).

The role of state health bureaucrats' discourse on disability rights was to challenge the public and parental opposition to the closure of the Templeton Centre. State health bureaucrats emerged as powerful advocates for people with intellectual disabilities, due to their personal commitment to the rights of the

disabled, their professional approach in the presentation of their arguments and their privileged management position within the state health bureaucracy which enabled them to promote deinstitutionalisation in the face of public and parental opposition.

The IHC, as a major service provider of residential support services, also had a major role in the political advocacy of disability rights. The IHC, as an advocate of the rights of the intellectually disabled, coupled with its discourse on the merits of community living for all people with intellectual disabilities, had a major effect on the development of state health policy in New Zealand. In 1991, Jenny Shipley, Minister of Social Welfare, appointed an IHC Review Working Party to provide recommendations to the Minister, on issues including the future role of the IHC and other service providers in the delivery of residential based services (Craig, et al. 1991). The Review Working Party stated that the original role of institutions had been the vocational training and social rehabilitation of people with disabilities into the community (Craig, et al. 1991). However, the Review Working Party argued that state institutions could not teach people with intellectual disabilities to live a normal life in the community. As the report stated, "It is not possible to learn to live in the community by being removed from that community" (Craig, et al. 1991 p. 2). The Review Working Party's report advocated the continuation of the shift from institutional to community living for the intellectually disabled, and concluded with the recommendation: "The Working Party believes that future arrangements between area health boards and service providers should be driven by a national policy directive aimed at moving the majority of people with an intellectual disability, who are at present in institutions, to community living over the next five years. This objective can only be met with the active support and participation of the IHC" (Craig, et al. 1991 p.30). Therefore, the IHC was able to advocate for disability rights as a ministerial policy adviser, as well as having a major role in providing the residential care required for people shifting from institutions into the community.

While the IHC, as a service provider, advocated for people with intellectual disabilities, their clients also self-advocated. The People First movement was formed as a self advocacy organisation with membership in the United Kingdom, the United States, Canada, Australia and New Zealand and included people with intellectual disabilities who had lived a part of their lives in state institutions (Martin, et al. 1998). The People First's membership of self advocates became a powerful group in the debate over the deinstitutionalisation of state institutions and while they lacked the political power or resources to shape government policy on deinstitutionalisation, their ability to express negative thoughts, feelings and experiences of state institutions, lent powerful support to state health bureaucrats and service providers who promoted the closure of state institutions such as the Templeton Centre. While the People First movement advocated for its membership of people with intellectual disabilities, individuals also acted as self-advocates.

In 1993, five self advocates made oral submissions to the CAHB consultation committee on its 'Development of a Five Year Strategic Plan (1993-1998) For Intellectual Disability Services' (CAHB, 1993). The CAHB's plan, which mentioned the relevance and importance of the self-advocates contribution to the plan, was to play a central role in the deinstitutionalisation of the Templeton Centre (CAHB, 1993).

In 1995, Healthlink South and the SRHA formed a six member panel to hear oral submissions on the proposal to close the Templeton Centre (Campbell, 1995). People First members, living in IHC homes, made oral submissions to the panel

strongly advocating the closure of the Templeton Centre and the placement of its residents in the community (Campbell, 1995).

While the People First movement and individual self-advocates' oral submissions were small in number, their major value was their ability to counter public and parental submissions which were in opposition to the deinstitutionalisation of the Templeton Centre. The public and parental written submissions to both the CAHB and the SRHA committees, were undermined by the self- advocacy of people with intellectual disabilities. As parents attempted to argue that their intellectually disabled 'child' was unable to live in the community. People with intellectual disabilities were able to undermine these claims with factual accounts of their successful transition into community life. However, it can be argued that parental concerns were targeted towards the needs of the more severely disabled, while the People First movement's membership and self-advocates comprised people with mild to moderate intellectual disabilities.

In the public arena, the People First movement and individual self advocates used the news media to recount negative stories of institutional care, as well as relating positive accounts of their return to the community. For example, in 1989 a self advocacy group of fourteen ex-Templeton residents was formed primarily to support other ex-Templeton residents in their transition to the community (McPherson, 1991). However, the self-advocacy group also began to promote the rights of current Templeton Centre residents to live in the community (McPherson, 1991). This self advocacy group featured in several newspaper articles supporting the Templeton Centre closure (MPheron, 1991).

In 1991, a self advocacy group achieved a national public relations success when a letter related to the Templeton Centre was read by Paul Holmes on the 'Holmes' television programme (A popular prime-time news and current affairs programme). Holmes has consistently been supportive of the right of people with intellectual disabilities to live a normal life in the community.

In 1996, the self advocacy movement achieved another public relation success with the forty eight minute documentary 'Out of sight', which debuted at the Academy Cinema in Christchurch (Martin, 1996, The Press, 1996). The documentary, co-produced by Gerard Smyth, was researched over a two year period and filmed over a eight month period with the aim of improving the community's acceptance of the intellectually disabled in their return to the community (Martin, 1996). Smyth personally advocated for Templeton residents when he stated "Although only a few of the 400 or so people at Templeton are portrayed in the film, it is clear an institution is not an ideal place to live" (The Press, 1996a) He further advocated for disability rights in a letter to 'The Press' newspaper: "450 residents are...being held in archaic surroundings against their will" (Smyth, 1997 p.7). In 1997, Smyth made a second documentary, which featured on Television One's 'Inside Out' programme (The Press, 1998). The second documentary, which included Templeton residents from the first film, showed the successful placement of these ex-Templeton residents in community homes in the Halswell area (The Press, 1998). The news media coverage of disability rights was supplemented by Angela Griffin, a person with cerebral palsy who had lived at the Templeton Centre and published a book, "My Life on Wheels", which promoted the image of a disabled person overcoming life in an institution, as well as their disability, to achieve success in the mainstream of society (Kenne, 1995).

The People First movement and individual self-advocates also advocated disability rights at a private level to complement their public discourse. The

People First movement advocated for other people with intellectual disabilities who were currently living in institutions, by encouraging 'other' intellectually disabled to claim their right to control their own lives and take responsibility for their own decisions (Martin, et al. 1998). A key strategy in the People First movement was to visit intellectually disabled people still living in institutions, to share their own experience of living in the community, which would hopefully encourage the residents to support the People First movement and deinstitutionalisation (Martin, et al. 1998). The People First members were able to increase their membership among the intellectually disabled, as well as gather more personal stories to use to promote deinstitutionalisation, by using this strategy (Martin, et al. 1998).

In summary, the Western disability rights groups' and deinstitutionalisation movements' advocacy of human and civil rights, can be seen to have occurred at both the local and international level. Disability rights groups and deinstitutionalisation movements have advocated for Government policies to improve the quality of life of the intellectually disabled. In New Zealand, the CAHB, SRHA and Healthlink South, in conjunction with the IHC and People First movement promoted the rights of people with intellectual disabilities to live a normal life. The merging of state health agencies, service providers and consumers, infused with the same social philosophy, created a powerful lobby for disability rights and deinstitutionalisation. The proponents of deinstitutionalisation shared a common goal: to apply the principles of normalisation to improve the quality of life of people with intellectual disabilities.

Chapter Four

The Theoretical Discourse of Normalisation

The Development of the Theoretical Discourse of Normalisation embedded within Deinstitutionalisation

In Western countries, the social theories of normalisation, social role valourisation, least restrictive alternative, non-restrictive environment and community integration were to shape the policy of deinstitutionalisation (Flynn & Nitsch, 1980, Barwick, 1995, Moore, 1995, Bachrach, 1989, Ziegler, 1989). These social theories, were to be central to the New Zealand state health authorities development of deinstitutionalisation policies for state institutions such as the Templeton Centre.

In 1959, Bank-Mikkelsen, head of the Denmark mental retardation services, introduced the principle of normalisation into the provision of services for people with disabilities (Biklen, 1979). In the mid-1960's, Bengt Nirje, executive director of the Swedish Association for Retarded Children, developed the theory of normalisation, in which he argued that people with intellectual disabilities should be able to experience the conditions of everyday life as close as possible to the patterns and norms of mainstream society (Biklen, 1979, Nirje, 1985). In the 1980s, Dr. Wolfensberger, wrote 'The Principle of Normalisation in Human Services', which defined the concept of normalisation as "utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible" (Biklen, 1979 p. 51). The state application of the principles of normalisation in state institutions, led to limited changes such as personal choice in food, clothing and leisure activities (Biklen, 1979).

However, the theory of normalisation was reformulated by social theorist, Dr. Wolfensberger, who developed the theory of social role valourisation (Biklen, 1979, Flynn & Nitsch, 1980, Wolfensberger, 1983, Steer, 1989). Dr. Wolfensberger argued that people with disabilities were at risk of developing 'social devaluation' as patients in institutional environments (Wolfensberger, 1972, Wolfensberger, 1987, Ramon, 1989). For example, institutions which modelled prison or hospital conditions, created a physical setting which encouraged staff to label people with disabilities as subhuman, deviant or as objects of fear, pity, ridicule or sickness (Wolfensberger, 1987). The staff labelling of people with disabilities, led to self-labelling and self-devaluation among patients (Wolfensberger, 1987). Dr Wolfensberger argued that the goal of normalisation was the enablement, maintenance and defence of socially valued roles for people with disabilities (Wolfensberger, 1987, Steer, 1989) The theory of social role valourisation argued that to enable people to be relabelled as 'valued' they needed to live and work in a 'valued setting' such as the community (Oliver & Barnes, 1993. Shannon & Hovell. 1993, O'Brien & Thesing, 1999). In the community, an individual would have the opportunity to develop 'valued competencies' which underpinned their valued social role (O'Brien & Thesing, 1999). While normalisation could be applied to a limited extent in institutions, the principles of social role valourisation demanded a community (valued) setting (O'Brien & Thesing. 1999). Therefore, to disability rights advocates, it was apparent that for people with disabilities to live a 'normal' life, all disabled persons had to be deinstitutionalised (O'Brien & Thesing, 1999).

The theory of social role valourisation was supported by the philosophical and legal concept of 'least restrictive alternative care' (Biklen, 1979, Wing, 1989). Dr. Wolfensberger, author of the book 'Normalization' (1969) argued that the physical design of institutions created a custodial and dehumanising environment, which affected the treatment of people with disabilities (Biklen, 1979). The least restrictive alternative, argued that people with disabilities needed to be placed in the least restrictive setting possible to enable them to reach their personal potential, with the support of a continuum of services (Biklen, 1979, O'Brien & Thesing, 1999). Also, the state and its health agencies were required to provide services and support to people with disabilities in a manner which caused the least restriction to individuals' freedom and least

disruption to their normal life pattern in society (Biklen, 1979). For example, children with disabilities have been 'main-streamed' into able-bodied schools, which allows children with a continuum of 'special needs support' to learn in an educational environment which is less restrictive than a hospitalised environment (Biklen, 1979). The legal application of the concept of least restrictive alternative care has been applied in the human service areas of education, rehabilitation and residential programmes (Biklen, 1979).

However, the least restrictive alternative concept with a continuum of services was challenged by the 'non-restrictive alternative' (O'Brien & Thesing, 1999). The non-restrictive alternative argued that the least restrictive alternative forced the individual to be placed with and dependent upon support services not of their own choosing (O'Brien & Thesing, 1999). The advocates of the non-restrictive alternative, argued that people with disabilities had the right to live in a community setting of their own choice, with the level of service support as demanded by the individual (O'Brien & Thesing, 1999). For example, the least restrictive alternative placed individuals in group homes, with other residents not of their choosing, dependent on the support of human services (O'Brien & Thesing, 1999) In comparison, the non-restrictive alternative allowed individuals to choose their residential setting and permitted personal choice between different human services, as and if required (O'Brien & Thesing, 1999).

While the deinstitutionalisation movement has adopted the theories of normalisation and social role valourisation and to a lesser extent, least-restrictive and non-restrictive alternatives; the community living movement developed its own discourse on living a 'normal life' in the community (O'Brien & Thesing, 1999). The community living discourse argued that five accomplishments were required to achieve a normal life, these included "community presence, community participation, respect, choice and competence" (O'Brien & Thesing, 1999 p. 8). These accomplishments form the basis of 'community living programmes' which are used in 'lifestyle plans' for people with disabilities, as well as a guide for service and support planning in community presence and participation programmes (O'Brien & Thesing, 1999).

The evolution of theories from normalisation to community living programmes can be seen to have several direct effects on the care of people with intellectual disabilities. These include the transfer of care responsibilities from large state institutions with specialised medical in-patient services, to small community group homes with a minimum level of service provision. Also the disabled persons' rights and needs are placed above those of the state, service providers or their families.

The New Zealand Government's Policy Incorporation of the Principles of Normalisation

In New Zealand, the emerging international social theories on service provision for people with disabilities, was to shape the Government's, state health authorities' and service providers' perception of the needs of people with intellectual disabilities. The social theories of normalisation, social role valourisation and least restrictive care, were the primary ideological force in policies for the deinstitutionalisation of the Templeton Centre.

In 1985, the 'Mental Retardation in New Zealand : Provisions, Services and Research' report argued that the current international trend towards normalisation and deinstitutionalisation, would require the New Zealand Government to develop programmes to transfer people with mild to moderate

intellectual disabilities into the community (Singh, et al. 1985). However, the report stated that psychopaedic hospitals ought to continue to be responsible for the care of people with severe and profound intellectual disabilities as well as multi-disabilities (Singh, et al. 1985). The report argued that people with severe, profound and/or multi-disabilities required 24 hours a day specialist care, from trained psychopaedic nurses, in a hospital environment (Singh, et al. 1985). The report advocated the development of psychopaedic hospitals as 'resource centres' to provide support services, specialists, information, advice, assessment, care-giver training and crisis intervention, for people in community placements (Singh, et al. 1985). Therefore, the report advocated a modified approach towards 'normalisation' with the usage of both psychopaedic hospitals to provide specialist care for people with more severe disabilities and community care options for the less disabled. The report's modification of the principles of normalisation were based on the doubts of the alleged superiority of community-based services for all people with intellectual disabilities (Singh, et al. 1985). The report also attempted to protect the medical model of care in health services which was embedded in institution-based care, from the sweeping changes demanded by the disability model which was infused in community-based care (Singh, et al. 1985). However, the report conceded that future development of health services for the intellectually disabled would need to place an increasing emphasis on community care for patients (less disabled) who had been inappropriately placed into hospital care (Singh, et al. 1985).

