DISLOCATION: DEINSTITUTIONALISATION IN THE LIVES OF FAMILIES OF PEOPLE WITH AN INTELLECTUAL DISABILITY

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ABSTRACT

This thesis is based on a research project that explored the deinstitutionalisation and eventual closure of a large residential facility for people with an intellectual disability. The thesis is focused on family experiences of deinstitutionalisation in order to understand how families interacted with this major process of social change, and pays specific attention to the role of adult siblings within this context.

Unstructured interviews were held with thirty-five families who had family members with an intellectual disability who were being resettled from an institution to alternative disability support services. Families were interviewed at three specific phases during the deinstitutionalisation process: prior to the resettlement of their family member; 1-3 months following resettlement; and one year after resettlement. In keeping with the constructivist paradigm that underpinned this qualitative study, repeated contact with families enabled me to develop some insights into how families made decisions relevant to their family members' transitions from the institutional environment.

The study findings highlight the complexity and heterogeneity of families. While families who participated in this study were found to have shared a similar journey toward institutionalisation, their responses and reactions to deinstitutionalisation and the decision-making associated with such a process were more diverse. My analysis presents the notion that taking a constructivist approach to theorising can facilitate an understanding of how families are influenced in their decision-making with regards to the resettlement of a family member with an intellectual disability. That is, we may be able to gain greater understanding of families' perceptions of their family members who have an intellectual disability and, subsequently, the decisions that families make regarding the care of that person by exploring the meanings they assign to their world. Ascertaining how families come to construct their understandings of disability is, in my view, critical to responding appropriately to families' needs within the context of disability support and service provision.

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CHAPTER ONE

INTRODUCTION

This thesis is based on a longitudinal research project that explored the deinstitutionalisation of a large residential facility for people with an intellectual disability situated near Christchurch, a city in the South Island of New Zealand. The institution had a seventy-year history and at the time this project commenced 480 individuals with an intellectual disability were living at Templeton Centre.

Despite the fact that a community based service system for people with an intellectual disability had been available in New Zealand for approximately twenty years, the process of closing institutions for people with an intellectual disability had moved slowly. There had often been opposition to proposals to change from institutional to community care, and this most usually came from parents, staff and the wider community. The deinstitutionalisation of Templeton Centre was no exception to this pattern. The process of closure implemented at Templeton Centre was a protracted one that involved high levels of conflict and emotion. This thesis presents research conducted with families prior to, during and following the deinstitutionalisation of Templeton Centre and the resettlement of their relative(s) into alternative services.

The idea for this thesis came to me seven years previously in the living room of a Christchurch family's home. I was present in that room as a participant in a meeting that was being held between the research institute that I was employed by and a number of families of children and adults with an intellectual disability. All of the families present had in the past chosen institutional care for their relatives. The current reality for these families was that Templeton Centre, the institution they had chosen, was in the process of planning for closure. The families were now faced with the prospect of their family members with an intellectual disability experiencing a major change in living circumstances and service delivery. They were soon to make a transition from the institution into the community.

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The purpose of the meeting was to establish what kind of research the families perceived as necessary to document the closure process. From this meeting, a research proposal was developed and eventually funded by the Health Research Council of New Zealand (HRC). The doctoral research formed the major part of that larger study. At the meeting in 1995 the families had many ideas about what would be useful to them. As a novice researcher I did not take an active part in the proceedings. Instead I watched, listened, and learned both from my employer, an experienced researcher who was running the meeting, and from the families, who had a vested interest in ensuring that the story of the Templeton Centre closure was heard. While my own views and opinions have changed in a multitude of ways since this early experience with Templeton Centre, one lasting impression remains with me – an impression that has formed and informed this thesis.

As I watched and listened I became acutely aware of what I interpreted as tension, anxiety, and in some cases, ambivalence that existed within individual family members (usually parents) as they described how they thought the closure of Templeton Centre would impact on their own and their relatives' lives. I also became aware of, and interested in, the tension and emotion that seemed evident **between** family members as they struggled to make sense of this planned major change in service delivery. Were all families united in their views? Did some family members want to say something different about deinstitutionalisation? Who and/or what influenced decision-making within families? These questions subsequently became the basis for this thesis. Over several years and through multiple interactions with families I have attempted to explore and to answer the following questions.

- What factors influenced families' earlier decisions to choose institutional care for their disabled relatives?
- Who and/or what influences the decisions that families make about transition from institutional to community based services?
- How do siblings interpret the experience of institutionalisation and deinstitutionalisation?
- How do families experience the impact of the transition of their disabled relatives from institutional to community based disability services?

It appeared to me that the preceding questions were important ones for two main reasons. Firstly, and as previously mentioned, time spent with families prior to commencing this study alerted me to the ambivalence that some families seemed to be feeling as they confronted the process of deinstitutionalisation and subsequent resettlement of their family member with an intellectual disability. Learning about why parents had chosen to institutionalise their son or daughter, and the impact such a decision had had on the entire family was of interest to me. Meeting with families in the development stages of this project also made me aware that the now adult siblings of Templeton Centre residents were, in some cases, becoming involved in the decision-making related to resettlement. This fact also influenced my decision to include a focus on siblings' experiences of institutionalisation and deinstitutionalisation.

The second influence over my choice of questions within this study was determined by my own knowledge of the literature in the area of deinstitutionalisation at the time I commenced this study. I was aware of several gaps in the literature in terms of how families interact with this major process of social change. Specifically I wanted to be able to contribute to an improved understanding of who and/or what influenced the decisions that families make about transition from institutional to community based services. I was of the view that deinstitutionalisation research had more commonly illuminated how families' attitudes toward deinstitutionalisation changed without including a robust interpretation of why such changes in attitudes occurred.

The present study has been undertaken within a constructivist paradigm. In general terms constructivism is based on the notion that multiple realities are present in the multiple constructions that people express about their social experiences (Schwandt, 1998). Taking a constructivist approach to the present study created an opportunity for families' constructions of institutionalisation, deinstitutionalisation and community living to be explored. Furthermore, due to the extended and multiple contacts with families, their reconstructions of these significant experiences became evident over time. The findings generated through the present study have also been theorised within a constructivist framework.

How this thesis is structured

Chapter Two presents a brief history of the Templeton Centre and outlines the stage that the process of deinstitutionalisation was at when the present research commenced. The chapter provides the reader with a context and background upon which to approach the findings of this research.

