Deinstitutionalisation: Community Living and Quality of Life for Ex-Templeton Centre Residents.

A thesis submitted in partial fulfilment of the requirements for the Degree of Master of Arts in Sociology in the University of Canterbury by John. R. Grant

University of Canterbury 2002
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Abstract

This thesis examines the lives of ten former Templeton Centre residents subsequent to deinstitutionalisation, through the eyes of their mothers. The central theme is concerned with how deinstitutionalisation has effected their quality of life. The aim is to provide a 'snap shot' of life in the community for persons with intellectual disabilities. In doing so, it will be argued that people with intellectual disabilities are a heterogeneous group, and thus have a variety of needs, wants and desires. A major factor in this regard is the type and/or level of disability. Consequently, the experiences of life in the community will be largely unique to the individual. Furthermore, due to this heterogeneity, the needs, wants and desires of persons with intellectual disabilities can not, in some circumstances, be adequately met through care in the community.
Acknowledgements

This thesis was made possible through a much wider project in the area of deinstitutionalisation and persons with intellectual disabilities in the Sociology Department at the University of Canterbury. The project coordinators Dr Arnold Parr and Hugh Williams provided assistance on a number of levels. This included the sharing of resources, access to participants and general advice in this area of research. Their assistance was very much appreciated.

There are a number of people I wish to acknowledge, and thank for their assistance, support, and encouragement throughout this process. Firstly to my supervisors; Dr Alison Loveridge and Dr Arnold Parr, who provided the rudder which enabled me to negotiate my way through uncharted waters, and arrive relatively unscathed! Next, my friends and colleagues at the University of Canterbury; in particular, Hamish MacClure, David Lemon and Brigid Thompson, whose knowledge and experience both in terms of deinstitutionalisation and the intellectually disabled, and thesis writing generally proved invaluable. I would also like to thank my family; my mother Margaret, my father Stuart, and my brother Chris, all of whom gave me the support and encouragement I needed to see this project through to its completion. I would also like to thank Jane and Geraldine for the time they gave up for proof reading, and alerting me to changes that needed to be made. Finally, to my partner Belinda, thank you for your patience and understanding throughout this project, and ensuring that my motivation was maintained through your little ‘pep talks’.
Chapter One

Introduction

The development and implementation of social policy can be a lengthy process involving a diverse range of groups and interests. Since the election of the Fourth Labour Government in 1984, and the subsequent adoption of a neo-liberal reform agenda, social policy has been the subject of considerable public and media interest (Cheyne et al 1997). The substantial social and economic changes that have taken place in New Zealand during this time have undoubtedly contributed to this increased interest. These changes, which have been shaped by both national and international forces, have transformed many of the fundamental features of the fabric of social and economic policy (Cheyne et al 1997).

Neo-liberalism includes an emphasis on economic rationalisation, which has led to policies of privatisation, and the cutting back of government responsibilities (McLennan et al 2000:93). Furthermore, there is the belief that the market provides the best means for allocating resources efficiently (McLennan et al 2000:93). This is an integral component within a neo-liberal policy agenda.

The adoption of neo-liberalism by the Fourth Labour Government marked the beginning of a revolutionary period in New Zealand politics, particularly in relation to economic and social policy. This move was strongly influenced by similar moves by other western governments, particularly the USA and the UK. The economic policies of the Fourth Labour Government and subsequent governments were based on the wholesale deregulation and restructuring of the economy, with a strong emphasis on the privatisation of many services previously provided by the government.

A significant development within the neo-liberal agenda relates to the provision of welfare services. The state’s role in the provision of welfare services has most certainly changed since 1984, particularly after the so-called “Mother of All Budgets” delivered by the
National Government in 1991. Through this budget there was a major dismantling of the welfare state. The National Government introduced major changes to the public health system including targeting for health and some user charges.

In regard to the changes in the health system there were a number of significant changes, one of the most important was the funder-provider split (Cheyne et al 1997). What this meant was that hospital boards were abolished and four new Regional Health Authorities (RHAs) were established.

The RHAs received funding from central government to purchase health services for the population of their region\(^1\). They entered into contracts with various providers (including GPs, specialists, the former public hospitals etc.) to deliver health care, with cost being virtually the only criteria to win a contract (Cheyne et al 1997). The former public hospitals were transformed into Crown Health Enterprises, which had a Board of Directors and were run very much along business lines. They competed with other providers for contracts from RHAs to provide services. The split between purchaser and provider was intended as a mechanism for achieving more efficient use of resources.

These health reforms were essentially economically driven due to the increased strain on the health system. The downturn in the economy meant increased government spending on unemployment benefits and a lower tax take. There was also the problem of an aging population, which equated to more spending on health care for the elderly and on pensions (Cheyne et al 1997). In short these reforms represented a major shift in the government’s role in the provision of health care. Free health care formed an integral part of the welfare state that most New Zealanders had come to take for granted.

Deinstitutionalisation as a social policy emerged as part of the changes that took place within the health system. In other words it was a response to both internal and external forces. As far as the internal forces are concerned these were in the most part

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\(^1\) For the purposes of this thesis the purchaser (funded by the government) of health services is the Southern Regional Health Authority (SRHA) and the service provider is Healthlink South. However, it should be noted that this system no longer operates and that health services are now administered by District Health Boards (Healthlink South 2000).
economically driven due to adverse economic conditions. The external forces were also strongly influenced by economics, particularly with the spread of global capitalism and the increased development of the world economy. In many countries, including New Zealand, this saw a redefining of the relationship between the state and the individual, which in many areas equated to less government control, as well as less government assistance and support. Another important component relating to external forces is the impact that various social movements and international non-governmental organisations have had on social attitudes and ideas. Moreover, it is the way in which these have influenced the policy process that is of importance. The groups concerned include civil and human rights groups as well as the feminist movement.

In the case of the Templeton Centre, particularly in the early phases of the implementation of deinstitutionalisation, there was a clash of ideals between parents and policy makers. Furthermore, it was the mothers that tended to be at the forefront of making the parents’ concerns public. The essence of these concerns was that deinstitutionalisation could potentially undermine the well-being and welfare of Templeton Centre residents being relocated into the community. Also, there was some degree of concern that it was essentially the medical professionals and experts that were making decisions about what was best for Templeton Centre residents. Many mothers felt that they were in the best position to be able to judge what their child’s needs were and how these would be best met.

The aim of this thesis is to provide a ‘snap shot’ of life in the community for persons with intellectual disabilities by focusing on issues relating to their quality of life, as articulated by the mothers of former Templeton Centre residents. In doing so, it will argue that people with intellectual disabilities are a heterogeneous group, and thus have a variety of needs, wants and desires. A major factor in this regard is the type and/or level of disability. In other words, those with severe intellectual disabilities, multiple disabilities, and challenging behaviour will have different needs, wants and desires to those with moderate and minimal intellectual disabilities. Consequently, the experiences of life
in the community will be largely unique to the individual. Furthermore, due to this heterogeneity, the needs, wants and desires of persons with intellectual disabilities can not in some circumstances be adequately met through care in the community. This will therefore have implications for issues relating to quality of life. It is becoming widely accepted that quality of life measures should be used as the basis for determining the success or otherwise of deinstitutionalisation efforts (Horner 1994, Lord & Pedlar 1991 cited in Bennie 1993).

The historical development of deinstitutionalisation both as an ideology and a social policy is examined in chapter two. In doing so it places the New Zealand experience into a broader context. In other words, it provides an account of the international or external factors that influenced the development of deinstitutionalisation in New Zealand. Accordingly, this chapter traces the development of deinstitutionalisation from its ideological beginnings in the 1960’s during a time of intense social change. At the forefront of this change was the rise of human and civil rights movements, which saw those with disabilities campaigning for equal rights. The disability rights movements argued that people with disabilities should have citizenship rights equal to able-bodied citizens, which included the right to fully participate in society (Oliver & Barnes 1993, Johnson 1998). The disability rights movements’ demands for citizenship rights and community inclusion led to the demand for deinstitutionalisation (Shannon & Hovell 1993, O’Brien & Thesing 1999). The principle of normalisation is also examined and how this was influential in the development of deinstitutionalisation.

From here deinstitutionalisation as a social policy is examined, with particular focus on the USA and the UK, as well as New Zealand. Many western governments adopted Deinstitutionalisation because it sat nicely in a neo-liberal policy agenda. In relation to New Zealand the discussion focuses primarily on the situation involving the Templeton Centre. The next section is concerned with the alternative to institutional care, namely community care, and how this operates.
In chapter three the focus narrows to look exclusively at the Templeton Centre. To begin with there is a background to the Templeton Centre which provides details of how the institution operated, the number of residents, the facilities and so on. From here the closure of the Templeton Centre is discussed, including Healthlink South’s rationale for its closure. Furthermore, the factors that Healthlink South considered important in relation to moving people from the Templeton Centre into the community are discussed. This includes things such as the needs assessment programme, accommodation options, facilities in the community and staff. In regard to the needs assessment this is discussed in more depth at the end of the chapter.

Next, the parents’ reaction to the closure of the Templeton Centre is looked at. This section talks about how some parents (predominately those involved in the Templeton Parents Association) reacted to the closure of the Templeton Centre, and discusses the issues of importance to them.

The final part of this chapter is concerned with the resettlement of residents into the community. This section talks about how this process worked, and provides an in depth discussion of the part played by Community Housing Limited. Also, there is a discussion relating to the establishment of the Brackenridge Estate, looking at the nature of this facility and how it came into existence.

Chapter four addresses a number of important methodological considerations. First and foremost there is a discussion relating to the participants, who are the mothers of former Templeton Centre residents. This main focus relates to the rationale for using mothers as the participants in this thesis, and the dilemmas that this may pose. From here there is a discussion of why qualitative research methods, by way of semi-structured interviews were used, with a consideration of other methods used in this area of research. The analysis process is looked at next. This starts with the transcription process, and from here the way in which the data was organised, analysed, and presented. Next there is a section looking at the all-important role of ethics in social research. This contains a general discussion on the role of ethics in the research process, and then addresses the
ethical considerations relevant to this thesis, including issues relating to informed consent, doing no harm to participants, and the publishing of research findings.

In the final part of this chapter there is a section relating to “quality of life”. This section is central to the thesis as a whole, as it provides a discussion of what constitutes “quality of life” in relation to persons with intellectual disabilities. Furthermore, it looks at the different ways of obtaining such information, as well as discussing how this was carried out in relation to this thesis and why. To finish with there is a brief consideration of the dilemmas faced when attempting to measuring “intellectual disability”, as well as examining how it was measured for the purposes of this thesis.

Chapter five of the thesis addresses two main areas. The first part traces the lives of Templeton Centre residents during their time there, the focus of which is issues relating to quality of life. This includes looking at physical and material well being, issues relating to the staff, the nature of social relationships and interaction, recreation and leisure facilities, and the potential for autonomy and independent living skills.

The next part of this chapter looks at the deinstitutionalisation process. Firstly, the needs assessment programme is discussed looking at how this operated, the groups involved, and the impact on the residents of the Templeton Centre. The final part of this chapter examines the relocation of former Templeton Centre residents into the community, again focusing on how this process operated, the groups involved and the impact on former Templeton Centre residents.

In chapter six the focus shifts from looking at quality of life in the Templeton Centre, to looking at quality of life in the community. Many of the topics covered are the same as those in chapter five. The chapter begins by looking at issues relating to physical and material well being. From here issues relating to staff, together with service providers and accountability are explored. The nature of social relationships and interaction constitutes the next section, followed by a discussion of leisure and recreation facilities. From here the potential for autonomy, personal choice, and independent living skills in the community is discussed. The chapter finishes by looking at individual behavioural
changes that have occurred in terms of this being an indication of quality of life. The various issues discussed throughout the chapter are integrated with literature from New Zealand and overseas.

The last chapter is the conclusion. This chapter pulls together the issues discussed in chapters five and six. Moreover, conclusions are made regarding the impact of deinstitutionalisation on the quality of life of persons with intellectual disabilities. Also, implications for the future are discussed which includes funding issues, service provision and the role of parents.
Chapter Two

Deinstitutionalisation: From Ideology to Social Policy

2.1 Introduction

Caring for the intellectually disabled outside of an institutional environment is not a new phenomenon in New Zealand. Care for the intellectually disabled in community settings has existed for up to forty years (Ministry of Health 1993). There were some fledgling community based programmes developed in the late 1960’s (Levien 1996:13). However, it was not until the early 1990’s that deinstitutionalisation was implemented on a wide scale. This occurred against a backdrop of major government restructuring within the public sector, particularly in the health sector. The intellectually disabled are now being relocated into houses within the community, with an assurance from policy makers that the necessary support services are available in the community. This however, is a point open to debate.

Prior to this the bulk of intellectually disabled people were cared for in an institutional setting. In New Zealand this occurred in psychopaedic hospitals (a term which is peculiar to New Zealand, and refers to hospitals that cater for people with intellectual disability, particularly children), and psychiatric hospitals (Levien 1996:13). There were four psychopaedic hospitals in New Zealand, that catered for over fifty percent of those with intellectual disabilities (Craig and Mills 1987:27, Levien 1996:13). The Templeton Centre south of Christchurch was one such hospital.

These institutions were seen as the most appropriate environment for people with intellectual disabilities from the late nineteenth century onwards. This is largely due to the fact that within the medical profession the pervading idea was that ‘defective people’
should be isolated from the rest of society. In other words, this relates to the medical model of intellectual disability whereby intellectual disability is seen as an abnormality and measured and classified by physical and intellectual “syndromes” (Levien 1996). Within this intellectual disability paradigm the individual is seen as dangerous and thus should be isolated and controlled for the protection of themselves and society (Levien 1996). Furthermore, families which include an intellectually disabled individual are seen as abnormal and unable to cope (Levien 1996).

As previously mentioned, in New Zealand community based programmes were beginning to be developed from the 1960’s and really took off in the 1990’s (Levien 1996:13). This occurred as a result of a number of converging factors, with both local and global influences. These will be discussed in more depth in sections 2.2, 2.3 and 2.4 of this chapter. Furthermore, deinstitutionalisation has seen the marriage of somewhat unlikely parties. These parties included scientists, clinicians, civil rights activists and fiscal conservatives, all of whom were convinced of the merits of deinstitutionalisation, albeit for different reasons (Bennie 1993).

2.2 International Background

Deinstitutionalisation represents a fundamental shift in the philosophy of how the intellectually disabled are cared for. As an ideology it emerged in the United States in the 1960’s, during a period of intense social change (Felton and Shinn 1981, Bachrach 1989). At the forefront of this change was the rise of human and civil rights movements which protested against discrimination suffered by people on the basis of ethnicity, gender, and sexual orientation. Those with disabilities also campaigned for equal rights. The disability rights movements argued that people with disabilities should have citizenship rights equal to able-bodied citizens, which included the right to fully participate in society (Oliver and Barnes 1993, Johnson 1998). The disability rights movements’ demands for citizenship rights and community inclusion led to the demand for deinstitutionalisation (Shannon and Hovell 1993, O’Brien and Thesing 1999). What followed was a stream of
litigation. Federal courts upheld the right of intellectually disabled people to treatment, to education and to reside in the least restrictive environment (Booth et al 1989:213). This saw the court ordered closure of state institutions and successful out of court settlements (Booth et al 1989:214).

The disability rights movement received support at an international level in the form of the United Nations Declaration on the Rights of the 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 emphasized 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 and 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 and 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 and Thesing 1999). These life chances included participation in areas such as personal relationships, family life, education, employment, culture and sport (O'Brien and Thesing 1999).

Adding impetus to the move towards deinstitutionalisation throughout the west was a change in public and official perceptions of the role that institutions played in caring for the intellectually disabled. Institutions were beginning to be viewed in negative terms; residents were beginning to be seen as 'victims' (Curtis 1986, Emerson 1985, Willer and Intagliata 1983). There was a belief that all institutions were large and depersonalised and that the staff were uncaring (Webb 1986). There were a number of factors contributing to this negative perception of institutions. These included government concerns, commissions of inquiry, public campaigns and legal action on scandals involving such things as patient overcrowding, and abuse and neglect in state institutions (Curtis 1986).
Another factor that had an impact on the move towards deinstitutionalisation was growing concern amongst government economists about the escalating costs of institutional care (Emerson 1985). Deinstitutionalisation, it was argued, would provide a more productive use of resources.

2.3 The Principle of Normalisation and Social Role Valorisation

Another important factor in the development of deinstitutionalisation was the emergence of the principal of normalisation (Ericsson and Mansell 1996). In the mid 1960’s Bengt Nirje, the 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 closely as possible to the patterns and norms of mainstream society (Biklen 1979). Normalisation is closely associated with deinstitutionalisation as it promotes ‘normal living’ in the home where a person dresses, washes, entertains and eats in different areas of the home, which constitutes normal living arrangements. In other words making sure that people with intellectual disabilities can have a life as close to normal as possible.

However, it was Dr Wolf Wolfensberger who developed the theory further, and incorporated the theory of social role valorisation (Biklen 1979, Wolfensberger 1983). Wolfensberger (1987) argued that people with intellectual disabilities were at risk of developing ‘social devaluation’ as patients in institutional environments. For example, institutions which modeled prison or hospital conditions created a physical setting which encouraged staff to label people with disabilities as subhuman or deviant or as objects of fear, pity, ridicule or sickness (Wolfensberger 1987). The theory of social role valorisation argued that to enable people to be relabelled as ‘valued’ they needed to live and work in a ‘valued setting’ such as the community (Wolfensberger 1983).

Underlying this belief is the idea that every person, no matter what his or her disability, is entitled to develop and to enjoy the maximum level of independence. This principle recognises the right of the individual to live in the environment that is the most
supportive and the least restrictive of his or her freedom. The implications of this principle are that community services must be able to provide full and comprehensive support, including specialist services, to ensure non-institutional life is a real option for people now living in institutions. Being included as part of the community means having ties and connections with others. People build up these ties and connections that give their lives meaning through friendships and acquaintances, making a home, keeping up interests, and active involvement with family and the neighbourhood.

By 1995, normalisation and the theory of social role valorisation were fully integrated into Scandinavian law. They were supported by the philosophical and legal concept of ‘least restrictive alternative care’ (Biklen 1979, Wing, 1989). Wolfensberger and Kugel (1969) argued that the physical design of institutions created a custodial and dehumanising environment, which affected the treatment of people with disabilities (Biklen 1979). Social role valorisation, it was argued led to wider community acceptance/greater inclusion of people with disabilities. If a person is seen to be adding to society, living in a local area, making it a better place, being employed, they are seen as being valued members of that society. It is thought that if people with intellectual disabilities live in the local community their social role will be valued more highly by the community at large.

The principle of 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 and Thesing 1999). Also, the state and its 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 pattern in society (Biklen 1979). For example, children with disabilities have been ‘mainstreamed’ 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 hospital 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).

In the community, an individual would have the opportunity to develop ‘valued competencies’, which underpinned their valued social role (O’Brien and Thesing 1999). While normalisation could be applied to a limited extent in institutions, the principles of social role valorisation demanded a community setting (O’Brien and Thesing 1999). Therefore, to disability rights advocates, it was apparent that for people with disabilities to live a ‘normal’ life, all disabled people had to be deinstitutionalised (O’Brien and Thesing, 1999).

Studies have challenged the policy of mainstreaming 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, mainstreaming in employment has been challenged as an environment of ‘normalisation’. This is because 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 may well be valued by the person with the disability (O’Brien & Thesing 1999).

While the least restrictive alternative has enhanced the quality of life of ‘higher-functioning’ individuals, the extreme application of this principle 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 theory of normalisation and mainstreaming has worked for higher functioning people with intellectual disabilities. However, the practical outcomes have not been beneficial to the more severely disabled group. 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).
2.4 Deinstitutionalisation as a Social Policy–UK, USA and New Zealand

As a social policy, deinstitutionalisation was widely implemented in both America and Britain in the 1970’s and 1980’s (Kemp 1990). As a result a large number of institutions caring for the intellectually disabled were closed. The pivotal factor for the implementation of deinstitutionalisation as a social policy was the fact that it suited the economic agenda of many western governments, and at the same time addressed politically sensitive issues relating to the rights of people with disabilities. In most cases the policy to reduce social expenditure was driven by cost saving strategies as well as efficiency gains in health and social care (Knapp 1988). Since the end of World War Two, the cost of repair and maintenance of large institutions had steadily increased, for example, the increased cost of employing large numbers of staff, which included doctors, nurses, cooks, cleaners and gardeners (Knapp 1988). In comparison, community-based care was considered the cheaper option.

The final and ultimate form of cost saving and efficiency is the privatisation of health and social services (Knapp 1988). Neo-liberal proponents of privatisation argued that private and voluntary sector services provide a more cost-effective and efficient alternative to public provision of social care services (Knapp 1988). While neo-liberal governments 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 caregivers) in most western countries (Knapp 1988).

In the case of America, deinstitutionalisation as a social policy has its origins as far back as 1971. In November 1971 President Nixon made a vow to the nation “to enable one-third of the more than 200,000 retarded persons in public institutions to return to useful lives in the community” (Booth et al 1989:213). Despite this it was not until 1976 that deinstitutionalisation became a Secretarial objective within the Department of Health, Education and Welfare’s operational planning system (Booth et al 1989:213).

Between the years 1977 and 1982 every state reduced the number of residents in its institutions (Booth et al 1989:214). During this five year period the size of the residential
population in large state hospitals fell by just over 20 percent; most residents were relocated in small group homes. These trends continued with increased momentum in America throughout the 1980’s. This was due to a large extent to the aggressive advocacy of the rights of people with intellectual disabilities by professional and user groups. Other economic and political forces began to add impetus to deinstitutionalisation policy. In particular, the Reagan Administration introduced cuts in federal funding of social programmes and a substantial shift in the domestic fiscal burden from federal level to state governments, thus adding incentive to move further toward deinstitutionalisation (Booth et al 1989:214). Furthermore, the recession in 1981 brought low corporate profits and high unemployment, which in turn squeezed state tax revenues while pushing up welfare spending. As a result, budgetary matters began to increasingly focus on the rising costs of state institutions, the end result being that increasing numbers of institutions were closed.

As far as Britain is concerned it would appear that the development of deinstitutionalisation as a social policy followed a similar time frame. In 1971 the White Paper, *Better Services for the Mentally Handicapped*, provided the first detailed guidelines for health and local authorities in relation to the provision of services for the intellectually disabled in the community (Hudson 1991). By 1981 there was evidence to suggest that the official strategy was floundering (Hudson 1991). This prompted the development of a consultative document, *Care in the Community* in 1981 by the Department of Health and Social Security (DHSS) which suggested that most people who require long term care should be looked after in the community (Hudson 1991:22). Furthermore, there was the suggestion that the transition from hospital to community care could be achieved within the existing resources (Hudson 1991:22). The essence of this initiative was embodied in the Health and Social Services and Social Security Adjudication Act 1983, which clearly set out how a programme of deinstitutionalisation would operate, and how it would be financed (Hudson 1991). The main component of this involved the District Health Authorities (DHA’s) making annual payments to local authorities and voluntary organisations for people moving out of hospital into community care (Hudson 1991:22).
As with America, large institutions for the intellectually disabled began closing in Britain, particularly from 1988 onwards (Hudson 1991, Cambridge et al 1994).

In 1989 the White Paper *Caring for People* and the 1990 National Health Service and Community Care Act, provided a new framework for the development of community care (Cambridge et al 1994:5). At the core of this new framework was a commitment by the government to ensure that the bulk of community care took place within a domiciliary setting, in preference to long-stay residence in hospital, residential care homes or nursing homes (Cambridge et al 1994:5). Furthermore, there was a commitment to ensure that the appropriate support systems were put in place (Cambridge et al 1994:5). This would involve local authorities overseeing the purchase of services from a range of service providers, particularly within the voluntary and private sectors (Cambridge et al 1994:5).

In New Zealand the move to adopting deinstitutionalisation was accelerated by the introduction of the neo-liberal reform agenda of the Fourth Labour Government. The years 1986-1990 represent a watershed in health policy (Cheyne et al 1997). It was during this time that arguments about the limits of public responsibility came to dominate policy, the emphasis being very much on private (individual and commercial) provision (Cheyne et al 1997:224). The reduction of public expenditure on hospitals, including in some circumstances closures, was seen as a major means to control state expenditure in the health and disability sectors (Department of Health 1986).¹ The deinstitutionalisation of people with intellectual disabilities sat nicely within this framework of restructuring. Community care was seen as facilitating more choice for residents because it offered an alternative form of service delivery to the traditional delivery of services through hospitals (Cheyne et al 1997:226). Furthermore, it was seen as being more cost effective than large scale institutions. For a discussion of policy implementation in New Zealand, with a focus on the Templeton Centre, see section 2.6 of this chapter.