In 1986, the Department of Health published its, 'Review of Psychiatric Hospitals and Hospitals for the Intellectually Handicapped' report for the Minister of Health, Dr M. E. R. Bassett (Department of Health, 1986). The report stated "Major and important changes have occurred in the philosophy and techniques of treatment and care of the psychiatrically disabled and intellectually handicapped; and an increased awareness has developed, worldwide, of the needs for new standards to be applied to the care of such patients" (Department of Health, 1986). The report argued that a large number of 'patients' in hospital environments would be more appropriately cared for in the community (Department of Health, 1986). However, the report expressed concern regarding the pursuit of the ideology of normalisation which, in the absence of adequate community facilities and resources, could lead to less community care and more community neglect (Department of Health, 1986). The Department of Health's major concern was that international trends towards deinstitutionalisation of suitable patients, had resulted in the development of 'good rehabilitation programmes', which were being nullified by the lack of adequate community resources (Department of Health, 1986). Therefore, the Department of Health recommended a strengthening of community resources, to enable rehabilitation and community care to be achieved (Department of Health, 1986). While the Department of Health's report supported the international trend towards normalisation and deinstitutionalisation, the issues related to the provision of quality rehabilitation programmes and the adequacy of community resources caused it to be cautious about the current progress being made towards high quality community-based services.

In 1991, the 'Report of the IHC Review Working Party' was sent to the Minister of Social Welfare, Jenny Shipley (Craig, et al. 1991). The Working Party argued that the transfer of people with intellectual disabilities into the community ought to be a national objective, as institution-based care was no longer appropriate in New Zealand (Craig, et al. 1991). While the Working Party was concerned that fiscal, resource, service and administrative constraints had slowed the implementation of deinstitutionalisation, it argued that three major social concerns had continued to slow the policy implementation of the principles of normalisation (Craig, et al. 1991). Firstly, the Working Party was concerned that parents and welfare guardians believed that institution-based

care was a better option than community-based care (Craig, et al. 1991). Secondly, the Working Party argued that the perception of people with profound intellectual disabilities as requiring intensive medical support was incorrect (Craig, et al. 1991). Thirdly, the Working Party was concerned that people with dual diagnosis (psychiatric and intellectual disability) were seen as inappropriate candidates for deinstitutionalisation (Craig, et al. 1991). The Working Party recommended a national programme to shift the majority of people from institutions to community care over a five year period (Craig, et al. 1991). The significance of the IHC Review Working Party document was its advocacy of the shift from a blend of institution and community services to private service providers who would meet the needs of all people with intellectual disabilities. The Working Party had argued that psychopaedic hospitals were inappropriate for people with severe and profound intellectual disabilities, people with multi-disabilities, high medical needs and dual diagnosis patients (Craig, et al. 1991). Therefore, the IHC, as advocates for the full implementation of the principles of normalisation, irrespective of disability, had a major role as a policy adviser in shaping the National Government's decision to apply deinstitutionalisation for all people with intellectual disabilities.

In 1993, the Central Regional Health Authority published a literature review to assist state health authorities' policy development on deinstitutionalisation, it was entitled 'Deinstitutionalisation : Critical Factors for Successful Transition to the Community (Bennie, 1993). The publication outlined both the positive and negative overseas experiences of deinstitutionalisation in the United Kingdom, United States, Canada and Australia (Bennie, 1993). While, the literature review presented negative accounts (predominantly psychiatrically disabled) of community care it conceded that "The twin imperatives of policy momentum and user preference suggest that the key issue is not whether deinstitutionalisation should continue but rather how it can be satisfactorily implemented" (Bennie, 1993, p.6). Therefore, the policy debate on deinstitutionalisation had shifted from its appropriateness for all people with disabilities, to a focus on the factors involved in the successful implementation of deinstitutionalisation. The literature review argued that policy makers had to incorporate the views of the disabled service user in policy design and implementation (Bennie, 1993). Also, the review argued that 'quality of life' factors ought to be used as the measurement to determine the success or failure of deinstitutionalisation (Bennie, 1993). This policy approach placed the person with the intellectual disability and their quality of life, at the core of health planning, implementation and assessment in deinstitutionalisation.

On the 30th of January 1993, the Canterbury Area Health Board (CAHB) established an independent committee to consult with the public on the development of a five year service plan (CAHB, 1993). This consultation paper was entitled, 'Development of a Five Year Strategic Plan (1993-1998) For Intellectual Disability Services - Consultation paper' (CAHB, 1993) The consultation paper's guidelines set the parameters for public input by stating that the key issues for consideration included overseas trends in institutional and community care, disability rights and quality of life for residents in the Templeton Centre (CAHB, 1993). The consultation paper sought public input on the range of services and support needed to meet the needs of people with different levels of intellectual disability in the changing health service environment (CAHB, 1993). For Templeton centre residents, this consultation paper was arguably the beginning of the development of community services based on quality of life issues, which stemmed from the principles of normalisation. The consultation paper also confirmed the policy shift from institution to community care (deinstitutionalisation) as well as the advocacy of disabled persons' quality of life (normalisation), as fundamental to health and disability policies.

In February 1993, the CAHB released the 'Report : Development of a Strategic Plan for the Board's Intellectual Disability Services' (CAHB, 1993a). The CAHB's report identified the different stakeholders in the provision of services for the people with intellectual disabilities (CAHB, 1993a). The primary stakeholders were identified as all people with intellectual disabilities (CAHB, 1993a). This guaranteed that the rights of people with intellectual disabilities, as the primary stakeholders, were paramount in the policy development of disability support services. The CAHB's report identified the parents and families of the intellectually disabled as an important, but secondary group of stakeholders (CAHB, 1993b). The report stated that "Parents' needs as stakeholders are intimately connected with their children's but are not identical", this statement revealed the fact that the rights and needs of parents and families were secondary in the policy implementation of deinstitutionalisation. While the CAHB committee identified all the other stakeholders, it ignored the fact that state health authorities were also stakeholders in the debate on disability services. Instead, the committee viewed themselves as an independent actor without its own agenda. This denial of a stakeholder's status enabled it to act as an unofficial spokesperson for people with intellectual disabilities. Therefore, it can be argued that the CAHB committee assumed the unofficial role of the primary stakeholder. This was to lead to conflict with Templeton Centre parents who saw their advocacy role as being devalued by the state health authorities.

Therefore, the CAHB committee, as a primary stakeholder was able to advocate normalisation as a right for the intellectually disabled, in spite of the large number of parents and families vehemently opposed to the deinstitutionalisation of the Templeton Centre. (CAHB, 1993a). The Templeton parents and families advocated a 'sheltered village' concept, which they argued would provide a more normal environment than a traditional institution, within a safe and secure area (CAHB, 1993a). The CAHB committee conceded that normalisation could occur in a large institution such as a 'sheltered village' if the institutional conditions changed to meet the principles of normalisation (CAHB, 1993a). The CAHB committee recommended continued consultation with parents and families about the concept of a sheltered village, on condition that the CAHB's intention to promote the rights of people with intellectual disabilities to live a normal life was not compromised. Therefore, the CAHB committee provided limited support towards the concept of a 'sheltered village, if it provided a normal life for its residents. This CAHB concession raised the hopes of parents and families that their views were being valued, to a limited extent, in the debate on the Templeton Centre. The CAHB report also sought public feedback on priority targets it had set, such as the provision of support services for the intellectually disabled in the community (CAHB, 1993a). The targets included the proposal to create a 'sheltered village', for 150 residents, in place of the Templeton Centre and the development of more residential care units for the current 300 Templeton residents (CAHB, 1993a).

In March 1993, the CAHB published 'The Report on Feedback in Relation to the Intellectual Disability Consultation Committee's Report on a Strategic Plan for the Board's Intellectual Disability Services' (CAHB, 1993b). The public feedback on the 'Strategic Plan', included 267 submissions (CAHB, 1993b). The Strategic Plan's proposal to create a sheltered village for 150 residents (237 replies) received merely 18% support (CAHB, 1993b). While the proposal to develop more residential care units (173 replies) received 65% support (CAHB, 1993b). The Templeton Centre Parents' Association which had advocated for the sheltered village concept, opposed the concept in this 'Strategic Plan' as the sheltered village had been limited to 150 residents (CAHB, 1993b). The Templeton Centre

Parents' Association argued that the sheltered village concept needed to be built for all the 450 Templeton Centre residents (CAHB, 1993b).

Therefore, the CAHB's report had primary data that a significant percentage of public feedback supported a shift from traditional institution-based care to community-based care (CAHB, 1993b). However, the CAHB's report recorded the entrenched view of the Templeton Centre Parents Association, that a sheltered village for all 450 residents had to be built on the Templeton site.

The CAHB's stance that a sheltered village ought to be restricted to 150 residents with residential care for 300 residents, and the Templeton Centre Parents' Association's stance on the sheltered village for 450 residents, was to act as the catalyst for conflict between the CAHB and the parents of the intellectually disabled. While the principles of normalisation were supported by both parties, the environment in which normalisation would be applied was at the centre of the debate on the deinstitutionalisation of the Templeton Centre.

In December 1993, the National Government's major disability advisory committee: the National Advisory Committee on Core Health and Disability Support Services, published 'Disability Services : Client Orientation', which continued the policy direction towards 'client orientated service provision (National Advisory Committee on Core Health and Disability Support Services, 1993). The committee placed major importance on the participation and inclusion of people with disabilities in the community. Therefore, the National Government's key policy advisory group and its state health authorities, were committed to the principles of normalisation in a community setting regardless of public or parental opposition .

On the 15th November 1994, the Intellectually Disabled Persons' Health Division of Healthlink South and the Southern Regional Health Authority (SRHA) released the 'A Proposal for the Deinstitutionalisation of the Templeton Centre : Discussion Document and Call for Comment' (Healthlink South & SRHA, 1994). The Healthlink South and SRHA's proposal referred to the previous CAHB's public consultations on the deinstitutionalisation of the Templeton Centre (Healthlink South & SRHA, 1994) However, this proposal would be the final document in the development of a strategic plan for the Templeton Centre. The proposal stated that the Templeton Centre would close without any consideration of up-grading it to a sheltered village (Healthlink South & SRHA, 1994). The Templeton Centre would be phased out over a five year period as all residents were placed into a range of residential programmes, which would include a blend of normal housing and specialised accommodation designed to provide a more normal family living environment (Healthlink South & SRHA, 1994). While 300 Templeton Centre residents would be placed into community-based residential care, 150 residents would be placed into the Princess Margaret Hospital's Nurses Hostel, which would be developed into a residential facility altered to meet the principles of normalisation (Healthlink South & SRHA, 1994). The 150 residents placed at Princess Margaret Hospital would be the most disabled of the Templeton Centre residents (Healthlink South & SRHA, 1994). The proposal declared that the principles of normalisation were the cornerstone of its policy of deinstitutionalisation and promised to engage in considerable consultation with the families and wider community on the process of deinstitutionalisation of the Templeton Centre (Healthlink South & SRHA, 1994). However, the decision to close the Templeton Centre was full and final (Healthlink South & SRHA, 1994).

The Healthlink South's and SRHA's proposal ignored the CAHB's consideration of a sheltered village for 150 residents as well as the Templeton Centre Parents'

Association's proposal of a sheltered village for 450 residents, on the Templeton Centre site. The proposal rejected the Templeton Centre due to its rural isolation, compared to the centralised location of the Princess Margaret Hospital Nurses' Hostel (Healthlink South & SRHA, 1994). The proposal's announcement of the Templeton Centre's closure, rejection of the sheltered village concept and the usage of the Princess Margaret Hospital's site brought widespread protest from the Templeton Centre Parents Association.

In March 1995, the Templeton Centre Parents' Association submitted a submission on 'The Proposed Deinstitutionalisation of the Templeton Centre' which argued that the Templeton Centre site ought to be retained and rebuilt as a 'Sheltered Village Complex' and managed as a community trust by the Templeton Centre Parents' Association (Eskett & Associates, 1995). The Templeton parents' submission endorsed the principle of normalisation, as a means to improve the quality of life of the intellectually disabled person, but promoted a blend of normal housing and specialised accommodation designed to enhance normal family living, being built in a sheltered village complex (Eskett & Associates, 1995). The Templeton parents' submission argued that the usage of the Princess Margaret Hospital Nurses' Hostel as a residential site would be unsuitable for the application of the principles of normalisation and challenged the right of Healthlink South and the SRHA to advocate on behalf of the intellectually disabled (Eskett & Associates, 1995). The Templeton parents' argued that Templeton Centre residents intellectual disabilities prevented them from making a totally independent choice on care options (Eskett & Associates, 1995). Therefore, the submission declared that Templeton Centre parents were the logical advocates for their 'disabled children', and that the parents had chosen to apply the principles of normalisation in a sheltered village at the Templeton site (Eskett & Associates, 1995). The Templeton parents' submission cited public support for its stance with the tabling of a 28,000 signature petition, against the Templeton centre's closure, in the House of Representatives at Parliament in March 1994 (Eskett & Associates, 1995).

In May 1995, the SRHA published 'A Proposal for the Deinstitutionalisation of the Templeton Centre- Summary of Analysis' which was based on 859 written submissions it had received (Bridgeport Group, 1995). Approximately 40% of the submissions came from parents, welfare guardians and families, 11% from professional care-givers and organisations, and 49% from church and community groups, local authorities, 'NIMBY' neighbours, and private individuals (Bridgeport Group, 1995). The majority of respondents endorsed the principles of normalisation embedded within the policy of deinstitutionalisation (Bridgeport Group, 1995). A minority of respondents supported the closure of the Templeton Centre, the most notable advocate being the IHC: the major service provider of community-based care services (Bridgeport Group, 1995). However, the vast majority of respondents believed it was both inappropriate and impractical to shift most of the Templeton Centre residents into the community due to the severity of their disabilities (Bridgeport Group, 1995). The summary of submissions concluded that the public required the Templeton Centre to remain open and to be developed into a sheltered village complex (Bridgeport Group, 1995). Therefore, the summary of submissions supported the stance of the Templeton Centre Parents' Association in the debate on deinstitutionalisation of the Templeton Centre.