Chapter Three provides an overview of literature relevant to this thesis including the area of deinstitutionalisation, a term used frequently throughout the present work. It also provides a more detailed discussion of the body of literature that exists in the area of family involvement in the process of deinstitutionalisation and the resettlement of people with an intellectual disability from the institutional environment into community based services. Research literature in two other specific areas related to the field of intellectual disability research is also discussed. The first of these areas is that of out-of-home placement for children and young adults with disabilities. The second is that of relationships between siblings with and without intellectual disabilities. The predominant focus of this particular section of Chapter Three is on the relationships evident between adult siblings with and without intellectual disabilities. All the literature included in this chapter has relevance to the analysis of the findings presented in later chapters of this thesis. Chapter Three concludes with a discussion of why the present study is necessary and relevant to the field of disability research.

Chapter Four is concerned with presenting and discussing the methodological framework used in this study. A constructivist paradigm position was taken in this research. Constructivism is discussed in a general sense, followed by an exposition of specific constructivist research approaches. Lincoln and Guba's (1994) "constructivist paradigm" is identified as the specific constructivist approach taken in the present study. Ideas central to this paradigmatic approach are presented in a general sense and then linked explicitly to the conduct of the present study.

Chapter Five describes how the study was designed and conducted. This chapter provides the rationale for particular decisions relating to why and how the study was carried out. This chapter also introduces the 35 families who took part in this

study and provides information about their family members with an intellectual disability who were to be resettled from institutional to community based services.

Chapter Six presents research findings related to the families' original decisions to seek out-of-home placement for their family members with an intellectual disability. These decisions were usually made many years earlier and the chapter identifies the factors that families took into consideration when moving toward the final decision to institutionalize disabled family members. Chapter Six presents the journey toward institutionalisation through a story of institutionalisation that appeared to be shared by all of the families who took part in the study. This chapter also presents findings relating to siblings' experiences of the institutionalisation of their brother or sister with an intellectual disability.

Chapter Seven presents findings that provide the reader with information about the families' continuing journeys through the process of deinstitutionalisation. This chapter explores families' responses and reactions to formal plans for institution closure and focuses on how families reached decisions regarding future plans for their family members with an intellectual disability. Chapter Seven provides information about the actual transition of people with an intellectual disability from Templeton Centre into alternative services, and reveals families' attitudes toward deinstitutionalisation soon after the transition of their family member.

Chapter Eight provides findings related to the final aspect of families' experiences of deinstitutionalisation – the final chapter of their story. This chapter examines the experiences and views of families one year following the resettlement of their family members with an intellectual disability into alternative disability services. Chapter Eight analyses the impact of such a major change in service delivery on families who have been involved in the process of deinstitutionalisation.

The constructivist position taken in the present study is apparent in all three findings chapters. In keeping with such an approach I have attempted to reveal families' constructions of institutionalisation, deinstitutionalisation and community living. To achieve this goal I have tried to elucidate the understandings that families held, both in the past and more recently, about disability and models of disability support. At the same time I have explored the meanings that families

attach to their social experiences of caring for a family member with an intellectual disability. The contradictions both within and between families' stories become apparent, as does the tendency for families to construct and reconstruct their understandings of disability and disability support as they experience the process of deinstitutionalisation.

Chapter Nine has the purpose of discussing the findings presented in chapters six, seven and eight of this thesis and is comprised of five sections. The chapter begins with an exposition of the research questions that underpin the present study. The questions are answered with reference to the literature reviewed in Chapter Three of this thesis. The second section of Chapter Nine represents an attempt to theorise the findings of the present study. In particular, the notion of constructivism is discussed and the ideas expressed within this paradigm have been used to theorise the findings of this study. The third section of the chapter illuminates the methodological issues arising through this work. Constructivism is presented here also as a useful way of interpreting the various methodological and ethical issues encountered during the conduct of the study. The fourth section of this chapter identifies the limitations of this research. The fifth and final section of this chapter suggests some implications for policy, practice and future research in the area of family involvement in deinstitutionalisation, and other areas of disability service delivery.

CHAPTER TWO

THE TEMPLETON CENTRE CONTEXT

A brief history of Templeton Centre

Templeton Hospital and Training School (as it was originally named) began operating in 1929 in a relatively isolated rural location 13 kilometres from the city of Christchurch. As the years passed this physical isolation from the wider community became less pronounced as Christchurch city grew and extended beyond its original boundaries.

The land that Templeton Centre occupied was originally purchased in 1917 with the intention of being used to meet the needs of people with psychiatric disabilities. The initial plan was to build a series of villas that could be used to accommodate people with psychiatric disabilities who were to be transferred from Sunnyside Hospital, a psychiatric hospital located in Christchurch itself. The first villa built on the site was named Matai, and in 1928, twenty-eight patients from Sunnyside moved into this villa. However, before any further development could occur the plans for this piece of land changed.

In his history of the Templeton Hospital and Training School, Shepard (1979) stated, *"The winds of change were blowing on the Mentally Deficient front however, and a number of events thwarted the psychiatric move south."* (p. 3).

The "winds of change" that Shepard refers to relate to the fact that during the 1920's concern was growing about the number of people with intellectual disabilities being accommodated in psychiatric institutions "for want of any better place." (p.3). Shepard also noted that many of these "mentally deficient people" (sic) were in ordinary schools and were in his view "quite unable to benefit from the type of education given."(p.3). At this time the conclusion was reached that this group of people were unsuitable to attend school and that they had a limited future

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after leaving school. Furthermore, there was no institution that existed that could replace school and/or psychiatric hospitals.

According to Shepard, the then Director of Mental Health at that time, Dr. T.G. Gray, visited the United States of America, the United Kingdom, and Europe and during this visit explored the notion and practice referred to as a Mental Defective Colony (institution for people with an intellectual disability). This convinced him of the need for changes in New Zealand. Upon his arrival back in New Zealand Dr. Gray led a process of submissions to Parliament that resulted in an amendment to the Mental Defectives Act. The amendment allowed certain institutions to be dedicated to the "care, control and training of mentally deficient children." (p.3). The rural land at Templeton was then destined for a very different future. The psychiatric patients who had moved into their new home on the Templeton Centre site were returned to Sunnyside and in August 1929 eight boys considered to have an intellectual disability were admitted to Templeton Hospital and Training School. The boys were aged between five and fifteen. Less than a year later in March 1930 three young women (who were aged 17, 19 and 20) began their lives at Templeton.