In summary, the neo-liberal government policy of deinstitutionalisation has been seen as a means to reduce social expenditure as well as simultaneously addressing the politically

¹ For an in depth discussion of New Zealand health reforms and deinstitutionalisation see Lemon (2001).
sensitive issue of disability rights and inadequacy in institution-based care in many western democracies (Glesson 1997). The neo-liberal 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. The net result for specific groups of people with disabilities (profound intellectual and chronic psychiatric disabilities) has been in many cases, an inadequacy in community-based care and support networks. This has been caused by under-funding, under-resourcing and lack of services and the shift of the ‘care burden’ from the public sector to the families, voluntary organisations and unpaid caregivers, all of whom are usually women (Glesson 1997).

2.5 Community Care
As previously discussed the alternative that evolved through deinstitutionalisation was that of community based care programmes. These programmes were aimed at providing the services that would effect the assimilation of intellectually disabled people into the mainstream of society. The requirements of adequate community care policy are acknowledged to be wide, including the need for transport, good quality housing, leisure facilities and employment and educational opportunities (Goodwin 1990:215). Also, there is emphasis placed upon the importance of the role of the private sector, voluntary groups and informal care (Goodwin 1990:215).

The process of supported physical and social integration was intended by policy makers to improve the quality of life experiences for the intellectually disabled (Emerson 1985). In this regard it was hoped that community based care programmes would enable intellectually disabled people to experience the autonomy, choices, dignity and respect that most members of wider society are afforded (Emerson 1985). Furthermore, it was hoped that living in the community would provide the intellectually disabled the chance to gain acceptance, and lead a more ‘normal’ life. These aims reflected strongly the principle of normalisation.
It would appear that community care did not follow a single model of care, particularly in Britain (Cambridge et al 1994). Rather, there were many different routes, services and ‘care technologies’ developed to help long stay residents move from hospitals into the community (Cambridge et al 1994:8). In other words, community care programmes were intended to be needs driven.

In community based care in New Zealand persons with intellectual disabilities typically live in group homes dispersed throughout residential suburbs. These homes are operated by a variety of different groups, including community organisations, church based organisations, trusts, and private companies. Also, they contain people of different age, disability, gender and ethnicity (Healthlink South 1994a). For day services there is travel to service provision facilities which are run by the same types of groups that operate the residential placements.

### 2.6 Policy Implementation in New Zealand

To help facilitate the implementation of deinstitutionalisation the Ministry of Health (1993) issued a paper in which it reviewed the planning process, as well as clarifying accountabilities. In short, the Ministry of Health would be responsible for over-seeing deinstitutionalisation through monitoring, policy co-ordination, and funding approval (Ministry of Health 1993:49). The Regional Health Authorities (RHAs) would be accountable for managing the process and purchasing the necessary services (Ministry of Health 1993:49).

The paper goes on to state that planning for deinstitutionalisation could be driven by two options. Firstly, *the client needs option* in which the client’s needs are taken into account (Ministry of Health 1993:51). This option, by definition, does not include cost as a factor in the planning process. Consequently, wards that are the most expensive to maintain could well be the last to close. The other option is *the cost option*, the foundation of which is built on achieving the greatest possible cost savings (Ministry of Health 1993:51). Under this option the deinstitutionalisation process would see the
closure of the most expensive wards first. The ideal, it is suggested, would be a combination of both options. The extent to which one of the options has dominated in relation to deinstitutionalisation is certainly open to debate. Deinstitutionalisation would see resources that were previously tied up in maintaining large institutions being redirected towards improved community based services. Katherine O’Regan, the former National Government’s Associate Minister of Health suggested that this would lead to those with intellectual disabilities being able to lead a life with some degree of dignity and success (O’Regan 1996:3). Furthermore, according to O’Regan; “care in the community can offer the support that people with disabilities need, and a better, more fulfilling life is possible”.

As far as deinstitutionalisation and the Templeton Centre is concerned, the process essentially began in November 1992 when the Canterbury Area Health Board set up an independent committee with the aim of facilitating community consultation on the future strategic planning for the Board’s Intellectually Disabled Services (Healthlink South 1994a). The committee received 150 submissions from relatives, residents, staff, interest groups and the general public (Healthlink South 1994a). The next step was the draft of a four year strategic plan for the deinstitutionalisation of the Templeton Centre, which was completed in December 1992 (Healthlink South 1994a). From here the draft was distributed by the Intellectually Disabled Persons’ Health Division of Healthlink South, with over 700 copies being made available to parties interested in the deinstitutionalisation of the Templeton Centre, with the aim of developing the strategic plan further (Healthlink South 1994a). Also in December 1993 the Southern Regional Health Authority released a discussion document which included proposals on a shift from institution based care to community living options for people with intellectual disabilities (Healthlink South 1994a). This document maintained that the option of community living for the intellectually disabled should be subject to this being an appropriate option for each individual and that the necessary resources to meet individual support needs were provided (Healthlink South 1994a). The final outcome of this part of
the process was that on the 15th of December 1994 Healthlink South and the Southern Regional Health Authority issued a joint news release to announce the implementation of the deinstitutionalisation of the Templeton Centre residents. According to Healthlink South (1994a) the deinstitutionalisation process would involve the expansion and development of a range of residential programmes. This includes a combination of 'normal' housing, together with specialised accommodation that is designed to create a more 'normal' family living environment (Healthlink South 1994a). This process would obviously involve the closure of the traditional institutional setting for the care of people with intellectual disability, which in this case is the Templeton Centre. Furthermore, as far as it is possible accommodation would be provided in community settings, and the support services that were present in the institution would be transferred to the community settings, for example vocational and recreational activity (Healthlink South 1994a).

Healthlink South (1994a:3) suggested that; “Deinstitutionalisation also reflects a change in community attitudes towards people with disabilities”. However, it is difficult to establish how Healthlink South staff were in a position to make such a broad sweeping statement. The announcement that the Templeton Centre would close was by no means met with universal approval. In particular, many parents of Templeton Centre residents were at the very least sceptical of the proposed closure of the Centre. Their concerns are discussed in section 3.5 of chapter three.

2.7 Conclusion
The emergence of deinstitutionalisation with its initial ideological underpinnings, which were strongly influenced by the disability rights movement, and subsequent development into social policy, has seen the marriage of somewhat unlikely parties. These parties included scientists, clinicians, civil rights activists and fiscal conservatives, all of whom were convinced of the merits of deinstitutionalisation, albeit for different reasons. This represents a rather unique alliance.
In New Zealand deinstitutionalisation has been applied on a wide scale in relation to people with intellectual disabilities. This has occurred as a result of both local and global factors, including the impact of the disability rights movement, and the influence of economic reforms. I will argue that this is the most important in terms of deinstitutionalisation being implemented as a social policy in New Zealand.

The alternative to institutional care is community care. Advocates of deinstitutionalisation argue that community care facilitates an increase in the quality of life for people with intellectual disabilities. By living in the community with the necessary support facilities, it is believed that this will allow for a more fulfilling and productive life for people with intellectual disabilities. A life that includes similar aspects, opportunities, and experiences to the rest of society.

The process of deinstitutionalisation in New Zealand has proven to be a long and involved one. Furthermore, it involves a diverse range of people including health officials, medical professionals, policy makers, parents, service providers, and of course the intellectually disabled themselves.

In chapter three the case of the Templeton Centre is examined. This includes providing some history and background information on the centre, together with looking at how the deinstitutionalisation process unfolded in this case. Some important areas that are examined include key issues for the transition of residents from the institution into the community as suggested by Healthlink South. Also, the needs assessment programme, parent's reactions, and the resettlement process are examined.
Chapter Three

*Deinstitutionalisation: The case of The Templeton Centre*

3.1 Background on the Templeton Centre

The Templeton Centre, one of the four psychopaedic hospitals in New Zealand, was located 13kms south of Christchurch. It opened in 1928 and operated as an institution providing for the care and welfare of people with intellectual disabilities. Between 1929 and 1950 the majority of the accommodation was built, which included large dormitory style villas (Healthlink South 1994a). These large dormitory style villas provided the bulk of the accommodation needs for the Templeton Centre residents, and were typical of such institutions throughout most western countries. The Templeton Centre contained a number of facilities including a chapel, gymnasium, vocational training centre, and in more recent times a swimming pool.

By 1964 Templeton residents numbered 581, and in 1974 the number peaked at 654 (Healthlink South 1994a). In 1994 the numbers had fallen to 480 for reasons including the transfer of elderly intellectually disabled residents to nursing homes and rest homes, together with naturally occurring deaths (Healthlink South 1994a:17). As of the 1st of January 1994, 450 residents were over the age of 17 years and only 30 were under the age of 17 years. The gender ratio of residents at this time was 306 male and 174 female. The ethnic groups that made up the population of the Templeton Centre included 461 European, 16 Maori, 2 Pacific Island, and 1 ‘other’ (Healthlink South 1994a:17). As far as the range of disabilities was concerned there were a number of different categories. These were as follows; 48 minimal needs with nil to moderate challenging behaviour, 66 minimal needs and severe 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 1994a:17). In other words, the Templeton Centre contained people with a wide variety of disabilities, and hence a wide variety of needs.

3.2 The Closure of the Templeton Centre

According to Health Link South (1994a, 1994b) there were a multitude of positive objectives that would be realised through the closure of the Templeton Centre. Underpinning these was the attempt to satisfy the needs of the individuals concerned. In other words the emphasis leaned towards the client needs option, as discussed in chapter two. This, according to Health Link South (1994a, 1994b), would be achieved through the development of a range of accommodation and lifestyle options, together with the provision of ongoing support. Moreover, deinstitutionalisation was seen as recognising the rights of people with intellectual disabilities. In other words, the intellectually disabled would now have the same rights as all other people in the community, and thus their ‘quality of life’ would be improved.

Healthlink South (1994a, 1994b) lists a number of more specific reasons for the closure of the Templeton Centre. First and foremost is the idea that persons with intellectual disabilities have the right to lead a life that resembles, as much as possible, the normal pattern of living enjoyed by wider society (Healthlink South 1994a, 1994b). This includes such things as shopping and various outings, together with assisting in their own personal care and household tasks such as cooking and cleaning, depending on their ability to perform such tasks. This aspect of deinstitutionalisation is strongly influenced by the theory of normalisation as discussed in section 2.3 of chapter two. This suggests 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).

Following on from this is the notion that deinstitutionalisation will improve the quality of life of those former Templeton Centre residents (Healthlink South 1994a:3). This notion
predominates within deinstitutionalisation policy discourse. Furthermore, ‘quality of life’ is measured in relation to activities undertaken by members of wider society. It is suggested that moving residents into the community at large will serve to eradicate the ‘institutional culture’ that has developed within the Templeton Centre (Healthlink South 1994a:4). This relates to a change in patterns of behaviour that have resulted from an institutionalised environment, behaviour that would be viewed as abnormal in wider society. It is difficult to ascertain the degree to which an institutional environment contributes to such behaviour. Despite this it would appear that research in this area suggests a decrease of inappropriate or anti-social behaviour amongst persons with intellectual disabilities who have been deinstitutionalised (Horner 1994).

A key aspect of improving quality of life relates to attempting to develop a family type atmosphere in the new community setting. This will, it is suggested, be achieved to some extent by the fact that a smaller number of people will have responsibility for care over a group of residents. It is expected that this will facilitate significant gains in a number of areas, including social behaviour, involvement in household life, reduced use of medication, increased family contact, behavioural gains, and improved community social contacts. It is firmly believed that the deinstitutionalisation of the Templeton Centre will reduce the stigma associated with intellectual disabilities (Healthlink South 1994a, 1994b). This is however, one important variable within the deinstitutionalisation paradigm that lies outside of the control of the policy makers. Furthermore, there are high expectations that people with intellectual disabilities living in the community in ordinary houses will interact and form friendships with people in the wider community. However, as far as these points are concerned they are ideals that may prove difficult to realise. A fundamental aspect of the plan is the need to provide choice for people with intellectual disabilities (Healthlink South 1994a, 1994b).

Accommodation options and the choices available were discussed with residents, parents, and significant others. The same applied in relation to designing appropriate recreation and activity programmes. The needs assessment programme provided the means by
which the most appropriate choice can be made from the options available (see section 3.4 of this chapter for a discussion of the needs assessment programme). An integral part of this process was the use of advocates to ensure that the best possible choices were made. This required the involvement of a large number of people including various professionals, families, caregivers, and independent advocates (Healthlink South 1994a, 1994b).

A further reason for the deinstitutionalisation of the Templeton Centre as outlined by Healthlink South (1994a, 1994b) related to what it saw as the inadequacy of this facility. Central to this is the belief that because this facility was built in 1929 it was no longer able to meet the needs of the residents (Healthlink South 1994a:4). Because the accommodation was largely dormitory style, catering for large group living, there was little scope for individuality and personal development due to an obvious lack of privacy. Although the accommodation had been modified to develop more homely and individual living, it was felt that this was still not adequate, and could not overcome the disadvantages of large villa living in an institutional setting. The support facilities at the Templeton Centre such as the gymnasium, swimming pool, vocational training centre and chapel, were also subject to criticism. It was believed that having these facilities located within the Templeton complex served to isolate the residents from the wider community and further identify them as different and unacceptable. It was suggested therefore, that such facilities needed to be either provided in the community or greater use needed to be made of facilities already in the community.

The geographical location of the Templeton Centre provided further impetus to the move towards deinstitutionalisation (Healthlink South 1994a:4). Its isolated position was seen as perpetuating the belief that to keep people with intellectual disability in a separate community was to their advantage. Whilst acknowledging the attractive surroundings and the purpose built support facilities of the Templeton Centre, it was concluded that this did not compensate for the disadvantages of a site which is so physically isolated from the community. Overall, the location of the Templeton Centre was considered to deny
people with intellectual disabilities the full range of experiences available to members of wider society.

The last area for consideration, and arguably one of the most important in terms of deinstitutionalisation becoming policy, related to the utilisation of financial resources (Healthlink South 1994a:5). According to Healthlink South (1994a) if the Templeton Centre did not close they would be required to invest substantial amounts of money in upgrading, maintaining, and replacing buildings to meet the required standards. The cost was estimated to be $18.9 million (Healthlink South 1994a:5). Furthermore, the closure of the Templeton Centre would enable cost savings in expenditure on administration, building maintenance, domestic services, food services, and ground maintenance (Healthlink South 1994a). The cost of running the Templeton Centre just before its closure totalled $21.3 million a year, with $14.1 million spent on patient care and treatment and $7.2 million for overhead costs (Healthlink South 1994a:2). Deinstitutionalisation was therefore seen to provide an improved utilisation of current financial resources. In this regard, the financial resources that were tied up in maintaining this large institution would be redirected to resident care and professional support services. The area of financial resources tended to be down played somewhat by government officials. However, given the nature of the neo-liberal reform agenda in New Zealand since 1984 (as discussed in chapter one), it could be argued that this aspect was of significant importance in relation to deinstitutionalisation being implemented as policy.

3.3 Templeton to the Community - Key Issues

According to Healthlink South (1994a) there were a number of key issues that required careful consideration to ensure the transition from institution to the community was as smooth as possible. The first major issue related to the needs assessment programme (see section 3.4). This was a comprehensive programme, which was used to determine the most appropriate level of care required for individual residents. This process involved family, staff, and where necessary advocates, to identify individual needs (Healthlink
South 1994a:6). Following on from the needs assessment programme was the development of an Individual Programme Plan (IPP) (Healthlink South 1994a:6). This included identifying the services that an individual required, together with the form of accommodation considered the most appropriate. Furthermore, there was a focus on opportunities for enhancing quality of life, as well as placing emphasis on skills for a positive transition and continued growth. Throughout this whole process families and caregivers were to be involved in the decision making. Moreover, their needs as well as the resident’s, were to be taken into account.

The next main issue related to the area of specialised residential care (Healthlink South 1994a:7). There was to be a specialised residential facility available to those who may require it. This unit was to be available as an option to meet particular needs as determined by the IPP. Furthermore, those residents who were not successful in community placements would be able to return to specialised residential care. This may be for a period of assessment and further training or for permanent readmission depending on individual needs. Also, if residents did not successfully adapt to one community setting they would be given the opportunity to trial alternative community homes. This has proved to be the case for some of the participants in this thesis. Staff and families as part of the Individual Programme Plan worked out the criteria for successful placement.

Staff involved in the caring process within the community setting was another important area that was given strong consideration (Healthlink South 1994a:7). Central to this was a philosophy of continuous staff development. To facilitate this a Staff Development Unit was to be established. According to Healthlink South this would allow the skills and knowledge base required for community care staff to be properly developed, and would be regularly reviewed and updated. Staff training needs would be identified through a system of staff appraisal. Of central concern is maintaining and enhancing the quality of care provided in community settings. Some staff are required to have professional nursing qualifications, but the majority have training to a level appropriate to the need of the individuals they are caring for. However, one must be mindful of the fact that ‘need’ in
this case is defined by Healthlink South. This could have implications for the quality of care that the intellectually disabled living in the community receive. As far as issues relating to staff development are concerned it is difficult to ascertain the extent to which these have been developed and implemented.

With regard to the accommodation itself, it was decided from the individual needs analysis that six options would be available (Healthlink South 1994a, 1994c). These ranged from ‘normal’ homes, with large garden and living areas that did not require any alterations, to a specialist facility (Brackenridge, in the case of the Templeton Centre), that would accommodate those with moderate to severe behavioural challenges. The remaining options in between these comprise of ‘normal’ homes that have undergone varying degrees of alterations, including such things as installing ramps, handrails, bath seats, together with widening hallways and doorways, and in some cases fences and locked gates.

According to Healthlink South (1994a:9) a key element to ensure the success of community based care is a comprehensive network of professional support services. These include such things as professional physiotherapy, occupational therapy, social work, speech and language therapy to assist in maximising independent functioning and manage difficult behaviour (Healthlink South 1994a:9). As a means of ensuring that the needs of every individual are met, a professional organisation, Systems and Monitoring Service (SAMS), monitors accommodation and care plans. There would also be provision made for the education and support of both community providers and the community generally in relation to the care and needs of people with intellectual disability. Once again the evidence of this is scant, and the extent to which this has been implemented difficult to ascertain.

Work and activity programmes constitute the final major area of consideration (Healthlink South 1994a:10). According to Healthlink South (1994a) a comprehensive range of day and activity programmes in the community would be developed. Central to this was the need for diversity and choice to ensure that individuals have access to meaningful
activities within the community. At this time only a proportion of the residents at the Templeton Centre had access to vocational services (Healthlink South 1994a:10).

3.4 The Needs Assessment Programme

Given the centrality of the needs assessment programme in the deinstitutionalisation process, it requires more in depth discussion. The needs assessment programme involved a comprehensive examination of all aspects of a person’s life, and was an important part of the deinstitutionalisation process (www.canterbury.cyberplace.co.nz/community/resweb, 09/01/01)\(^1\). The main aim of the programme was to establish the most appropriate level and type of care required for each individual. This was achieved by assessing a person’s needs, including physical, health and medical, their spiritual and emotional support needs, as well as their support networks (including family). Also included are their cultural, behavioural support needs, and their need for education, and for meaningful work. Finally, their recreation and leisure, together with transport and accommodation needs are also included.

Of central importance is the direct link between the needs assessment programme and funding levels. In order to obtain special benefits a person’s disability has to be verified in a way that is acceptable to the Health Funding Authority. The needs assessment programme was the only acceptable method. Those who require residential care are allocated a Support Needs Checklist score (SNC), which places them on a disability scale from A to C, and thus determines the amount of funding available to purchase the services that are required. Furthermore, residents were placed into one of the nine specific categories contained within these three broader categories. The categories are as follows:

- **A -Minimal needs, no behavioural challenge**
- **Minimal needs, moderate behavioural challenge**
- **Minimal needs, severe behavioural challenge**

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\(^1\) Some of the information on the needs assessment programme came from the Rescare NZ web site. Rescare NZ are an independent organisation that is dedicated to bringing information and support to those caring or advocating for people with an intellectual disability.
B - Moderate needs, no behavioural challenge
- Moderate needs, moderate behavioural challenge
- Moderate needs, severe behavioural challenge

C - Intensive needs, no behavioural challenge
- Intensive needs, moderate behavioural challenge
- Intensive needs, severe behavioural challenge

It was believed that placing residents into one of these categories would facilitate a smooth transition into the most appropriate community setting, because this would match their predetermined needs. ‘Needs’ in this case were ultimately determined by Healthlink South.

The needs assessments were conducted by a number of different private businesses throughout New Zealand that were under contract to the Government. The programme involved a number of different groups including parents, staff from the institution, and in some circumstances, advocates (Healthlink South 1994a:6). All needs assessors had to complete a standard form to ensure, as much as possible, consistency of assessment.

There were two types of needs assessment, initial and comprehensive. The former was completed with input from the client, the client’s family or support people, and the assessor. The latter differed in that it involved the assessor accessing reports from the specialists or professionals involved with the individual concerned.

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 1994a). The IPP covered such things as the person’s individual care, treatment, services, accommodation options and follow up assessments (Healthlink South 1994a). A Service Co-ordinator was responsible for the facilitation and co-ordination of a package of services identified in the client’s needs assessment, as well as liaising with families on care related issues (Healthlink South 1994a).
The needs assessment programme can be seen as part of the psychological/educational model of intellectual disability, which supports deinstitutionalisation. This model views an intellectually disabled person as having the right to live in a more "normal" environment, and thus should live in the community (Levien 1996). However, within this paradigm the professional remains the "expert", although there is a shift from medical expertise (as with the medical model of intellectual disability), more towards educational and psychological expertise (Levien 1996).

3.5 Parents Reaction

When the news that the Southern Regional Health Authority was planning to close the Templeton Centre became public, many parents were outraged. It would appear that similar reactions have occurred in these sorts of situations overseas. For example, in the United States parent associations affiliated with state institutions very quickly initiated efforts to block legislation to close state institutions (Landesman and Butterfield 1987:811). The core of the parents' argument was that secure, state operated institutions were the most appropriate setting for their children.

At the centre of the parents' concerns regarding the closure of the Templeton Centre, and the subsequent relocation of residents into the community, was the belief that it actually restricted their rights. In other words, there would be no other alternative available. The parents maintained that intellectually disabled people should have the right to the best possible care, which they believed in the majority of cases would be a sheltered village on the Templeton site (The Press: Oct 16 1995).

The Templeton Centre Parents Association did not see a sheltered village as an alternative to community care, rather they saw it as complimentary to community care. Parents envisaged a facility that would begin with a base for about half to two thirds of the residents that were in the Templeton Centre (The Press: Oct 16 1995). This facility would provide twenty-four hour care, and would consist of family type accommodation. Moreover, there would be accommodation for people needing intensive nursing, as well as
on site supervised “flats” that would cater for those with some degree of independence. When and where it was deemed appropriate residents could be moved from the on-site accommodation into group houses or flats in the community.

Furthermore, parents wanted all residents, whether living within the village or in community-based accommodation, to have access to on-site recreation and workshop facilities (*The Press*: Oct 16 1995). Not only would this guarantee that the high grade recreational and vocational facilities at the Templeton Centre would be accessible to those living in the community, but it would help maintain the social networks that had been established between residents and staff in the Templeton Centre. Many parents felt that if intellectually disabled people living in the community were left without stimulating recreation and vocational opportunities, they would become isolated (*The Press*: Oct 16 1995).

Another very important question that was raised by parents at this time was why it was assumed that the life of an intellectually disabled person would be enhanced by them living next door to “normal” people (*The Press*: Oct 16 1995). This was seen by many parents as being a somewhat elitist attitude. Moreover, parents from the Templeton Centre Parents Association felt that intellectually disabled people should be valued as they are, and not have beliefs about what is “normal” forced on them.

The Southern Regional Health Authority rejected the parent’s demands for a sheltered village on the former Templeton Centre site. Despite the continued lobbying from the Templeton Parents Association for a 150-bed facility, it was decided by the Southern Regional Health Authority that this did not fit the criteria for deinstitutionalisation (*The Press*: Aug 14 1996). The association’s secretary, Heather Absalom-Smith, said Templeton residents had once again been denied the choice of living within a safe haven, something that a sheltered village would provide (*The Press*: Aug 14 1996).

Another area of concern for parents related to the level of support services that would be available in the community. By the end of 1987, according to the Southern Regional Health Authority, all the necessary support services were already in place, including
behaviour support, allied health, a full complement of nine independent service coordinators, and a friendship-linking service *The Press*: Dec 26 1997). Day programmes would also come into operation.

The issue of funding was also an area of concern for parents. Sande Ramage, Southern Regional Health's service development manager, reassured parents that; “Community care is government policy and the Government will continue to have a responsibility for funding of services for people with intellectual disability in whatever setting they live”. *(The Press: Dec 26 1997).*

For many parents, particularly those involved in the Templeton Centre Parents Association, the closure of the Templeton Centre was the cause for concern in relation to how their children’s quality of life would be effected. Many parents did not share the optimism that the policy makers maintained in terms of the positive aspects deinstitutionalisation would bring to the lives of people with intellectual disabilities. Central to this were concerns based around funding levels, staff issues and the attitudes of the wider community towards people with intellectual disabilities.