In summary, this overview of the major policy documents related to the proposal to close the Templeton Centre, has shown that a deep rift existed between the advocates of community-based care and the development of a sheltered village. The CAHB had advocated both for the rights of people with intellectual disabilities to have an increased quality of life, as well as lending some limited support to the establishment of a sheltered village complex at the Templeton site. The Templeton Centre Parents' Association had expressed a

willingness to manage the sheltered village complex and apply the principles of normalisation in the everyday lives of the residents. In contrast, the IHC Working Party had argued that all people with intellectual disabilities needed to be placed in the community, the IHC's argument being based on the view that normalisation required the intellectually disabled to have daily access to community residences, employment and recreation comparable with other able-bodied citizens. In contrast, Healthlink South and the SRHA advocated community care for 300 Templeton Centre residents and the redevelopment of Princess Margaret Hospital Nurses' Hostels site, to enable the principles of normalisation to be applied for the 150 more disabled residents.

The state health authorities, service providers, families and self-advocates, all sought to advocate for Templeton Centre residents, and endorse, to varying degrees, the philosophy of normalisation. However, conflict arose over which group legitimately had the right to act as advocates for the intellectually disabled, and whether their specific interpretation of the appropriate site for normalisation, would most meet the needs of people with intellectual disabilities.

Chapter Five

Neo-Liberal Governments and Deinstitutionalisation

The role of the Neo-Liberal Agenda in the Social Policy of Deinstitutionalisation

While Western nations pursued the social discourse of normalisation as the primary ideological force in shaping their disability policies, the economic discourse of neo-liberalism emerged as a secondary ideology interwoven with state policies on deinstitutionalisation. As Western countries have pursued the social discourse of normalisation as a human and civil rights issue, it has been argued that neo-liberal governments have sought to use policies on deinstitutionalisation as part of an economic agenda to reduce state health expenditure (Curtis, 1986). In New Zealand, the National Government also pursued neo-liberalism in its health, social welfare and disability policies which affected its policies related to the deinstitutionalisation of the Templeton Centre.

In the 1980s, Western Governments adopted a 'new right' (neo-liberal) agenda in health, social welfare and disabilities policies, which reduced social expenditure on state institutions and services, as well as shifting the responsibility for the provision of services to the private sector (service providers, voluntary sector and families). The Western Governments' pursuit of neo-liberalism to reduce social expenditure, led to the closure and depopulation of state hospitals and institutions, as well as the diversion of potential patients to community-based care (Bachrach, 1989, Gleeson, 1997). However, critics of the Western Governments' reduction in state social expenditure and service provision, have argued that the required parallel development of adequately funded community-based care services has not occurred (Gleeson, 1997).

Western Governments have sought increased public accountability in social spending and service performance, as well as restricting service provision and eliminating inefficient practices (Knapp, 1988). Also, Western states have shifted from public sector funding of expensive state institutions and in-patient services, to more cost effective community services (Knapp, 1988). Therefore, Western Governments' policies and practices in community services have sought to increase cost effectiveness and service efficiency, which has been interpreted as meaning "an efficient service is a cheap service" (Knapp, 1988 p. 150).

While Western states and disability rights movements advocated the philosophy of normalisation as a civil rights issue in the public arena, Western Governments

privately implemented the policy of deinstitutionalisation as a 'value for money' exercise to reduce social expenditure (Curtis, 1986, Knapp, 1988). An example of this dual approach is seen the United Kingdom's 1981, Department of Health and Social Security consultative paper, 'Care in the Community', in which the policy aims included "an improvement in the quality of clients lives" coupled with an investigation of "how cost-effective community services might be provided" (Knapp, 1988 p. 154).

Western Governments' policies to reduce state expenditure in the disability sector was also promoted by cost saving strategies (Knapp, 1998). Prior to World War Two, the majority of state institutions had been built for people with disabilities. However, since the end of World War Two, the cost of repair and maintenance of these large institutions had steadily increased as the facilities had aged and depreciated (Knapp, 1988). In addition, the cost of new state hospitals or the upgrading of existing run-down institutions, was considered too expensive especially during the economic recession of the 1970s (Knapp, 1988). Also the cost of employing large numbers of staff, which included doctors, specialists, nurses, allied nurses, cooks, cleaners, maintenance workers and gardeners had also steadily increased (Knapp, 1988). In comparison, community care was considered the cheaper option due to the lower cost of building small residential units and the employment of less skilled care-givers. In the United Kingdom's 'Better Services for the Mentally Handicapped III', the policy stated that community services would be no more expensive, and possibly cheaper, than hospital or institution-based care (Knapp, 1988).

While the neo-liberal short-term agenda sought to reduce social expenditure, save costs and increase service efficiency, its long-term goal was the privatisation of health, social welfare and disability services (Knapp, 1988). Neo-liberal proponents of privatisation argued that private and voluntary sector services provided a more cost-effective and efficient alternative to public provision of social services (Knapp, 1988). While neo-liberals attempted to shift from a state funded institution-based model to a privatised community-based model, the end result has been a mix of state expenditure, private contract and informal care (unpaid care-givers) (Knapp, 1988).

In summary, Western Governments' policies on deinstitutionalisation have sought to reduce social expenditure as well as simultaneously addressing the politically sensitive issue of disability rights and inadequacy of services in institutions (Gleeson, 1997). The Western Governments' advocacy of deinstitutionalisation as a quality of life issue, has often masked the hidden economic agenda of cost savings, cost transfer, efficiency goals and privatisation. However, the neo-liberal agenda has adversely impacted on specific groups of people with disabilities (people with profound intellectual and multi-disabilities), who as community placements, have struggled to have their needs met due to state under-funding and under-resourcing of community programmes. These community placement failures have caused the 'care burden' to be shifted from the public sector to voluntary organisations and families, which rely on unpaid care-givers, most of whom are women (Gleeson, 1997).

New Zealand Health Reforms and Deinstitutionalisation

In the 1970s, New Zealand's national economic performance began to decline, due to middle-east oil price increases and the reduction in sales of agricultural products to the United Kingdom (Bertram, 1997). The decline in New Zealand's economic performance created pressure on the state to reduce public expenditure on specific sectors of the state infrastructure (Singh, et al. 1985). Therefore, the National Government cut state expenditure on the replacement, upgrading

and/or maintenance of existing psychiatric and psychopaedic institutions, to reduce costs in the mental health and disability infrastructure (Department of Social Welfare, 1990). In 1974, a state moratorium was imposed on the construction of psychiatric and psychopaedic hospitals to assist in the containment of health expenditure (Singh, et al. 1985). The state moratorium, received health sector support from a survey of psychopaedic hospitals, which showed that 45% of residents currently in hospitals were capable of living in the community, while the actual number of hospital residents transferred into the community was merely 11%, these were primarily people with mild to moderate intellectual disabilities (Singh, et al. 1985). Therefore, the 1974 state moratorium on state institutions, supported with the psychopaedic hospital survey's recommendation that more people with intellectual disabilities ought to be transferred into the community, established the precedence between an economic agenda to reduce public expenditure on institutions and the social goal of the deinstitutionalisation of people with disabilities.

In the 1980s, New Zealand's economy continued to decline and the need for cost containment continued in the health and disability sectors (Department of Health, 1986). The reduction of public expenditure on hospital replacement, upgrading and/or maintenance, as well as the closure of psychopaedic institutions was seen as a major means to control state expenditure in the health and disability sectors (Department of Health, 1986). However, due to the closure of hospitals and institutions, the number of available beds for patients decreased, which increased the demand for alternative 'cheaper' community care for people with intellectual disabilities (Board of Health, 1987, Department of Social Welfare, 1990, Healthlink South & SRHA, 1994). Therefore, the New Zealand Government increasingly sought to use community services as an appropriate alternative to state institutions, as a means to reduce public expenditure and to alleviate the problems created due to the lack of state institutions (Department of Health, 1986, Board of Health, 1987).

By the mid-1980s, the New Zealand Labour Government's Area Health Boards (AHBs) began to determine which hospital and institution based services, could be transferred to a service provider in the community, to a similar standard at a lower cost (Board of Health, 1987). As the Labour Government and AHBs embarked on their economic agenda, to use community services to reduce public expenditure on institutions, the social discourse of normalisation emerged to set the social goal of promoting community services as a civil right for people with disabilities incarcerated in state institutions. Therefore, New Zealand's prolonged economic decline, the Labour Government and AHB's attempt to lower public expenditure to contain infrastructural costs and the emerging trend towards normalisation, converged to increase the momentum towards the deinstitutionalisation of state institutions.

In 1987, as the Labour Government and AHBs investigated which hospital services could be transferred to the community, the Board of Health (BOH) formed the 'Hospital and Specialist Services Committee' to investigate financial issues related to institutional and community services (Board of Health, 1987). The BOH committee report, stated that the public health service was under considerable financial pressure and its health funding was deteriorating relative to other countries (Board of Health, 1987). The BOH committee, argued that a significant proportion of financial resources was being spent on hospitals and institutions, compared to other Western countries (Board of Health, 1987). Therefore, the BOH committee suggested that hospital and institution based services ought to be transferred to the community, on condition that services of a similar standard at a lower cost would be provided to people with disabilities (Board of Health, 1987). However, the BOH committee conceded that the short-term costs associated with the establishment of community care would be expensive, but it argued that

the long-term cost savings, from reduced long-term institutional care, would help to off-set the initial set-up costs of community services (Board of Health, 1987, Ministry of Health, 1993).

The short-term costs associated with the setting up of community services, were referred to as 'hump costs' or 'transition costs', which were created during the process of deinstitutionalisation of state institutions (Craig, et al. 1991, Department of Health & Department of Social Welfare, 1992). The hump costs included the administration costs, the continued hospital cost until the last person left the ward, hospital employee redundancy payments, and the cost of establishing and equipping a new community residence (Craig, et al. 1991). The BOH committee recommended an injection of funds to cover the hump costs in the establishment of community services (Board of Health, 1987, Department of Social Welfare, 1990). In addition to the injection of funds to meet hump costs, the decision to shift services from institutions to the community also had to be based on the relative effectiveness of the community services and their acceptability to the client and their respective families (Board of Health, 1987). The community service had to improve the quality of life for the person with the disability as well as offer better value for the health budget (Board of Health, 1987, Department of Social Welfare, 1990).

The late 1980s saw the continuing convergence of New Zealand's declining economic performance, the pressure to reduce health and disability expenditure, and the adoption and entrenchment of normalisation with the resulting shift to community services. The convergence of these factors was to shape the National Government's policies of deinstitutionalisation throughout the 1990s.

In 1990, the National Government gained office with an agenda of radical social reform, in an attempt to solve the continuing economic crisis caused by the decline of New Zealand's economy (Bolger, 1990). In December 1990, Prime Minister Jim Bolger, presented the National Government's Economic Statement 'Economic and Social Initiative' in which he argued the need for dramatic measures to avoid economic crisis in New Zealand (Bolger, 1990). Bolger, cited as evidence of New Zealand's continued economic crisis, the country's ranking of nineteenth in the OECD for gross domestic product per head of population as well as its rapid increase in state social spending of about one billion dollars per year (Bolger, 1990). Bolger, declared that the New Zealand state was borrowing overseas to support "one of the most generous welfare systems in the world" (Bolger, 1990, p.438). Therefore, a dramatic curb in social expenditure in the areas of health and social welfare, was required to lift "the crushing burden of Government spending" from the economy (Richardson 1990, p.442). Bolger, outlined four principles to guide the National Government's social reform in social policies, these were; targeting of dependent populations (people with intellectual disabilities), encouraging self-reliance (normalisation), increased personal choice in the use of alternative service providers (community service providers) and increased cost efficiencies in services (cheaper community services) and (Bolger, 1990).

In July 1991, the National Government embarked on a major reform in the health and disability sector with the release of its Green and White paper entitled 'Your Health and the Public Health', by the Minister of Health, Simon Upton (Upton, 1991, Upton, 1991a, SRHA, 1994). Upton's, opening statement declared that the primary objective of the health reforms was to secure access for New Zealanders of an acceptable level of health care (Upton, 1991, Upton, 1991a). Upton stated that New Zealand, as a heavily indebted country, needed to keep health expenditure within the limitation of its national income, or else demands from increasing consumer expectations for better health care would outstrip its

limited resources (Upton, 1991, Upton, 1991a). Upton argued that the New Zealand health care system needed to be re-structured to encourage the development of a fair, efficient, effective and affordable health service to meet the needs of the community (Upton, 1991, Upton, 1991a).

Upton's proposed state health sector restructuring, which included the disestablishment of the fourteen AHBs, who acted as both purchasers and providers of hospital-based services, sought to eliminate the AHBs dual role which was seen to create a conflict of interest (Upton, 1991, Upton, 1991a). The fourteen AHBs were replaced with four Regional Health Authorities (RHAs) to act as purchasers of services while Crown Health Enterprises (CHEs) were established to manage public hospitals and community services. (Upton, 1991, Upton, 1991a, SRHA, 1994a, SRHA, 1995). The shift from the AHB's monopoly on purchasing and providing of hospital services, to the RHAs and CHEs purchaser and provider split, was intended to achieve 'better value for money', by introducing competition. The RHAs, as purchasers of services, were able to force CHEs to replace institution based services with cheaper community services, to compete more effectively for service contracts from the RHAs. The RHAs were under no obligation to fund CHE hospital-based services, instead, purchasing services from the CHE community services as well as private and voluntary sector services was encouraged if it provided a quality service, which was cost effective as well (Upton, 1991, Upton, 1991a).