When the first villa (Matai) was built on the site, it was erected in the middle of a paddock with no road access. To reach the villa visitors needed to use a track from the farmyard that became almost impassable in wet weather. Much of the early development of the Templeton site was performed by Sunnyside patients. Working parties came out from Christchurch on a daily basis and assisted with the farm, built roads, and created lawns and gardens. As the need for haste became greater a group of Sunnyside patients moved out to Templeton for a period of six months so that they could be more productive and not have to waste time travelling to and from Templeton. During the first eight years of the Templeton Hospital and Training School the institution built up facilities on site which meant that the hospital became increasingly self sufficient. Towards the end of the 1930's attention turned to the task of meaningful occupation for hospital residents – an issue that had been central to the move toward a facility of this kind in the first instance.

In order to give boys the opportunity to learn a trade, an occupational block began operating in 1936. This block performed furniture repairs and boot repairs. This activity soon expanded and Templeton residents were involved in producing a

range of goods for sale. During the Hospital's early years it appears that Templeton residents were expected to play a large part in the everyday operation of the institution.

While male and female residents had always been segregated, it was not until 1947 that the segregation of male and female staff within the villas occurred. Up until this point nursing sisters had maintained overall responsibility for each villa regardless of whether it accommodated male or female residents. At this time it was decided that female staff should be responsible for the female villas at the north end of the site while male staff took over responsibility for male residents at the south end of the site. Most staff lived on site in purpose-built accommodation. Templeton Hospital was increasingly developing an identity and role of its own. The training of nurses working in the field of intellectual disability became a nursing specialty in its own right with nurses completing a three-year training period at The Templeton School of Nursing. This nursing specialty in the area of intellectual disability was referred to as psychopaedic – a term not used anywhere else in the world. The Templeton School of Nursing closed in 1987 when it was recommended that nursing education should be conducted within Polytechnics.

While Templeton Hospital expanded rapidly throughout the period 1940-80, the farm was transferred to the Agriculture Department in 1967. Shepard (1993) stated that the need for this transfer was due to a reduction in the number of residents capable of carrying out the type of work needed to make the farm an economic unit. This is an interesting assumption given that institution admissions in New Zealand were at their peak during the 1960's and 1970's. Up until the farm was transferred to the Agriculture Department, Templeton Hospital had not only supplied all its own fresh produce, but had also supplied other North Canterbury Hospitals. Despite the loss of the farm, Templeton grew in many other ways. The Hospital had a range of facilities including a Chapel, a swimming pool and a school. The Welfare Council had been established in 1958 and had the aim of making contributions that led to the betterment of resident welfare. The Templeton Parents' Association, a group which would later have a great influence throughout the closure of Templeton Centre, commenced in 1971.

By the 1980's the changes that were occurring at Templeton Hospital and Training School were, to some extent, reflecting the types of services that were being delivered in the community based setting. The institution changed its name to Templeton Centre in 1988. At this time a re-integration of male and female staff occurred. A Community Support Team became part of the services delivered by Templeton Centre and this team provided information and liaison, and assessment and clinical intervention. Perhaps the strongest evidence that Templeton Centre was attempting to deliver a service in line with the current disability movement was the development of a Statement of Rights for Residents, along with a General Philosophy and Policy Manual. Templeton Centre remained however, a self-contained entity. While some residents may have experienced increased contact with the community at large, the reality was that Templeton was designed to have the ability to meet all residents' needs. Residential, vocational, educational, recreational and spiritual services could all be delivered on site – and in most cases were.

At the time in 1994 that plans for closure started to impact on the lives of Templeton Centre residents and their families, 450 men and women with intellectual disabilities lived at Templeton Centre.

Planned for closure

This doctoral research was developed following the official announcement of plans for the deinstitutionalization and complete closure of Templeton Centre. The following section describes the process by which families were made aware of the major changes planned to occur for their relatives living at Templeton Centre.

On 15 November 1994 the Crown Health Enterprise (CHE) and the then Southern Regional Health Authority (SRHA) made a joint announcement that Templeton Centre would be deinstitutionalised and that residents would be resettled into community based services. At this time, the New Zealand health system had undergone extensive reform and restructuring. In simple terms, the New Zealand health system was characterised by what was referred to as a "funder-provider" or "purchaser-provider" split (Gauld, 2003). In the situation of Templeton Centre both the SRHA as the purchaser of intellectual disability services, and the CHE as a

current provider of hospital based intellectual disability services initially were working together to achieve the goal of deinstitutionalization.

The announcement that Templeton Centre would be deinstitutionalised was accompanied by the release of a document outlining preliminary plans for the deinstitutionalization process. This document became known as the "blue book" (Healthlink South and the Southern Regional Health Authority, 1994). The blue book outlined the intended process and referred to a proposal to utilize Princess Margaret Hospital in the city of Christchurch as a location for residential services for a significant number of Templeton Centre residents who were labelled as unsuitable for resettlement within community based services. Princess Margaret Hospital was at the time undergoing restructuring while remaining largely involved in the provision of aged care services.

The SRHA and the CHE followed the release of the blue book by inviting families with specific questions about the proposed deinstitutionalization to contact them directly. Additionally, a series of meetings were held throughout New Zealand to enable families with family members living at Templeton Centre to hear "first-hand" about the planned changes. Families and other interested persons were also invited to make submissions about the planned changes to Templeton Centre services as part of a consultation process put in place by the CHE and the SRHA.

The process of moving towards closure

The announcement of the planned closure, and the call for submissions provoked a huge response. Families and other interested members of the community were invited to forward written or oral submissions to the CHE and the SRHA. These submissions were analyzed by the Bridgeport Group, a private agency working as a public policy consulting group. A report was completed and released in May 1995. The report recorded that the overwhelming majority of submissions were opposed to the changes planned for Templeton Centre services. Another significant area of concern was the proposal to use Princess Margaret Hospital as a site for residential services for Templeton Centre residents.