There is no doubt that in the early stages of the deinstitutionalisation process many parents were concerned at what the future might hold for their children. Furthermore, there were many parents who felt a sheltered village was an option that needed to be available. However, policy makers thought otherwise. Despite this, a committed group of parents continued to lobby government with the final result being the establishment of the Brackenridge Estate (see section 3.7 of this chapter).

### 3.6 Resettlement into the Community

The resettlement of former Templeton Centre residents into the community has proven to be a long and involved process. Furthermore, it is a process that incorporated a number of different and quite diverse groups of people. These groups consisted of the service providers, parents, real estate agents, vendors, local councils, people from neighbouring properties, and various trades’ people.
At the core of this process was Community Housing Limited, a subsidiary company of the Housing Corporation of New Zealand\(^2\). They were responsible for overseeing the bulk of the resettlement of former Templeton Centre residents into community houses. The resettlement programme commenced in December 1996, and was completed by March 2000. During this time Community Housing Limited provided 60 residential properties which fulfilled the accommodation needs of 373 residents. Included in this were forty six-bedroom homes, and five ten-bedroom homes. Also included in this process was the establishment of four residential style non-residential properties for use as day centres.

The path to a community house was a rather involved one that required varying degrees of input from the aforementioned groups. In the first instance the service provider would approach Community Housing Limited with the intention of obtaining a community house. However, before this process could proceed the service provider had to meet certain criteria. Firstly, the purpose, aims and goals of the group had to be made clear. Also, the activities of the group, together with the intended use of the house, had to be clearly set out. This included the maximum number of residents that were intended for the house. Obviously, the specific details of the type of house that was required needed to be established. This included such things as location and proximity to shops and services, as well as the size of the house including the number of bedrooms and bathrooms. Furthermore, if there were certain essential features that were required, such as wheelchair ramps or a garage, for example, these needed to be identified.

There were also a number of administrative matters that had to be addressed. These included forwarding a copy of the group’s registration as an Incorporated Society, Trust Deed, or Company Deed, together with a copy of the group’s last annual report. Community Housing Limited also required a copy of the financial budget to run the home, which had to include a rent component. The final significant administrative issue that

\(^2\) The information provided on the relocation process was provided via an informal interview with a staff member of Community Housing New Zealand for which I am very grateful.
needed to be addressed was the confirmation of a community consultation strategy that had been agreed with the funder or purchaser. The community consultation strategy needed to show how the group intended to facilitate the move into the particular community that had been chosen, and how potential problems might be dealt with.

However, the pivotal component in this process was one of funding. It is this component that largely determined whether or not a group was eligible for a house through Community Housing Limited. Funding, therefore, had to come from the Crown by way of the Health Funding Authority (HFA). A contract was required with the HFA to pay for publicly funded health and disability support services. This contract, together with a confirmation of funding, had to be presented to Community Housing Limited.

Once all the criteria had been met the process of finding a house began. The first option that was looked at was the houses available from Community Housing Limited’s stock. Next, properties owned by government organisations would be considered, and finally those available on the open market were looked at. Once Community Housing Limited had found some houses that met both the needs of the service provider and also satisfied their own criteria the viewing process began. When the right house was found the likely rent was negotiated.

Once the rental charges had been agreed the process of purchasing the property began. Before the service provider could take possession of the house, Community Housing Limited would ensure that all the necessary alterations and renovations had been made and they met all the legal requirements. These included compliance with the Building Act 1991, and Building Regulations 1992, which related mainly to situations where improvements had taken place or new buildings had been erected on the property. In some circumstances the Resource Management Act 1991 had to be taken into consideration, for example if the house was to be used for a purpose other than its specified zoning allowed. Finally, the Fire Safety and Evacuation Regulations 1992, which specify the standard of fire safety that was required in the house, had to be adhered to. The final phase of this process was the negotiation and signing of a Tenancy
Agreement. These were standard type agreements that fell within the obligations of either the Residential Tenancies Act or the Property Law Act.

3.7 Brackenridge Estate

As discussed in section 3.5, one of the concerns parents had was that community based services would not adequately meet the needs of their children. Despite a concerted effort by a group of parents to convince the government that a sheltered village was a necessary option, particularly for those people with multiple disabilities, the government did not agree.

However, a small and committed group of parents continued to lobby the government for the development of a village style service alternative (Mirfin-Vietch et al 2000). The determination of these parents paid off. In 1998, an announcement came from the Health Funding Authority that a facility would be developed on the former Templeton Centre site, four years after the original announcement of closure (Mirfin-Vietch et al 2000). The Brackenridge Estate caters for those with multiple physical and intellectual disabilities, people who are medically fragile, together with those with severe challenging behavioural problems (Mirfin-Vietch et al 2000). Many parents believe that a sheltered village such as the Brackenridge Estate provides a safer and more secure environment for their children (Mirfin-Vietch 2000). The eligibility for admittance to Brackenridge was established through the needs assessment programme. Interestingly, this process established that only a mere 80 ex-Templeton Centre residents were eligible for admission to Brackenridge (Mirfin-Vietch et al 2000). The Brackenridge Estate consists of 14 stand-alone houses with communal living areas and individual bedrooms.

3.8 Conclusion

The Templeton Centre on the outskirts of Christchurch was one of four psychopaedic hospitals in New Zealand which provided a ‘home’ for persons with intellectual disabilities for seventy years. During its peak in the 1970’s it accommodated over 650
residents. Contained within its extensive grounds were a number of facilities including a gym, vocational training centre, chapel, and swimming pool.

In November 1994 Health Link South announced that the Templeton Centre would close, and residents would be relocated into the community. This implementation of deinstitutionalisation as a social policy represented a convergence of social, political, and economic factors. By closing the Templeton Centre a number of positive objectives would be realised, according to Health Link South, many of which were influenced by the theory of normalisation. Underpinning this social policy, according to policy makers, was the right of persons with intellectual disabilities to lead a life that resembles as much as possible the normal pattern of living enjoyed by wider society. This will, it was suggested, increase the quality of life for persons with intellectual disabilities as well as decrease the stigma attached to these people’s lives. However, there were many parents that felt that deinstitutionalisation could impact negatively on the quality of life of their children.

Adding impetus to the move to deinstitutionalisation was the negative way in which institutions accommodating those with intellectual disabilities were viewed. In short they were no longer seen as appropriate or adequate, particularly by policy makers. Another important factor that featured in developments that saw the closure of the Templeton Centre, was the financial cost of running and maintaining it. The Templeton Centre was in need of an investment of substantial amounts of money to upgrade, maintain, and replace buildings to meet the required standards. Moreover, the closure of the Templeton Centre would enable cost savings in expenditure on maintaining and administering such an institution. This was arguably the most influential factor in the implementation of deinstitutionalisation.

The needs assessment programme represented an integral part of the deinstitutionalisation process. It was a comprehensive programme, which was used to determine the most appropriate level of care required to meet individual needs. Accordingly, the level of care determined the level of funding available. To ensure the success of community care
Health Link South outlined a number of factors that were seen to facilitate this. This included providing a range of accommodation options to meet a range of needs, together with having appropriately trained staff. Furthermore, there would be a comprehensive network of professional support services including professional physiotherapy, occupational therapy, and speech and language therapy.

Many parents felt that community based services would not adequately meet the needs of their children. This provided the impetus for some parents to petition government for the option of a sheltered village. Their perseverance paid off with the announcement in 1998 that the Brackenridge Estate would be constructed on the former Templeton Centre site. As far as the resettlement process was concerned, this was handled by Community Housing Limited, a subsidiary company of the Housing Corporation of New Zealand. They were responsible for overseeing the bulk of the resettlement of former Templeton Centre residents into community houses, which was completed by March 2000.

In chapter seven, the conclusion, the factors that Healthlink South outlined as important in terms of why the Templeton Centre should close together with what would be achieved through community care are discussed in relation to the findings from this research. Also, some of this material is referred to in chapters five and six, together with literature from New Zealand and overseas. However, before this the methodology chapter outlines a number of important issues relating to how the data was gathered, the participants and the analysis process. Also, issues relating to “quality of life” are examined, with particular attention to what constitutes quality of life in relation to people with intellectual disabilities, and how this information can be obtained.
Chapter Four

Methodology

4.1 Introduction

The aim of this thesis is to evaluate the impact of deinstitutionalisation on residents of the former Templeton centre. Of central importance is the quality of life of former Templeton Centre residents living in the community. This thesis will argue that the intellectually disabled are a heterogeneous group, with differing levels of functionality, accordingly they have a variety of needs, wants, and desires, not all of which may be met to a satisfactory level in a community setting. Moreover, chapter six will show that there is a correlation between resource levels and quality of life, particularly in relation to leisure and recreation activities.

It would appear that quality of life outcomes have provided the foundation for the development of deinstitutionalisation of the intellectually disabled both as an ideology and a social policy. Therefore, it follows that an evaluation of quality of life issues is one of the most effective means by which to establish the degree of success or failure of deinstitutionalisation. Furthermore, it will be of considerable importance to establish which specific areas of the life of an intellectually disabled person have been improved, or not as the case may be.

This information will prove beneficial to a broad range of groups involved in the deinstitutionalisation and community care process. Such groups include caregivers who would benefit from such information, so as to enhance their understanding of the issues relating to the quality of life of those under their care. This would therefore increase the caregiver’s potential to become more aware of what was required to maximize the welfare and well-being of their clients. Policy makers would also benefit from such information; they could utilise the data from research such as this to formulate policy that is better tailored towards the needs of those concerned. Ultimately, this would lead to a more
fulfilling life for the intellectually disabled. Emerson (1985) suggests that the aims of impact evaluation are to provide authoritative feedback to various groups including policy makers, consumers, and service providers. Moreover, well researched evaluations of existing programmes will facilitate in generating models, concepts, and empirical generalisations that will serve to shape future policy (Emerson 1985:277). Deinstitutionalisation is a social policy that would benefit greatly from such an impact evaluation.

This thesis was made possible through a wider project in the area of deinstitutionalisation, and persons with intellectual disabilities in the Sociology Department at the University of Canterbury. This project involved the efforts of four other people, three graduate students and one staff member. Operating in a ‘research cluster’ such as this had a number of advantages. Firstly, it enabled the sharing of resources. This was extremely valuable in terms of saving time locating literature, together with being able to utilise some literature that I might otherwise not have discovered. Next, it helped in relation to accessing participants as the network of potential participants was greatly increased by virtue of the number of people involved in the project. Also, it proved useful in terms of some of the decisions that were made during the research process, particularly in regard to selecting the participants. Finally, there was the support and encouragement aspect. It helped to have others close by who were working in the same area, particularly when it came to discussing ideas and different perspectives.

This chapter begins by looking at why mothers were used as the participants in this thesis, together with how access was gained, and how they reacted in the interview situation. From here the research methods are looked at. Accordingly, there is a discussion of why qualitative research methods, by way of semi-structured interviews were used, with particular emphasis on the flexibility that such a method allowed. Next, the analysis process is discussed, looking at how this was constructed, the problems that arose and how these were overcome. Ethical considerations constitute the next area of the
methodology, the focus of which is concerned with issues relating to the participants. These include accessing and selecting the participants, and the idea of informed consent, together with doing no harm to participants. The next area relates to assessing “quality of life” in relation to persons with intellectual disabilities, and how for the purposes of this thesis it was constructed through the eyes of the mothers. Furthermore, this section explores the way in which this has been constructed in regard to other studies and the dilemmas that researchers face when dealing with a concept such as this. Finally, the concept of “intellectual disability” is looked at, and how this can be seen as a social construct. However, for the purposes of this thesis differing levels of “intellectual disability” are determined by the needs assessment categorisation.

4.2 Participants

The participants in this thesis are the mothers of those people who have been moved from the Templeton Centre into the community. The rationale behind using parents (or in this case mothers) to obtain the required data is discussed in section 4.7 later in this chapter.

Gaining access to participants was conducted using the snowball sampling technique. This approach is often used to obtain a sample when there is no adequate list that could be used as a sampling frame (Arber 1993:73). Snowball sampling involves contacting a member of the population of interest and asking whether they know anyone else with the required characteristics, and so the cycle continues (Arber 1993:74). One possible difficulty can be that establishing initial contact may prove time consuming, however this was not an issue in this case.

This thesis looks at the experiences of ten former Templeton Centre residents through the eyes of their mothers. Of the ten former Templeton Centre residents eight are male and two are female. The average length of time spent in an institution is 29.2 years, with a range of 22 years up to 40 years. Residents have been in a community setting for a period between eighteen months and three and a half years. They were relocated from the
Templeton Centre between February 1997 and October 1998. In terms of the needs assessment categories seven are category C and three category B. The following table provides an indication of the heterogeneity of those involved in this study;

<table>
<thead>
<tr>
<th>Name</th>
<th>Needs Assessment</th>
<th>Community Placement</th>
<th>Individual Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heather</td>
<td>B</td>
<td>“A”</td>
<td>Challenging behaviour</td>
</tr>
<tr>
<td>Christine</td>
<td>B</td>
<td>“A” and “B”</td>
<td>Brain damage as a baby, challenging behaviour cerebral palsy, difficulty controlling bowel motions.</td>
</tr>
<tr>
<td>Sam</td>
<td>B</td>
<td>“C” and “D”</td>
<td>Downs syndrome, deaf.</td>
</tr>
<tr>
<td>David</td>
<td>C</td>
<td>“E”</td>
<td>Brain damage as a baby, nearly deaf, partial blindness, non-verbal.</td>
</tr>
<tr>
<td>Hugh</td>
<td>C</td>
<td>“F”</td>
<td>Non-verbal, severe intellectual disability, requires special diet, difficulty controlling bowel motions.</td>
</tr>
<tr>
<td>Kirk</td>
<td>C</td>
<td>“G”</td>
<td>Challenging behaviour, non-verbal</td>
</tr>
<tr>
<td>Peter</td>
<td>C</td>
<td>“H”</td>
<td>Multiple disabilities, in wheelchair, speech difficulties</td>
</tr>
<tr>
<td>James</td>
<td>C</td>
<td>“I”</td>
<td>Autism, challenging behaviour, behavioural problems.</td>
</tr>
<tr>
<td>Mark</td>
<td>C</td>
<td>Brackenridge</td>
<td>Autism, multiple disabilities, difficulty walking.</td>
</tr>
<tr>
<td>Ben</td>
<td>C</td>
<td>Brackenridge</td>
<td>Cerebral palsy, wheelchair, non-verbal, feeds through tube.</td>
</tr>
</tbody>
</table>
The use of just mothers as participants was not initially by design. The first person contacted was the mother of an ex-Templeton Centre resident and she provided the names of other mothers willing to take part. As the interviewing process unfolded it became apparent that mothers were more than willing to talk about a sensitive area such as that covered in this thesis. Moreover, it also became apparent that for many, taking part in this research provided a vehicle whereby they were able to talk about the thoughts and feelings they experienced before, during, and after the deinstitutionalisation process. For some it was an opportunity to vent some of the anxiety and frustrations that they had experienced throughout the process, and for others it was a case of talking about the positive changes that they had noticed since their children moved into the community.

Obtaining participants for this study did not present any real problems once contact had been made with a mother whose child was an ex-Templeton Centre resident. For many parents the closure of the Templeton Centre was a source of great concern, as it would affect the welfare and well-being of their children in some way or other. From the outset debates raged between parents and health officials as to the perceived wisdom of such a decision. Parents’ concerns very quickly attracted considerable media attention. The essence of the parents’ concerns was that deinstitutionalisation actually restricted the rights of their children (The Press Oct 16 1995). In other words, there were no other alternatives available, other than living with parents, which for most was not a viable option. Many parents supported the idea of building a sheltered village on the Templeton site that would cater for the bulk of former Templeton Centre residents, whilst some would be moved into community placements (The Press Oct 16 1995). However, heath officials did not see this as a viable alternative. The point being that because many parents (or in this case mothers) were so closely involved in the process they were happy to talk about their children’s experiences. Moreover, for many of the mothers it was the feelings of uncertainty, concern, and frustration that predominated during the early stages of deinstitutionalisation that made them happy to talk about the experiences of their children.
The interviews were between one and one and a half hours long. Of the ten participants one was re-interviewed to clarify several issues from the first interview. During the interviews it was obvious that the deinstitutionalisation process had at times been stressful for parents. As experiences of how the deinstitutionalisation process affected their children were recalled a mixture of emotions came through. These included anxiety, fear, and anger, particularly when parents talked about deinstitutionalisation in the early stages. For many this changed to feelings of relief and happiness when talking about how their children were after a period of time in the community.

4.3 Mothers as Informants

There are a number of issues in relation to mothers as informants that require clarification. Firstly, it is important to appreciate that the mother’s views of the Templeton Centre itself were coloured by their experience of deinstitutionalisation. Furthermore, for most of the mothers the relocation of their son or daughter was a relatively recent occurrence. In addition to this the parents’ initial reaction to the closure of the Templeton Centre was in many cases one of disappointment and uncertainty as to what the future might hold for their children. Therefore, it is conceivable that these factors could in some way or other impact on the way in which the mothers viewed the quality of life of their children in the Templeton Centre. In other words, the positive aspects of life in the Templeton Centre may have dominated the accounts of some parents.

Another factor that needs to be considered relates to the personalities of the mothers concerned. In this regard it should be noted that some of the mothers had more to say about the various aspects relating to this project than others. This may have been for a variety of reasons. There is no doubt that those who were more outgoing spoke in more depth about the issues of concern for them. These mothers also tended to be younger and have stronger views in relation to deinstitutionalisation. Furthermore, two of these mothers were politically active in relation to the closure of the Templeton Centre in the early stages of the deinstitutionalisation process. There is no doubt that at this time the
plans to close the Templeton Centre caused many parents, particularly mothers, to become actively involved in the process.

A factor that caused mothers particularly, to become politically involved in the early stages of the deinstitutionalisation process could relate to the fact that experts and professionals were the ones that ultimately held the power in the decision making process. This was a factor that Munford (1992) in her New Zealand study found when interviewing mothers of children with intellectual disabilities. They had a feeling that experts and professionals had increasingly more control over knowledge as they became the group that defined what level of disability should determine what level of support was required (Munford 1992:95). In other words, mothers could potentially feel that this undermined their ability as mothers to know what level of support their children required. Furthermore, Munford (1992:96) found that mothers felt that their status was interwoven with that of their children. Accordingly, they felt that their children were devalued because of the negative view of disability in society, and this in turn influenced the ways in which the women were viewed by society (Munford 1992:96).

4.4 Design

This thesis uses qualitative research methods by way of semi-structured interviews. The main advantage of this is that it allows for some degree of flexibility when it comes to individual mothers talking about their respective children's experiences of deinstitutionalisation. In other words, due to the fact that each story is different, semi-structured interviews can facilitate discussion that may go in different directions in different situations. Good qualitative analysis according to Fielding (1993:168) is able to document its claim to reflect some of the truth of a phenomenon by reference to systematically gathered data. This ideal should remain at the forefront of the researcher's considerations, and did so throughout this research process.

As far as this thesis is concerned a set of key questions initiated and directed the discussion. These questions established information on the effects of moving the
intellectually disabled from an institutional environment into the community, and at the same time allowed for flexibility as discussed above. (See Appendix 1; "Interview Schedule"). Firstly, life in the Templeton Centre was looked at, with an emphasis on quality of life and the factors that contributed to this. The next area examined was the impact of the move in the initial stages, together with the nature of life in the community. Once again the focus is on quality of life issues. Areas that are looked at include such things as the levels of care and the facilities available, together with daily routines and patterns of behaviour in both settings. Another important aspect that is examined relates to social networks, the nature of which are explored in the institutional setting and compared to the situation in the community. As far as social networks in the community are concerned the extent to which these include members of the wider community constitutes an important consideration. This is because advocates of deinstitutionalisation see this as an important part of the community care philosophy.

4.5 Analysis
Taped interviews form the basis of the data collection procedure. Invariably, qualitative research provides the researcher with a vast quantity of data. Therefore a key task is to devise an effective way to code, sort and organise the data collected (Burgess 1993:142). The first step in this process was to transcribe the interviews, which proved to be a somewhat time consuming process. However, this step is an important one in that it represents the first real opportunity for the researcher to actively engage with the research data, thus gaining a feel for the important issues that relate to the research question(s). After transcribing the interviews the next step in the process was to search through the material to identify emerging patterns and themes, and edit the transcripts accordingly. This was achieved by adopting Kvale’s (1996) meaning condensation approach.
Kvale (1996) suggests that there are five main approaches to interview data analysis, which are by no means mutually exclusive. These include: categorisation of meaning, condensation of meaning, structuring of meaning through narratives, interpretation of meanings, and finally, ad hoc methods for generating meaning. Furthermore, Kvale (1996) suggests that the purpose of the qualitative research interview can be viewed as the description and interpretation of the subjects’ lived world. This captures the essence of qualitative research methods.

As previously mentioned the data analysis process for this thesis was essentially that of meaning condensation by way of organising the data into case study format before being written up. In this instance “case study” simply refers to each person’s experience as told by the mothers. Whilst this format did not constitute the “final product” as it were, it did prove useful in identifying the major themes that emerged from the interview data. This is because I organised the interview data into time periods. These related to life in the Templeton Centre, the deinstitutionalisation process, and life in the community. Isolating the data into these time periods made it easier to process and thus enabled the identification of important themes. Meaning condensation thus involves a reduction of large interview texts into a shorter and more concise format. Kvale (1996) suggests that there are five steps involved in this process.

The first step that I undertook was to read the entire interview to get a sense of the whole. This part of the process proved to be very time consuming, as interviews needed to be read several times. However, it was important in terms of developing a strong sense of all the issues involved, and the degree to which they impact on the overall process of deinstitutionalisation. From here the "natural meaning units" as expressed by the research participant are determined by the researcher (Kvale 1996:194). "Natural meaning units" in this case simply refers to the answers given by participants to questions that I asked from the interview schedule (see Appendix 1). This provided the detail that helped to illustrate the major themes that emerged. The next step was to identify in clear and simple terms the theme that dominates a natural meaning unit (Kvale 1996:194). This
was achieved through the case study process as previously discussed. As suggested by Kvale, (1996) once I had done this the meaning units were then related to the main questions within the thesis, which related to the quality of life for the former Templeton Centre residents living in the community. In other words, this editing process allowed the researcher to utilise only the data that related directly to the research topic. This process was helpful in maintaining a clear focus. Finally, the essential non-redundant themes of the entire interview can be tied together into a descriptive statement (Kvale 1996:194). This involved summarising those themes that are seen as secondary to the research question(s), but still have some degree of relevance. These are identified as such when referred to in chapter six.

4.6 Assessing "Quality of life"

As suggested earlier, "quality of life" outcomes constitute a significant component within the development of deinstitutionalisation of the intellectually disabled. Furthermore, assessing quality of life issues is the foundation upon which this thesis is constructed. Therefore, a discussion of the issues relating to what constitutes "quality of life", how this is measured and by whom is of considerable importance.

Quality of life has shifted in the last decade from being primarily a topic of academic discourse, to playing an essential role in decisions that have a major impact on people’s lives (Borthwick-Duffy 1996). This is clearly evident in the formulation and subsequent implementation of a social policy such as deinstitutionalisation. Quality of life has formed a central part of these policies. There are two fundamental questions about the measurement of quality of life. First, what aspects of a person’s life should be considered, and second, what procedures or approaches should be used in measurement (Schalock 1996:46).

Haycox (1995) identified the importance of focusing on 'final outcomes', such as quality of life in relation to service provision for those people with intellectual disabilities who are living in the community. The next issue to be addressed according to Haycox (1995)
relates to constructing a practical measurement of such outcomes. This involves the development of a *social welfare paradigm*, which encapsulates the aspects of welfare that are deemed important and thus defines the elements that must be incorporated in a quality of life measure (Haycox 1995:73). These usually examine individual characteristics of the client's physical and social environment, together with levels of skills and behaviour (Haycox 1995:73). According to Haycox (1995) to be of value such a quality of life index must fulfil three criteria; validity, reliability and sensitivity. As far as validity is concerned it simply relates to the data measuring that which it is intended to measure. In terms of reliability the data must be stable, consistent, and dependable. Finally, in regard to sensitivity the data must capture and reflect changes in the factor being measured.

Generally speaking, efforts to measure quality of life have focussed on either objective or subjective indicators (Schalock 1996:46). Objective indicators refer to external, environmentally based conditions such as health, social welfare, friendships, standard of living, education, public safety, housing, neighbourhood, and leisure activities (Schalock 1996:46). Such indicators are useful for measuring the collective quality of community life, but are insufficient for measuring a person’s perceived or subjective quality of life. Subjective indicators focus on the person’s evaluation of psychological well-being or personal satisfaction, including physical and material well-being, interpersonal relationships, social and community activities, and personal development (Schalock 1996: 46). As far as this thesis is concerned the data provided by the mothers was subjective in the sense that it was their interpretation of the lives of their children in the Templeton Centre and in the community. In other words, it was their perceptions of the systems, structures, and circumstances that contributed to, and maintained their children’s quality

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1 Quantitative methods are used in this area of research as a means of evaluating quality of life issues. Conroy’s (1996) study utilised Shackleock’s Quality of Life Questionnaire (QOLQ). This particular scale has been used in a number of studies in the United States, as well as other countries (Conroy 1996). The QOLQ is designed as a direct interview of the person, or whoever knows the person best (Conroy 1996). A fundamental problem with the use of quantitative methods to measure quality of life is that the researcher is faced with the dilemma of what characteristics of life quality should be assessed and included in the measure (Haycox 1995). Moreover, such methods only capture certain measurable aspects of quality of life. In addition to this it has to be decided what weights should be attached to each of the individual characteristics in order to construct an overall quality of life measure (Haycox 1995).
of life. Whether using subjective or objective measures the evaluation of social reforms such as deinstitutionalisation has inherent methodological problems (Jennssen 1995).