In 1992, the Minister of Health and Minister of Social Welfare released the 'Support for Independence : A Discussion Paper on the Funding and Delivery of Disability Support Services' (Shipley & Upton, 1992). The Support for Independence paper, sought public submissions on issues related to disability support services. These public submissions helped to shape the publication of 'Support for Independence for People with Disabilities : A New Deal' in August 1992 (Shipley & Upton, 1992a). Both 'Support for Independence' documents stated that the goals for disability support services was to create a positive attitude towards people with disabilities, promote rehabilitation, provide appropriate services, be culturally sensitive and community orientated, as well as minimising disruption to the lives of people with disabilities and being cost effective (Shipley & Upton, 1992, Shipley & Upton, 1992a). The 'Support for Independence' documents argued that people with disabilities often received inappropriate services for their needs, as state expenditure on disability support services was "locked into institutional and hospital services even though many people would prefer more support to stay at home or in the community" (Shipley & Upton, 1992, Shipley & Upton, 1992a, p.3). Therefore, the RHAs, which were due to be established on the 1st July 1995, were to be given incentives to free financial resources to fund better support services for people with disabilities in the community. This would include a greater emphasis being placed on rehabilitation programmes for the disabled (Shipley & Upton, 1992a). The RHAs were also responsible for purchasing disability support services, with the aim of purchasing the most appropriate services for clients needs from the most cost effective options (Shipley & Upton, 1992a). The 'Support for Independence' documents summarise the National Government's agenda in its health and disability reforms with the statement "These goals reflect the Government's desire to improve the quality of life for people with disabilities. They also recognise the financial realities facing the country today" (Shipley & Upton, 1992a, p.25).

The National Government's policy direction was confirmed in its 'Policy Guidelines to Regional Health Authorities', which set out purchasing priorities for health and disability support services (Minister of Health, 1992). For disability support services, the priorities included the managed process of moving people with disabilities out of institutions, improving assessment and

rehabilitative services, and supporting ex-residents to become independent in the community (Minister of Health, 1992).

In May 1993, the National Government passed the 'Health and Disability Act', which was founded on the principles within the 'Green and White' paper of 1991 (SRHA, 1994a). In July 1993, the new legalisation created the RHAs as purchasers of services from the CHEs, acting as providers of services (SRHA, 1995). In the Canterbury Region this led to the creation of the Southern Regional Health Authority (SRHA) - the former Canterbury Area Health Board being replaced by three Crown Health Enterprises (CHEs) (SRHA, 1995). The RHAs were now able to use public resources to purchase services from any provider whether it be hospitals or community organisations (SRHA, 1995). The change in health sector structure and its accompanying flexibility in funding arrangements, was vital to enable the policy shift from CAHB owned and managed hospital-based institutions to CHEs community-based services for people with disabilities (SRHA, 1995). The RHA's next step was to conduct public consultation to gauge public attitudes towards the shift to community-based services and identify the core health and disability support services required to enable deinstitutionalisation of hospitals and institutions for people with intellectual disabilities.

The National Government established the National Advisory Committee on Core Health and Disability Support Services, as an independent ministerial advisory committee to recommend which health and disability services ought to be purchased within the limited fiscal means of the government (National Advisory Committee on Core Health and Disability Support Services, 1994) The national advisory committee released several documents related to developing disability policies, these included 'The Best of Health', 'Best of Health' 2, 'Priorities' and 'Self Help and Empowerment : People with Disabilities Challenging Power, Promoting Change' (National Advisory Committee on Core Health and Disability Support Services, 1992).

The Best of Health document began public consultation on the core health services required by New Zealanders. It questioned 'what are the benefits of services?', 'is the service value for money?', 'is there fair access to the service?' and 'is the service what the community want?'. The consultation paper posed the question "A suitable house near Jim's work has come up which the IHC could buy with the assistance from the Regional Health Authority. Do you think this is an appropriate use of government money? Houses in the community make it possible for people to leave institutions - care that is expensive for the government. (National Advisory Committee on Core Health and Disability Support Services, 1992). Therefore, the Best of Health document provided a framework for public consultation, in which community care was established as the better and cheaper option for health and disability expenditure and people with intellectual disabilities.

In Best of Health 2, the advisory committee presented summaries of public submissions on issues raised in 'Best of Health', and made recommendations on what public consultation ought to be sought. (National Advisory Committee on Core Health and Disability Support Services, 1993a). In relation to 'Best of Health' the public submissions supported community care, as people with disabilities were seen to benefit from placement in the community. The public submissions viewed the provision of specialised disability support services as enabling independent living in the community as well as providing better value for money than institution based services. The public submissions, expressed the view that community care created fairness, as it focused on developing the potential of the disabled person as well as being consistent with the

community's values (National Advisory Committee on Core Health and Disability Support Services, 1993a).

In 'Priorities', 'Self Help and Empowerment : People with Disabilities Challenging Power, Promoting Change' and 'Core Services for 1994/95', the national advisory committee identified the role of the state, as enabling people with disabilities to participate in the design and implementation of appropriate support services to create community services which both enhanced 'quality of life' and were cost effective (National Advisory Committee on Core Health and Disability Support Services, 1993b). However, the social goal of full participation for people with disabilities in the mainstream of society required the issue of geographic location to be confronted (National Advisory Committee on Core Health and Disability Support Services, 1993c). Therefore, the national advisory committee argued that disability support services needed to be designed and delivered in a community setting to assist in the deinstitutionalisation of hospital and institutions (National Advisory Committee on Core Health and Disability Support Services, 1993c). The committee recommended that the state shift its allocation of resources from the institution based model to community based disability support services, which would then alter the social, physical and environmental factors that prevented the person's ability to fully participate in society (National Advisory Committee on Core Health and Disability Support Services, 1993c). The national advisory committee summarised the principles of community support services to enable people with disabilities to be involved in the design of secure, consistent and responsive services, enabling participation in society, empowerment of the disabled, improvement of quality of life, as well as operating as cost-effective and affordable services (National Advisory Committee on Core Health and Disability Support Services, 1993d).

In mid-1993 the National Government changed its funding structure to facilitate the shift to community-based care for people with disabilities. The Department of Health would no longer bulk-fund Hospital Boards, which allocated a share to intellectual disability services (CAHB, 1993a). Instead, the Regional Health Authorities, acting as purchaser of services, required competing service providers to apply directly for funding allocation, which obligated them to provide detailed information on the number, type and services it provided for intellectually disabled clients (CAHB, 1993a). Therefore, the health funds which followed the intellectually disabled person into the community were more closely related to their individual needs (CAHB, 1993a). The Government hoped that the new funding structure would create better value for money by encouraging competition and improving targeting of clients' needs (CAHB, 1993a SRHA, 1997).

In Summary, the National Government's neo-liberal health reforms sought to reduce state expenditure on health and disability services by increasing cost effectiveness. The RHA's and CHE's purchaser/provider split introduced competition, which promised increased cost effectiveness and efficiency in service delivery. The Government's shift from hospital-based care to community-based services also promised to reduce state expenditure as well as appeasing disability rights advocates in the state health bureaucracy, private service providers and disability rights groups. The convergence of neo-liberal economic management and disability rights normalisation discourse was to become central to the RHA's approach to deinstitutionalisation. For neo-liberals, the hospital-based care model was seen as providing poor value for state expenditure due to its monopoly in the provision of services. The introduction of community-based services promised to create cost savings via competition for service contracts, which would lower overall costs. For disability rights advocates the hospital-based model was seen as neglecting the human potential of people with disabilities while the closure of hospitals would allow resources to be

allocated to specialist disability support services, which would enable people with intellectual disabilities to shift to independence living in the community. Therefore, the National Government's health reforms, neo-liberal economic management principles and advocacy of the principles of normalisation converged into the policy of deinstitutionalisation, which was pursued for both political, social and economic gains.

State Expenditure Savings and the Templeton Centre Closure

While the National Government promoted the health reforms for political reasons and the SRHA and Healthlink South promoted the principles of normalisation for the social gain of the intellectually disabled, the deinstitutionalisation of the Templeton Centre also achieved economic gains. These economic advantages included reduced state expenditure on hospital facilities, reduced operating costs, development of flexible housing stock, proposed land sales and reduced staff salaries.

In the Healthlink South site announcement, on the 15th November 1994, it stated that the Templeton Centre provided poor facilities, used outmoded treatment models and wasted funds on overhead expenses through the lack of economies of scale (Healthlink South & SRHA, 1994). Healthlink South argued that if the Templeton Centre was not closed, then a substantial sum of state health expenditure would be required for the upgrading, maintenance and replacement of buildings to meet licensing requirements (Healthlink South & SRHA, 1994). Healthlink South stated that the cost of upgrading and modifying the Templeton Centre's facilities was estimated at \$18.9 million with an additional maintenance cost of \$1.47 million for 1993/94 (Healthlink South & SRHA, 1994).

The closure of the Templeton Centre also promised to reduce operating costs in expenditure on administration, building maintenance, domestic services, food services, and grounds maintenance (Healthlink South & SRHA, 1994). While the Templeton Centre cost \$21.3 million to operate each year, only \$14.1 million (66%) was directed towards patient care, the other \$7.2 million (33%) was spent on overhead costs (Healthlink South, 1994). However, Healthlink South argued that cost savings made through the closure of the Templeton Centre, would be redirected into community-based care programmes for ex-residents transferred into the community (Healthlink South & SRHA, 1994, O'Regan, 1996).

Another major advantage of shifting from institutional accommodation to residential homes was the development of flexible housing stock, as houses or flats purchased in a suburb were a readily realisable asset should the demand for residential services in that locality decline (Craig, et al. 1991). Also, should demand for residential services increase in any area, then additional houses could be readily purchased (Craig, et al. 1991). This degree of flexibility was unavailable with the state ownership of large institutions, such as the Templeton Centre (Craig, et al. 1991).

The IHC, as the major service provider of residential properties for people with intellectual disabilities, had a large housing stock of a readily realisable nature (Craig, et al. 1991). Also, the IHC only received 63% public funding (Department of Social Welfare and Ministry of Health) with 37% coming from private funding (annual appeals, donations, fees, grants, and legacies) for its residential-based services (National Advisory Committee on Core Health and Disability Support Services, 1994). In contrast, in 1994, the SRHA had to provide 100% funding for the Templeton Centre (National Advisory Committee on Core Health and Disability Support Services, 1994). Therefore, the SRHA could

reduce its expenditure on residential accommodation by utilising and exploiting the IHC's reliance on private funding sources for subsidising its residential services.

The Templeton Centre's site rationalisation also promised a major financial reward in the form of proposed land sales. The Templeton Centre occupied 74 hectares of rural land, which could be subdivided into residential sections (Bruce, 1998, Bruce, 1998a, Robson, 1999). Healthlink South proposed the development of 435 residential sections, accommodating up to 1500 residents, at the Templeton Centre site (Bruce, 1998, Bruce, 1998a). Healthlink South claimed that any proceeds from the sale of the Templeton Centre site would be spent on other health services (Bruce, 1998, Ministry of Health, 1994).

The Templeton Centre's closure also promised to reduce state expenditure on the salaries of psychopaedic specialists and support personnel. In 1993, the Templeton Centre's staffing level was set at 430 'Full Time Equivalents' employees, which included 248.5 psychopaedic nurses, 102.3 support (cleaners, food service, gardeners), 39.6 allied support professionals, 37.9 management and administration and 2 medical personal (CAHB, 1993). The 248 psychopaedic nurses were qualified and experienced professionals with specialist knowledge and skills in the care and management of people with intellectual disabilities. However, the shift to community care and the application of the principles of normalisation meant that less qualified and experienced care-givers could be used to care for the intellectually disabled. While psychopaedic nurses received specialist psychopaedic training and required a three year registration, community care-givers merely required, at most, a one year generic qualification in the area of disabilities (Certificate in Teaching People with Disabilities, re-titled Certificate in Human Services) (CAHB, 1991). Therefore, the state health authorities were able to reduce expenditure on salaries with a combination of specialist staff reduction and with the employment of less-qualified and experienced community care-givers. The closure of the Templeton Centre also eliminated the need to employ 102 support personnel in an institutional environment. The principle of normalisation encouraged people with mild to moderate disabilities to engage in everyday housekeeping in community-based care, which removed the need for the employment of cleaners, food service workers, maintenance workers and gardeners.

However, the economic gains from the deinstitutionalisation of the Templeton Centre was dependent upon several variables, including the speed of deinstitutionalisation, the off-set of hump funding costs, the ability to completely close the site, and the sale of the site for residential sections (Waikato Area Health Board, 1991, Ministry of Health, 1993). In the closure of the Templeton Centre, the speed of deinstitutionalisation was paramount, as the hospital had to remain open and operating whether it had 450 or 45 residents (Minister of Health, 1996). Also the hospital operating losses were rapidly increasing, while patient numbers were in gradual decline during the transition period (Minister of Health, 1996). For example in March 1982, the Templeton Centre operating costs were 11 million for 624 residents, while in March 1992 the operating costs had increased to 20 million for 460 residents (CAHB, 1993). Therefore, if the SRHA could press ahead with deinstitutionalisation, it would reduce hospital operating costs and save unnecessary health expenditure. Also the problem of 'hump' costs could be off-set if the Healthlink South could dispose of surplus assets (Templeton Centre land), in the minimum amount of time, to enable funds from property sales to be redirected towards the short-term increase in funding required for residential accommodation. Therefore, the ability to close the Templeton Centre rapidly and completely, was paramount to enable Healthlink South to realise the asset value of the 74 hectares for residential development.

The SRHA, as purchaser of disability support services, achieved major savings in the deinstitutionalisation of hospitals and institutions for people with intellectual disabilities. In 1995, the SRHA had spent \$25 million dollars to support 700 patients in institutions, compared to merely \$11 million spent on supporting 625 people in community care (SRHA, 1996). The National Government was able to achieve major savings from deinstitutionalisation nationwide as well. For example, in 1996, the Central Regional Health Authority (CRHA) had 26% of its intellectually disabled clients in institutional care at the cost of 68% of its health service expenditure (CRHA, 1996). In comparison 39% of its intellectually disabled clients were in community care at the cost of 27% of its service expenditure (CRHA, 1996). However, the ideal cost saving strategy, was the placement of 35% of people with intellectual disabilities in the family home at the cost of merely 5% of its health expenditure (CRHA, 1996). Therefore, the Government's closure of institutions nationwide reduced service expenditure and transferred the cost to families and the community.