The submission process was, from the perspective of the CHE and the SRHA, a method of consultation with families and the wider community and not an opportunity for those opposed to the closure of Templeton Centre to reverse the decision. The CHE had included with the blue book and submission document an information sheet which stated that "consultation is not negotiation", therefore indicating that the decision to deinstitutionalise Templeton Centre would not be reversed. The submission process did, however, have some influence over some elements of the deinstitutionalisation process. For example, the strong opposition recorded by families to the use of Princess Margaret Hospital for residential services, halted all plans to progress with that particular proposal. On 15 September 1995, the SRHA issued a media release stating that a programme of deinstitutionalization would take place at Templeton Centre over the next five years. In 1997 I commenced working with families who had relatives being resettled from Templeton Centre and began to share their experiences of the process of deinstitutionalisation. My interaction with families was part of a wider study of this area as explained in Chapter Five of this thesis.

CHAPTER THREE

FAMILY INVOLVEMENT IN DEINSTITUTIONALISATION: A REVIEW OF LITERATURE

Introduction

This chapter presents a literature review relevant to the development of this doctoral research. This literature is subsequently used to critically interrogate the research findings and in consideration of the implications drawn from the research. Included in the literature is a section on the general principles, processes and outcomes associated with deinstitutionalisation – the major focus of this work. The second area covered in this chapter is that of family involvement in the process of deinstitutionalisation. The third section of this review chapter presents information relating to current research on out-of-home placement for children and young adults with disabilities. The fourth and final section focuses on research in the area of siblings of people with an intellectual disability, and in particular on the relationships between adults with an intellectual disability and their brothers and sisters.

Deinstitutionalisation and people with an intellectual disability

Deinstitutionalisation is generally understood to refer to the movement of people out of institutions and into community based services (Sobsey, 1994). Kim, Larson and Lakin (2001) describe deinstitutionalisation as a policy and practice that has led to dramatic changes in the sizes and types of places where people with an intellectual disability live. Impetus for the deinstitutionalisation movement is largely attributed to three main factors: a response to the appalling conditions experienced in institutions (Taylor, 2001); the principles of normalization, which propose that disabled people have life experiences like those of others in the culture and society within which they live (Nirje, 1985, Wolfensberger, 1992); and, to the subsequent development of a community based service system (Mansell & Ericsson 1996).

Conditions for people with an intellectual disability within the institutional environment

During the 1950's and 1960's the appalling conditions experienced by people with an intellectual disability who were living in institutions began to be exposed. Prior to this time it was almost universally accepted that adults and children with an intellectual disability could only be cared for in an institutional environment. Burton Blatt and Fred Kaplan (1974) conducted a piece of research that greatly influenced the public view of conditions inside institutions. Blatt, an eminent educator and academic, and Kaplan, a photographer, spent time in a number of different American institutions towards the end of 1965. Their aim was to expose the aspects of institutional living that were not usually seen by those outside of the institutional environment. The result of their work was the photographic expose *Christmas in purgatory; A photographic essay on mental retardation*. Their book provided a shocking pictorial of life for adults and children who had an intellectual disability and who were living in American institutions.

Blatt and Kaplan's provocative work gave credence to some of the concerns that families and others involved in the disability field were having about some of the practices that were being experienced by children and adults who had an intellectual disability and who were living within an institutional environment. Ericsson and Mansell (1996) stated:

> The move towards community services has its origins in the 1950's when parents through their criticism turned their attention towards the conditions offered in institutions. (p.7).

An increasing awareness of the degrading conditions within institutions led to one of the most significant events in the history of deinstitutionalisation. In 1977 an American district court judge Raymond Broderick ruled that the Pennhurst State School and Hospital, a large institution for people with an intellectual disability, was *"incapable of providing constitutionally appropriate care and habilitation"*. (Conroy & Bradley, 1985, p.1). This finding led the judge to conclude that all people either living at Pennhurst, or who may potentially use Penhurst's services in the future should be provided with service options in the community environment.

The principle of normalisation

Occurring alongside the growing concern about the way people with an intellectual disability were being forced to live their lives inside of institutions was the development and implementation of a concept referred to as normalisation. The concepts encompassed by the term normalisation were discussed first by Bank-Mikkelsen during the late 1950's. Bank-Mikkelsen advocated for people with an intellectual disability to have the opportunity to obtain an existence as close as possible to normal (Wolfensberger 1972). Nirje elaborated on Bank-Mikkelsen's earlier work and described the normalisation principle as:

> Making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society. (Nirje, 1969, p181 cited in Wolfensberger, 1972, p.27).

However the most common understanding of the normalisation principle has its origins in the work of Wolf Wolfensberger (1972) who discussed the principle in terms of its application to the development of human services. Wolfensberger stressed that the normalisation principle should be perceived as culture specific and redefined the previously offered definitions in the following way:

> Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible. (p.28).

Despite the myriad of reformulations and critiques of the normalisation principle that have been forwarded over the past four decades, it is impossible to dismiss the influence of the principle over where, and how, children and adults with an intellectual disability have been able to live their lives. Whilst highlighting that deinstitutionalisation programmes are implemented for different reasons in different countries and contexts, Valerie Bradley (1996) identified the concept of normalisation as being a consistent feature underpinning such initiatives. Bradley commented:

> While the reasons for deinstitutionalisation are complex and vary across national political contexts, one common factor is the embrace by advocates of the concept of normalisation and the rejection of segregation of people with intellectual disabilities from the rest of society. (p. iv).

The development of the community based service system

Community models based on principles of normalisation began to be established during the 1970's. Such services were usually offered to those with a mild or moderate disability, however, the belief that people with more significant disabilities could also live within their local communities became more widespread over time. During the 1970's the numbers of adults and children with an intellectual disability living in institutions began to decline, a trend which continued for the next 30 years. American disability academic and researcher Steven Taylor (2001) provided a succinct account of deinstitutionalisation from its inception to the current day.

> ...the momentum of deinstitutionalisation and community inclusion has continued unimpeded, and indeed has gathered steam, over the past 30 years. From the late 1960's until today, institutional populations have declined at a steady pace and an increasing number of professionals, parents, persons with disabilities, and researchers support the right of all persons with developmental disability to community living. (pp.23-24).

Is deinstitutionalisation considered to be a positive initiative?

Deinstitutionalisation is widely accepted internationally as representing a positive step toward increasing the independence and quality of life experienced by people with an intellectual disability and now forms the basis of government policy regarding provision of services for people with disabilities in New Zealand.