In particular, there is a problem in measuring psychological concepts such as "quality of life" in participants with inadequate language and communication skills (Jennssen 1995:535). Obviously this means that they are unable to adequately answer questions regarding experiences of well-being and quality (Jennssen 1995:540). Therefore, in the absence of the ability for reliable information to be obtained from those concerned, the researcher has to decide upon the most appropriate alternative in relation to the study being undertaken. One such alternative is participant observation. Within the context of this particular research area the researcher can study other indicators such as observations of conditions and behaviour over time (Jennssen 1995). This, however, is a rather time consuming process, and one that would require recording observations of participants in their institutional environment to enable a comparison to be made to life in the community. Therefore, this particular research method precludes itself from use in this project.

Another possible option for obtaining information on quality of life issues within this area of research is by way of the staff in both the institution and in the community setting. However, the logistics of such a method render it impractical in this case because the institution is closed. Also, the potential for bias is greater, given that for many staff this may be their only source of income and they therefore would not want to potentially jeopardise this by speaking of their employer in negative terms. Furthermore, they would not want to possibly paint themselves or work colleagues in a negative light. Conversely, in some circumstances a staff member may feel compelled to portray a situation in overly negative terms in the hope that it might improve the situation for the client (Jennssen 1995:541).

Despite the inherent methodological problems that exist in this area of research, attempts have been made to obtain data directly from participants who are intellectually disabled. Booth et al (1989) devised a method that combined elements of the life stories method
using Conroy and Bradley's (1985) 'visual game' technique. This involved taking photographs of the participants in their everyday context, together with the people with whom they had daily contact (Booth et al 1989:370). From here the researcher and the participant would together make up a photograph album, which would be used in subsequent interviews. Their use in the interviews helped to make the situation more relaxed and informal, together with increasing the potential for communication (Booth et al 1989:372). Moreover, the photographs were used in conjunction with a set of pictures depicting happy/sad faces to ask simple questions regarding the participant's feelings about past, current, and possible future placements (Booth et al 1989:372). For example, the participant would be shown a picture of the unit where they live together with three stylised faces, one with a happy expression, another with a sad expression, and one with a neutral expression, and then asked what sort of face they would have if they lived there (Booth et al 1989:372).

Hughes and Hwang (1996) suggest that assessment of quality of life should involve a triangulation of methods, and multiple sources of information. To this end findings derived from interviews and questionnaires should be corroborated by direct observation to minimise bias and increase reliability and validity of assessments (Hughes and Hwang 1996:58). There is no doubt that this approach represents the ideal when it comes to research methods in this area of social research. However, in regard to this thesis it was not logistically possible to achieve such an ideal. Accordingly, the decision had to be made in respect to the most appropriate method for obtaining information relating to quality of life for this thesis. It was decided, for a number of reasons, that parents (or in this case mothers) were the most appropriate people to obtain the necessary data from. This is discussed in depth in section 4.7 of this chapter.

One final methodological consideration in this area is that the concept of "quality of life" is in itself problematic. The main point of consideration in this regard is who is defining "quality of life", and by what standards. In some research situations such standards tend to be defined by the social scientists themselves, particularly in relation to defining such
things as quality of life, happiness and personal well-being (Jennssen 1995:540). This is something that the researcher in this case attempted to avoid. There is a tendency to think that what is "good" for us is good for everyone. In relation to intellectually disabled persons who have been deinstitutionalised the mere availability of normal pleasures and services need not equate to happiness (Jennssen 1995:543).

4.7 "Quality of life" - A Parent's Perspective
Due to the fact that the focus of this thesis relates to quality of life issues in the community, obviously information regarding the quality of life in the institutional environment is required to enable conclusions to be drawn in relation to quality of life in the community. In terms of this thesis the most efficient means of acquiring such information is via parents. Participant observation is precluded mainly because it would not be possible to observe life in the institutional setting due to the fact that residents had already been moved into the community. Obtaining information from the staff of the institution was a possibility, however as discussed earlier this option was not pursued for this thesis.

The mothers were involved in their children's welfare and were monitoring their children's welfare carefully. These mothers were emotionally involved in their child's welfare, particularly in this case as mothers were clearly concerned about the welfare and well being of their intellectually disabled children. Moreover, their role as mothers was constructed within a context where there was pressure to be seen as 'model carers' and were expected to 'keep going' for the good of the family as a whole. This situation is reflected by Munford (1992), when she states that the women in her study were encouraged by their partners to stay at home and care for family members (including those with an intellectual disability); this was seen as the most acceptable behaviour for the women.

According to Terrill (1996) when it comes to defining quality indicators for persons with disabilities, it is critical that people with disabilities and their families are asked for input.
Terrill (1996) has identified six quality of life indicators from a parent’s perspective, and these provided the foundation for the analytical framework used in chapters five and six. They are; location, community participation, choices, safety, and control of finances and health. The essence of location is that it should as much as possible replicate a home environment (Terrill 1996:35). Interdependence of community members is a central component of quality (Terrill 1996:35). Friends, neighbours, and family form the basis of most peoples’ social and support networks. According to Terrill (1996) the measure is the more people you have in your life who touch you during any given day and are not paid to do so, the higher the quality of life. As far as choices are concerned, the important thing is that people should be free to make choices. Moreover, people should have increased opportunity to make informed choices, and there should be a consideration of the quality as well as the quantity of choices in life (Terrill 1996). Terrill (1996) suggests that eliminating all risk would result in over protection and unnatural settings. Furthermore, by eliminating risk you also eliminate many choices and options. In the area of finances Terrill (1996) suggests that it is important for people to know that they have some control over expenses and income. Lastly, in relation to health it is important that a person’s health needs are adequately met, and should include dental, physical, and mental health (Terrill 1996).

Hughes and Hwang (1996) provide the other major component of the analytical framework. For the purposes of this thesis the researcher adopted five main areas of what Hughes and Hwang (1996) suggest need to be examined when looking at quality of life issues for people with intellectual disabilities living in the community. These are; physical and material well-being, social relationships, followed by self-determination, autonomy and personal choice, recreation and leisure, and finally independent living skills and personal competence. These, together with Terill’s (1996) quality of life indicators from a parent’s perspective, form the basis for the analytical framework that directs the discussion of the results in chapters five and six.
4.8 Measuring "Intellectual Disability"

The final area of methodological consideration relates to the way in which intellectual disability is measured for the purpose of this thesis. This is an area fraught with a number of dilemmas. The term "intellectual disability" can be seen as much as a social construct as it is a measurable and clearly defined condition (Levien 1999:169). Furthermore, its definition and measurement have varied across time and place according to such things as social beliefs, needs and practices (Levien 1999:169). Consequently, there are a vast number of methods that exist in relation to evaluating intellectual disability.

However, the way in which “intellectual disability” is measured is not a primary concern in this thesis. What are important are the different levels of functionality of those concerned. For the purposes of this thesis the level of intellectual disability is determined via the needs assessment programme, which is essentially based on the psychological/educational model of intellectual disability.

As discussed in section 3.4 of chapter three the needs assessment programme was conducted, by and large, by health professionals and parents. The process involved the completion of a standard form throughout the country that was designed to assess the needs of each client in the community. Clients were placed on a disability scale from A to C. This had a number of implications in terms of how the deinstitutionalisation process would unfold for particular clients depending on where they were situated in relation to this scale, particularly in light of the correlation between the category of assessment and funding levels.

4.9 Ethical Issues

The role of ethics in social research represents an attempt to formulate standardised codes of conduct in relation to the researcher, as a means of ensuring the well-being of the research participants. However, despite much theorising it would appear that absolutes in ethics are somewhat elusive and much is left up to the researcher's discretion.
Therefore, allowing for ethical considerations may prove rather problematic, particularly given the difficulty in predicting how events may unfold during the research process.

The first area that required ethical consideration was that of accessing and selecting participants. Of central concern in this regard is 'informed consent'. Informed consent implies a responsibility on the part of the researcher to explain as fully as possible, in terms meaningful to participants, what the research is about, why it is being undertaken and how it is to be disseminated (Hornsby-Smith 1993:63). The participants in this thesis were fully informed as to the nature of the information that was being sought, and how this information would be used and presented. This took place at the beginning of each interview.

The next area for ethical consideration was the interviews. This provided a whole raft of issues that had to be carefully considered. Underpinning this are the ideas of doing no harm to participants, obtaining informed consent and maintaining confidentiality and anonymity (Babbie 1995). Given that this research concerns the welfare and well-being of a somewhat vulnerable group, and the close relationship that participants have with them, it follows that some mothers may have found it rather distressing talking about such a sensitive area. This was at the forefront of the researcher’s considerations during the time of the interviews, with the view that if it became obvious that the interview was too stressful for the participant it would be terminated. Fortunately the situation never arose.

The final area for ethical consideration relates to the publication of the research findings. In this regard, Tolich and Davidson's (1998) notion of New Zealand as a "small town" is a valuable one. This involves the researcher acknowledging that New Zealand is a small place and accordingly the identities of research participants could be revealed if appropriate measures are not taken. As a means of counteracting this the use of pseudonyms and the disguising of places and events are useful (Tolich and Davidson 1998:79). The use of pseudonyms was employed as a means of protecting the participants in this thesis. However, at no stage during the interview process did any of
the mothers express concern over the possibility of being identified through taking part in this thesis research. Also, the location of various community placements referred to in this project have been disguised to protect all concerned. This includes parents and their intellectually disabled children, together with the service providers who administer the care in the community houses.

Ethical issues are complex, relative, and situational, and there are no easy answers to dilemmas that may arise. Research ethics are not just access related, focusing on gaining informed consent from those in the study, but rather must be carried right through the research process. It is the well being of participants that underpins ethical considerations.

4.10 Conclusion

Quality of life issues constitute a significant part of deinstitutionalisation as an ideology, as a social policy, and in practice. For the purposes of this thesis it is the quality of life of those intellectually disabled that have been moved into the community that has provided the central focus. Furthermore, quality of life in the community is compared with quality of life at the Templeton Centre, together with the objectives articulated by Healthlink South. This thesis argues that due to the heterogeneity of the intellectually disabled, and diverse levels of functionality, the needs, and hence quality of life of people with intellectual disabilities can not always be met in the community. In other words, the way in which deinstitutionalisation has been designed and implemented gives the appearance of a ‘one policy fits all’, and thus overlooks the fact that there are a wide variety of needs in relation to people with intellectual disabilities living in the community, particularly those with severe and multiple disabilities. Also, there is a correlation between the resource levels of a community residential service provider and quality of life.

There are number of methodological issues that required careful consideration. At the forefront of these considerations is what constitutes quality of life in relation to people with intellectual disabilities, how this is measured and by whom. It was decided that
mothers would provide the information required for this thesis. However, there were a number of issues in this regard that required clarification. These included the reaction of the mothers at the time of the closure of the Templeton centre, how they viewed themselves as mothers and how they viewed the role of the “experts” in the deinstitutionalisation process.

For the purposes of this thesis Terrill’s (1996) indicators for quality of life from a parent’s perspective, together with Hughes and Hwang’s (1996) five areas for evaluating the quality of life for people with intellectual disabilities, provide the framework for the discussion of the research findings in chapters five and six. The data from the mothers is discussed within this framework, together with relevant literature.
Chapter Five

From Templeton to the Community - The Situation Leading up to the Move

5.1 Introduction
This chapter examines the mothers’ perceptions of the experiences of ten former Templeton Centre residents. To begin with there is a brief discussion relating to their life in the Templeton Centre. The purpose of this is to provide a background on their quality of life in the Templeton Centre, which thus enables comparisons to be made to their quality of life in the community. In other words, this provides the means whereby the experience of life in the community can be placed into a broader context.

Next, the deinstitutionalisation process is examined. This section is concerned with how the relocation process operated, what was involved and how it affected the residents of the Templeton Centre. This includes the impact of the needs assessment programme. Moreover, the correlation between funding levels and quality of life will be discussed.

The mothers’ interpretation of life in the Templeton Centre provides not only a sense of what life was like for residents, but also extrapolates the factors that contributed to maintaining and enhancing their quality of life. Moreover, it details the idiosyncratic nature of behaviours, wants, needs, and desires, all of which impact on the construction of how one assesses the quality of life of an individual.

This is particularly important in relation to how one may view the life of an intellectually disabled person. There can be a tendency to view the “intellectually disabled” as a homogeneous group, thus denying the diverse range of behaviours, needs, wants and desires that intellectually disabled people have. In other words, the intellectually disabled are a heterogeneous group whose quality of life is influenced by different sorts of needs, wants, desires and behaviours.
As discussed in chapter three the announcement in 1994 that the Templeton Centre would close was the cause of a considerable amount of stress for many parents. Obviously, at the core of the parents’ concern was how all this would impact on their children. More specifically, it was impact on their children’s quality of life that was the dominant concern. At the forefront of this concern were issues of how their welfare and well-being would be affected.

It follows then, that the time leading up to and including the relocation of Templeton Centre residents into the community was stressful for many parents and residents alike. In this regard, the individual experiences that follow will provide a sense of how these process, including the needs assessment, impacted on former Templeton residents.

The analytic framework that has been adopted draws on aspects of Terrill's (1996) quality of life indicators, together with Hughes and Hwang's (1996) dimensions for measuring quality of life (as previously discussed in chapter four). Terrill (1996) has identified five quality of life indicators from a parent's perspective, which relate to assessing the life of an intellectually disabled person living in the community. This provides a broad framework for the subsequent chapter that focuses on quality of life in the community. Hughes and Hwang's (1996) dimensions for measuring quality of life help to provide a sharper focus for this chapter.

Hughes and Hwang's (1996) dimensions are particularly useful when examining the three broad categories of safety and security, the staff, and the facilities in the Templeton Centre in more depth. The dimensions that are utilised in this regard are; physical and material well-being, social relationships and interaction, self-determination, autonomy and independent living skills, and recreation and leisure facilities. There are a number of sub-categories within these broad categories that provide a comprehensive framework to explore the relevant issues.
5.2 The Initial Move to the Templeton Centre

The decision to place a family member into the Templeton Centre represented, at that time, a heart wrenching decision for many parents. It would appear that a number of mothers agonised over making this decision, and it was not made easily. For example Anna speaks of the anguish one faces in the first instance when a parent discovers that their child has an intellectual disability, let alone the anguish one faces when deciding on whether or not you are capable of caring for the child at home. Anna says;

“It has a tremendous effect on a family or on parents initially to be told that their family member is intellectually disabled. This is the first thing that has to be faced and worked through and then as the person’s disability does not go away and does not improve and comes to effect the rest of the family. Then you are faced with making another decision that will not only affect that family member but the whole of the family. The dilemma was whether to let the family disintegrate to keep Mark in the family.”

Anna goes on to talk about making the decision to have Mark placed in the Templeton Centre;

“Mark’s behaviour as a child was extremely demanding, he screamed incessantly for the first 3 years of his life morning, noon, and night, and refused to take any food whatsoever. Once he began walking knowing where he was at any point in time was almost impossible. Therefore, it seemed that an institution would be the only viable alternative where he would receive the intensive care that he required.”

Anna openly acknowledges that this is one of the hardest decisions that a parent has to make.

The sense of anguish that many parents felt when the announcement that the Templeton Centre would close is captured in what Edna felt when this happened;

“It was the end of the world. Because it had taken years to realise that we had done the right thing to have her go out to Templeton, what would happen to Heather if Templeton closed. She needs 24 hour care, she has a heart problem and epilepsy, she could not manage without 24 hour care”.
As part of her study, Munford (1992) interviewed fifteen mothers of people with intellectual disabilities living in an urban area of New Zealand. The mothers in this study had experienced similar feelings to those in this thesis in relation to having their child placed in an institution. According to Munford (1992) all the mothers felt a tremendous amount of guilt if they had a child who had to go to a long stay institution.

The point to consider therefore, is that some parents obviously faced a considerable degree of anguish in terms of making the decision to have their child placed into the Templeton Centre, but after a period of time were happy that this was the right decision. However, when the announcement came that the Templeton Centre would close and residents would be relocated into the community, once again parents were placed in a position where they faced a number of dilemmas in regard to the welfare and well-being of their children. Moreover, there was a sense of anguish amongst parents in terms of how this process would affect them. The closure of the Templeton Centre represented a leap into the unknown, and many parents were unsure what the consequences of this leap might be. There is no doubt that some parents felt that this process would in a sense reopen old wounds in regard to the welfare and well-being of their children.

5.3 Life in the Templeton Centre - A General Overview.

The mothers reported a number of fundamental elements that contributed to establishing and maintaining the quality of life for the residents in the Templeton Centre. These are grouped into three broad categories. Firstly, there are issues that relate to the safety and security of residents. Linking from here there are issues that relate to staff at the Templeton Centre. By and large these are associated with the quality of care administered at the Templeton Centre. Finally, there are issues that relate to the activities and the day to day life of the residents generally. In this section the facilities at the Templeton Centre will be looked at and how these contributed to the quality of life of the residents.
These three categories are by no means mutually exclusive. There is no doubt that they intersect with, and impact on one another. In particular, issues relating to the staff have obvious connections to both the safety and security, and the day to day lives of residents. As each of these three categories are examined the connections will become clearer. It would appear that a number of former Templeton Centre residents thought of the Templeton Centre as their ‘home’. This is reflected in Edna’s comments in relation to when Heather would come home for the weekends and holidays;

“When she came out of Templeton on home visits, by the end of the weekend she would say that she had had enough and wanted to go ‘home’ to the Templeton Centre. On longer visits home for example Christmas and Easter holidays after about four days she would have her bags packed and again say she wanted to go ‘home’.”

This illustrated to Edna that the Templeton Centre was a place where Heather felt safe and secure, both in terms of the surroundings and the staff.

However, it would appear that not all the parents held the Templeton Centre in the highest of regard. There were some who commented that in the past (around thirty years ago) there had been aspects of the Templeton Centre that needed to be improved. For example, the hygiene within the villas. At the extreme end of the scale Judy had this to say about the conditions that her son James faced in the early stages of his stay in the Templeton Centre thirty years ago;

“In those days the hygiene left much to be desired at Templeton. Places like the Templeton Centre used to be dreadful places years ago. He always seemed to have worms, and sores, which went right through the villa. The hygiene was quite bad until there were more women staff or it might have been a new boss that got things fixed up.”

Despite this however, Judy did go on to say that James became well integrated into the Templeton Centre and was safe and secure in the knowledge of the daily routines at the Templeton Centre.
However, the system of routines in institutions caring for the intellectually disabled were seen by many as one of the negative aspects associated with such institutions (Horner 1994). According to Horner (1994) the negative aspects of living in an institutional environment are well documented. These include the institutional environment as being generally unstimulating, unchanging, impersonal and far removed from the pattern of life that exists in wider society (Horner 1994:161). Furthermore, Horner (1994) suggests that two strongly negative features of institutions are that they promote dependence and powerlessness.

Also, there is the issue of social control exercised over residents and their families in relation to service provision in an institutional setting. It would appear that when families visited their son or daughter at the Templeton Centre they did so in a way that was largely determined by the staff. For example, Andrea recalls when she and her husband would visit David at the Templeton Centre;

“They would take him from the day room, or wherever he was and bring him to the office. So we would only ever really see him in quite an isolated environment.”

Levien (1996) suggests that because of the social control exercised over service provision at Mangere Hospital this led to residents and their families being constrained in ways that impinged on their relationships and lifestyle. This included having visits curtailed, families being denied knowledge and understanding and staff assuming primary responsibility (and therefore control) for decisions related to residents (Levien 1996:343).

5.4 Physical and Material Well-being

Hughes and Hwang (1996) suggest that there are three important elements that contribute to maintaining physical and material well-being. These are; personal safety, food, clothing and shelter, and physical health.
Personal safety was an important issue for all parents. They acknowledged that there was a connection between the safety and security of their children and their quality of life. This related to both their physical and social environment.

In terms of the geography of the Templeton Centre it lent itself to residents being able to wander around in relative freedom. This is because it was located on 73 hectares of land. Furthermore, it was situated thirteen kilometres from Christchurch in a semi-rural location. This greatly reduced the possibility of residents “coming to harm”, as there was little in the way of traffic, other people and so on. Therefore, the physical location, isolation and size of the Templeton Centre contributed greatly to the personal safety of the residents.

The importance of personal safety is reflected in a number of different accounts from parents. For example, Andrea recalls how her son David developed a nicotine addiction;

“Smoking became problematic for David at the Templeton Centre, because he loved the smoke smell. Any staff member who smoked he loved them, he sat on their knee and went right up to their face because he could smell it. Fortunately David was incapable of smoking. He went through an addiction of picking up cigarette butts and sucking them.”

His addiction had developed to a rather serious degree. Consequently, he would endeavour to search out cigarette butts, which could result in him climbing out of windows. As a result of this he would wear a helmet in case he fell out of a window.

“This caused him a lot of stress...he would be bashing his head until he had stitches. He has scars all over his head through bashing against walls. Even though he has limited sight he was able to see butts on the ground because of the yellow ends”.

The importance of the somewhat physically isolated location of the Templeton Centre would be reinforced when Andrea and her husband Graham would take David out for a drive and an ice-cream at the weekends.
“We would take him down to the park for an ice-cream. However, a major problem was that David would pick up cigarette butts in the park, and obviously there are always quite a few lying around the parks.”

As previously mentioned, another important aspect of the geography of the Templeton Centre was its size. This meant that residents were relatively free to go for a walk when they so desired, or it was deemed desirable by the staff. This is illustrated nicely by Frances talking about her daughter Christine whose behaviour Frances described as “extremely demanding”, due to her tendency to have temper tantrums, and to be very noisy;

“The extensive grounds meant residents could safely go for a walk when they wanted to. In fact, if a resident became stroppy, they were told to go for a walk. When they came back they were completely different. I think it was a great idea. If they were upset about anything, you know, or throwing a wobbly they could get some fresh air and a walk. They would come back completely different people. They would have forgotten what it was they were angry about. There was a lot of space out at the Templeton Centre.”

The positive aspects of the size of the Templeton Centre are also reinforced by Anna speaking of her son Mark. Of major concern for Anna was how Mark was prone to wandering off as soon as he was able to walk. The fact that the Templeton Centre had abundant grounds was reassuring for Anna because she knew that when Mark wandered off there was little chance of him coming to harm.

Personal safety was at the forefront of Judy’s concerns for her son James, and this contributed to him being admitted to the Templeton Centre when he was six years old back in the late 1960’s. Judy’s concerns were similar to those of Anna, in that James was prone to wandering off and required constant supervision.

“He would go into other people’s homes. He was becoming unmanageable. His behaviour was becoming worse, he would take no notice of what anybody would say.”

As far as food, clothing and shelter is concerned it would appear that these necessities of life, which constitute a fundamental aspect of “quality of life”, were met to a high degree
at the Templeton Centre. All the mothers interviewed were satisfied that these aspects of their children’s welfare and well-being, and hence quality of life, were being met to a standard they were happy with.

In regard to physical health, the last element that Hughes and Hwang (1996) suggest contributes to physical and material well-being, it would appear that parents were largely satisfied these issues were well catered for. There is overwhelming support for the quality and competence of the staff at the Templeton Centre. All parents felt that the staff at the Templeton Centre had the best interests of the residents at heart. Parents were of the opinion that the staff not only had a sense of empathy, and a genuine concern for their welfare and well-being, but were able to cope with the many and varied situations that they encountered. This is reflected in a number of different accounts provided by parents. For example Edna tells of her daughter Heather and how she became ill at the age of thirteen;

“When Heather was aged 13 she developed cancer. The staff cared for her admirably throughout the entire process. They prepared her for the stay in hospital by doing such things as making special nighties, giving her soft toys and so on.”

Edna described the staff at the Templeton Centre as “fantastic”. She went on to say that many of them gave their own time, such as taking residents home in the weekends, and away on holidays.

Edna also had this to say about the staff;

“Heather developed a number of skills whilst in the Templeton Centre, this was achieved to a large extent through the efforts of the staff. She was taught to feed herself and dress herself, and later on to work in the printing department. It would appear that the level of care Heather received at the Templeton Centre was of quite a high standard”.
These quotes illustrate nicely the holistic approach taken by some of the staff at the Templeton Centre to the care of residents, which in some incidences included taking residents to their homes.