In Summary, it is clear that the closure of the Templeton Centre reduced state health expenditure. The deinstitutionalisation of the Templeton Centre saved expenditure on the up-grading, maintaining and replacing of out-dated facilities. Deinstitutionalisation also eliminated the expenditure on administration, domestic services, food services and grounds maintenance at the Templeton Centre. The shift from state ownership of institutions to IHC residential housing stock also reduced state expenditure. The Templeton Centre closure also facilitated the shift from specialist nurses and allied personal on higher salaries to the employment of low skilled community care-givers on lower wages. Finally, the proposed sale of the Templeton site as residential sections, promised to off-set the hump costs in establishing community homes, which would be cheaper than institutional care in the long-term. Therefore, the cheaper cost of community care was a major factor in the shift from institutional based services. It is doubtful that the National Government would have pursued the policy of deinstitutionalisation had it required an actual increase in state health expenditure during a time of poor national economic performance, with the need to reduce state expenditure in health, disability and social welfare. However, the major state cost-saving strategy, was less to do with dollars and cents, instead it was the philosophical shift from state responsibility to provide institutional care, to the care burden being placed upon competing community service providers. The state was no longer morally bound to provide long-term care for the intellectually disabled. The long-term responsibility for people with intellectual disabilities passed to their families (unpaid care-givers) and cheaper community service providers (increasingly reliant upon annual appeals and donations).

The National Government's Implementation of Deinstitutionalisation

The National Government's economic agenda to reduce state expenditure on the Templeton Centre, required the expeditious implementation of deinstitutionalisation to avoid protracted operating costs occurring due to a slow depopulation of its institution. Therefore, the SRHA and Healthlink South planned to close the Templeton Centre over a three year period, with annual relocation targets (Healthlink South & SRHA, 1994). The annual relocation targets were: in 1995/96 one hundred patients would be relocated to community housing (Healthlink South & SRHA, 1994). In 1996/97 another one hundred patients would also be placed into community housing, including an additional transfer of one hundred and fifty patients to specialised accommodation (high needs patients) (Healthlink South & SRHA, 1994). In 1997/98 a further one hundred patients would also be relocated to community housing (Healthlink South & SRHA, 1994). The exact relocation targets per year were subject to individual needs assessment, public and parental consultation and patient choice (Healthlink

South & SRHA, 1994). However, any parental or patient opposition to the process of community placement or the timetable of relocation was not to be allowed to disrupt the enforced implementation of deinstitutionalisation. The creation of a close relationship between Healthlink South and Templeton families, was seen as extremely important for the long-term success of deinstitutionalisation, as parental opposition could cause delays in the shift from institution-based care to community care (Healthlink South & SRHA, 1994). For the SRHA and Healthlink South, any and all parental interference with the relocation timetable meant increased state expenditure on protracted operating costs of the Templeton Centre. The Ministry of Health was to later blame the delays in the implementation of deinstitutionalisation which resulted in continued operating costs and loss of asset realisation, on the protracted public consultation with parents and families in attempts to undermine their opposition to the closure of the Templeton Centre (Ministry of Health, 1996, Ministry of Health, 1997, Ministry of Health, 1997a).

The Healthlink South process of deinstitutionalisation included a preliminary and comprehensive 'needs assessment' to determine the priorities of a person's needs and appropriate type and level of care required by the individual in their relocation into the community (Ministry of Health, 1993, Ministry of Health, 1995, O'Regan, 1996, SRHA, 1995a, SRHA, 1996, SRHA, 1996a). A 'care and treatment plan', which covered required services and housing options, for each Templeton resident was prepared (Healthlink South & SRHA, 1994). The needs assessment included input from the person's advocate, parents, families and staff members (Healthlink South & SRHA, 1994, Ministry of Health, 1994). The comprehensive needs assessment was followed by an 'Individual Programme Plan' (IPP), which focused on enhancing the person's quality of life with an emphasis on positive transition, skills development and personal growth (Healthlink South & SRHA, 1994). The IPP covered the person's individual care, treatment, services, accommodation, community placement and follow up assessments (Healthlink South & SRHA, 1994, O'Regan, 1996).

A Service Coordinator was responsible for the facilitation and coordination of a package of services identified in the client's needs assessment (Ministry of Health, 1994a, Ministry of Health, 1994b, O'Brien, 1996). The Service Coordinator was also required to liaise with families on care related issues (Healthlink South & SRHA, 1994). Families and care givers were encouraged to be involved in the development of the needs assessments and IPPs, as both of these processes played a major part in the successful community placement of their disabled dependent (Healthlink South & SRHA, 1994, Ministry of Health, 1994c). While the needs assessments and the IPP's process involved full consultation with families, any concerns or opposition to deinstitutionalisation from families was excluded from the process of consultation and decision making, as the decision by the SRHA and Healthlink South to close the Templeton centre was full and final.

The Templeton Centre residents' community placement involved a trial placement in small residential accommodation units (Healthlink South & SRHA 1994). The trial placement was followed by an assessment of the person's experience of the transfer from the villa unit to the community-based residential unit, to assess any problems or needs (Healthlink South & SRHA, 1994). The success of community placements required in the deinstitutionalisation process involved the re-education of staff in the principles of normalisation and the teaching of community living skills in residential units, which were located in the Christchurch area, outlying towns and rural areas (Healthlink South & SRHA, 1994). However, the selection of residential properties was dependent on property availability and suitability, public transport, access to facilities

and services as well as the wishes of the person with the intellectual disability and their respective families (Healthlink South & SRHA, 1994).

The community placements in residential units mixed people of different age, disability, gender and ethnicity (Healthlink South & SRHA, 1994). The range of residential accommodation included normal homes (property unsecured), homes with safety features (locked gates and fences), homes with strengthening (locks on service areas and safety glass), homes with mobility aids (hand rails and ramps), special purpose built or significantly adapted homes (extensive alterations) and intensive staffing homes (moderate/severe behavioural challenges) (Healthlink South & SRHA, 1994). From this list of housing options, 'normal' homes appeared suitable for people with mild or moderate intellectual disabilities, while people with severe or profound intellectual disabilities and challenging behaviour (dangerous to themselves and/or others) required a more 'mini institution' type housing option in the community.

All Templeton residents required 24 hour supervision and care support in any and all of the housing options regardless of the level of their disability (Healthlink South & SRHA, 1994). In addition, community support teams provided other specialist services which were required including advocacy, clinical psychologist, occupational therapy, nurse specialist support, physiotherapy, social workers and speech and language units (Healthlink South & SRHA, 1994, O'Regan, 1996). Also, specialist community support teams were established to provide specific services in rehabilitation, habitation, behavioural intervention and counselling services (Healthlink South & SRHA, 1994). Also, a comprehensive range of vocational, work and day activity programmes in community-based settings were established (Healthlink South & SRHA, 1994). These often required a high level of volunteer support to enable people with disabilities to engage in these programmes (Healthlink South & SRHA, 1994).

The SRHA and Healthlink South's plan, placed the majority of Templeton Centre residents into community-based care. However, the plan to place 150 people with profound and multi-disabilities into Princess Margaret Hospital Nurses' Hostel met with powerful public opposition (Healthlink South & SRHA, 1994).

The Brackenridge Estate

While the SRHA and Healthlink South's programme of community placement for 300 of its less disabled Templeton Centre residents gradually achieved its goals, the decision to shift 150 people with severe disabilities to the Princess Margaret Hospital Nurses' Hostel, met widespread parental, family and public opposition (Wells, 1995b). The Princess Margaret Hospital plan proposed the placement of 160 Sunnyside Hospital patients and 150 Templeton Centre residents in a five storey re-modelled modern institution located at the old Nurses' Hostel (Fahey, 1995, Gilling, 1995a, Halls, 1995, McNeil, 1995). However, the political and public pressure expressed in letters to the editor, public meetings and public submissions, forced the SRHA to abandon its proposal to use the Princess Margaret Hospital site (Mirfin-Veitch, 1998). On the 15th September 1995, the SRHA announced its abandonment of the Princess Margaret Hospital Nurses' Hostel, proposal as it conceded that it would merely result in the transinstitutionalisation of Templeton and Sunnyside residents (Mirfin-Veitch, 1998). However, the SRHA still needed alternative residential accommodation for the 150 Templeton Centre residents. While the CAHB, SRHA and Healthlink South had consistently rejected the parents' advocacy of a sheltered village concept for all Templeton Centre residents, it conceded that the development of a small specialist facility was needed for the 150 Templeton Centre residents, who would no longer be transferred to Princess Margaret Hospital Nurses' Hostel site.

In 1998, the Health Funding Authority (HFA), announced the setting up of the Brackenridge Estate, a specialist facility, on a reduced part of the Templeton Centre site (Mirfin-Veitch, et al. 2000). The Brackenridge Estate was established to meet the needs of people with multiple physical and intellectual disabilities, people who were medically fragile, as well as people with severe challenging behavioural problems (The Press, 1999, Mirfin-Veitch, et al. 2000). Brackenridge Estate consists of 14 stand-alone houses with communal living areas and individual bedrooms (McNeil, 1999, Calcott, 2000). While the state health authorities had rejected the concept of a sheltered village for the majority of the Templeton Centre residents, the political lobbying of parents and families against the Princess Margaret Hospital site and their advocacy of a specialist unit (modified sheltered village) had forced the development of the Brackenridge Estate (The Press, 1999, Mirfin-Veitch, et al. 2000). However, the Brackenridge Estate did not accept all 150 Templeton residents, who would have been transferred to the Princess Margaret Hospital Nurses' Hostel, instead the needs assessment process established that merely 80 of the ex-Templeton residents were eligible for this specialist facility, the 'others' were placed into community placements with varying degrees of success (Mirfin-Veitch, et al. 2000).

Chapter Six

The Public Reaction to Deinstitutionalisation

The Community, Public and Parental

Reaction to Deinstitutionalisation

In Western countries, the community's response to the deinstitutionalisation of people with intellectual disabilities has had a disabling effect on the implementation of the principles of normalisation and social role valorisation

in the community setting (Dear, 1992, Tse, 1994, Gleeson, 1997). The community reaction has often developed into the classic NIMBY ('not in my back yard') syndrome, which in turn has led to political opposition by neighbourhood associations to the establishment of community-based homes in 'their' area (Young, 1990, Gleeson, 1997). The political opposition to community-based homes can include the use of council zoning regulations to limit the location of the community home, which denies the person with a disability personal choice in housing, access to facilities, services and social networks (Gleeson, 1997). The political reaction of neighbourhood associations is seen by disability rights groups to raise issues such as social injustice, discrimination and violation of civil rights (Gleeson, 1997). The community stigmatisation and discrimination against people with disabilities can be a major reason for the failure of people with disabilities to successfully reintegrate into the community (Shadish, et al. 1989).

The NIMBY syndrome has been studied extensively in the United Kingdom, United States, Australia and New Zealand (Burnett & Moon, 1983, Foreman & Andrews, 1988, Gleeson, et al. 1995, Gleeson, 1997). These studies have shown that the NIMBY syndrome is usually based on public anxieties about different 'categories' of people with disabilities being placed in the local neighbourhood, fear of potential dangerous encounters with ex-patients and the feared affect on property values, (Shadish, et al. 1989, Gleeson, 1997).

In Western capitalist societies, the ownership of private property is recognised as an important and valuable asset (Walker, 1981). Its value as an asset includes its social value as a residential living setting as well as its exchange value (sale price) (Walker, 1981). Therefore, the location of community-based homes is seen as a threat to the 'character' and/or 'quality' of the neighbourhood (Gleeson, 1997). The NIMBY syndrome can be seen to be embedded in the class interests of private able-bodied land owners against the 'property-less' people with disabilities (Gleeson, 1997).

The NIMBY reaction to the establishment of community-based group homes in residential areas has at times been hostile, creating feelings of social isolation and alienation for community group home residents (Dear, 1992, Shadish, et al. 1989). Social scientists have argued that NIMBY reactions are a major threat to the deinstitutionalisation process by its creation of hostile political and legal resistance to the establishment of community-based homes (Gleeson, 1997). The state's response to the political and legal resistance to community homes has been the adoption of 'avoidance strategies' (Gleeson, 1997). The state avoidance strategies include the concentration (ghettoization) of community homes in 'places of least resistance', such as low socio-economic residential areas (Gleeson, et al. 1995). Therefore, a major threat to deinstitutionalisation has been the combination of the NIMBY syndrome and state avoidance strategies which at times have resulted in the violation of disabled people's environmental, human and civil rights (Gleeson, 1997).

Community Reaction to the Deinstitutionalisation of Templeton Residents

The community's reaction to the deinstitutionalisation of the Templeton Centre and the placement of people with intellectual disabilities in the community is revealed by a summary of letters to the editor on this subject in the 'The Press' from 1994 to 1998. The large number of community responses overwhelmingly and vehemently defended the Templeton Centre as the ideal community setting for the intellectually disabled. The Templeton Centre supporters included parents, families and concerned citizens. However, a small number of responses argued that the Templeton Centre, as an institution, ought to close and promoted the placement of the intellectually disabled in the community.

These Community Living supporters tended to be people with disabilities acting as self advocates.

The Templeton Centre supporters expressed dismay at the National Government's state health authorities' decision to close the Templeton Centre which was seen as a victim of the 'slash and burn' approach to health sector reform of the National Government in the 1990s (McGuigan, 1994, Cain, 1995). The SRHA and Healthlink South's planned deinstitutionalisation of the Templeton Centre was seen as a screen for an economic agenda attempting to achieve long-term cost savings in the health and disability sector (Collins, 1994, Finlay, 1994). For Templeton Centre supporters the closure of the Templeton Centre was a political issue which needed to be debated at a parliamentary level (Walker, 1995). The National Government health reforms were seen as creating RHAs and CHEs which placed profit and cost saving strategies ahead of the welfare of the intellectually disabled (Walker, 1995). However, National Government MP, David Carter, countered "health reforms have moved us beyond the stage when parliamentarians could interfere with the decision-making process currently under way" (Carter, 1995, Wyles, 1995). However, for Templeton Centre supporters, the National Government health reforms were to blame for the deinstitutionalisation of the Templeton Centre (Harman, 1995, Harman, 1995a, Mayell, 1995, McElhinney, 1995, McElhinney, 1995a, Venning, 1995). The National Government was seen, in effect, as abdicating its moral responsibilities in the care of the intellectually disabled (Keeble, 1995, Rutherford, 1995).