> In keeping with international trends the New Zealand Government announced in 1985 that it was adopting a policy of community living for people in long-stay institutional care. (O'Brien, Thesing & Capie, 1999, p.6).

Although a point often disputed by opponents of deinstitutionalisation, research has informed and secured this policy decision by consistently documenting the positive effects of deinstitutionalisation on previously institutionalised individuals (Booth, Simons & Booth, 1990; Conroy & Bradley, 1985; Larson & Lakin, Lord & Hearn, 1987; Moloney & Taplin, 1990). In a recent commentary, Bigby (2004) made the following statement. *"Three decades of research has unequivocally demonstrated the improved quality of life outcomes that result from the move out of institutional environments." (p.202.)*

As Bigby's comment explicates, the process of deinstitutionalisation has been the focus of a substantial body of research (Conroy & Bradley, 1985; Cummins, Polzin & Theobold, 1990a, 1990b; Lord & Hearn, 1987; Mansell & Ericsson, 1996).

Most deinstitutionalisation research has concentrated on determining the changes in quality of life and adaptive behaviour of the individuals with an intellectual disability involved in the transition processes (Dunt & Cummins, 1990; Emerson & Hatton, 1996). There is little doubt that such research has found that deinstitutionalisation represents an improvement in the lives of most previously institutionalized people (Kim, Larson & Lakin, 2001; O'Brien, Thesing, Tuck & Capie, 2001; Young, Ashman, Sigafoos & Grevell, 2001). For example, Spreat and Conroy (2001) provide the following summary of research in the area of deinstitutionalisation.

> In general, research regarding the deinstitutionalisation of persons with mental retardation offers a positive picture. Skills increase and quality of life improves. Proponents of community placement argue that community inclusion is a good idea, even for individuals who have the most severe disabilities. They argue that community placement can provide increased opportunity to participate in a wider range of enjoyable activities, closer proximity to family members, increases in some skill areas, and a lifestyle based on typical community living patterns rather than congregate care. (p.107).

However, in order to ensure appropriate community integration disability researchers and others in the disability field have recognized that desired service goals must be broader and more complex and should encompass other than the composition of a person's residential accommodation. For example, some resesarchers have contended that there must be a greater emphasis on self-determination, integration, and societal acceptance of people with an intellectual disability (Spreat & Conroy, 2001). There have also been assertions that deinstitutionalisation should be viewed by disability researchers and others in the disability field as a positive goal in itself. That is, a reliance on measurable outcomes should not always be at the centre of arguments relating to the value of deinstitutionalisation. Kim, Larson and Lakin (2001) stated that "...one of the reasons that deinstitutionalisation is such a powerful policy is that is seeks to maximize inclusion for people with intellectual disability." (p.44).

During a commentary on deinstitutionalisation Bradley (1996) put forward the argument that research in this area should focus on the continued improvement of community based services and increased self-advocacy able to be exercised by people with an intellectual disability themselves. She said:

> The recognition that deinstitutionalisation should be more than a change of address coincides with the emergence of a new paradigm or set of assumptions regarding the conduct of services to people with intellectual disabilities. This new set of assumptions acknowledges that people with intellectual disabilities are capable of making choices about their own lives, respects their right to do so, and focuses on individualised supports and empowerment. (p.xi).

Family involvement in the process of deinstitutionalisation

Although empirical evidence supports deinstitutionalisation (Kim, Larson & Lakin, 2001; O'Brien, Thesing, Tuck & Capie, 2001; Young, Ashman, Sigafoos & Grevell, 2001), research suggests that many families who have relatives involved in such a process are often fearful of the planned changes (Tuvesson & Ericsson, 1996) and in some cases actively oppose any change to the model of service delivery currently offered to their relative (Tossebro, 1996). This resistance could be perceived as surprising given the role that other families have played in many settings in supporting the deinstitutionalisation movement since its earliest stages.

Families of people with an intellectual disability were responsible, in part, for creating the early impetus for deinstitutionalisation. Alongside like-minded professionals, families utilized a variety of strategies to ensure that deinstitutionalisation programmes were implemented (Frohboese & Sales, 1980).

In the New Zealand context parents of children and adults with an intellectual disability were also instrumental in changing the model of service delivery that was available. Through her feminist exploration of caregiving and activism Sonntag (1993) presented evidence of parental lobbying that had commenced in the 1950's.

> Reports of questions asked in the House reached New Zealand newspapers. Ministers of the Crown were being asked in parliament during the 1950's why educational amenities were difficult to access if children were intellectually disabled, and for their comment on parental stress and distress.

Also why funding for short stay homes/hostels was being delayed or shelved. (p.38).

The central figures in such activism at this time were Wellington couple Margaret and Harold (Hal) Anyon. The history of the Anyons' activism is detailed by Millen (1999). Margaret had given birth to a son with Down syndrome in 1936 and unlike many parents of this era, had rejected the suggestion that he should be institutionalised. Instead, she embarked on a frustrating and fruitless search for support and services for her son. In the late 1940's Margaret and Hal campaigned for an occupational centre for people with an intellectual disability in Wellington. In August 1948 the Anyons received confirmation from the then Education Minister that the Wellington Education Board was committed to such a project. However, when no progress was forthcoming the Anyons collected a small group of parents around them and embarked on their own plan of action. The activism of this couple eventually resulted in the establishment of an incorporated society titled the Intellectually Handicapped Children's Parents' Association (IHCPA). Included in the IHCPA's early goals was the establishment of "cottage homes" which would replace the large state institutions. Over the next 50 years the IHCPA evolved into New Zealand's largest intellectual disability service provider and, as an organization, has continued to lobby for the closure of institutions.

Given this history it is somewhat ironic that families also have been some of the most vehement opponents of deinstitutionalisation. It has been common for families, and in particular parents, to actively resist the closure of institutional facilities for people with an intellectual disability. Payne (1976) identified what he referred to as the deinstitutionalisation backlash - a counter-movement of parents committed to retaining institutional services for their family members with an intellectual disability. As deinstitutionalisation programmes and other major changes in service delivery have become more prevalent, many families continue to express concerns regarding what they see as the negative implications of such processes.