Whilst all the accounts of staff in the Templeton Centre contained positive elements there was one in particular that alluded to some negative aspects of the staff. Carol had this to say;

“The staff at Ben’s villa really made an effort to have the villa looking bright and attractive, most of the nurses were young and many were mothers. Ben went with a group on a holiday to Surfers to the fun parks and some of the nurses came along to help with his care. Unfortunately not all the residents had this level of care. There were parts of Templeton that were archaic. There were staff that were very militant union people, and they were only there looking after their own interests.”

Nancy, speaking of the care and attention that her son Kirk received at the Templeton Centre, had this to say about the staff;

“The nursing staff were very caring and took personal pride in their work. The staff were always very welcoming. At Templeton there were always trained psychopaedic nurses. Now there is no psychopaedic training.”

This illustrates an aspect that all parents found to be a major factor in relation to the competency of the staff at the Templeton Centre, namely the psychopaedic nursing training that they undertook. The next section provides an overview of psychopaedic nursing as a profession, looking at its history and the nature of the training involved. Some of the examples drawn on relate to the Kimberly Centre in Levin.

5.5 Psychopaedic Nursing

There were a number of issues that parents felt were integral to the establishment and maintenance of the quality of life of their children in the Templeton Centre that related to the staff. Broadly speaking it was the specialist training of the staff that many parents felt contributed to the quality of care that their children received.
From 1960 onwards a new term emerged which distinguished between caring for those who were mentally ill and those who were intellectually disabled; this was psychopaedic nursing (Hunt 2000). The term was derived from the Greek word “paidea”, which refers to the upbringing, education and the development of character of children (Hunt 2000:55). This it would seem, is a philosophy that many of the staff at the Templeton Centre practiced. The new psychopaedic curriculum was introduced in 1961, and was intended to reflect the increased knowledge and changing attitudes toward people with intellectual disabilities (Hunt 2000:55).

Hunt (2000) suggests that the development of psychopaedic nursing increased the care that intellectually disabled persons received in their institutional setting. Moreover, she suggests “the social stigma attached to the mentally subnormal person had created very real barriers in preventing adequate care and training being sought or provided” (Hunt 2000:59). In describing how psychopaedic staff at the Kimberly Centre in Levin would interact with residents, Hunt (2000:60) suggests that “It was not just an improvement in nursing. Staff would take residents to functions without payment. Staff took residents shopping in Levin without payment. We did it for free - it was that sort of atmosphere”. Another important staffing issue in relation to the Templeton Centre was the staff-to-residents ratio. The mothers felt that a higher ratio of staff to residents allowed for more individual care. Furthermore, this was something that they felt was important in maintaining their children’s quality of life.

5.6 Social Relationships and Interaction
It would appear that social relationships and social interaction for residents of the Templeton Centre occurred on a number of different levels, and was largely dependent on the level of functionality of the individual residents concerned. Social relationships and social interaction by and large involved contact between residents and their families, together with the staff and other residents.
As far as the interaction between residents and their families is concerned it would appear that this varied from case to case. In some circumstances it would involve parents coming to visit their child at the Templeton Centre in the weekends. In the case of Andrea and Graham they would visit David in the weekends, and sometimes take him off the Templeton Centre site;

“We would take him out for a drive, which he was never really that keen on. He would be ready for ‘home’ in two minutes.”

In other cases parents would visit their child at the Templeton Centre, and also have them at home to stay at various times throughout the year. During this time parents would take their child on outings of various sorts. It would appear that in many circumstances this was fraught with problems. Family life, even in the short period of a weekend, could face disruption. This was most often the case where the intellectually disabled child had behavioural problems. For example Edna speaks of how family life was when Heather would come and stay;

“When Heather stayed family life was characterised by disruptions. Even a simple trip to the beach would be cut short by Heather’s unruly behaviour”.

However, there were also occasions when outings went along quite smoothly. This was the case when Frances took Christine, who is a big music fan, to see Cliff Richard when he came to Christchurch. This is despite the fact that Christine can tend to be noisy, and is at times unable to properly control her bowel motions.

Social interaction between Templeton Centre residents and their parents and families for the most part tended to be somewhat limited. Limited in the sense of where the interaction took place, as well as the nature of the interaction. In relation to the nature of the interaction this depended very much on the level of functionality of the individual concerned. In some cases this meant parents simply sitting with their child and talking and tending to their needs, whether it be at home or in the Templeton Centre. In other
cases social interaction involved parents and families taking their child to public places such as the park, the beach, or entertainment such as concerts.

As far as social interaction between residents is concerned this once again is largely dependent on the level of functionality of the individuals concerned. It would seem that there is quite a degree of variation in this regard. For those individuals who are non-verbal then obviously the degree of social interaction with other residents is going to be minimal. However, there are those residents who are capable of a much higher degree of social interaction with other residents. This is illustrated nicely when Frances speaks of her daughter Christine and her love of music;

"Christine is a big music fan, she is mad about music. She also enjoyed the company of other residents at the Templeton Centre. When she was in Templeton she had a radio and tape player. If they wanted to play music they would go into a room and they would play music in there and dance away."

In regard to the social interaction between the residents and the staff, this occurred in the most part during the course of the day to day care of the residents. However, it was difficult for the mothers to make any substantial and conclusive remarks in relation to the nature of these relationships. This is due to the fact that parents had rather limited first hand experience of the nature of the interaction, and relationships between their son or daughter and the staff. Parents only spent a very small amount of time in the company of both the staff and their son or daughter, and when this occasion did arise it tended to be in a somewhat “controlled environment”. This is a point alluded to by Andrea when she spoke of going to the Templeton Centre to pick up David. She spoke of how they would wait in the office while the staff would bring him from the day room or wherever he may have been. The point being that there was limited opportunity to witness the interaction between the staff and their child. Consequently, it was largely through what parents were told by staff, together with their own observations of how their child seemed in the presence of various staff members, that formed the basis of the parents opinions of the relationships between their child and the staff.
5.7 Recreation and Leisure Facilities

An important factor that contributed to the facilitation of social interaction between residents, and between residents and staff, were the facilities at the Templeton Centre. Moreover, parents saw the facilities at the Templeton Centre as providing the basis for much of their children’s recreation and leisure activities, and thus contributing to their quality of life. In the 1970’s the Templeton Centre expanded. A new chapel, gym complex, hall, and in subsequent times swimming pool was built. This gave residents the opportunity to increase the number of recreational activities that they were involved in. It would appear that the swimming pool was a particularly popular facility that was utilised by many of the residents. In fact when the announcement came that the Templeton Centre was to close many parents were upset that the facilities that contributed so much to the quality of life of their children would be abandoned, in particular the swimming pool. When speaking of the facilities at the Templeton Centre Frances had this to say about her daughter Christine;

“Whilst living in the Templeton Centre Christine enjoyed many of the facilities that were available. This included the swimming pool, she loved to go swimming.”

The facilities at the Templeton Centre were another positive feature that provided some benefit to Heather, particularly in relation to establishing social networks with fellow residents. These facilities included such things as the swimming pool, the playing grounds that provided so much space, and the hall that provided the venue for the concerts that were a source of fun and entertainment. Edna recalls the concerts with much joy;

“The concerts were marvellous. They got a lot of satisfaction from that.”

Largely as a result of these activities Heather was able to make many friends.
The swimming pool was able to be utilised by a vast number of residents with a wide range of both intellectual and physical disabilities. For example, because of the extent of David's disabilities his involvement in activities at the Templeton Centre was somewhat limited. He could not for example, take part in any art or craft activities. However;

"One activity that David was involved in and really enjoyed was swimming. He loves the water. They also had a snoozalum room at the Villa he was in at the Templeton Centre. This is a room where they have a lot of flickering lights, and a bicycle wheel with ribbons and a small fan which makes the ribbons flutter. There were also plastic tubes with lights in. It was all designed for sensory stimulation. He would also do a variety of exercises. This was largely due to the fact that he had had an operation when he was a child to straighten the tendons in his legs. David was, however, not able to establish any real social networks. He did not have any friends as such. He was quite isolated".

In summary, it can be concluded that the recreation and leisure facilities at the Templeton Centre contributed to quite a large extent to the quality of life for the residents. This was essentially on two levels. Firstly, there was the obvious enjoyment that was gained from residents participating in activities such as swimming, arts and crafts, and concerts, all of which were made possible through the facilities at the Templeton Centre. The other aspect relating to the facilities was the fact that these assisted in facilitating social interaction between the residents. Moreover, in some circumstances residents were able to develop friendships as a result of participating in some or other of the recreation and leisure activities at the Templeton Centre.

5.8 Autonomy, Personal Choice, and Independent Living Skills
In regard to issues relating to autonomy and independent living, Hughes and Hwang (1996) outline a number of components that make up these two categories. For the purposes of this discussion the following components will be looked at, firstly in relation to issues of autonomy; preference and choice, personal decision making, and independence. As far as independent living skills are concerned the following components
will be looked at; self care skills, independent living skills, domestic skills, and communication and language skills.

As far as preference, choice, and personal decision making is concerned, once again this is influenced to some extent by the level of functionality of an individual. For example, David who is partially blind and unable to communicate verbally had some degree of difficulty in being able to make decisions of preference and choice and communicate these. However, a person such as Heather who is fully sighted and able to communicate verbally has more potential to be able to make such decisions and communicate these. Moreover, the way in which institutions such as the Templeton Centre operated on a daily basis, generally speaking, were not conducive to residents being able to exercise much in the way of preference and choice. In terms of decisions relating to things such as what a resident would wear, what they would eat and when, together with what activities would be undertaken, it would seem that these were largely left up to the staff.

As with preference, choice, and personal decision making issues relating to self care skills, independent living skills and domestic skills are influenced by differential levels of functionality, together with the institutional structures that existed in the Templeton Centre. This is not to say however, that residents could not have some degree of control in these areas, or develop skills in these areas. For example, Heather, largely through the efforts of the staff, learnt to feed and dress herself, and thus increased her level of self care skills. However, a person such as David, because of his lower level of functionality, needed assistance to be dressed and fed, and had little control over his self care skills. Obviously, due to the nature of institutional life, there was little potential for the development of independent living skills and domestic skills.

5.9 Conclusion - Life in the Templeton Centre

In conclusion, it would appear that most of the mothers felt that there were some fundamental elements within the Templeton Centre that contributed to creating and maintaining their children's quality of life. These fell into three broad categories. Firstly,
there were issues relating to safety and security, next there were issues that related to the staff at the Templeton Centre, and finally issues relating to the facilities, which included looking at the recreation and leisure activities.

In regard to the issues of safety and security it would seem that, by and large, these centred on the geography of the Templeton Centre. More specifically, it was the fact that the Templeton Centre incorporated large grounds (73 hectares), and was somewhat physically isolated, given that it was located thirteen kilometres from Christchurch. It was felt that this contributed to residents having the potential to be able to wander around in relative freedom and safety.

As far as the staff at the Templeton Centre were concerned this was another area that most of the mothers felt quite strongly about in terms of contributing to their children’s quality of life. At the forefront of these issues was the fact that the staff received specialist training in the form of psychopaedic nursing. It was felt that the staff at the Templeton Centre were in touch with the needs of the residents, and had their best interests at heart. Furthermore, some mothers spoke of the kindness of some members of staff, and that they would involve residents in activities that were not part of their job requirements.

Finally, there were aspects of the quality of life of the former Templeton Centre residents that related to the recreation and leisure facilities at the Templeton Centre. Moreover, the recreation and leisure facilities contributed to establishing social interaction between the residents and the staff. The recreation and leisure facilities included such things as the gym complex, hall, and swimming pool.

However, as well as the positive aspects that mothers felt the Templeton Centre offered their children, there were also downsides to life in this institution. Some mothers spoke of hygiene being not up to standard at times, while others spoke of staff as being militant and not working in the best interests of the residents. There is no doubt that in some respects life in the Templeton Centre stifled the progress of residents in certain areas. This is particularly the case in relation to issues relating to personal choice and autonomy.
5.10 The Deinstitutionalisation Process - An Overview

As discussed in chapter three the announcement in 1994 that the Templeton Centre would close was the cause of a considerable amount of stress for many parents. At the core of the parents’ concern was how all this would impact on their children. Moreover, it was the impact on their children’s quality of life that was the dominant concern. At the forefront of this concern were issues of how their welfare and well-being would be affected by shifting from the Templeton Centre into the community. Many parents had been secure in the knowledge that the Templeton Centre provided a safe and secure environment in which their children had lived quite happily, and this was central to their notion of welfare and well-being.

As far as the Templeton Centre is concerned the deinstitutionalisation process began in November 1994 with the announcement by Healthlink South that it would close and residents would be relocated into the community. Residents began to be relocated from December 1996, and relocation was completed in March 2000. There were two main aspects of this that impacted in some way or other on the residents, the needs assessment programme and the relocation process itself.

5.11 The Needs Assessment Programme

The process of deinstitutionalisation included a preliminary and comprehensive ‘Needs Assessment’ to determine the appropriate type, and level of care required by an individual in their new location within the community (as discussed in chapter two). The Needs Assessment included input from the person’s advocate, parents, families and staff members (Healthlink South 1994a, Ministry of Health 1994). The Comprehensive Needs Assessment was followed by the development of 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 1994a). This provides a good illustration of the influence of the normalisation discourse in the
deinstitutionalisation process. The IPP covered the person’s individual care, treatment, services, accommodation, community placement and follow up assessments (Healthlink South 1994a, O'Regan 1996).

It would appear that although the needs assessment process was quite a rigorous, and at times protracted process, according to the mothers the disruption to the residents was minimal. Furthermore, this is in spite of the fact that some residents underwent more than one needs assessment. In some cases the needs assessment programme took a number of twists and turns, ultimately resulting in residents taking a different path from that which had emerged initially. For example, after David’s initial needs assessment it was established that he would stay on the site of the Templeton Centre in the Brackenridge facility. This was on account of the fact that his disabilities were so severe. However, a subsequent needs assessment reversed this decision, it was now decided by the ‘experts’ that David’s needs could be met in the community. This came as quite a devastating blow for Andrea and Graham as they believed that David’s well-being could now be in jeopardy by him being placed in the community.

There was some speculation amongst the mothers as to why some Templeton Centre residents underwent more than one needs assessment. The speculation centred on the connection between the needs assessment programme and the funding levels. Some mothers believed that the reason some residents underwent multiple needs assessments was that too many were being classified ‘C’. This meant that because those in this category needed specialist care they required more in the way of funding. Because of this it would appear that some of those that were classified ‘C’ were reclassified as ‘B’. This is certainly how Eve felt after the first needs assessment of Hugh;

“Eventually I was able to get him a ‘C’ category for that, he was originally given a ‘B’ category. It is all to do with funding...it’s all to do with the amount of funding that is to be allotted to each person...through the needs assessment he fell into the ‘B’ category. But I wasn’t satisfied with that.”
The ‘B’ rating did not attract as much funding and she thought that Hugh needed the maximum funding possible.

It could be argued that the connection between the needs assessment programme and quality of life lies in the fact that the category of assessment determines the level of funding available, and thus the resources that may be accessed. This in turn impacts on the support and supervision an individual receives, and thus their quality of life.

There were also some positive comments regarding the needs assessment programme. Some mothers felt that the needs assessment provided the necessary information to ensure that the most appropriate community placement could be found for their child. Moreover, it was felt that the needs assessment identified not only the needs but also the capabilities of an individual. In other words, it would assist in increasing the potential for maintaining, or possibly increasing an individual’s quality of life. For example, Zita commented on how the needs assessment for Sam discussed not only various medical problems but also identified things such as the fact that he was not prone to running away, that he did not make loud noises, and also that he could feed himself. She felt that this ensured that he was put into the most appropriate community placement. Overall, there were mixed comments in regard to the needs assessment programme. However, the most important point to emerge is that of the correlation the mothers saw between the needs assessment programme and funding.

5.12 The Relocation Process

The relocation process was certainly a disruptive one for Templeton Centre residents. There is no doubt that being taken out of an environment that had been “home” for many residents for a significant period of time would cause problems of one sort or another. Furthermore, as residents were being moved and the Templeton Centre was gradually being closed down the well being of those who remained was undermined. This is due in part to the fact that, as some residents were being relocated into the community, other
residents were moved into villas with people they had had little or no previous contact with.

This was certainly the case for David. When residents began to be moved out of the Templeton Centre and into the community David was relocated into a villa which contained people with which he had had little or no contact. This had some rather unfortunate consequences, as David had been involved in an ‘incident’;

"He had stitches, due to a cut on his head, which had been inflicted by an autistic child. This happened because as various Villas were closing some of the residents were moved into other Villas, including the one that David was in. He was not used to being in the company of autistic people."

Furthermore, it would appear that in some cases the fact that residents could, as part of the relocation process, be moved from one villa to another was used as a means for motivating parents to make decisions quickly about community placements for their children. For example, Frances and her husband received a letter and were told that if they did not get moving and find a community placement for Christine that she would be moved from villa to villa. The advocacy group Life Links\(^1\) did not provide much in the way of help and support for Frances, her husband, and Christine. Frances comments;

"If we were given a list of places and asked if we wanted to go around and have a look, that would have been good. But they did absolutely nothing. I thought that they could have kept us informed about what houses were opening where."

This suggests the possibility that in some cases parents may have been under pressure to make important decisions regarding the welfare and well-being of their children without having the necessary time and support to make as informed a decision as possible.

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\(^1\) Life Links is an independent organisation providing services to people with disabilities. This includes needs assessments and service co-ordination. They will assist in finding the most appropriate service providers to meet the specific needs of clients (www.lifelinks.co.nz, 25/03/02).
The fact that residents were being moved from villa to villa as the deinstitutionalisation process began to be implemented was also of concern for Eve. She explains that as residents began to be moved out of the Templeton Centre those who were left began to be moved into a smaller and smaller number of villas. As far as her son Sam was concerned, she felt anxious about his well being as he was grouped with more and more residents and staff who he did not know. Eve felt that in the latter stages of the Templeton Centre closing it became a disjointed, and even hostile place.

However, there were some cases where the relocation process flowed more smoothly. For example, Edna indicated that the deinstitutionalisation process itself was a smooth one for Heather, with very little in the way of disruptions. Even the needs assessment programme was such that it provided a minimum of disruption. Edna insists that she was consulted all along the way. In the initial stages of the deinstitutionalisation process the primary concern for Edna was not knowing where Heather was going to live, and whether or not she would have twenty-four hour care. This is where the advocacy group Life Links provided some assistance. Heather was assigned a case manager to oversee her move into the community. During a three-month trial period Heather was questioned about her choice of residence to help ensure that she was placed in the most appropriate environment. When it came to deciding on a place for Heather to live Life Links were responsible for most of the negotiating with service providers, which certainly made the process less stressful for all concerned.

5.13 Conclusion - The Deinstitutionalisation Process

From the time Health Link South announced in 1994 that the Templeton Centre would close, many parents of Templeton Centre residents were anxious about the future of their children. Moreover, a central concern for many parents was how their children’s quality of life would be affected. The prospect of having their child moved from the Templeton Centre into the community was for many fraught with uncertainty, particularly in relation to issues of safety and security.
The needs assessment programme was the first major phase in the deinstitutionalisation process. This involved having residents assessed to determine the appropriate type, and level of care required by an individual in their new location within the community. Despite the needs assessment programme being quite a rigorous, and at times protracted process, it would appear that the impact on Templeton Centre residents was minimal. However, an issue that emerged in relation to the needs assessment programme was the correlation between the level at which an individual was assessed and the corresponding level of funding they received. There were some mothers who felt that this is why some residents underwent multiple needs assessments. In other words, it was felt that because a large number of residents were being classified in the ‘C’ category which commanded higher levels of funding, and that the necessary funding was not available, some were being reclassified as category ‘B’.

Lastly, it would seem that as the relocation process began there were varying degrees of disruption for Templeton Centre residents. In particular, there were some residents that suffered some quite severe disruptions within the Templeton Centre itself. This was due to the fact that as some residents were moved out of the Templeton Centre, others were relocated into villas where they had not previously lived, with people they had had little or no contact with.

In the next chapter life in the community is explored. The framework for the discussion once again draws on Terrill’s (1996) indicators of quality of life from a parents perspective, together with Hughes and Hwang’s (1996) areas that need to be examined when looking at quality of life issues for people with intellectual disabilities living in the community. The mothers provide an insight into how they view the quality of the life of their intellectually disabled children since the implementation of deinstitutionalisation.
Chapter Six

Life in the Community

6.1 Introduction
In this chapter the focus shifts to look at the transition from life in an institution to living in the community, and the impact of this on former Templeton Centre residents. This chapter provides an insight into life for persons with intellectual disabilities living in the community. The emphasis is on the variety of experiences that occur due to the variety of needs, wants, desires, and behaviours of persons with intellectual disabilities, which is strongly influenced by differing levels of functionality. The impact of the transfer to community care upon life quality is unique to each individual (Haycox 1995). As individuals we all react to changes in our environment and in our circumstances in different ways, the same applies to persons with intellectual disabilities (Haycox 1995).

The discussion addresses issues relating to quality of life as articulated by the mothers, arguing that due to the heterogeneity of persons with intellectual disabilities there are those whose needs can not be satisfactorily met in the community. Furthermore, the discussion is integrated with appropriate literature from New Zealand and overseas. This enables the experiences of these former Templeton Centre residents to be placed in a broader context, and thus allows for some conclusions to be drawn in regard to the impact of deinstitutionalisation and community living on persons with intellectual disabilities moved out of the Templeton Centre.

The focus of this chapter is how life in a new environment is impacting on former Templeton Centre residents. The chapter begins with a general overview of the move into the community. There are some comments in relation to the policy objectives of deinstitutionalisation, with specific focus on issues relating to quality of life. From here
physical and material well being is examined, with particular emphasis being placed on issues relating to safety and security, and staff in community placements. The next section addresses concerns relating to service providers and accountability, and the implications of this on the quality of life for residents. An examination of social relationships and interaction constitutes the next section, an important part of which relates to contact between former Templeton Centre residents and the wider community. From here leisure and recreation facilities in the community are looked at, this includes what they consist of, and how they are organised and operate. Autonomy, personal choice, and independent living skills makes up the next section, which looks at how these have developed (or not) in a community setting.

The final section differs from the rest of the chapter in that it does not examine circumstances, conditions or systems that have an effect on the level of the quality of life experienced, but rather it looks at indicators of well being as a means of assessing the level of quality of life an individual has experienced in their new environment. The focus of this section is on behavioural changes and the implications of this on quality of life.

6.2 The Move into the Community- An Overview

The deinstitutionalisation process effectively began with the announcement in November 1994 that the Templeton Centre would close. As discussed in chapter three the actual resettlement of Templeton Centre residents commenced in December 1996, and was completed by March 2000. This process represented a major disruption to the lives of the former residents of the Templeton Centre. Moreover, quality of life issues were at the forefront of considerations for both parents and it would seem, those involved in the policy making and implementation process.

The mothers primary concern was how deinstitutionalisation would affect the quality of life of their children. From the time Healthlink South announced that the Templeton Centre was to close many parents were concerned that living in the community could adversely affect their children’s quality of life. It would appear that in the early stages of
deinstitutionalisation parents had many questions about the welfare and well-being of their children that to some extent remained unanswered.

As for the policy makers, it would appear that “quality of life” constituted an integral component in regard to deinstitutionalisation as a social policy. For them “quality of life” translated to the right for persons with intellectual disabilities to live in the community, and to be released from the shackles of institutional life. Institutions, it was suggested, stifled the ability for persons with intellectual disabilities to lead fulfilling lives, and the only way to overcome this was to move them into the community.

Furthermore, “quality of life” within this context involved people being able to make choices. These choices included things such as what time to go to bed, what time to get up, whether to have a shave or not, what to eat, and when, and so on. However, there are some choices that intellectually disabled persons, by virtue of their level of functionality, are unable to make. Also, this may impede their ability to move around within the community and to access “community resources”, such as parks, sporting facilities, public transport, recreational facilities, and other such resources, and thus hamper their quality of life.

This raises a fundamental question in relation to the effectiveness of deinstitutionalisation in realising some of the key goals set out by the policy makers. Whilst there is no denying that through deinstitutionalisation persons with intellectual disabilities are “in the community”, could it be argued that they are “of the community”? In other words, how much agency are the intellectually disabled living in the community afforded when it comes to decisions that affect them, and following on from this, has their quality of life been improved in the ways in which the policy makers suggested that it would?

This leads us to consider a variable within the deinstitutionalisation conundrum that seems to have been largely overlooked. For deinstitutionalisation to work as it would seem the policy makers intend it, then it would require some degree of understanding and acceptance on the part of wider society toward persons with intellectual disabilities. In other words, the degree to which persons with intellectual disabilities are allowed to
integrate into the wider community is, to a large extent dependent on the attitudes and actions of wider society. Healthlink South (1994) only go as far as saying that deinstitutionalisation itself reflects a change in community attitudes towards people with intellectual disabilities. However, it is difficult to claim that the implementation of a government policy such as this reflects widely held public opinion. Changes in public attitudes and opinions take time to develop, consequently more time and research is needed to be able to make any definitive claims in this regard.