The Healthlink South's proposed community care rationale based on normalisation, was seen as inherently flawed (Finlay, 1994). The philosophy of normalisation was challenged as a successful model for the care of the intellectually disabled, as overseas research allegedly showed that it resulted in negative experiences (Tranter, 1997). However, the overseas research was often based on the negative life experiences of psychiatric patients placed into community care programmes (Tranter, 1997).

The public concerns included the shift of the care burden from state institutions to allegedly under-funded and under-resourced community disability support services (Finlay, 1994, Newman, 1997, Shaw, 1997). The lack of adequate community support services, required by normalisation, was seen as a major flaw in the application of deinstitutionalisation of the Templeton Centre (Adams, 1997, Adams, 1997a, Wells, 1997).

Templeton Centre supporters also expressed the concern that SRHA and Healthlink South's consultation process was merely a public relations exercise, as the decision to close Templeton was irreversible and inevitable (Hunt, 1994). For some correspondents the value of public submissions on the proposal to close the Templeton Centre was of doubtful value and to others, a complete waste of time, due to the perceived unwillingness of Healthlink South to be open to parental and public debate on the merits of deinstitutionalisation (Farrow, 1995, Lewis, 1995, Moreton, 1995, Nathan, 1995, Well, 1995, Wells, 1995a). For Templeton Centre supporters, the state health authorities had promised to consult them about the health services the public wanted, it then ignored their public petitions and submissions (Moreton, 1995) The SRHA and Healthlink South seemed to be totally committed to deinstitutionalisation regardless of the parents' and public's needs or wants (Griffiths, 1995, O'Connell, 1995, Wells, 1995a, Well, 1995b). The SRHA and Healthlink South had ignored the 80% of submissions who opposed the deinstitutionalisation of the Templeton Centre (Bennett, 1995, Corkin, 1995, Lewis, 1995). As one writer despaired "For 'consultation' read: it doesn't matter what you think, we're making the decisions" (Wells, 1995c).

Templeton Centre parents, families and supporters often disclosed their personal experiences of contact with people with intellectual disabilities to support their views (Hunt, 1994, McGuigan, 1994, Gillespie, 1995, O'Connell, 1995). Templeton Centre parents often wrote emotional letters about their fears of what would happen to their dependent child in community care. As one parent stated "My severely handicapped son is now 27 years old. He cannot talk. He regularly throws tantrums, possibly because he is in pain, but cannot express himself. He has seizures about once a month. His bedroom is lined with inch particle board, because in anger he kept punching holes through the plasterboard" (Harman, 1995, p.23). As the Templeton parents engaged the debate at an emotional level with personal experiences, the managers of the SRHA and Healthlink South were seen as lacking the personal contact and empathy with the intellectually disabled and their families, to enable them to fully understand or to make decisions on behalf of the disabled (McGuigan, 1994).

The Templeton Centre supporters, rejected the description of the Templeton Centre as an 'institution', as an old and out-dated concept (McGuigan, 1994, McElhinney, 1995). Instead, the Templeton Centre was often described as a safe, caring, warm, happy, stable and tranquil environment for the intellectually disabled and it was argued that the intellectually disabled residents needed and wanted to live in this 'special home' environment (Hunt, 1994, Begg, 1995, Fleischman, 1995, Hird, 1995, McElhinney, 1995, McGuigan, 1994, Gillespie, 1995, Wells, 1995). The Templeton Centre's rural and open environment, without locks, gates and walls, was seen as conducive to a better lifestyle for the intellectually disabled, (Gillespie, 1995, Graham, 1995). Templeton Centre residents were seen as being able to engage in "riding bikes, playing games and going out walking without the fear of harassment, or danger of traffic" (Wells, 1995, p.7). A significant number of Templeton Centre supporters praised the work of nursing staff and support staff to enable people with intellectual disabilities to have a high 'quality of life' within the Templeton Centre (Davidson, 1995, Russell, 1995).

In contrast Templeton Centre Supporters saw community care as being a hostile environment for the intellectually disabled, in which the Templeton residents would endure abuse, discrimination, blatant exploitation and personal endangerment (Finlay, 1994, Taylor, 1997). Some Templeton supporters argued that community care was so dangerous due to community reaction, that it risked 'destroying' the quality of life of the intellectually disabled (Collins, 1994). As one person argued "local residents have no option but to gaze out of their kitchen windows at unfortunate people who have feelings like everybody else, and do not like being stared at?" (Garlick, 1995). Some correspondents argued that deinstitutionalisation ought to be delayed so that the public could be 'educated' to accept the presence of the intellectually disabled in the community (Finlay, 1994). However, it was never stated how long such 're-education' would take, nor the method to measure the attitudinal change of the community in the future.

While Templeton Centre supporters advocated that people with disabilities ought to be protected from the community, some also argued that the community needed to be protected from ex-Templeton residents (Davis, 1995). As one writer stated "Patients have rights to support and security; at the same time the ordinary, tax-paying citizen also has rights to a safe community" (Davis, 1995, p.11). A major concern was that people with intellectual disabilities would commit crimes against people and property, because of their alleged inability to assess the consequences of their actions (Newman, 1995, Adams, 1997, Taylor, 1998). The establishment of a special needs unit at Paparua Prison for people with

intellectual disabilities convicted of crimes, was cited as evidence of the danger of releasing potentially dangerous people into the community (Newman, 1995). However, the public debate about community safety, was often based on the perception of Templeton Centre residents as being psychiatric patients, instead of people with intellectual disabilities. This misunderstanding was partially caused with Healthlink South announcement to shift Sunnyside patients (psychiatric) to Princess Margaret Hospital, as well as 150 ex-Templeton residents. This merged the imagery of the psychiatric and psychopaedic disabilities together into one public perception of the disabled (Byrom, 1995).

While, the majority of Templeton Centre residents were seen as too disabled to adapt to community living arrangements, there was some limited support for community care for people with mild intellectual disabilities with appropriate disability support services (Consedine, 1995). However, as Templeton Centre residents began to move into community homes a different form of concern began to emerge, this being the adverse affect on property values and ability to sell neighbouring properties (Hart, 1997, Sutherland, 1997). This manifested into the classic NIMBY syndrome as experienced overseas.

Templeton Centre supporters also vehemently opposed the 'incarceration' of people with intellectual disabilities into the Princess Margaret Hospital Nurses' Hostel (Hunt, 1994, Fahey, 1995, McElhinney, 1995, Morrison, 1995). The Princess Margaret Hospital site was sometimes compared to a prison, a ghetto, or 1900s mental hospital, which would reduce the 'quality of life' of ex-Templeton residents (Hunt, 1994, Hird, 1995, Davis, 1995). The reason for these labels was the proposed locks and bars on windows (for safety reasons) and the restriction on freedom of movement (risk of pedestrian accidents caused by high traffic flow on the main road) associated with the site (Hurndell, 1995). The proposed usage of the Nurses' Hostel, a multi-storeyed complex with stairs and lifts, for people with multi-disabilities (intellectual and physical) raised concerns about resident safety in the event of fire (Bundle, 1994, Byrom, 1995). Also, the shift of 150 Templeton Centre residents to the Princess Margaret Hospital site was seen as a form of transinstitutionalisation rather than deinstitutionalisation (Tait, 1995). The state expenditure on up-grading the Nurses Hostel for the disabled, was seen as being better spent on up-grading the Templeton Centre, which did not required the same emphasis on safety or restriction of movement of residents (Gillespie, 1995).

Finally, a large number of Templeton Centre parents, families and supporters advocated the development of a 'sheltered village' to provide specialist care from health professionals for the intellectually disabled (Corkin, 1995, Harman, 1995b, McElhinney, 1995b, Wells, 1995c, Cooper, 1996, Wells, 1996, Cooper, 1997). The Templeton Centre's accommodation, workshops, halls, gym and swimming pool were seen as physical and social assets, which could form the structure on which the sheltered village complex could be built (Hughes, 1995, Moreton, 1995a).

While the over-whelming majority of public discourse on the deinstitutionalisation of the Templeton Centre argued against its closure, a small number of self-advocates and their families supported the shift to community living. As one self-advocate stated "I am in favour of it closing because the people of Templeton should be in the community like me" (Russell, 1995a, p.11.). A parent supported this view " As a parent whose son has recently been moved into the community. I find that this is the best thing that has happened to him. He is living in a 'home', not a institution. He is a changed person with his own room and freedom of choice". (Gillies, 1997, p.4.). Another community living advocate cited overseas research, which supported claims that

people with intellectual disabilities gained a better quality of life in the community (Shaw, 1995).

In summary, the Templeton Centre supporters viewed the National Government health reforms and the state health authorities cost-cutting agenda as a major reason for the closure of the Templeton Centre. The SRHA and Healthlink South's public consultation process was seen as an ineffective tool as parents and families' personal experiences and views were devalued, compared to the SRHA's and Healthlink's adherence to the application of the philosophy of normalisation. The Templeton Centre supporters argued that Templeton was a modern specialist care facility, which provided a safe, secure and positive environment for the residents. In contrast community care and the Princess Margaret Hospital site proposal were seen as endangering the quality of life of people with intellectual disabilities. Therefore, public opposition to deinstitutionalisation was primarily based on an attempt to defend the intellectually disabled person's 'quality of life' at the Templeton Centre, as well as preventing their placement in cheaper community care in a hostile able-bodied society. In contrast, the Community Living advocates argued that Templeton Centre denied people with intellectual disabilities the ability to live a 'quality of life', which could only be acquired in a community setting.

Parental Reaction to Deinstitutionalisation

Research studies in the United Kingdom, United States, Australia and New Zealand have shown families' reaction to deinstitutionalisation has been both positive and negative (Cummins & Dunt, 1990, Seltzer & Heller, 1997) Parents have expressed negative concerns towards the philosophy, policy and process of deinstitutionalisation, as well as a mix of positive and negative views on the outcome of deinstitutionalisation (Seltzer & Heller, 1997, Tossebro, 1998). For some parents and families the immediate reaction to the deinstitutionalisation of a family member, was hostility towards proponents of the principle of normalisation and fears for the safety and welfare of their disabled 'child(ren)' (Frohboese & Sales, 1980, Cummins & Dunt. 1990).

The policy of deinstitutionalisation, as advocated by health professionals, argued that the application of the principles of normalisation were essential for the enhancement of the quality of life for people with disabilities (O'Brien & Thesing, 1999). The health professionals' advocacy of deinstitutionalisation in the 1980s, was a complete reversal of the medical profession's advice to parents and families prior to the 1980s, which advocated the placement of children with disabilities into institutions to enhance the 'quality of life' for parents, siblings and the 'disabled child' (O'Brien & Thesing, 1999). For parents, the placement of their 'disabled child' into an institution was often a painful and guilt ridden decision, which was often made under immense pressure from extended family members and friends or caused by marriage or relationship crisis, personal illness or the birth of a subsequent child (Somerville, et al. 1976, O'Brien & Thesing, 1999).

Parental reaction to the policy of deinstitutionalisation included concerns for the safety and welfare of their 'disabled child' as well as the feared 'dumping' of care responsibilities, on parents or siblings if community-based care failed (Zimmerman, 1978, Willer, et al. 1979, Mowbray & Bryson, 1984). Critics of deinstitutionalisation have argued that the ultimate consequence of the dumping of care responsibilities will be the creation of a 'care burden' on unpaid caregivers (especially women), foster families and voluntary agencies (Zimmerman, 1978, Willer, et al. 1979, Mowbray & Bryson, 1984). While government officials and health professionals used public consultation to offer reassurance to

parents and families, the process of deinstitutionalisation was irreversible and families' high levels of anxiety and distress were seen as a short-term problem which would decline as disabled family members successfully reintegrated into the community (O'Brien & Thesing, 1999).

While some parents and families reacted negatively towards hospital and institution closure, other parents and family members were positive and accepting of the deinstitutionalisation programme (O'Brien & Thesing, 1999). For some families, the final decision to place a dependent family member in an institution, had been influenced by the lack of community-based facilities, services and resources as well as public and extended family attitudes towards the presence of the person with the disability in the family and community (O'Brien & Thesing, 1999). The proposed establishment of community-based group homes offered these parents and families the chance to re-establish contact with a daughter, son, sister or brother in a supportive and welcoming environment (O'Brien & Thesing, 1999).

Templeton Centre Parents' Association Reaction to Deinstitutionalisation

The Templeton Centre Parents' Association, was the primary advocate for parents and families affected by the SRHA and Healthlink South's proposal to deinstitutionalise the Templeton Centre (Bourke, 1994, Bourke, 1994a). Templeton parents consistently rejected the planned closure of the Templeton Centre, the transfer of residents to the Princess Margaret Hospital Nurses Hostel, as well as placement in the community (Bourke, 1995, McElhinney, 1995c). Templeton parents and families, instead argued for the development of a sheltered village on the Templeton site (Bourke, 1995, McElhinney, 1995c).

The Templeton Centre Parents' Association organised both submissions and a 28,000 signature petition, arguing that parents had the right to choose where their disabled 'child' ought to live, and that a sheltered village was their choice (parents and disabled 'child') (Bourke, 1995a, Bourke, 1995b, Bourke, 1994c). In a postal survey 292 out of 294 respondent Templeton Centre Parents' Association members, supported the retention and development of a sheltered village at the Templeton site (Bourke, 1995b).