Due to the highly visible nature of familial opposition to deinstitutionalisation, research has frequently attempted to identify the concerns held by families involved in such a process. Willer, Itagliata and Atkinson (1979) suggested that deinstitutionalisation presents a potential crisis for families of people with an

intellectual disability. According to these authors deinstitutionalisation causes a "painful revisitation" of the original decision to institutionalise their familiy member with an intellectual disability. They expand on this point further by asserting that if the original decision was influenced by problems relating to the provision of care, the crisis of deinstitutionalisation is experienced more acutely.

Lord and Hearn (1987) agree that for many families deinstitutionalisation presents a crisis. This view led them to assert that *"..understanding the crises which led to institutionalisation is absolutely essential to fully understanding the later processes around the closure and deinstitutionalisation."* (p.7).

Recent Australian research (Funnell, 2001) into the closure of a large institution focuses on families' experiences of the institutionalisation of a family member with an intellectual disability. Approximately 35 families participated in the study with family groups including parents and, in some instances, siblings. Utilising a narrative methodology, findings generated through this study stressed the negative impact of removing a person with an intellectual disability from the family environment. Whilst there was an acknowledgement by some families that specific stresses were diminished following the institutionalisation, other emotional problems were often created for parents, siblings and the person with an intellectual disability him or herself. Funnell highlighted the centrality of familial love to developing an understanding of how institutionalisation and deinstitutionalisation impacts on families.

Other researchers have also identified the issue of deinstitutionalisation as having the effect of forcing families to revisit painful decisions made in the past. The decision by families to institutionalize their family member with an intellectual disability was often accompanied by a mixture of guilt and relief (Booth, Simons & Booth, 1990). Sonntag (1993) talked of the extreme pressure that some parents were subjected to by doctors and other health professionals who adhered to the view that institutionalisation was the superior model of care. Frohboese and Sales (1980) noted that many families institutionalized their relatives when it was "the accepted and popular thing to do". With the rise of the deinstitutionalisation movement some families have felt that they are viewed as unfeeling and wrong to have made this earlier decision (Frohboese & Sales, 1980).

Because so many families institutionalised their relative on the advice of professionals, researchers have contended that it has been very difficult for some families to accept that deinstitutionalisation and the utilization of services in the community may now be appropriate for their family member (Cummins & Dunt, 1990). Families are sometimes suspicious of policies prompted by new and unfamiliar ideologies of care that envisage their family members living in ways that they do not perceive as realistic or possible. Families' evaluations of their family member's ability or potential for more independent living has often been informed by the early advice of professionals and remained unchallenged for long periods of time. After accepting the prognosis that an individual has no potential for personal development, it is understandably difficult to accept at a later stage that the same individual has the ability to learn new skills or adjust to a whole new lifestyle (Booth, Simons & Booth, 1990; Conroy & Bradley, 1985; Cummins & Dunt, 1990; Grimes & Vitello, 1990; Lord & Hearn, 1987)

A number of studies have investigated the issue of familial satisfaction with institutional care (Heller, Bond & Braddock, 1988; Meyer, 1980; Rudie & Riedl, 1984; Spreat, Telles, Conroy, Feinstein & Colombatto, 1987). Through the administration of a family attitudes survey, Meyer (1980) reported that 83% of the family participants believed that a large institution was the best available placement for their children. Spreat et al. (1987) reported that the families of individuals with an intellectual disability were very satisfied with institutional services. Heller et al. (1988) reported that families were generally satisfied with institutional services. Rudie and Riedl (1984) contended that satisfaction with institutional services derived from the fact that families desire the maintenance of the "status quo" and hypothesised that families would demonstrate satisfaction with community placements following the resettlement of their family member with a disability. To determine whether this assumption was substantiated, these researchers asserted a need to extend their investigations of family reaction to deinstitutionalisation to include data collected in the post-relocation setting as well as the pre-relocation setting. All of the four studies reported here were conducted in the American context and utilised postal surveys as the primary method of data collection.

American researchers Conroy and Bradley (1985) contended their study was the first deinstitutionalisation study to investigate the feelings and concerns of families both before and after resettlement occurred. It was therefore the first study to examine changes in families' attitudes during the process of deinstitutionalisation. Participants were found to be well satisfied with the standard of care their family member with an intellectual disability was receiving in institutional care prior to that person being resettled. The most striking finding of the post-resettlement phase was that these same families indicated that they were just as satisfied with the community living arrangements as they had been with the institution. The change from a negative attitude toward community based services to a positive attitude toward such services has been a significant feature of deinstitutionalisation studies which have implemented data collection procedures both pre- and post-resettlement (Booth, Simons & Booth, 1990; Conroy & Bradley, 1985; Grimes & Vitello, 1990; O'Brien, Thesing & Capie, 1999).

As mentioned earlier in this chapter Canadian researchers Lord and Hearn (1987) also conducted a study that included pre- and post-resettlement data on families and made the following comment. *"The change from fear and resistance to strong approval was so marked that it cannot be attributed simply to inevitable resignation in the face of change. Families truly seemed to embrace the idea of community living."* (p.146).

The marked increase in the quality of life and general happiness of their family member with a disability has often been identified as one factor that influences family attitudes regarding the appropriateness of the community resettlement of their family member(s) with an intellectual disability (Booth, Simons & Booth, 1990; Conroy & Bradley, 1985; Ford & Barlow, 1994; Lord & Hearn, 1987). Whilst it is important not to assume that families are able to accurately assess and report on their relatives' subjective wellbeing (Cummins & Baxter, 1993), it is clear that families are often in the best position to describe changes in the quality of life and general happiness of a person with an intellectual disability.

Lord and Hearn (1987) explored the process of closing Tranquille, a large institution for people with an intellectual disability located in British Columbia, Canada. Lord and Hearn followed the closure from the original announcement by the British Colombia Government to close Tranquille, to the actual closure 18

months later. A follow up of the men and women who left the institution was also conducted one year after resettlement had occurred.

This study focused on a range of individuals and organisations central to the process of deinstitutionalisation. The experiences of families of the people leaving the institution were explored in depth. Lord and Hearn examined the initial experiences that resulted in institutionalisation and identified a significant lack of support at the time for families who attempted to care for their sons and daughters with disabilities at home. Themes that they identified as central to families' stories included a sense of isolation and rejection, an ongoing search for support including little hope or support offered by professionals, the wearing down of the mother, and eventually the crisis of institutionalisation.