As mentioned in section 3.6 of chapter three, deinstitutionalisation and care in the community represents a process that involves a diverse range of groups. This is true to some extent, when looking at the residential and day programme service providers. Broadly speaking the groups involved in this area consist of community groups, charitable trusts, and commercial businesses. Accordingly, there exists in the provision of these services differing philosophies of care, levels of facilities, and the kind of staff employed (in terms of qualifications and experience). These are important variables when considering the different experiences that ex Templeton Centre residents have encountered in relation to community care.

What this ultimately brings us back to is a consideration of how the quality of life for the former residents of the Templeton Centre has been affected by deinstitutionalisation. The following is a discussion based on the mothers’ assessment of the quality of life of their children, subsequent to the closure of the Templeton Centre, together with literature from New Zealand and overseas. The objective is to illustrate that people with intellectual disabilities are a heterogeneous group, and thus have a variety of needs, wants and desires. Accordingly, their experiences of life in the community are in many ways unique to the individual.

6.3 Physical and Material Well-being

As with the previous chapter, Hughes and Hwang’s (1996) dimensions for measuring quality of life, together with Terrill’s (1996) quality of life indicators form the basis for
the analytic framework. Physical and material well being constitutes an important consideration for all the mothers.

At the forefront of concerns in relation to physical well-being was the safety and security of former the Templeton Centre residents now living in the community. Safety and security constitutes a primary theme to emerge from this research. The main concern in this regard was that those moved into a community setting were being placed in a physical environment that was very different from that of the Templeton Centre. The move from the relative safety and security of the Templeton Centre, into the community presented the potential for issues to arise in relation to the safety and security of residents.

As discussed in chapter five, mothers were satisfied that the geography of the Templeton Centre provided the means whereby their children’s physical safety and security was ensured. However, the move into the community represented, amongst other things, a complete contrast in relation to the physical locality of residents. This meant that new potential dangers had to be considered and accounted for. As discussed in the previous chapter there were some former Templeton Centre residents whose quality of life was enhanced by the physical size of the Templeton Centre which allowed them to wander in relative safety.

As far as most mothers were concerned road safety in the community was a pressing issue. The main concern was that residents might wander from their house onto the road. This was of particular concern for Andrea in relation to her son David;

“He had no comprehension of the dangers that a car could pose, for example. He had to be contained within a safe environment. He needed to be in a complete lock up unit. He could not have any railings, he could climb a six foot fence in two minutes. He loved to climb up things.”

As a result of these concerns Andrea and husband “Graham” were very particular in relation to the set up of the community house that David would move into. They wanted to be certain that David’s physical safety would be preserved. According to Andrea they
are, to a large extent, satisfied that David’s physical safety and security is being adequately met in the community placement where he currently resides. However, there were a number of alterations that had to be made in order for Andrea and “Graham” to feel that safety and security issues were being met. In terms of road safety issues the alterations that needed to be made included putting the latch on the gate higher, together with taking off the railings on the fence.

Another area relating to issues of safety and security was that of internal alterations. In some cases there were a number of such alterations that were required to ensure that safety levels within the confines of the house were maintained. In the case of David’s community placement;

“They put a gate across the kitchen to prevent entry at certain times. In the living room there was a fireplace which had a substantial guard put up. Also they had installed safety glass in all the windows.”

Given David’s somewhat inquisitive nature and his tendency to climb it is easy to understand that these alterations would be integral to ensuring that the necessary safety standards were maintained. Furthermore, the residents in the community placement where David is living are all of a similar level of functionality.

The levels of functionality play an important part in regard to the type of alterations and additions that are required to achieve the necessary standards of safety and security. This point is illustrated when David’s situation is contrasted with that of Christine and Heather, both of whom are residing in a community placement where the residents are of a higher level of functionality. Whilst there were some alterations made these were not as comprehensive as those in David’s community placement.

In relation to food, clothing, and shelter it would seem that these necessities of life were being met to a satisfactory level, according to those mothers interviewed. This is particularly true in regards to clothing and shelter. That is to say that residents in the various community placements, and the Brackenridge Estate were provided with adequate shelter and clothing. However, when it came to food there was one notable exception.
Eve speaks of the problems Hugh faced in the first six months of life in his community placement;

“The first six months were quite hairy. My Hugh had lost a lot of weight. He (the Life Links facilitator) had not read his notes properly. The first few weeks that he was there he was given meat sandwiches. They had not got into their heads that this child cannot chew. He had lost weight”.

Whilst this was obviously a food issue, it also represented a staff issue. Moreover, it draws attention to the fact that there appeared to be a lack of communication between two important groups involved in the administration of community care. As a consequence of this Hugh’s needs were not met as they should have been, with quite disastrous results.

As far as physical well being is concerned issues of safety and security were at the forefront of the mothers concerns. This was the case for the majority of mothers. By and large this was due to the fact that in the Templeton centre some residents relied on having a physical environment that lent itself to allowing for people to wander relatively freely. For example David, Mark and “James” were all prone to wandering off whilst living in the Templeton Centre, for one reason or other. Also, Christine with her tendency for temper tantrums needed to have the ability to go for a wander and “cool off”. Therefore, the physical size and location of the Templeton Centre ensured that, in some circumstances, quality of life was maintained in terms of providing the means whereby residents could wander around in relative safety.

The concerns that mothers had regarding safety issues, particularly in the early stages of the move into the community, were reflected in Mirfin-Veitch et al’s (1998) study of former Templeton Centre residents living in the community. Family members in this study had concerns in two main areas. First and foremost, a significant number expressed concern that their relative did not have the necessary skills to ensure their own safety in the community (Mirfin-Veitch et al 1998). The other main issue of concern related to the harm that some parents felt their child may cause to others (Mirfin-Veitch et al 1998).
However, these concerns do not appear to be paramount for some parents whose children have been relocated from an institution into the community in New Zealand. For example, O’Brien and Thesing (1999) in their study of intellectually disabled former residents of the Kingseat psychiatric hospital reported that less than one quarter of families interviewed felt that by having their child relocated into the community they experienced a loss of security that they had in an institution. For those that did, a part of this loss of security was seen to arise from the loss of space that occurred as a result of moving into the community (O’Brien and Thesing 1999). This is reflected in a comment from a participant in O’Brien and Thesing’s (1999: 111) study who was a former Kingseat resident;

“I’d ask if I could go for walks, but I’d be scared to do it own my own.”

There were also some former Kingseat residents that took quite the opposite view. For example there was one community resident who valued living in the community because there was more space to move around in (O’Brien and Thesing 1999:118). He enjoyed the luxury of increased personal space in the community where he lived, he said; “I have more environment…yeah more space to move around in” (O’Brien and Thesing 1999:120). It would appear that the participants in this study were at the higher end of the scale in terms of functionality.

To summarise, it would appear that most mothers experienced some degree of trepidation and concern about issues relating to physical and material well-being, particularly in the early stages of the move into the community. At the forefront of these concerns were issues relating to safety and security. This related to the fact that ex-Templeton Centre residents were now living in quite a different physical environment. Also, some mothers had concerns about the safety within the community residence itself, and in most circumstances alterations had to be made in and around the house to ensure safety issues
were addressed. Despite the mothers’ feelings of concern there were no reports of residents in the community coming to any harm.

6.4 Staff

This leads us to consider issues relating to staff in the various community placements. There is no doubt that issues relating to staff in a community setting are paramount where quality of life is concerned for people with intellectual disabilities. Accordingly, this constitutes another primary theme for a number of reasons that will be discussed in this section. Community care facilities in many circumstances represent a relatively unknown environment with, in some cases, inexperienced staff working for relatively newly formed private organisations. In other words, there are a number of potential problem areas within this new environment, none more so than the level of care which residents receive. Quality care in any residential setting rests largely on the relationship between the staff and resident, together with the competency of staff (Hill and Bruininks 1984, Firth and Short 1987).

As a means of facilitating quality care caregivers must be able to work in a stable environment with a known group of residents (Curtis 1986: 44). This will enable a caregiver to develop some knowledge of those in their care, and may encourage some degree of personal attachment (Curtis 1986:44). However, rapid turnover of staff, poor management, and escalating costs are in no way conducive to achieving this ideal. Further compounding this issue is the fact that many problems in a community care situation are largely hidden from view. It would appear that under most circumstances the state is unable to penetrate private agencies to observe the day to day quality of life the residents are experiencing (Curtis 1986:45). (See section 6.5 later in this chapter for further discussion).

As with life in the Templeton Centre all the mothers felt that the staff in the community placements were a pivotal factor in relation to their children’s quality of life. It would
appear that despite the mothers being generally happy with the quality of care there was some degree of variation in relation to the staff in various community placements. The most complimentary reports came from the mothers of Heather and Christine, both of whom are resident in a community placement administered by a community group that has a Christian foundation. There is a possibility that the Christian influence has had an effect on the philosophy of care. There is a strong emphasis on maintaining a loving and caring atmosphere, the aim being to replicate as much as possible a family home like atmosphere. Moreover, it would appear that many of the staff employed within this organisation hold similar “Christian” type values, such as those that related to caring for others, particularly those who are seen as being less fortunate. Edna has been pleased with the quality of the care that Heather has received at community placement “A”. This has come as quite a relief as she was happy with the quality of care at the Templeton Centre.

Frances makes this comment in regards to the care Christine receives at community placement “A”;

“The care that Christine is receiving at community placement “A” is wonderful. The staff have a genuine sense of caring for the residents. If Christine got a tummy upset, the girls would run a bath so she could lie in a warm bath. At community placement “A”, whatever they want to do you know is okay. There is a high degree of flexibility. It is a home”.

Another important aspect of the staff at community placement “A” is the contribution made by volunteer workers. It would appear that their efforts have contributed in a most positive way to the quality of life of the residents. The volunteers have included not only local people but also volunteers from overseas. Their efforts have been extraordinary, and have incorporated a multitude of different tasks. As well as the day to day activities volunteers have been involved in such things as a lengthy fund raising process that eventually saw residents travelling to Disneyland in America. Furthermore, they were instrumental in establishing the activities centre where such things as arts and crafts and
life skills are taught. The activities centre will be looked at in more depth in section 6.7 of this chapter dealing with leisure and recreation facilities.

In the case of Christine she had spent time in another community placement before moving to community placement “A”, and this according to Frances was not a particularly positive experience. This was due to a large extent to the staff employed at community placement “B”, and the person who ran the place. Frances was not happy with the attitudes in this place;

“Everything had to be polished. And everybody had to be sitting up straight. She (the woman who ran the place) always had complaints. One day I went around and she said Christine is letting people in the house. I didn’t believe that for one moment because people could ring and ring the door bell and she would sit. Even if people called out she wouldn’t get up. I didn’t believe that for one moment.”

On other occasions the woman who ran community placement “B” tried to make Christine sit and not say a word for so long. It would seem that there was a high degree of discipline at first community placement “B”. According to Frances the staff were not ex Templeton Centre, and did not seem to have any formal training in the care of people with intellectual disabilities.

Another negative aspect of community placement “B” was that it was made very clear that Christine would not be able to have a radio. This came as a big shock to Frances. Christine loves music and this was a real blow.

Also, at this community placement there was much less room than there was in the Templeton Centre. This meant that it was difficult for Christine to go for walks because all they had was a small piece of lawn and the house was on a very busy road. According to Frances it did not seem that the staff were particularly interested in taking residents for walks.

Frances went on to say that in community placement “B” there was a higher level of discipline than there was in the Templeton Centre, and this was a bit of a shock for Christine. There were more expectations placed on the residents than there were in the
Templeton Centre. The residents had to meet certain standards. For example, they were made to sit in the living room. There were no books that Christine could colour in or draw.

Zita recalls similar experiences in relation to her assessment of the staff at the two community placements in which Sam has lived. Firstly, Zita felt that the staff at community placement “C” were not as caring as the staff in the Templeton Centre, in fact she thought they were “militaristic” in their treatment of residents. For example;

“Sam was not allowed to have his TV on at night in case he woke anyone else up. They could all watch TV in the lounge or in their rooms and then they would all go to the kitchen and have a cup of tea and something to eat with the staff and then they would all go to bed.”

Furthermore, Zita felt that Sam was not being fed properly at community placement “C”

“I rang him one weekend to see how he was and all the girls were away for the weekend.” She found that “he was on his own with one staff. I asked what he had for lunch?” He answered, “spaghetti. What did you have for tea? Baked beans.”

Zita felt the staff member who was duty on was too lazy to make him a proper meal.

However, the staff at the community placement in which Sam currently resides are of a more caring nature, and more in tune with Sam’s needs. According to Zita the staff at community placement “D” have gone out of their way to create a ‘homely’ atmosphere. Furthermore, Zita is pleased with the manager there because, amongst other things, there is a major effort made to keep in touch with families.

As far as the staff in the Brackenridge Estate facility (see chapter three for a discussion of Brackenridge) are concerned it would appear that there are a number of ex-Templeton Centre staff working here. However, according to Anna it was not automatic that if you worked at the Templeton Centre you would get a job at the Brackenridge Estate. As far as she knew the process for staff selection involved the input of a consultant, and
required potential staff to go through a rigorous two day appraisal. Anna went on to say this about the staff at the Brackenridge Estate;

"I have seen care under psychoeducic training, and I have seen care under people who have good hearts, who want to do the best thing for the residents, but they are not trained in handling the diverse behaviours of the people they're caring for. I will tell you who I would choose and that is the trained staff, I am sorry but I would choose the trained staff. And I believe that the psychoeducic training, the three year course was very useful because within it, it had a component of how to manage challenging behaviour people."

Despite the fact that there are a "few" psychoeducic nurses at Brackenridge, according to Anna there are not enough. This she believes is due to insufficient funding on the part of the government, and the fact that they did not take into account the number of people with challenging behavior that would end up in the Brackenridge Estate facility. Anna goes on to talk about the value of the ex Templeton Centre psychoeducic nurses, as opposed to those care givers in the Brackenridge Estate facility without this specialist training;

"They (the psychoeducic nurses) know the value of a structured life that will give the intellectually disabled person probably the optimum quality of life they are able to have. Whereas people who don't know that framework and out of the kindness of their heart or whatever their motivation want to look after these people, give them three meals a day and just look after them and take them out and all will be well. I think they are finding out that this is not necessarily so, and this goes for Mark and I think the others as well, he needs a structured life"

The positive aspects of having ex Templeton trained staff working in a community placement is also backed up by Andrea. She believes that the care David is receiving is more than meeting his needs. Furthermore, this is a pivotal factor, she believes, in promoting David's quality of life;

"The employees are mostly ex Templeton trained, most of them had worked with David over the years, so they were familiar with his needs. There is one member of staff that stays over night, and during the day there are between two and three. The staff at community placement "E" have certainly created a family type atmosphere. All the staff there absolutely love him. There has been some improvements in his
behaviour. His temperament has altered to the point whereby he is much less likely to break things, which he tended to do in the Templeton Centre."

According to Andrea the improvements in David's behaviour is in some ways attributable to the efforts of the staff, and being ex Templeton Centre trained (that is to say psychopaedic trained) would seem to be a major contributory factor. Overall she feels that David is well looked after in community placement “E”;

"The level of personal care in the residence is great. They wash, shave and dress him every morning. We have never gone in and seen him dirty, or not properly groomed. If he is thirsty they get him a drink. His needs are definitely met."

Another important issue in relation to the staff in some community placements is that of staff turnover. Eve did not feel happy with the skill level or the high turnover of staff at community placement “F” where her son Hugh resides. Moreover, she felt this was having a negative impact on his quality of life;

"At one stage every time you went over, there was a new face because the different providers pay different rates and of course the different homes have different levels of funding."

Eve felt that Hugh needs continuity of care. She also felt that he needs the best care possible, but the carers that he has got are not as skilled as Eve thinks they should be.

Eve has also found that some caregivers had good ideas but for various reasons did not follow through with them;

Hugh was supposed to have a "special carer" but he moved to Britain "so it all fell down." They had this fine plan... A personal enrichment programme. The programme looked promising, and it was divided into categories – support needs and action and long-term goals and action. Other support needs included community participation, safety management, social skills, physical, medication, communication and others for example road safety."
Eve was concerned that there would be no follow through with the plan put in place to develop Hugh's skills.”

A positive aspect that some mothers talked about in relation to staff in community placements was that visiting was made easier due to the more informal nature of community houses. This was certainly the case for Frances and her daughter Christine and Edna and her daughter Heather at community placement “A”. Anna reported that visiting her son Mark was made easier by virtue of the fact that there was more flexibility in the daily routine of community placement “B”. Furthermore, some mothers commented that staff in community placements were welcoming and friendly when they visited. For example Andrea had this to say;

“Sometimes when I visit David I will sit and have a coffee with the staff and they will tell me what he has been up to.”

Levien (1996) found that almost every family in her thesis research commented that there was a more open approach to visiting a community based residence. Furthermore, the staff tended to be welcoming and accommodating (Levein 1996:343). Also, the atmosphere was more conducive to visiting for longer periods, particularly because there were no routines to impede visiting (Levein 1996:343).

Research in the area of quality of life for persons with intellectual disabilities widely recognises that there is a strong co-relation between the competence of staff, and quality of life. This is particularly the case in regard to life in the community for persons with intellectual disabilities. In a recent report compiled by the Donald Beasley Institute, looking at the experiences of ex-Templeton Centre residents, almost all the families taking part in the study were of the belief that the success of the new model of service delivery to their relatives would be determined by the quality of the staff working in the community based houses (Mirfin-Veitch et al 2000:12). However, there were differences of opinion in relation to what constituted “quality” staff. Some families believed that
their relatives needs would be best met by registered nursing staff (Mirfin-Veitch et al 2000:12). Accordingly, these families hoped that as many former Templeton Centre staff as possible would work in the new community homes, as they saw them as experienced and suitably trained (Mirfin-Veitch et al 2000:12). For others it was the values and attitudes of staff over nursing qualifications that were seen as the most important factor (Mirfin-Veitch et al 2000:12).

Horner, (1994) in one of the first New Zealand studies of persons with intellectual disabilities living in the community also, recognised the pivotal role that staff in community placements play in relation to quality of life. Furthermore, she suggested that in some cases the way in which a community house was run did not at times resemble a home-like setting. For example, one of the mothers taking part in the study reported that the staff at her daughter’s house were demanding, and their manner was not conducive to creating a family atmosphere. This was reaffirmed when Horner herself visited the community house. She noted that; “Staff often appeared to be involved in carrying out their organisational and other duties. There seemed to be little time available for talking with residents.” For example, residents wanting to talk to staff when they arrived home often got the response ‘Go and put your bag in your room’, or ‘Get in the shower now’ (Horner 1994:168).

The issue of staff turnover is one that also receives attention in research in the area of community based services for the intellectually disabled. Nearly a quarter of families in O’Brien and Thesing’s (1999) study expressed concern in relation to staff turnover. One of the main problems in this regard is that staff turnover interrupts the continuity of care for residents. This can in some cases prove to be detrimental to the security that many intellectually disabled people obtain from routine, and thus have a negative effect on their quality of life.

Overseas studies have revealed similar concerns in regard to issues pertaining to staff. For example, Haycox (1995) suggests that in some circumstances staff involved in community care are often unable to adequately deal with situations which may arise due to a lack of
the necessary training and guidance. Cambridge et al (1994) suggest that good community care relies heavily on the quality of the staff involved. They go on to say that the abilities of staff can help determine whether people with intellectual disabilities enjoy well integrated and more ordinary lives (Cambridge et al 1994:35). Furthermore, they concluded that in England, in-house, local and national training programmes and courses in community care were not adequate to meet the rapid changes in management and practice demanded by the community care reforms (Cambridge et al 1994:38). Landesman and Butterfield (1987) in an American study suggest that over time “good” community placements can become “bad”, perhaps because of changes in staff commitment, administrative style or support.

Wing (1989) in her study of former Darent Park Hospital residents in Kent, England canvassed parents for their opinion of staff in community placements. Overall the community units rated higher than the hospital in terms of the quality of care administered. However, the interesting point was that private placements rated the lowest and the NHS (government controlled) and social services hostels rated the highest. This suggests the possibility of a correlation between privately operated service providers, which are run on a profit making basis, and the quality of staff employed. In other words, in an attempt to minimise costs private service providers may pay less in wages and thus attract less qualified and competent staff, which may ultimately impact negatively on the quality of life of residents.

To summarise, there were a number of issues that the mothers felt were important in relation to staff in the community. There was a consensus amongst the mothers that there is a correlation between the quality of staff and quality of life. A pivotal factor in this regard were issues relating to staff training (of lack thereof). Most of the mothers felt that there were advantages to be gained through psychopaedic nursing training. Staff turnover was also an issue for some mothers, they felt that this disrupted the continuity of care. Finally, there were some mothers that noted more flexibility in terms of daily routines which made visiting easier.
6.5 Service Providers- Monitoring and Accountability

A secondary theme to emerge out of issues relating to staff matters was that of service providers and accountability. In a New Zealand report prepared for the Central Regional Health Authority (1993) Bennie suggests that community based service providers should be comprehensively evaluated by groups that are independent of providers and purchasers. However, the apparent lack of accountability of residential and day programme service providers was a concern for some mothers, and they felt that this could affect their children’s quality of life. For example, Eve tells of how staff at community placement “F” where Hugh resides, do not like you to arrive unannounced;

“They window dress all the time... I want to know what goes on every day. I want to know the truth about how Hugh lives. I do not want to be lied to.”

One thing Eve noticed when she did turn up unannounced was Hugh’s lack of cleanliness. Eve complained about Hugh’s attire, especially after meals, because they let him move around with food stained clothing. She comments;

“I must say that ever since I have created a stink there have been no problems and Hugh is much cleaner.”

There was a feeling amongst some mothers that at the Templeton Centre there was more in the way of accountability. Nancy comments;

“At Templeton because it was big, because it was state run, because there were lots of parents to keep an eye on things, there was accountability.”

The privatisation of community providers is a concern for Nancy. She recalls a situation she heard of in America;

“I think of the case in the U.S., that began the deinstitutionalisation fashion. If one provider was doing it cheaper was that going to exert pressure on others to lower their standards.”
In New Zealand there is a monitoring organisation, the Standards and Monitoring Service (SAMS). SAMS is an organisation that emerged out of the IHC in 1991, it is an independent Trust that is made up of former IHC staff, and parents (www.sams.org.nz 13/12/01). The primary focus of SAMS is to work in partnership with consumers, families, and various agencies to improve community services for people with a disability (physical and intellectual), and/or mental health issues, with a strong emphasis on ensuring that services keep focused on enhancing quality of life (www.sams.org.nz 13/12/01).

Therefore, part of the function of SAMS consists of visiting community placements to ensure that certain standards are adhered to. These standards relate in the most part, to the living conditions in the various community placements. This includes making sure that residents are well cared for, that they live in a safe, clean, and happy environment. However, when a visit is to take place the community placement concerned receives prior warning, thus allowing for the potential for “window dressing” as suggested by Eve.

Despite this however, it would appear that SAMS do act where conditions are particularly bad. For example Zita talks of a situation she heard of where a house containing intellectually disabled people was shut down by SAMS because the residents were kept inside most of the time.

Most of the families taking part in the “Templeton Resettlement Family Experiences Project” expressed some concern regarding service providers in the community (Mirfin-Vietch et al 2000:13). The main issue centered around the “track record” of service providers. Often families were inclined toward a service provider that they had prior knowledge or experience of (Mirfin-Vietch et al 2000:13). Many of the families had concerns regarding the stability and long term financial security of services. Where a service provider had been operating in the community for some time this was seen as a positive (Mirfin-Vietch et al 2000:13).

Also, it would appear that there is an absence of on-going, in-depth research on the part of the government in relation to how the deinstitutionalisation process has, and continues
to folding. Apart from very brief statements in annual reports, which are almost exclusively financially focused, there seems to be little else. This is the case for both The Ministry of Health and Healthlink South.

6.6 Social Relationships and Interaction

As far as social relationships and social interaction in a community setting are concerned, this represents a significant component within deinstitutionalisation policy discourse. Meaningful social relationships and social interaction are seen as contributing significantly to the quality of life for persons with intellectual disabilities living in the community (Cambridge et al 1994:61). Once again this area represents a primary theme to emerge from this research. Therefore, it is of some interest to examine the nature of these relationships since deinstitutionalisation. Of particular interest in this regard is how much social interaction there is between persons with intellectual disabilities living in the community, and the wider community. Once again the level of functionality is an important variable in relation to the nature of the social relationships and social interaction a person with an intellectual disability is capable of.