In 1995, five Templeton Centre Parents' Association management committee representatives joined a SRHA and Healthlink South 'Working Party' to "achieve a coordinated planning and decision making process for the future of the Templeton Centre and its clients" (Bourke, 1995b, p.2.). The Templeton Centre Parents' Association committee representatives argued against the closure of the Templeton Centre at the policy level and advocated instead, for the concept of a sheltered village (Bourke, 1995b, p.2.).

While the Templeton Centre Parents' Association argued against the closure of the Templeton Centre, it supported the principles of normalisation which are embedded in the policy of deinstitutionalisation (Absalom-Smith, 1995). However, Templeton Centre parents and families argued that the principles of normalisation could be better applied in a sheltered village complex than in a hostile community environment (Absalom-Smith, 1995). Templeton Centre parents argued that the Templeton Centre, as a sheltered village, could supply 24 hour care and family-style accommodation similar to community-based units (Absalom-Smith, 1995). People with mild intellectual disabilities could attain a level of independence with supervised on-site flats while people with severe intellectual disabilities could receive intensive nursing care in clustered housing if required (Absalom-Smith, 1995). All Templeton residents would have access to

recreation, clubs, sports, music, vocational and social activities similar to community-based care (Absalom-Smith, 1995). The Templeton Centre parents viewed a sheltered village as enabling people with disabilities who failed to adjust to, or were stressed by community care to return to a supportive environment (Absalom-Smith, 1995). The Templeton parents viewed the sheltered village concept as compatible to the SRHA's policy emphasis on the 'least restrictive' aspect of normalisation as the sheltered village concept allowed greater flexibility in the care options of people with different levels of disability (Absalom-Smith, 1995). In contrast, the community living option was seen to reduce the options of the intellectually disabled to one - the community (Absalom-Smith, 1995). However the SRHA and Healthlink South consistently rejected the sheltered village concept.

Some SRHA and Healthlink South bureaucrats and disability rights advocates possibly viewed the Templeton Centre Parents' Association as a reactionary force, which wanted to keep their intellectually disabled 'children' in a institutional environment. Templeton parents and families acted in the best interests of their dependent family members. This manifested itself in the form of advocating for a sheltered village, which it believed was the best option for their intellectually disabled 'children'. While the Templeton Centre Parents' Association did not halt the closure of the Templeton Centre, it arguably played a role in preventing the transinstitutionalisation of Templeton Centre residents to the Princess Margaret Hospital Nurses' Hostel, as well as assisting in the establishment of the 'Brackenridge Estate' for the most disabled, on part of the Templeton site.

In summary, the SRHA and Healthlink South, disability rights groups and people with disabilities who advocated the philosophy of deinstitutionalisation, faced a mixed response from parents, families, welfare guardians and the community. The state's policy application of deinstitutionalisation involved the use of state pressure to force parents and families to accept its community-based care policies. Public consultation was arguably a means to undermine parental and public opposition to deinstitutionalisation. The state's reversal of past policies, informed by experts, of placing disabled children into institutions, undermined present confidence in the 'expert' advice which advocated deinstitutionalisation. This lack of confidence in government policy and experts helped to create the fear of care responsibilities being dumped onto families. While the philosophy of normalisation emphasised the quality of life for people with intellectual disabilities, it inadvertently created a concern among families of the impact upon their own quality of life if community-based care failed.

Disability rights advocates were often seen by parents and the community as idealists who masked the economic agenda of the state with their discourse on the rights of the disabled. For many parents and families, the disability rights advocates assumed the right to advocate on behalf of the their disabled 'child', which unintentionally dis-empowered the family unit from representing one of its own members. The self-advocacy of people with intellectual disabilities failed to allay the fears of parents and families, as people with mild intellectual disabilities were seen as being unable to advocate on behalf of people with profound and multi-disabilities.

For parents and the community, their reaction to deinstitutionalisation has been who has the right to advocate for those unable to voice their own needs and wants, the state, disability rights advocates, self-advocates, medical personnel, parents, families or the community?. Also, would the advocates of normalisation and deinstitutionalisation be willing and able to help the

intellectually disabled and their families if community care failed?. Therefore, the parental and community long-term appraisal and acceptance of deinstitutionalisation would be dependent on the success or failure of community-based care for both the person with the disability, their families and the community.

Chapter Seven

A Summary of the Outcomes of Deinstitutionalisation

The Positive Outcomes and the Negative Consequences of Deinstitutionalisation

Since the closure of psychopaedic institutions, international research has been conducted on the success and/or failure of community living for people with intellectual disabilities. This research has shown that deinstitutionalisation has provided the majority of people with intellectual disabilities increased personal choice and quality of life in the community. However, research has also shown that a minority of intellectually disabled persons have failed to integrate into able-bodied society. This research has been conducted in the United Kingdom, United States, Australia and New Zealand.

In the United Kingdom, the consequences of deinstitutionalisation have been investigated and reviewed in forty five studies published between 1980 and 1994 (O'Brien & Thesing, 1999). A review of these studies has shown that the majority of people with intellectual disabilities have successfully adapted to community life with adequate disability support services (O'Brien & Thesing, 1999). These studies have been supported with findings from the 'British Care in the Community project' which conducted assessments of 25 pilot programmes over a five year period (O'Brien & Thesing, 1999). The British projects' assessments supported many of the claims made by disability rights movements, that people with intellectual disabilities benefit from community-based care, as well as revealing that people with intellectual disabilities developed a positive attitude to community life as residents in community-based group homes (O'Brien & Thesing, 1999). Also, the assessment has shown that the employment of professionally trained staff, adequate funding of support services and consideration of the limits of the disability was essential in enabling people with disabilities to develop and maintain self-help and daily living skills (Felce, 1988).

British research studies have concentrated on people's presence, participation, personal growth and ability to overcome challenging behaviour in everyday activities as residents of community-based group homes (Emerson & Hatton, 1996a). The studies have shown that individuals' presence and participation in everyday activities increased in community-based group homes compared to

hospitals and institutions (Emerson & Hatton, 1996a). The individuals' participation in community-based facilities and activities such as clubs, shops, sports and recreation also increased, promoting residents' self-reports of personal growth and resulting in staff reports of the decrease in manifestations of challenging behaviour (Emerson & Hatton, 1996a). The United Kingdom's studies revealed that community-based residents enjoyed increased personal choice, access to consumer goods and services, improved living standards, vocational skills, access to employment and increased acceptance in the community (Emerson & Hatton, 1996b). The United Kingdom's studies have also shown that community-based residents developed increased self-help and daily living skills such as the ability to plan, organise and participate in activities which included daily food preparation, housework, employment and leisure activities (O'Brien & Thesing, 1999). In addition, it was revealed that many individuals developed limited social networks with co-residents, staff, families and ex-patients in different community group homes (Dudley, 1987, O'Brien & Thesing, 1999).

In the United States, literature is replete with accounts of successful community-based programmes (Elpers, 1987). Research studies have emphasised the importance of developing a community-based group house as people's 'homes' instead of impersonal 'micro-institutions' (Felce, 1998). The emphasis on creating a feeling of a 'home' included home style furnishings in living areas and personal choice of decor in bedrooms (Felce, 1998). The placement of typical sized (community-based) houses in suburban settings was important in integrating people with disabilities into the mainstream of modern suburban society (Felce, 1998). The self-reports of people with intellectual disabilities and their families were positive towards the "homelike, well located, reasonably staffed environment" which were established in suburban-based communities (O'Brien & Thesing, 1999 p. 12)

In Australia, the impact of deinstitutionalisation on people with intellectual disabilities has been extensively studied, including a review of thirteen studies from eight projects as well as a study of 98 children with profound intellectual disabilities (Cummins & Dunt, 1988, Young, et al. 1998). The studies showed that individuals adaptive behaviour increased in areas such as daily living skills, self-help and social skills (Young, et al. 1998). The self-care skills included toilet, washing and eating-related behaviours and social behavioural skills (Cummins & Dunt, 1988). The studies showed that people with intellectual disabilities enjoyed increased everyday routines, social interaction, family contact and community participation and access to community-based recreation and leisure facilities (Cummins & Dunt, 1988. Young, et al. 1998). Both individuals and families reported increased levels of satisfaction with community based group homes compared to dissatisfaction with institution-based care (Young, et al. 1998).

In New Zealand, research on people's experience of deinstitutionalisation has focused on aspects such as the transition from institution to community-based care, residential cohabitation, health issues, daily living skills, quality of life and community reaction (O'Brien & Thesing, 1999). In 1989, the Health Research Council of New Zealand funded a study of the consequences of the deinstitutionalisation of fifty four people with intellectual disabilities from Kingseat Hospital in 1988-1989 (O'Brien & Thesing, 1999). The research study stated that "in all areas the overwhelming impression is that life in the community is better than it was in the institution" (O'Brien & Thesing, 1999). The study declared that people with disabilities reported positive experiences of deinstitutionalisation (O'Brien & Thesing, 1999, p. 139).

The Positive Outcomes of the Deinstitutionalisation of the Templeton Centre

In 1997, the Donald Beasley Institute, a specialist research unit on intellectual disabilities, began a research project entitled the 'Templeton Resettlement Family Experiences Project', which included an evaluation of the positive experiences of families related to the deinstitutionalisation of the Templeton Centre (Mirfin-Veitch, et al. 1998, Mirfin-Veitch, et al. 2000). While some parents and families encountered problems during the transition phase to the new community-based service, the majority of families involved expressed positive outcomes for the disabled family member in the long-term (Mirfin-Veitch, et al. 2000). A key factor in the success of a community placement was the development of open and effective communication between parents, staff and management to resolve any specific health issues or behavioural problems (Mirfin-Veitch, et al. 2000). Therefore, the importance of staff with appropriate qualifications, work experience, as well as 'people' skills was fundamental to the positive experience of community placement. Also, the parents' and families' increased involvement in the placement, consultation and contact with their family member, enhanced the families inter-relationships to the benefit of the disabled person (Mirfin-Veitch, et al. 2000).

In the research project, 86% of the families in the study (54 families), reported a positive outcome for their family member (Mirfin-Veitch, et al. 2000). Also 49% of the families changed their negative attitude towards deinstitutionalisation, formed during the transition phase, to a positive outlook on the community resettlement of their disabled family member (Mirfin-Veitch, et al. 2000). However, 14% of families recorded negative outcomes to the community resettlement (Mirfin-Veitch, et al. 2000). In the research project, the perception of a positive outcome was based on the small number of people in a community home (five to six), the physical appearance of the accommodation, the quality and experience of the staff, the performance record of the service provider and the close proximity of the community home to the families homes (Mirfin-Veitch, et al. 2000).

While the 'Templeton Resettlement Family Experiences Project' reported on the families' experiences, there has been limited research on the Templeton Centre residents themselves. In the news media self-advocates with mild intellectual disabilities have reported their personal experiences of deinstitutionalisation through 'human interest' articles presenting people with intellectual disabilities as enjoying personal freedom and independence in community homes (McPherson, 1991, O'Hanlon, 1998). People spoke of their ability to enjoy their own personal space and possessions and express their personal choices (Martin, 1996a, McNeil, 1999). The Community placement was seen to nurture personal potential and personal growth to create a full and happy life (The Press, 1998a, McNeil, 1999a). Former Templeton Centre residents reported increased involvement in vocational, employment and recreational activities (McNeil, 1999). However, the positive outcomes for people with more severe intellectual disabilities has not been properly covered in research, as these individuals are unable to advocate for themselves. This has forced research to rely on the views of other parties such as service providers, parents and families.

In summary, the closure of the Templeton Centre has resulted in positive outcomes for a large number of people with intellectual disabilities and their families. However, the evidence of positive outcomes are based on the self-reports of people with mild to moderate intellectual disabilities and secondary sources such as parents and families. The clear evidence of positive outcomes for people with severe intellectual disabilities, multi-disabilities and/or challenging behavioural problems are absent from any research or reports. This is due to the fact that parents, families and care-givers can only observe physical changes, such as signs of happiness on facial features and body language. The subjective experience of normalisation of people with severe intellectual disabilities is beyond the reach of any observer or researcher.

The positive changes for people with mild to moderate intellectual disabilities are reported as being caused by the change of service provider, service philosophy and the change in the physical environment. The intellectually disabled person's right to a normal life coupled with supportive care-givers has helped improve people's quality of life. Community placements have enabled greater access to community resources such as vocational, employment and recreational resources. Therefore, it can be argued that people with mild intellectual disabilities have benefited from the application of the principles of normalisation in a community-based environment due to access to adequate community resources, while people with more severe disabilities may benefit from the application of the principles of normalisation in a more sheltered environment (Brackenridge Estate), where access to community resources is less meaningful in their daily lives.

The Negative Consequences of Deinstitutionalisation

While in Western countries the shift of people from state institutions to community-based care has improved the lives of many people with disabilities and their families, the positive outcomes of deinstitutionalisation have not been universal (Curtis, 1986). While deinstitutionalisation has benefited people with mild to moderate disabilities, its application to people with severe disabilities and/or challenging behaviour has been less than satisfactory (Curtis, 1986). In Western countries, social research and the media have revealed the negative consequences of deinstitutionalisation for people with intellectual disabilities (Curtis, 1986). These negative consequences include trans-institutionalisation, crime and imprisonment, failure to learn community living skills, termination of supportive social networks and the failure of 'mainstream' policies in education and employment (Bennie, 1993).

Trans-institutionalisation has caused a significant number of people with intellectual disabilities to become victims of deinstitutionalisation (Curtis, 1986, Bennie, 1993). The closure of state hospitals and institutions, which specialised in the care of people with intellectual disabilities, has forced many individuals to be transferred into other institutions such as nursing homes, retirement centres, psychiatric institutions and prisons (Bennie, 1993). The closure of state institutions, which provided long-term care, has caused the termination of established supportive social networks, between the person with the disability, staff and co-residents. The person with the disability is often placed in a new and different environment and forced to endure social stigma, social isolation, conflict and tension from the able-bodied residents (Gottlieb, 1975, Dudley, 1987). This can often be exacerbated if the aged intellectually disabled person has a severe disability or challenging behaviour which acts as a catalyst for negative reaction from able-bodied co-residents (Gottlieb, 1975).