Once the announcement to close the institution had been made Lord and Hearn reported that although families may have been ambivalent about their son's or daughter's life in the institution, most were fearful or hesitant about the planned changes. One significant factor that cemented many families' feelings of opposition to closure was the lack of useable and useful information about what was proposed when the announcement had been made. Resentment among these families grew as they tried, without success, to have their questions answered.

The families who had sons and daughters involved in the Tranquille institution closure were not invited to participate in initial planning for the closure. Families felt this omission meant that they were removed from the major process of change that was about to occur in the lives of their sons and daughters. This issue also raises the issue of whose rights are paramount in such situations: the rights of adults with an intellectual disability or the rights of parents.

Lord and Pedlar (1990) followed up this initial study of the Tranquille closure with a project designed to describe and analyze life in the community in terms of outcomes for the people with an intellectual disability who had now left Tranquille. The study focused on: life in the home; community participation and integration; social networks and satisfaction with community living. The study centred on eighteen individuals who lived within group homes in the community and whom Lord and Pedlar assessed as representative of the 260 people who were resettled

during the deinstitutionalisation process. The researchers claim that many of the people selected to take part in the study had no verbal communication or any other form of communication and on this basis they asked staff and family to provide the information for the study. The researchers also conducted extensive participant observations within the group homes and other relevant settings in order to ascertain the outcomes for people involved in the Tranquille deinstitutionalisation process four years after it had taken place.

Lord and Pedlar stated that four years after leaving the institution their families continued to provide the primary non-paid relationships in the lives of these people with an intellectual disability living in the community. The study found that the individuals who had been resettled in the community had very little other social contact four years after the transition had occurred. Family involvement in the lives of those resettled also varied greatly. Some families visited only sporadically, if at all, and did not appear to be strongly connected to their family member. Other families were heavily involved with their family member immediately following resettlement but decreased their level of involvement when they felt reassured that the transition had been successful. Lord and Pedlar noted that families did not try to establish wider social links and networks for their family member even if they engaged with them socially themselves. Lord and Pedlar assumed that this was because families were unaware of the importance of "connecting" or "bridge-building" between their family member and the wider community.

Tuvesson and Ericsson (1996) explored the closure of institutions for people with an intellectual disability in Sweden. Tuvesson and Ericsson explained that in their country institutions were viewed as miniature societies that had the aim of providing for all the needs that a person with an intellectual disability may have. This view of responsibility and resourcing by the institution extended to the relationships apparent between institutions and family. Tuvesson and Ericsson elaborated on this point through the following statement:

> When the person was admitted to the institution his family, parents, siblings and others, were not expected to assume any responsibility for their care of welfare. The location of these (often regionally sited) institutions also contributed to making contact more difficult. Initially visiting hours and

times were also closely regulated, only being allowed at certain times. Such limitations contributed to the difficulties in maintaining normal relationships between families and relatives at the institution. (p.200).

In this context Tuvesson and Ericsson sought to explore "how relatives understand and react to the process of deinstitutionalisation which their family members have experienced" (p.201). Interviews were conducted with the families of thirty-six people with an intellectual disability who had already left an institution between one and four years earlier. In total fifty-three interviews were conducted: 28 with parents; 14 with sisters and brothers; and 11 with other relations. The analysis of the semi-structured interview data grouped relatives' views about institutional closure as positive, negative or neutral. Ten relatives were categorized as having a positive view toward deinstitutionalisation both prior to and following resettlement. Fifteen relatives were assessed as having been negative toward deinstitutionalisation prior to the move of their relative. Two of these relatives were found to continue to hold negative views, four had become neutral, and nine had changed their original view and were positive about deinstitutionalisation. One person continued to hold a neutral position and one person had changed from a neutral to a negative position.

Tuvesson and Ericsson contend that their study illustrated the strong bond between families and their relatives with an intellectual disability. This bond is significant even if people with an intellectual disability have lived away from their families for long periods of time.

While this study contributes useful information about family attitudes toward institution closure, the findings should be interpreted cautiously. Findings generated through retrospective studies of attitudes toward deinstitutionalisation have been identified as having the potential to achieve a less accurate picture of families' attitudes prior to resettlement (Larson & Lakin, 1991). Larson and Lakin contend that because families have consistently been found to change their attitudes toward deinstitutionalisation very rapidly after deinstitutionalisation occurs (Conroy & Bradley, 1985; Lord & Hearn, 1987), it is possible that the intensity of feeling that families actually experienced prior to and during the deinstitutionalisation of their relative with an intellectual disability may not be reflected in retrospective interview data.

Tossebro (1996) described the context for deinstitutionalisation in Norway. Policies to close institutions were enshrined in the law in Norway thus lending extra support for the view that institutions were not appropriate places for people with an intellectual disability to live. Tossebro found that a parent lobby group had strongly advocated for this reform. However in Norway, as in many other countries engaged in deinstitutionalisation programmes and policies, the media frequently reported stories of opposing or anxious parents who were having their wishes to retain institutional services ignored. Tossebro draws attention to what he refers to as a "puzzle" whereby a progressive policy such as deinstitutionalisation is supported by some parents, and opposed by others. In attempting to make sense of this puzzle Tossebro provides an explanation of "why ordinary parents oppose deinstitutionalisation" (p.209).

Tossebro's research is based on data obtained through a postal survey administered to 484 relatives of people with an intellectual disability. Sixty-five percent of the respondents to the survey were parents, twenty-eight percent were siblings and seven percent other relatives. Telephone calls were made to approximately forty survey respondents to obtain additional information about the living conditions within institutions. The data collection procedures took place during a time of unease and uncertainty when plans for deinstitutionalisation had not been confirmed or finalized. As Tossebro points out, the findings of this research need to be considered in terms of this very specific stage in the process of deinstitutionalisation.

At the time this Norwegian research was conducted only fifteen percent of the families surveyed believed that the proposed closure would result in an improvement in the level of services offered to their family members with an intellectual disability. In fact, two thirds of the families involved in this study were of the view that deinstitutionalisation would result in worsening conditions. Tossebro described the reaction of a family member to his request for information for this study. The response showed the level of agitation that some families felt during this particular stage in the deinstitutionalisation process which is characterized by uncertainty and a lack of formal decision making. The following two quotes illustrate the agitation that two participants were feeling.