In the case of David, for example, it would appear that his social relationships are of a similar nature to those which existed in the Templeton Centre, with one or two exceptions. For example, when his parents visit there would seem to be a more relaxed atmosphere than in the Templeton Centre, Andrea commented that she sometimes sits and has a coffee with the staff on duty at that time. Furthermore, due to the fact that the living space in a community residence is far more compact than in an institutional setting, Andrea is able to see more clearly how David interacts with staff and other residents. However, in regard to any sort of social interaction with members of the wider community, it would appear that this is negligible. As far as immediate neighbours are concerned according to Andrea there were one or two people that were unsure about having a residence containing intellectually disabled people, to begin with, but seemingly there is not a problem now. Despite this however, there does not seem to be any contact
with the neighbours. An important variable to consider is David’s level of functionality. David was assessed as category “C”, and has quite a low level of functionality. Moreover, he is unable to communicate verbally, so this obviously places severe limits on his potential for social interaction, and thus restricts the nature of his social relationships. For Christine and Heather who are residents of community placement “A”, the pattern of social interaction, and social relationships was a little different from the experiences of David. This is due to a number of factors. First and foremost community placement “A” contains 19 residents, and consists of four different houses. According to Edna, Heather’s mother, there is a high degree of interaction between residents. It would appear that this occurs on a number of levels.

Firstly, there is the day to day interaction between residents within their ‘home’ environment. This is largely based on certain domestic chores that residents are actively involved in. The degree of involvement is determined by the task in question. Activities such as tidying rooms (involving dusting and vacuuming) and doing the dishes involve little in the way of risk, therefore these tasks lend themselves to full participation on the part of the residents. However, tasks such as cooking and ironing require supervision for obvious safety reasons. Another aspect of the day to day routine for some residents is going to work. This involves going to a ‘sheltered workshop’ where they are involved in a range of repetitive activities such as sticking labels on boxes, for which they receive payment.

As far as the residents interacting with members of the community at large is concerned it would appear that this is minimal. According to Edna the only time that this would occur is on things such as shopping trips and organised activities outside community placement “A”. However, it would appear that there is a general acceptance by residents within a close proximity of community placement “A”, given that there have been no objections or complaints about its existence. According to Edna this is not the case at some other residences. At another place Edna looked at for Heather the neighbours wanted a six foot
high fence build because this person “did not want her grandchildren looking at people like that”.

The issue of neighbour contact is a rather interesting one, and is of some importance when looking at social interaction with members of the wider community. It would appear that whilst many neighbours seem to be accepting of having a house containing people with intellectual disabilities, the situation does not seem to extend much beyond this. In other words, there is little or no evidence that supports any meaningful social interaction between neighbours and residents. This situation is supported to some extent by O’Brien and Thesing (1999), in their study of former residents of Kingseat Hospital who are now living in the community. Their research suggested that over forty percent of residents had no contact with neighbours, according to staff that were interviewed (O’Brien and Thesing 1999:53). However, it would appear that some degree of social interaction did exist between neighbours and residents, culminating in just over twenty percent of staff reporting reciprocal visits of some sort or other (O’Brien and Thesing 1999:53). Horner (1994) also found that contact between residents and the wider community was minimal. Furthermore, she goes on to suggest that many people with intellectual disabilities living in the community are lonely, and have fragile or non-existent support networks (Horner 1994:171).

Some studies have revealed that there is a stark difference between community attitudes in principle and in practice (Bennie 1993). That is to say that in principle attitudes are generally accepting and in reality they are generally rejecting, and thus not conducive to intellectually disabled people integrating into the community (Bennie 1993). This is a crucial factor to be considered when assessing the effectiveness of deinstitutionalisation.

In regard to social relationships and interaction in the Brackenridge Estate it would appear that circumstances are similar to those which existed in the Templeton Centre. The potential for social interaction and establishing social relationships is reduced by virtue of the fact that residents are all category “C”, and thus have lower levels of functionality.
Furthermore, there are many who have multiple disabilities, including those with quite severe physical disabilities and those unable to communicate verbally.

Another important factor that contributes to reducing social interaction, particularly with members of wider society, is the location of the Brackenridge Estate. As discussed in chapter three the Brackenridge Estate is located on the site of the former Templeton Centre. One reason for its location on this site, according to Anna was the fact that there are a number of residents who fall into the category of “challenging behaviour”. A person in this category tends to have a history of violent and aggressive behaviour. Anna suggests that many of these people were not put into the community due to the fact that their behaviour could potentially place them before the courts, and possibly in jail.

Anna believes that the Brackenridge Estate is the best place for Mark, because amongst other things it provides him with a safe and structured environment;

“Mark has stayed at the sink and made pots of tea or coffee until it is just running down his legs, or vomiting all over the place. So he has to be in a structured environment, and he has to have guidance, which he doesn’t readily accept.”

Anna goes on to talk about what she believes were some of the ideological foundations that contributed to the development and implementation of deinstitutionalisation as a social policy;

“You have intellectually disabled people who are pretty powerless. One of the ideas of deinstitutionalisation was to return the power to the person. For them to make their own decisions, or more realistically help them make their own decisions. That was a good idea, but you can take that too far, because with making decisions comes responsibility. And do they have the mental capacity to be able to be accountable for the decisions they make? And no they are not. Well he is not in the frame of mind to accept it.”

The issue of having the ability (or lack of) to take responsibility for one’s decision making was one factor that Anna believed necessitated the existence of a facility such as the Brackenridge Estate.
According to Nancy a negative aspect of care in the community is the inability for Kirk to visit other resident’s houses. She comments;

“Out at Templeton if someone in this villa wanted to go and visit someone in that villa, well they could walk. Now if someone in one house wants to visit someone in another house they can’t, they can’t walk, they need transport because they are not in walking distance. Okay this would have little institutions all over the place but I don’t see anything wrong with that, if it gains them the independence of walking from one place to the other. But the houses all being scattered like that means you can’t walk to visit your friends.”

The reduction in social interaction between ex Templeton Centre residents was also an issue of concern for Carol;

“Health Link South who managed Templeton ran a few social activities, which were really good because they were able to come back, meet up with old friends that had gone in different areas, and I thought this was quite healthy. Some providers said no they have got to put this behind them, the institution was all bad, and they cut off contact. Unless they saw ex villa residents in day programmes, there would be no contact.”

Nancy’s point illustrates a paradox that exists in relation to aspects of social interaction in the community for persons with intellectual disabilities. In terms of social interaction with other residents this has in many cases declined in comparison to the Templeton Centre. The dynamics have altered in terms of the number of residents living within close proximity of one another, and thus the potential for social interaction with other residents has greatly diminished. It could be argued therefore, that this reduces the quality of life for some people with intellectual disabilities living in the community, as there is a restriction on the number of residents that an individual can interact with.

The experiences of the mothers reflect similar findings from studies undertaken in America and Great Britain, where deinstitutionalisation operated for some time before it was implemented in New Zealand. For example, Emerson (1985) suggests that research findings in relation to the ability of deinstitutionalisation to achieve some of the objects discussed, particularly in relation to social interaction and social relationships, indicates
that there has been limited success. According to Emerson (1985) the evidence suggests that intellectually disabled people “living in the community” interact mainly with other handicapped persons or paid staff. Furthermore, they experience loneliness as a considerable problem and continue to be excluded from the labour force. Therefore, deinstitutionalised persons in this context experience very little autonomy, and thus their experience of the everyday aspects of “living in the community” are extremely limited. Moreover, intellectually disabled persons who have been deinstitutionalised are not, and do not perceive themselves to be living in the normal community (Emerson 1985). Instead, they may be seen as inhabitants of a physically and culturally distinct social system. In other words, community care programmes have themselves ended up being a repackaged form of institutionalisation.

However, Cambridge et al (1994) reported that most of the participants in their study had a number of friends, albeit a relatively low number. Most friends had been met through clubs, day provision and when they moved into their homes in the community, or they were long-standing friends from hospital (Cambridge et al 1994). Satisfaction with social contacts varied. In terms of contact with friends who were not co-residents (that is friends living elsewhere) only fifty percent of participants were satisfied with the frequency of contact. These sentiments resonate with some of the parents in this thesis, particularly those of Nancy, who felt that living in the community restricted Kirk’s ability to visit residents of other houses.

Haycox (1995) suggests that community opposition can be dichotomised into two general areas of concern. Firstly, concerns are expressed about a range of practical problems that arise from relocation such as the implication for local house prices, and the possibility of additional noise and inconvenience resulting from service vehicles calling at the property (Haycox 1995:108). The second set of concerns relates to fears for the safety of neighbours, especially their children (Haycox 1995:108). Haycox (1995) rightly points out that overcoming community prejudice is fraught with difficulty. There is evidence from some parents interviewed that they have experienced such community opposition,
particularly in relation to the safety of neighbours and their children. For example, Edna encountered some problems in this regard when looking for an appropriate community placement for Heather.

In some circumstances community opposition can manifest itself in a more malicious way. For example, Booth et al (1989) reported that some residents in community placements in the UK had been subjected to unwelcome attention and even harassment. One house had been the unwelcome focus for local children and this had caused problems for residents as the children had been ringing doorbells and banging on windows (Booth et al 1989:381). There was also a case where a man with a pronounced hump on his back was subjected to frequent abuse by children and adults (Booth et al 1989:381). However, the mothers taking part in this thesis research did not report any such incidents.

To summarise, there were a number of issues to emerge in relation to social relationships and social interaction. Some mothers felt that social interaction between residents had been reduced by the virtue of the fact that they were dispersed throughout the community. It would appear that almost all social interaction took place between staff, other residents (both at the community residence and day care facilities) and family members. Social interaction with the wider community appeared to be minimal, to the point of being insignificant. This is particularly true of contact with neighbours. However, there were no reports of harassment.

6.7 Leisure and Recreation Facilities

Issues relating to leisure and recreation facilities are to a large extent secondary issues that relate to social interaction and social relationships. This is because of the fact that leisure and recreation activities can provide the basis for social interaction between residents, staff, families, and possibly the wider community.

However, there is no doubting that leisure activities are part of a ‘normal’ and valued lifestyle (Cambridge et al 1994). As discussed in chapter five there was a consensus amongst parents that leisure and recreation activities contributed immensely to the quality
of life of their children. Broadly speaking, leisure and recreation activities are significant on two levels. Firstly, there is the personal enjoyment gained from engaging in such activities, which undoubtedly contributes to an individual’s quality of life. Secondly, such activities can provide a platform that facilitates social interaction, and establishes and maintains social relationships. The following section will examine the significance of leisure and recreation facilities, together with looking at issues relating to the way in which leisure and recreation facilities and activities are organised and accessed.

There were some parents who initially felt the move into the community would reduce the ability for residents to be involved in leisure and recreation activities. The fact that there was a significant presence of leisure and recreation facilities on site at the Templeton Centre was seen by many as an integral factor in the variety and frequency of activities at the Templeton Centre. Furthermore, some parents felt angered by the fact that these facilities would be abandoned. This is captured in “Judy’s” comment on the subject;

“Another thing that really annoys me is that the community Lions etc raised money to build facilities, swimming pool, hall, chapel and so on, they will bulldoze them. They don’t want to maintain them.”

However, it would appear that these initial fears were in some circumstances unfounded. For example, according to Edna and Frances there is a raft of activities provided at community placement “A”, both on site and off site. Frances makes the following comment regarding the leisure and recreation activities;

“In community placement “A” there is something always going on. She is taken on regular walks. Also, there are regular sing-a-longs and concerts. Other activities include going swimming and ten pin bowling. They also go on organised trips to places such as Living Springs and Hanmer”.

Frances tends to be included more in Christine life at community placement “A” due in some part to the activities that are organised there.

An important feature of the leisure and recreation activities at community placement “A” is the on site activities centre. The activities centre provides the basis for everyone in the
community to come together. Moreover, it provides the focal point within the community. The residents are taught such things as arts and crafts and life skills. A less frequent form of interaction involves a monthly social gathering where special occasions such as birthdays are celebrated. The volunteers at community placement “A” were instrumental in setting up the activities centre.

In the case of David it would appear that the move into the community has in no way impacted in a negative way on the extent to which he is involved in leisure and recreation activities, in fact quite the opposite. According to Andrea;

“It would seem that David is actually busier now than when he was at Templeton, there is not a day when he is home all day. They are involved in a variety of activities. For example they visit an activities centre (day programme) on a regular basis, where they can swim or have a spa. On other days they might go and have a picnic down by the beach in Summer. They have their own van so getting around is relatively easy. Even though life has become busier they seem to know their routine.”

However, there were some mothers who felt that the leisure and recreation activities available in the community were not at the same level as those at the Templeton Centre. According to Eve her son Hugh’s activities are more limited than they were in the Templeton Centre;

“He wants to go horse riding. He used to do it at Templeton. When he was at Templeton he used to do far more activities than he does now.”

Eve is of the opinion that Hugh’s quality of life has suffered as a result of deinstitutionalisation.

It would appear that the level and quality of leisure and recreation activities differs from one community placement to another. For example, according to Zita community placement “C” where her son Sam was placed after moving out of the Templeton Centre did not provide enough in the way of leisure and recreation activities.

Zita became concerned at the lack of activities that were provided for Sam;
“He was not going to mass, which had done regularly at Templeton Centre. He was not doing other activities that he used to do either. As a result of this lack of activity and the treatment of the staff, Zita found that Sam had become withdrawn at community placement “C”.”

Zita did not think there were adequate resources at community placement “C”; “Video machines were shared between all the homes so they had to book three weeks in advance. The minibus was also shared, so they ended up paying for taxis out of their own pocket.”

Because of the lack of resources and the treatment by the staff at community placement “C” Zita believed that Sam’s quality of life was being adversely affected. As a result of this Zita had Sam moved to a new community placement. In community placement “D” Sam is involved in more activities;

“At community placement “C” he did not do the activities he does now. He goes out to swimming classes and is in the bowling team. In a smaller group they learn to start to think about others. The home has become a family, sharing activities, and they go on trips. Sam recently traveled to Arthur’s Pass by train. He is also involved in Theatre. He pays for some things out of his own pocket.”

In the case of Carol and her son Ben a major issue for concern in relation to the provision of some day programmes was that challenging behaviour and medically fragile people were mixed. Carol makes the following comment;

“At some day programmes they were going to mix challenging behaviour and medically fragile. “Bens” at too much of a risk. Parents were told that at the community day centre “1” that they would have challenging behaviour one day and medically fragile the next, but when we were about to sign up we were told they couldn’t afford to do that, because of this we felt that Ben was at too much risk. I have seen challenging behaviour people break safety glass, it would only take a big challenging behaviour person to grab his arm in the corridor and he would probably break it. Ben has to be in a safe environment”.
Carol goes on to say that;

“At some day care programmes all they do is sit around and watch TV. A lot of day care providers have set up in old factories in Sydenham, to me that is not as good as being out in the fresh air in Templeton. At the community day centre “1” it is not a very nice environment as there are no windows to look out of as it is an old warehouse.”

In her thesis looking at the experiences of former Mangere Hospital residents living in the community Levien (1996) discovered that many residents were able to take advantage of a variety of community based services and organisations. These incorporated a wide variety of facilities including the library, video library, recreation and community centre, and Disability Resource Centre. According to Levien (1996:349) there is one particular house where on any given week’s recreational activities, three and a half days are spent mainly as a group attending various community activities or going out for lunch together. Furthermore, residents are also able to access other “community resources”. For example, there are two large parks nearby, as well as a beach down the road where residents can enjoy long walks (Levien 1996:349). Another house reported a similar set of circumstances, and reinforced the idea that residents’ lifestyles were varied between individual and group activities, some with fellow residents and some with others (Levien 1996:349).

Levien’s (1996) thesis indicated that former Mangere residents living in the community experienced an increasingly varied daily routine in comparison to the “regimented” lifestyle that they experienced in an institution. Levien (1996) suggests that opportunities in an institutional environment such as Mangere Hospital were restricted by the nature of a large organisation in which demarcation between groups had developed. According to Levien (1996:350) such demarcation meant that residents were often not able to attempt basic tasks and caregivers could not always provide the variety of experience that they would have preferred.
O’Brien and Thesing (1999) found that most of the residents in their study were able to access and participate a wide variety of recreation and leisure activities. The participants in this study are high functioning. The activities operated on three levels. Firstly, residents participated in a number of different leisure activities within their residential placement, these included listening to music, watching television, baking and gardening. Next there were the activities undertaken at day placements. These were centered around socialising, craft, music and reading, amongst other things (O’Brien and Thesing 1999). Lastly, many residents took part in community activities such as shopping, sports, eating out, visiting friends, travel and rides, with the majority of activities experienced being integrated rather than segregated. It would appear that residents gained much enjoyment from these activities.

Overseas studies have found that in some cases persons with intellectual disabilities living in the community have the opportunity to engage in new leisure activities. For example Booth et al (1989) found that a quarter of participants in their study talked about the opportunities for new leisure pursuits including gardening and going hiking. Cambridge et al (1994) found that many residents of community placements simply enjoyed being able to watch television, or listen to the radio in their rooms without restrictions. They also concluded that whilst living in the community provided the opportunity to participate in leisure activities such as going to pubs, cafes and clubs this did not necessarily ensure community participation, integration or access to wider social networks (Cambridge et al 1994:68). In other words, the intellectually disabled living in the community could experience social isolation and segregation.

To summarise, there were mixed feelings amongst the mothers in relation to leisure and recreation facilities. It would appear that in some cases the quality and frequency of these improved and in other cases they declined. A major variable in this regard relates to the resource levels and philosophy of care of service providers.
6.8 Autonomy, Personal Choice, and Independent Living Skills

Autonomy, personal choice, and independent living skills represent a significant component in relation to deinstitutionalisation both as an ideology and as a social policy. Consequently, they constitute a primary theme in this thesis. It was hoped that community based care programmes would enable intellectually disabled people to experience the autonomy and choice that most members of wider society are afforded (Emerson 1985).

Furthermore, it was hoped that living in the community would provide the intellectually disabled the chance to gain acceptance, and lead a more ‘normal’ life. Leading a ‘normal’ life involves things such as shopping and various outings, together with assisting in ones’ personal care, and household tasks such as cooking and cleaning.

The degree to which this can be achieved depends on a number of factors. Firstly, the level of functionality of an individual. This is possibly the most significant factor influencing the degree to which autonomy, personal choice, and independent living skills can be achieved. Another important factor relates to the staff at individual community placements. In order to achieve certain elements relating to autonomy, personal choice, and independent living skills an individual may require help and assistance from the staff at community placements. In other words, it may require additional input and effort on the part of staff that could in some cases be seen as being ‘above and beyond the call of duty’. Another important factor relates to the philosophy of care that is adopted and implemented by individual service providers. This may have quite a strong influence on whether or not areas relating to autonomy, personal choice, and independent living skills receive much attention. The location of the community placement may also have an impact on the scale to which these things can be achieved. For example, the ability to access certain community resources such as parks, and shopping and entertainment facilities will be influenced by the physical location of a community placement and the transport facilities available.
The experiences of residents in this area revealed a variety of levels to which aspects of autonomy, personal choice, and independent living skills were being achieved. The main variables in this regard relate to the level of functionality of the individual concerned, together with the type of care administered by individual service providers and the philosophy of care adopted by the service provider. For example, in regards to Heather and Christine both of whom reside at community placement “A” it would appear that independent living skills are actively encouraged, particularly in relation to domestic skills. Where possible residents are actively involved in domestic chores. The degree of involvement is determined by the task in question. Activities such as tidying rooms (involving dusting and vacuuming) and doing the dishes involves little in the way of risk, therefore these tasks lend themselves to full participation on the part of the residents. However, tasks such as cooking and ironing require supervision for obvious safety reasons.

The staff at community placement “A”, it would seem, are proactive in developing skills that relate to independence and autonomy. Moreover, they appear committed to the well being and welfare of residents. This is reflected in a number of ways in addition to those already discussed. These include the efforts in establishing the activities centre, which has become invaluable to the residents in community placement “A”. Furthermore, the staff (particularly volunteers) were involved in a lengthy fund raising process which eventually saw residents traveling to Disneyland in America. The staff according to both Edna and Frances have worked hard to create and maintain a loving and caring atmosphere that is very much like a family home, and are very flexible when dealing with residents.

There are some whose level of functionality precludes them from participating in a number of areas relating to autonomy, personal choice, and independent living skills. For example, David requires twenty four hour care, as he is partially blind, almost totally deaf, and is unable to communicate verbally. Furthermore, he has to be fed, and his food is all in liquid form.
However, the staff at community placement “E”, where David resides, would appear to exercise some degree of flexibility in the way in which things are run. Andrea comments;

“It would appear that the routine is not as stringent as it was in the Templeton Centre, sometimes David will lie in bed until 10.30am, and they will still make him breakfast. There is definitely more flexibility in the routine.”

Kirk’s situation is similar to that of David. According to Nancy, Kirk has not advanced much past the mental age of about eighteen months, and he is now in his late forties. He is unable to communicate verbally, and he requires twenty four hour care, as everything has to be done for him. Therefore, he is unable to participate in most areas relating to autonomy, personal choice, and independent living skills. For example he must be supervised when on an outing in the community, and the fact that he cannot communicate verbally makes it difficult to exercise personal choice. As far as participating in domestic chores is concerned this is not practical, in fact the kitchen is a ‘no go’ area for Kirk for the sake of his safety;

“They have now barred Kirk from the kitchen and I’m not a bit surprised I think that it was idealistic to expect. I couldn’t cope with him here when I am getting food ready. He’s a big boy, he’s got a long arm. They have discovered that he has got to be barred from the kitchen. I think most of the ones there are barred from the kitchen. I don’t think many of them go in. They have got a sliding door that is three foot high so it goes in under the bench and they can see what happens. It just keeps them out of the way.”

In the case of Peter, there was evidence that residents of community placement “H” where he lives were able to exercise personal choice in certain areas, for example;

“They had a kitchen there and they were involved to some extent in choosing what they had to eat, which was never done at Templeton. He was tending to eat stuff that made him put on weight. So it was the Life Links person who alerted everyone to that. As a result of that they have got a dietician in and talked to them and got them to realise that the food that they were choosing wasn’t always the best for their health.”

Mel goes on to say that living in the community provides Peter with more opportunities;
"The more opportunities there are he can actually do a home type-living. When they were at Templeton the place was big and you can't have people in the kitchen helping to cook. Whereas here they do, and so they are starting to do things so his world is opening up."

As far as the residents of Brackenridge are concerned it would seem that their capacity for exercising autonomy, and personal choice, and developing independent living skills is limited by a number of factors. First and foremost, the residents of the Brackenridge facility are at the lower end of the scale in terms of functionality. Furthermore, some residents have multiple forms of disability which include both intellectual and physical which makes it particularly difficult to develop independent living skills for example. There are also those who are unable to communicate verbally which can make exercising personal choice very difficult. In relation to developing domestic skills, once again the potential is somewhat limited, on account of low levels of functionality. Furthermore, there are issues of safety to be considered. For example, Anna talks of a situation involving Mark;

"Mark has stayed at the sink and made pots of tea and coffee until it is just running down his legs... He has to have guidance which he doesn't readily accept"

Levien (1996) suggests that former Mangere residents living in the community are more able to exercise autonomy and choice. This is due to a number of factors. Firstly, the demarcation between groups that had existed in the institution was eliminated (Levien 1996:350). Moreover, the smaller number of residents per staff (an average of five residents and two staff per house) meant that residents were more able to exercise autonomy and choice (Levien 1996:350). Her research reported increased efforts by residents to be independent often without staff necessarily needing to prompt them (Levien 1996:350). Therefore, residents were able to take greater responsibility for themselves, thus reducing the control and restraint they had experienced in Mangere. This is illustrated in a staff report from one house; "Rick helps to load and unpack the
dishwasher, Colin has decided he should be the one to hang out the washing...Bill rakes the leaves and pine needles, and chats to the neighbours” (Levien 1996:350). Stancliffe and Abery (1997) concluded that persons with intellectual disabilities living in the community had a greater degree of choice in their lives than those living in an institution. However, the degree of choice varied according to the level of functionality, with those who had lower levels of functionality exercising less choice (Stancliffe and Abery 1997). This is particularly the case for those who are non-verbal and have limited skills with which to identify and communicate their preferences (Stancliffe and Abery 1997). Wing (1989) found that another variable in the degree of personal independence that an intellectually disabled person living in the community was able to achieve related to the type of accommodation they were in. They found that those living in private hostels experienced a loss of independence, whereas those who were tenants of small houses experienced an increase in independence (Wing 1989:98).

To summarise, there were mixed reports from the mothers in relation to the degree to which autonomy, personal choice and independent living skills were achieved. The three main variables in this regard were the level of functionality of an individual, the quality of staff, together with the philosophy of care of service providers.

6.9 Behavioural Changes and Quality of Life

Behavioural changes can provide a general indication of an individual’s well being, and hence quality of life. This is particularly useful when looking at persons with intellectual disabilities who have been moved from an institutional setting into a community setting (Hill and Bruniks 1984). Behavioural changes constitute a primary theme in this thesis, particularly in regards to providing an insight into the level of quality of life experienced in the community.

Booth et al (1989) suggest that the relocation of intellectually disabled persons from an institutional environment can result in short-term behavioural deficits. This is referred to as “transition shock”. In essence, transition shock is a stress reaction with symptoms that
include emotional, behavioural, and mental health changes. These stresses include such things as the pressures of adjusting to a new physical and interpersonal environment, confusion and resentment regarding helplessness, and anxiety about the future (Booth et al 1989:216).