The ability of community-based care to facilitate the development of self-help and daily living skills for people with intellectual disabilities, is often limited by the level of the person's intellectual disability (Wing, 1989, Bennie, 1993, O'Brien & Thesing, 1999). For example, an individual with a profound intellectual disability or dual diagnosis (psychiatric and intellectual disability) would be less able, or even unable, to learn self-help and life skills compared to an individual with mild or moderate intellectual disability (Wing, 1989, Bennie, 1993, O'Brien & Thesing, 1999). Therefore, people with severe disabilities (unable to develop self-help and daily living skills due to the limitation of their disability) cannot participate in a 'normal' life, as required in the principle of normalisation (Wing, 1989, Bennie, 1993). This raises the issue, should people with severe/profound disabilities and/or challenging behaviour, who cannot achieve the skills required for community living, be forced to leave specialised hospitals and/or institutions. This is a

major concern when centralised, specialist hospitals; designed to meet the needs of people with high medical needs, severe/profound intellectual disabilities and/or challenging behaviour; are closed and replaced by community-based homes which provide less qualified staff and fragmented support services.

Research studies have shown that people with profound intellectual disabilities and/or challenging behaviour have limited, superficial or non-existent social contacts with the able-bodied (Beecham, et al. 1996, O'Brien & Thesing, 1999). The failure of people with intellectual disabilities to form friendships with the able-bodied would be expected to be caused by the able-bodied person's lack of respect and indifference towards the disabled person and the lack of a shared life experience, culture and history, which allows interaction at a mutual level of understanding. The inability of people with severe or profound intellectual disabilities to establish social networks, undermines the successful application of the principle of normalisation in their lives (Curtis, 1986, Wing, 1989).

Studies have challenged the policy of main-streaming in education and employment, as special needs units are usually in separate facilities on school properties (Wolfensberger, 1995). This can result in limited interaction between disabled and able-bodied children (Wolfensberger, 1995). Also, main-streaming in employment has been challenged as an achievement of 'normalisation', as most people with intellectual disabilities work in segregated sheltered workshops or are employed on low wages in manual labour which has little or no status to the able-bodied, though admittedly it is valued by the person with the disability (O'Brien & Thesing, 1999).

While deinstitutionalisation has enhanced the quality of life of 'higher-functioning' individuals, the extreme application of the principle of normalisation to all people with intellectual disabilities, irrespective of the level of disability, has resulted in dissatisfaction and failure in all Western countries (Lamb, 1981, Curtis, 1986).

The Negative Outcomes of the Deinstitutionalisation of the Templeton Centre

While the majority of Templeton Centre residents and families have successfully adapted to the persons' transfer into the community, there have been some negative experiences. These include parents' negative reactions, the flawed application of normalisation, SRHA and Healthlink South's dis-empowering public consultation, hostile community reaction, trans-institutionalisation and crimes committed by ex-Templeton residents including murder, sexual assaults against children and infecting people with the HIV virus (Keenan, 1994, Petrovic, 1997, O'Hanlon, 1999).

In the 'Templeton Resettlement Family Experiences Project' the researchers stated that 14% of the sample population reported negative experiences towards the resettlement of their disabled relative following deinstitutionalisation (Mirfin-Veitch, 2000). The parent and families reaction has included distress during deinstitutionalisation and rekindled feelings of guilt and shame about the original decision to place their disabled 'child' in a state institution (O'Brien & Thesing, 1999). This emotional reaction included a sense of betrayal of trust which had been placed on the original advice from health professionals (Healthlink South & SRHA, 1994, O'Brien & Thesing, 1999). A major concern of parents and siblings, was the fear that the closure of a state institution which specialised in the care of people with intellectual disabilities would lead to the 'dumping of care responsibility' onto families (Wilier, et al. 1979, Mowbray & Bryson, 1984, Healthlink South & SRHA, 1994) This concern on the dumping of

the care responsibility was based on the perception that community-based care would be an inadequate replacement for institution-based care (Healthlink South & SRHA, 1994). For some parents and families the level responsibility forced upon them was too high, especially when community care-givers were unable to properly care for the disabled relative (Mirfin-Veitch, 2000). For a minority of parents and families the failure of initial community placement or continuing problems has led to feelings of frustration with inept service providers (Mirfin-Veitch, 2000). In general parents and families have lacked confidence in the long-term security of community care for their dependent relative (Mirfin-Veitch, 2000).

Parents and families of profoundly intellectually disabled relatives perceived the Templeton Centre as a state institution which was more able to provide better care, from more experienced staff, in a safer and more secure environment than alternative community-based care (Healthlink South & SRHA, 1994). Families have also expressed concerns with the ideology of normalisation which is embedded in the policy of deinstitutionalisation (Healthlink South & SRHA, 1994). The principle of normalisation, with its emphasis on changing people's behaviour by shifting them from a institution-based environment into a community setting, was seen as being unrealistic and ignoring the disabling effect severe, profound, multi-disabilities and/or challenging behaviour has on individuals regardless of their physical environment (Bennie, 1993, Healthlink South & SRHA, 1994).

While the closure of the Templeton Centre included public consultation, it can be argued that the policy decision was full and final, and that the SRHA and Healthlink South's public consultation process was merely a 're-education programme' for opponents of deinstitutionalisation such as parents and families. When the public consultation process failed to win the 'hearts and minds' of parents, families and community, the state health bureaucracy appeared to pursue a 'no compromise' approach in forcing deinstitutionalisation. While the SRHA and Healthlink South's public consultation process advocated an inclusive approach towards the rights of the disabled, it ignored the right of parents and families to advocate effectively on behalf of their disabled relatives.

The community's reaction to the deinstitutionalisation of the Templeton Centre included social stigma towards people with intellectual disabilities and a hostile response to their placement into community-based homes (Healthlink South & SRHA, 1994, Gleeson, 1997). The community's negative reaction tended to be caused by the labelling of people with intellectual disabilities as having mental illness. In several public meeting related to the closure of the Templeton Centre, concerned citizens expressed concerns about the placement of people with mental illness back into the community (Dunbar, 1998, The Press, 1998b, Petrovic, 1997). The SRHA and Healthlink South argued that such concerns would be addressed by ongoing discourse between national, regional and local government leaders and community leaders (Healthlink South & SRHA, 1994). However, the issue of daily discrimination towards people with intellectual disabilities was not adequately addressed by either the SRHA or Healthlink South.

Trans-institutionalisation has arisen as an issue with Templeton Centre residents who were discharged into the community care. Trans-institutionalisation affected twenty seven elderly Templeton residents, who were transferred to nursing or rest homes between 1983 and 1993 (Healthlink South & SRHA, 1994). The trans-institutionalisation of these elderly Templeton residents, raises concerns about the termination of long-term social networks within the Templeton Centre and the ability of these individuals to establish new social networks in able-

bodied nursing and rest homes. Also, Templeton Centre staff were concerned for the mental health of elderly Templeton Centre residents stressed by deinstitutionalisation (Petrovic, 1997a). As some Templeton Centre staff commented "The villa is their home and now they're having it taken away. The whole process is disruptive and unnecessarily harmful" (Petrovic, 1997b, p.4).

The deinstitutionalisation of the Templeton Centre has resulted in several cases of ex-Templeton residents committing various crimes, which have led to their conviction and imprisonment (Healthlink South, 1994, Martin, 1999). These crimes have included arson, murder, sexual assaults against children, fraud, vagrancy and infecting people with the HIV virus (Keenan, 1994, Gilling, 1995b, Martin, 1999).

Arsons cases involved a ex-Templeton Centre resident who developed a 'child like' fascination with fire lighting (Gilling, 1995b). The murder charge against a ex-Templeton resident resulted after an incident immediately following his discharge from the Templeton Centre (Keenan, 1994). A sexual assault case involved a ex-Templeton Centre resident being sentenced to preventive detention after three convictions of sex offences against children over a four year period (Keenan, 1994). Tragically, the Templeton Centre staff had warned authorities of the danger posed to children from this man if he was discharged into the community (Keenan, 1994). Templeton Centre staff had also warned the authorities about a former patient who preyed on the elderly, the ex-patient was later imprisoned for befriending and defrauding several elderly persons (Keenan, 1994). For community police, another problem was instances of vagrancy related to ex-Templeton Centre residents scavenging through rubbish bins (The Press, 1991). Also, the Christchurch City Mission was allegedly required to provide food and shelter for ex-Templeton Centre residents who wandered around the inner city streets of Christchurch (Shaw, 1997).

However, the most infamous criminal case concerning a ex-Templeton Centre resident, involved Christopher Ian Truscott (O'Hanlon, 1999). Truscott had spent most of his life at the Templeton Centre, until he reached his early 20s, when he was then placed into the community (O'Hanlon, 1999). Truscott allegedly had the mental age of an 11-year old and doubts were expressed by Templeton Centre personnel about his ability to function in the community (O'Hanlon, 1999).

Truscott, aged 30, became a prominent figure in the gay community for both his obvious intellectual disability and his willingness to engage in anonymous sex with men at public places such as the Hagley Park toilets (The Palace) in Christchurch (O'Hanlon, 1999). People in the underground gay sex scene were known to take advantage of his intellectual disability for sexual pleasure (O'Hanlon, 1999). As Steve Attwood a gay news journalist stated, "He is the victim, rather than the villain,"...There are people out there who are predators and have preyed on him" (O'Hanlon, 1999). However, his victim status was undermined by his "insatiable appetite for sex" and his willingness to exploit his sexuality for profit since he worked as a sex worker in Auckland, Wellington and Christchurch (Martin, 1999a, p.3). Unfortunately, Truscott had been a HIV carrier since May 1991 and engaged in unprotected sex with a large number of men (allegedly 4000 men) (Martin, 1999a, The Dominion, 1999). In 1999, Truscott became the subject of police and public health authorities health warnings when he was charged with engaging in unprotected sex without declaring that he had the HIV virus (Martin, 1999a, O'Hanlon, 1999). Truscott was indefinitely detained in isolation under section 79 of the Health Act at a Christchurch suburban home (The Press, 1999a, The Evening Post, 1999, Rush, 2000).

Finally there been several cases in which ex-Templeton Centre residents have been admitted into psychiatric institutions or special needs units within prisons (Healthlink South & SRHA, 1994). This has included people with

behavioural problems, who have committed self-mutilation or attempted suicide (The Press, 1995).

Arguably the crimes committed by ex-Templeton Centre residents would not have occurred if the individuals had not been deinstitutionalised. Therefore, the closure of state hospitals and institutions has resulted in people with intellectual disabilities being reinstitutionalised into prisons and psychiatric hospitals which has dramatically undermined their quality of life (Healthlink South & SRHA, 1994). However, the numbers of intellectually disabled in prisons and psychiatric hospitals is extremely low in comparison to the able-bodied population (Gilling, 1995). Also, the state could not be expected to detain Templeton Centre residents on the basis of their alleged danger to themselves and/or others. While the principle of normalisation promised people with intellectual disabilities a better quality of life in the community, there was never any guarantee it would succeed for all people with intellectual disabilities. As a final point, it can be argued that the negative experiences of some people with intellectual disabilities in community placement is simply a part of a normal everyday life, as a percentage of the able-bodied population also fail in life as well.

Conclusion

This M.A. thesis has shown that the inception, role and decline of the Templeton Centre paralleled Western countries' policies and practices towards people with intellectual disabilities in state institutions.

In part one, it was shown that in Western societies the convergence of families' inability and/or unwillingness to act as care-givers, the rise of the capitalist mode of production and the need of the state to confine and control the intellectually disabled, led to their social exclusion and incarceration in state institutions. The Templeton Farm Colony, a geographically isolated institution, provided vocational and rehabilitative training so the

intellectually disabled would conform to the norms of family life and contribute to the capitalist mode of production. In Western countries, scandals of abuse and neglect in institutions promoted public criticisms and legal recourse which opened the discourse on the alternative of community living for people with intellectual disabilities. In New Zealand, the review of state institutions, allegations of abuse and neglect and overseas experiences undoubtedly promoted the shift to community care for Templeton Centre residents.

In part two, the research paper contends that both the Labour Government (1984-1990) and the National Government (1990-1999) pursued a neo-liberal economic agenda to reduce social expenditure on the health infrastructure, to lessen the economic burden of social spending on New Zealand's economic performance. The CAHB, SRHA and Healthlink South pursued policies and practices to reduce expenditure on state hospitals and institutions in order to achieve the neo-liberal objective. At the same time the IHC, People First movement, and self-advocates promoted the social agenda of normalisation and social role valourisation for people with intellectual disabilities to the CAHB, SRHA and Healthlink South. Therefore, the SRHA and Healthlink South's decision to close the Templeton Centre was due to a convergence of these social and economic agenda, to the extent that the application of normalisation enabled the state health authorities to reduce expenditure on the health infrastructure and appease the demand for social inclusion and participation of people with intellectual disabilities in society.

In part three, the paper has shown that Western communities' reaction to the deinstitutionalisation of psychopaedic institutions has often been negative which is comparable to that of parents' and families' reaction towards the closure of the Templeton Centre. While the Western communities' reaction has often been negative towards deinstitutionalisation of state institutions, the outcomes for the majority of people with intellectual disabilities have been positive experiences with some notable exceptions.

In conclusion, the paper argues that Western countries' policies and practices will undoubtedly continue to shape New Zealand's policies in disability support services for people with intellectual disabilities. While the convergence of normalisation and neo-liberal discourse caused the deinstitutionalisation of the Templeton Centre, the long term success of community placement is dependent on the separation of the application of the principles of normalisation and neo-liberalism in the health and disability sector. The social philosophy of normalisation has continued to promote the social inclusion and participation of people with intellectual disabilities while neo-liberalism has declined in the political discourse of the health sector. However, the resurgence of neo-liberalism, caused by the impending crisis of an ageing population and a reduced taxable work-force will create fiscal pressure on state expenditure on the health infrastructure. Should New Zealand governments once more adopt neo-liberalism as its economic discourse, the freedom and independence currently enjoyed by most people with intellectual disabilities may be undermined by neo-liberal cost saving strategies in the health infrastructure.

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