Transition shock is a form of overload on an individual's adaptive resources, the severity and duration of this is influenced by an individual's capacity for new learning (Booth et al 1989:217). There are four main factors that influence transition shock as a stress reaction to the relocation of a deinstitutionalised person who is intellectually disabled (Booth et al 1989:218). Firstly, there is the capacity of the individual to cope (or not) with the move. The second factor is their subjective feelings about the move. This is followed by the degree of environmental change, as well as the relative quality of the old and the new settings. For many then, deinstitutionalisation involves the disruption of familiar social relationships, loss of friends and the upheaval in established routines.

It would appear that some of the mothers became aware of certain behavioural changes that coincided with the move out of the Templeton Centre into the community. For example, Frances noticed that Christine behaviour became violent about two months after leaving the Templeton Centre and taking up residence in community placement “B”, the community placement prior to her move to community placement “A”. She recalls that;

"She was hitting out. She was quite aggressive, quite violent, this sort of behaviour hadn’t been present at Templeton."

It could be possible that the way in which community placement “B” was run, that is to say in a seemingly regimented and somewhat inflexible way, provided further impetus to this change in behaviour. According to Frances there was no immediate improvement in this violent behaviour after her move to community placement “A”, although it did gradually begin to settle down.
Zita also noted some changes in Sam’s behaviour soon after his move into the community. However, these changes differed from the violent and aggressive behaviour of Christine discussed above, Zita explains;

“He began to become introverted. He normally gave me a big hug when he met me. He wasn’t giving me any hugs.”

However, Zita believes that to a large extent this behaviour was brought on by Sam’s treatment by a particular member of staff at community placement “C”. Sam’s case manager was brought in and described him as “depressed and withdrawn”. Subsequent to this it was discovered that Sam had bruises, and it was revealed that a particular member of staff had slapped Sam if he was too slow to get his meal, and that also on occasions he had actually missed meals. Following this Zita had Sam relocated to community placement “D” where after a couple of months he settled in to the point where his introverted behaviour had begun to disappear. Furthermore, after having now lived there for over a year he has ‘come out of his shell’ and is not depressed.

There is evidence to suggest that the two main factors which influence transition effects are the circumstances of the move, and the characteristics of the individuals concerned (Booth et al 1989:216). Furthermore, it would appear that in some cases the effects may actually be beneficial rather than traumatic. This is illustrated through Andrea’s recollection of David’s changes in behaviour, which occurred relatively soon after moving out of the Templeton Centre;

“There has been some improvements in his behaviour. His temperament has altered to the point whereby he is much less likely to break things, which he tended to do in the Templeton Centre.”

For those people moving from an institutional environment such as a hospital, the removal of familiar stimuli undermines their ability to rely on habitual behaviour (Booth et al 1989:217). In this context familiar stimuli include such things as familiar physical arrangements, schedules and routines, together with distinctive sights, sounds and aromas.
Furthermore, familiar faces, voices and habits of both staff and other residents also constitute familiar stimuli. The lack of such stimuli prevents the presence of guides to behaviour, as well as implicit assurances that all is well, and one is “at home”.

There is no doubt that the mothers saw familiarity with an institutional environment as contributing to their children’s quality of life. This is particularly the case in relation to their physical surroundings, together with familiarity of staff and residents. Many of the mothers commented that the Templeton Centre was where their child considered ‘home’.

The claim that residents moved from an institutional setting into a community setting exhibit different forms of behavioural changes is supported in a study by Kleinberg and Galligan (1983). According to Kleinberg and Galligan (1983), in the first few months after moving, lower functioning clients showed increases in anti-social behaviour. Conversely, higher functioning clients actually decreased their anti-social behaviour (Kleinberg and Galligan 1983). There is therefore, evidence to suggest that the immediate effects of relocation differ depending on the functional level of the client. It would appear that higher functioning clients exhibited a prevailing pattern of withdrawal, and lower functioning clients displayed increased activity levels (Kleinberg and Galligan 1983:24).

The particular types of behaviour that appeared to improve included language development, domestic activity, and socialisation (Kleinberg and Galligan 1983:25). It is important that conditions peculiar to a community residence situation should be examined in an attempt to ascertain if this affects the type of improvement experienced. (Kleinberg and Galligan 1983:25). For example, there is obviously increased opportunity to engage in domestic activities such as cooking and washing dishes in a community residence compared with an institution. Accordingly, one can assume that there may be a direct correlation between improvements in this area and living in a community residence.

O’Brien and Thesing (1999) found that overall almost seventy five percent of parents and staff interviewed observed positive changes in behaviour of residents relocated into the community. Staff spoke of residents that were happier, and more responsive and willing
since their relocation (O'Brien and Thesing 1999:66). Those who exhibited the most marked improvements were higher functioning individuals (O'Brien and Thesing 1999:6).

6.10 Conclusion
There is no doubt that living in the community represents a fundamental change in the lives of persons with intellectual disabilities, and this is reflected in the accounts provided by the mothers. These changes have occurred on a number of levels in a number of different areas. Firstly, in terms of physical and material well being the move into the community-altered aspects of this part of the life of former Templeton Centre residents. The fact that many former Templeton Centre residents are living in houses in the community is highly significant. This represents a much different physical environment. For some, this meant that because they were living in a far more confined space their ability to wander about freely in relative safety has been stifled. Also, many of the mothers felt that road safety was an issue in this in new environment.

It would appear that residential service providers have attempted to minimise many of the risks that relocation into the community has presented. Most of the community houses have had to undergo alterations. These alterations included both internal such as safety glass, safety guards, together with external alterations such as altering gates and fences. Furthermore, none of the mothers reported any incidents where their children had suffered any real physical harm.

Another important issue that mothers felt impacted on the quality of life of their children living in community residences related to staff. Many of the mothers felt that in some circumstances there were inexperienced and unqualified staff working in community placements. Moreover, it was felt that as a consequence of this some staff were not adequately meeting the needs of their children, and hence their quality of life suffered. Also, it would appear that the level of personal attachment between staff and residents was not on the same level as it was in the Templeton Centre. For example, there were no accounts of staff taking residents home at the weekends as occurred in the Templeton.
Centre. The role of volunteers it would seem added to the quality of care for some residents. This was particularly the case in relation to community placement “A”, where the input of volunteers provided an increase in the quality of life for the residents. As far as the Brackenridge Estate is concerned the mothers felt that the fact that some of the staff were ex Templeton Centre staff, and thus psychopaedic trained, to be an advantage. They felt that because of this the staff were more in touch with the needs of their intellectually disabled children. Accordingly, they felt that their quality of life was being largely maintained.

Another staff related issue that was a concern for some mothers was that of staff turnover in residential placements. Some felt that staff turnover was having a negative impact on the quality of life of their children because they needed to have continuity of care. Also, there was a feeling amongst some mothers that the rates of pay that some caregivers were receiving was not conducive to retaining staff for any great length of time.

Some mothers felt that there is a lack of accountability of residential and day programme service providers. Moreover, there was a feeling that this impacted in a negative way on the quality of life of their children. This is because where circumstances in the community were not up to standard they were in some cases not being detected, despite the existence of the monitoring organisation SAMS. There were those mothers who felt that there was more in the way of accountability and transparency at the Templeton Centre due to the fact that it was state run, and it centralised the care of the intellectually disabled. This is somewhat of a contrast to community care where care is fragmented throughout the community.

Social relationships and interaction form an integral part of deinstitutionalisation as an ideology and social policy. There is no doubt that in many cases the nature of these was changed through deinstitutionalisation. For many this has been largely positive. However, there were some circumstances that did not meet the ideals of deinstitutionalisation as laid out by policy makers. None more so than the degree to which former Templeton Centre residents living the community interact with the wider
community. It would seem that this is minimal. For example, contact with neighbours was minimal at best. Conversely, however, there did not seem to be any evidence of discrimination and harassment, as has been shown in other studies both in New Zealand and overseas. However, that is not to say that this does not, nor will ever happen.

Another important point that emerged in relation to social relationships and interaction relates to the potential for residents of community placements to visit the houses of other residents. There were some mothers who felt that community living limits social interaction, because it is very difficult for residents to visit friends in other community placements. This is quite different from the Templeton Centre where if someone wanted to visit a resident in another villa they could simply walk across to that villa.

As far as the Brackenridge Estate is concerned it would appear that the nature of social relationships and interaction is very similar to the situation that existed in the Templeton Centre. The location of the Brackenridge Estate together with the fact that residents are of a lower level of functionality are two major factors that inhibit social interaction with the wider community.

Another important factor that contributes to the quality of life for the intellectually disabled living in the community is the leisure and recreation facilities available. It would appear that the level and quality of leisure and recreation activities and facilities differs from one community placement to another, and from one day programme provider to another. When you have a situation where private companies are providing health services such as those relating to the care of the intellectually disabled living in the community, there will always be the potential for a variation in the quality of the service provided given that such companies rely on making a profit for survival. In other words, because of the quest for profit costs have to be keep to a minimum, whether it be in terms of the facilities within the community placement, or the wages paid to caregivers.

In relation to autonomy, personal choice and independent living skills, another significant area within the deinstitutionalisation paradigm, there were some interesting results to emerge. It would appear that the degree to which these ideals can be achieved depends on
three main factors. First and foremost, the level of functionality of an individual is a crucial variable in determining the degree to which autonomy, personal choice, and independent living skills can be achieved. Next is the staff at community placements. In this regard it is the competency of the staff, both in terms of qualifications and an appreciation of the needs of persons with intellectual disabilities, together with their commitment to the job. Another important factor relates to the philosophy of care adopted and implemented by individual service providers. To develop and encourage skills that facilitate the exercising of autonomy, personal choice, and independent living skills requires adequate resources, together with dedicated and competent staff. Given that community service providers are made up of a divergent group of organisations, ranging from Christian based organisations to private companies, it is not surprising that there is a variety of experiences in this area. However, there is no doubt that residents have been able to develop some independent living skills, and exercise some degree of personal choice.

As far as behavioural changes are concerned it is widely accepted that these can provide an indication of well-being and hence quality of life. As far as this thesis is concerned it would appear that there was quite a variation in terms of behavioural changes, something which is reflected in the literature. Therefore, it could be argued that this reflects the different needs, wants and desires of the intellectually disabled, which are largely determined by the level of functionality of an individual.
Chapter Seven

Conclusion

7.1 General Overview
Deinstitutionalisation as a social policy emerged as part of economic and social changes that took place as a result of the adoption of neo-liberalism. This occurred in the first instance within western democracies such as the USA and the UK. Subsequently, it was adopted and implemented in New Zealand. Deinstitutionalisation had rather strong ideological beginnings in the 1960’s during a time of intense social change. At the forefront of this change was the rise of human and civil rights movements, which saw those with disabilities campaigning for equal rights. The disability rights movements argued that people with disabilities should have citizenship rights equal to able-bodied citizens, which included the right to fully participate in society (Oliver & Barnes 1993, Johnson 1998). The principle of normalisation was also influential in the development of deinstitutionalisation. In addition, the logic of deinstitutionalisation sat nicely within a neo-liberal policy agenda, and this facilitated the implementation of deinstitutionalisation both here and overseas.

7.2 The Templeton Centre
The Templeton Centre on the outskirts of Christchurch was an institution that had provided care for the intellectually disabled for over seventy years. For many intellectually disabled people this was their ‘home’. Health Link South announced in 1994 that The Templeton Centre would close, and many parents were concerned about the future of their children. The greatest concern for many parents was how their children’s quality of life would be affected. The prospect of having their child moved from the Templeton Centre into the community was for many, fraught with uncertainty.
Many parents felt that there were a number of positive aspects associated with the Templeton Centre that contributed to their children’s quality of life. Firstly, according to the mothers in this study their children’s physical well-being was made safer and more secure by virtue of the size and location of the Templeton Centre. It would appear that some residents needed to have plenty of physical space to cope with life, and thus maintain their quality of life.

Issues relating to the staff at the Templeton Centre appeared to be another important area that the mother’s felt contributed to their children’s quality of life. A major factor in this regard was the fact that the staff received specialist training in the way of psychopaedic nursing training. It was felt that the staff at the Templeton Centre were in touch with the needs of the residents, and had their best interests at heart. Furthermore, some mothers spoke of the kindness of some members of staff, and that they would involve residents in activities that were not part of their job requirements. However, some mothers felt that the staff were too controlling when it came to where and when they could see their children. Also, there were some mothers who felt that the staff at the Templeton Centre were militant and more concerned with their own interests.

Also, many of the mothers felt that the recreation and leisure facilities contributed to their children’s quality of life. Furthermore, these facilities according to some mothers assisted in establishing social interaction between the residents and the staff. The recreation and leisure facilities included such things as the gym complex, hall, and swimming pool.

Despite the fact that mothers had many positive things to say about certain aspects relating to the quality of their children’s lives at the Templeton Centre, there were also downsides to life in the Templeton Centre. For example, at one time the hygiene at the Templeton Centre had not been up to an adequate standard. Also, in terms of autonomy, preference and independent living skills it would appear that the opportunities for this were somewhat limited in the Templeton Centre. This is due to the way in which institutions such as the Templeton Centre operated. Also, due to the nature of
institutional life there was little potential for the development of independent living skills and domestic skills.

The other major factor that impacts on the degree to which autonomy, preference, and independent living skills can be exercised is the level of functionality of an individual. In other words, those classified with moderate and minimal levels of disability are more able to exercise preference and develop independent living skills. Whereas, those with severe intellectual disabilities, multiple disabilities and challenging behaviour were far less able to exercise choice and develop independent living skills.

7.3 The Deinstitutionalisation Process

The needs assessment programme was the first major phase in the deinstitutionalisation process. This involved having residents assessed to establish their individual needs and thus determine the appropriate type and level of care required by an individual in their new location within the community. This was done through the IPP (Individual Programme Plan) which covered individual care, treatment services, accommodation, community placement, and follow up assessments. Despite the needs assessment programme being quite a rigorous, and at times protracted process, it would appear that the impact on Templeton Centre residents was minimal.

However, an issue that emerged in relation to the needs assessment programme was the correlation between the level at which an individual was assessed and the corresponding level of funding. There were some who felt that this was why some residents underwent multiple needs assessments.

It would seem that as the move into the community began, there were varying degrees of disruption for Templeton Centre residents. In particular, there were some residents that suffered quite severe disruptions within the Templeton Centre itself. This was due to the fact that as some residents were moved out of the Templeton Centre, others were relocated into villas where they had not previously lived, with people they had had little or no contact with.
It is clear that many parents were concerned about what the future would hold when the announcement came that the Templeton Centre would close. At the forefront of the parent’s concerns were issues relating to the quality of life of their children. For many of the mothers in this study the announcement reopened old wounds, as it was reminiscent of the original decision many years prior when their children were admitted to the Templeton Centre. Another important issue related to the selection of a community placement, this provided a dilemma for some parents, as they were unsure of what various community placements had to offer. It would appear that for some parents the Life Links organisation (see section 5.12 in chapter five) provided some assistance in this regard.

7.4 Life in the Community
There are certain conclusions that can be drawn from the information provided by the mothers, particularly in relation to aspects of deinstitutionalisation as outlined by Healthlink South and the Southern Regional Health Authority. In chapter three the rationale behind the closure of the Templeton Centre, together with key transition issues as outlined by Healthlink South was discussed. These will now be commented on in relation to the information provided by the mothers.

Firstly, in relation to the notion that quality of life is measured in relation to activities undertaken by wider society, the evidence would suggest that many intellectually disabled persons living in the community do not participate in activities practiced by wider society to any great extent. This is largely determined by the level of functionality of an individual. Also, to a lesser extent, the philosophy of care and the level of resources of different service providers play a part.

A key component of improving quality life, according to Healthlink South (1994a), related to creating a family type atmosphere in the new community setting. It would appear that there has been mixed results as far as this is concerned. Some of the mothers made quite positive comments in this regard, and others were quite negative. A pivotal factor appears to be the staff at various community placements, together with the
philosophy of care adopted by service providers. In other words, the degree to which a family type atmosphere can be developed is largely dependent on the efforts of staff. Moreover, it requires staff to develop a sense of the individual needs of residents. Another expectation that Healthlink South (1994) held in regard to ex-Templeton Centre residents living in the community was that this would facilitate interaction and the development of friendships with members of the wider community. However, the evidence would suggest that this ideal within the deinstitutionalisation paradigm has not yet been realised to any significant extent. The bulk of interaction with the members of the wider community tended to occur on occasions such as shopping trips and organised activities in the community. There was no evidence of any meaningful interaction with neighbours. Conversely, there was no evidence of discrimination, harassment or resentment from neighbours towards the residents of community placements. This is a solid foundation from which interaction could develop. In other words, if there is no evidence of negative attitudes from neighbours toward ex-Templeton Centre residents living in the community, then over time interaction may take place and relationships may develop.

In terms of community care providing the possibility for a choice of accommodation options, there is certainly evidence that some parents have taken advantage of this. There were two mothers who moved their children form one service provider to another. The main reason for doing so was dissatisfaction with the way in which a particular service provider operated. Moreover, there was a feeling that their children’s quality of life was being adversely affected.

Whilst there is certainly the ability for parents to move their children from one community service provider to another, there are no other options available. There is nothing in the way of a sheltered village or other such facilities that may offer a different type of care. The only other option available is for parents to have their children at home, which for most is not a viable option. Whilst there is a specialist unit in the form of the Brackenridge Estate, this only caters for a small number of high needs individuals,
and there is no facility for respite care. Admittance into the Brackenridge Estate is purely on the basis of the needs assessment. Accordingly, if an individual does not fall into the ‘C’ category, and have severe or multiple disabilities, they are unable to gain admittance into the Brackenridge Estate. Herein lies a paradox within the deinstitutionalisation paradigm, in that whilst there are choices available in terms of accessing different community service providers, there are no other options available. It is possible that this lack of choice may impact negatively on the quality of life for some former Templeton Centre residents.

Whilst there is no denying that there is a financial dimension to deinstitutionalisation, it is difficult to accurately determine the degree of influence this had on its development into social policy. Despite this it is the opinion of the researcher that this played a significant role, and provided the impetus for its development into social policy. Healthlink South (1994) made it clear that if the Templeton Centre did not close they would be required to invest a substantial amount of money in upgrading it so as to meet the required standards. Furthermore, Healthlink South acknowledged that the closure of the Templeton Centre would enable cost savings on administration, building and ground maintenance, together with domestic and food services.

When comparing life in the Templeton Centre with life in the community there are a number of conclusions that can be drawn. Firstly in relation to physical and material well-being; in the Templeton Centre, many of the mothers felt that the size and location of the Templeton Centre assisted greatly in maintaining their children’s safety and security. This, it was felt, enabled residents to wander around in relative safety, which for some residents was an important part of maintaining their quality of life. As far as physical and material well-being in the community is concerned this was an issue for all the mothers. Many felt that with residents being placed in this new physical environment their ability to move around in relative safety was stifled, and brought with it new concerns such as road safety. However, despite these concerns there was no evidence of residents coming to harm. The mother’s concerns, particularly in relation to
safety and security resonated with the 1998 study of former Templeton Centre residents (Mirfin-Vietch et al 1998). However, O’Brien and Thesing (1999) found that issues of safety and security were not such a concern for the families in their study.

Another important area relates to issues pertaining to staff. There was a consensus that staff play a pivotal role in the quality of life for people with intellectual disabilities, both in an institutional setting and in the community. As far as the Templeton Centre is concerned most mothers felt that psychopaedic nursing training provided a number of positives in terms of the quality of care their children received. Conversely, many of the mothers felt there was a lack of training amongst staff in the community. Also, some mothers felt that there was a higher level of staff turnover in community placements, which they saw as interrupting the continuity of care, and hence the quality of life of their children. However, a positive aspect pertaining to the staff in community placements was that some mothers felt that visiting was made easier due to the flexibility of staff.

Some mothers felt that there was not enough in the way of accountability in relation to community service providers and they felt that this could have a negative impact on their children’s quality of life. Also, it would seem that there is very little in the way of ongoing research on the effects of deinstitutionalisation by both the Ministry of Health and Healthlink South (now the Canterbury District Health Board).

Many of the mother’s sentiments regarding staff related issues are reflected in other studies. It is widely recognised that there is a correlation between the quality of staff in community placements and quality of life (Mirfin-Vietch et al 2000, Horner 1994). There are those who believe that their relatives needs would be best met by registered nursing staff (Mirfin-Vietch et al 2000). As with some of the mothers in this study Levien (1996) found that most families in her study experienced a more open approach to visits and were able to visit for longer. Some mothers were concerned at the apparent lack of monitoring and accountability of community service providers, this was an issue reiterated by Mirfin-Vietch et al (2000). Overseas studies such as Haycox (1995),
Cambridge et al (1994) and Wing (1989), have revealed similar issues in relation to staff in community placements as discussed in chapter six.

As far as social relationships and interaction in the Templeton Centre was concerned these were primarily between staff and residents, and the residents themselves. Family contact constituted the other main site for social interaction, and this varied from one individual to another. It would appear that in the community the bulk of interaction is still between the staff and residents, and the residents themselves. It would appear that family contact has remained similar to that in the Templeton Centre, although some mothers reported an increase in contact. However, as far as contact with members of the wider community is concerned this was minimal to the point of being insignificant. This is particularly the case in regard to contact with neighbours. However, there were no reports of residents suffering any form of harassment.

Other studies such as O’Brien and Thesing (1999), Horner (1994) and Emerson (1985), have revealed similar results, particularly in relation to contact (or lack thereof) with neighbours. Overseas studies such as Booth et al (1989) have found that community opposition to houses containing intellectually disabled people can manifest itself in malicious ways. Fortunately, there was no evidence of such circumstances in this study.

In relation to leisure and recreation facilities, most of the mothers felt that these were of a high standard in the Templeton Centre, particularly the swimming pool and hall. Furthermore, it was felt that these assisted in facilitating social interaction between residents and staff. As far as leisure and recreation facilities in the community are concerned it would appear that there have been a variety of experiences. In some circumstances there were positive comments made in this regard. However, there were some mothers who felt that the leisure and recreation facilities in the community had declined in comparison to those at the Templeton Centre. It would appear that a major factor in this regard is the resources that individual service providers have available, together with the philosophy of care adopted.
As much as residents in this study participated in recreation and leisure activities organised by service providers, both in their residence and day programmes it would appear that accessing “community resources” was somewhat limited. However, other New Zealand studies, such as O’Brien and Thesing (1999) and Levein (1996) found that residents in the community were able to take advantage of community based services and organisations. Overseas studies such as Booth et al (1989) and Cambridge et al (1994), have revealed similar findings.

Lastly, in relation to autonomy, personal choice and independent living skills it would appear that these were largely stifled in an institutional environment. As much as the degree to which these can be achieved depends on the level of functionality of an individual there is no doubt that being in the community has assisted in positive gains in this regard. However, an important variable relates to the competency and dedication of staff, together with the philosophy of care adopted by respective service providers. Autonomy, personal choice and independent living skills constitute an important aspect of deinstitutionalisation. It would appear that studies both in New Zealand and overseas have found that gains have been made in this regard. For example, Levien (1996) found that former Mangere residents in her study were able to exercise more autonomy and choice. This is supported by overseas studies such as Stancliffe and Abery (1997) and Wing (1989).

This thesis has provided a snapshot of how life in the community has been for ten former Templeton Centre residents. However, deinstitutionalisation is a constantly unfolding process, both in terms of former Templeton Centre residents adjusting to their new environment and the wider community readjusting their perceptions of the intellectual disabled. There is no doubt that the relocation of former Templeton Centre residents into the community has brought with it some fundamental changes to their day to day lives. Whilst there is no denying that for many the move from the Templeton Centre into the community has been a positive one, there are those whose experiences have not been so positive. It would seem that those who have had the most positive
experiences in the community are higher functioning. Those with multiple disabilities and severe challenging behaviour are far less able to interact and integrate into wider society. The notion that the intellectually disabled are a heterogeneous group, whose level of functionality largely determines their needs, wants and desires, and thus quality of life must predominate. Accordingly, there are many that will benefit from living in the community, and conversely there will be some that will not.
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Web Resources

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Appendix 1

Interview Guide

I am interested in the quality of life of TC clients before during and after the transition to ‘the community’.
When did your son/daughter first become a TC resident?
What were the circumstances leading up to their admission?
What were the alternatives at that time?
What were the pressures?
What would it have been like if TC had not existed?
Was there pressure to have your son/daughter move into the community?
How has this affected his/her life?
How difficult/easy was the deinstitutionalisation process for your son/daughter (including the needs assessment programme).
What category was your son/daughter assessed at?
What are your hopes/fears for your son/daughter in the community?
Are there issues of safety or well-being that give you concern?
How do you see safety in the community compared to TC?
What advantages would your son/daughter have in a sheltered environment?
Do you think the level of care has altered?
How do the facilities in the community compare to those of TC?
How much contact does your son/daughter have with their friends from TC?
How much contact does your son/daughter have with people in the community?
What activities is your son/daughter involved in?
Has the level of recreation and leisure activities altered in the community?

Are there any other issues you have in regard to your son/daughter living in the community?