You cannot relocate him. You are turning me into a nervous wreck. You know he will be troublesome if relocated. Why are you doing this? (p.211).

This is horrible – sending letters about relocation of the children. Parents are supposed to decide for their children. Such letters open old wounds; the retarded will never be normal. This has gone much too far. Stop it instead of sending such letters. (p.211)

With regard to his original question "what makes ordinary parents oppose institutions?" Tossebro identified two broad issues as being critical. The first problem is that of uncertainty or anxiety about what is planned to occur. Despite that fact that community based services had been available and used by people with an intellectual disability for long periods of time, many families had not experienced any alternative to the institutional service environment The second issue identified by Tossebro is that families viewed contemporary institutions as satisfactory and progressive and therefore viewed deinstitutionalisation as an unnecessarily risky venture.

When exploring the somewhat contradictory context of a parent lobby focussed on achieving deinstitutionalisation, and an equally significant group of parents focussed on retaining institutional services, Tossebro records that families committed to retaining institutional services often try to discredit the efforts of the pro-deinstitutionalisation parent lobby by defining them as the parents of people with a mild intellectual disability. That is, the principles of deinstitutionalisation may be achievable for these parents' sons and daughters but not for their own more severely disabled sons and daughters. Tossebro contends that this assumption is not correct as no correlation has been found between parent attitudes toward deinstitutionalisation and the level or degree of disability of their family member.

British researchers Brown, Orlowska and Mansell (1996) focussed on parents in order to understand why parents shifted from accepting poor services to advocating for better ones. Their investigation concluded that all parents are committed to the long-term wellbeing of their sons and daughters with an intellectual disability. However, despite this long-term commitment parents are equally able to work against innovative community based services as they are to lobby and strive for improvement in service quality. This point is particularly

relevant to the process of deinstitutionalisation. Brown et al. contend that it is important to conduct research that identifies and clarifies factors critical to ensuring the relationships and alliances between parents and professionals are positive ones.

The New Zealand Context

In New Zealand, research pertaining to the topic of family involvement in deinstitutionalisation is limited. Levien (1992) conducted a telephone-administered survey that generated information relating to families' views of a move from institutional to community-based services for family members with an intellectual disability. The study involved family members of 84 people with an intellectual disability who had been resettled. This study showed that 83% of families that responded felt an extremely high level of satisfaction with the community based service that their family member was using. This finding contrasted with the finding that nearly 40% of these same families had felt that their family member should always live in an institutional setting prior to a move actually occurring. It must be noted that families were asked about their earlier views retrospectively – that is they were asked about how they had felt about plans for deinstitutionalisation after they had experienced the move.

Despite the high level of satisfaction that families had with community-based services they did express a number of enduring concerns. Staffing in community-based services was a particular concern for families. Families questioned the level and appropriateness of staff training and they also questioned staff continuity. Families were dissatisfied with the amount and kind of information that they received from the community-based services regarding their family member. In particular families wanted more information about their family member's everyday life and their abilities and progress in specific areas. Levien contended that if families have access to such information then they are more likely to be able to be meaningfully involved in decision-making concerning their relative.

A more comprehensive exploration of deinstitutionalisation in the New Zealand context can be found in the work of O'Brien, Thesing and Capie (1999). O'Brien et al. investigated the experiences of fifty-four men and women who had been resettled into community based services following the deinstitutionalisation of a

psychiatric institution that they had been residing in for many years. The men and women who took part in this study had an intellectual disability only but had been accommodated at the psychiatric institution. This practice has not been uncommon in New Zealand.

The study aimed to investigate the outcomes for this specific group of people with an intellectual disability who made the transition from the institution (Kingseat, Auckland) into community based residential services provided by one large New Zealand intellectual disability service provider (IHC). O'Brien et al. had the following aims: to collect demographic information pertaining to the day/work history of their focus group of people with an intellectual disability after they had left the institution; to explore the perceptions of the people who had been resettled, their family, and staff about the effects of the move; and to examine the extent to which people had become involved in the community after resettlement. A range of strategies and the utilization of both quantitative and qualitative methods were used to generate data for the study.

A retrospective survey of family members identified that the initial reaction of families to plans for institution closure were diverse and ranged from hostility to viewing the move as a positive change. Families were, however, generally satisfied with the move from institutional to community based services eight years after it had occurred. The study also indicated that eight years following resettlement only one third of the 54 focus people for the study (i.e. men and women with an intellectual disability who had moved out of the institution) had regular contact with their families. For half of the focus people, the parent who had supported them during the transition from Kingseat had died by the time the study was conducted. Other family members had stepped into a support role for only some of the people with an intellectual disability who were the focus of this study. This finding emphasizes the fact that when elderly parents die, adults with an intellectual disability can be left without family support.

O'Brien et al. provided a history of institutionalisation based on information that was provided to them during semi-structured interviews with a smaller subset of families. This history highlighted the pain that families felt when confronted with the need to place their family member in an institution. This pain was brought to

the fore when plans for deinstitutionalisation were announced. This finding is common in deinstitutionalisation research that involves families and has been described earlier in this section (Booth, Simons & Booth, 1990; Cummins & Dunt, 1990; Lord & Hearn, 1987).

O'Brien et al. found that many families felt guilty about having to place their child in the institution and did not enjoy the experience of visiting their family member in the institutional environment. Despite this, many families described the placement as one that had relieved the extreme stress and pressure associated with trying to care for their family member at home.

Issues of on-going concern for families

The research literature shows that family involvement in deinstitutionalisation often demonstrates a clearly defined pattern. Families often are resistant to major changes in the model of service delivery for their relative when they are first made aware of plans for deinstitutionalisation. Frequently they modify this view at a later date as they witness for themselves the positive impact that deinstitutionalisation can have on the lives of their family member with an intellectual disability.

Acknowledging a positive improvement in aspects of their relatives' lives as a result of transition from institution to community does not, however, prevent some families from continuing to feel dissatisfaction and concern with aspects of the process of deinstitutionalisation. Many families have reported feeling ill-informed and in some cases, entirely excluded from the decision making regarding their family members' community resettlement.

Grimes and Vitello (1990) reported for example that the 32 Australian families who took part in their study were less than satisfied with the assistance they received from case management services at the time of their family members' resettlement. It was reported in the same study that some families felt that they had received inadequate information about their relatives' accommodation, adjustment and habilitation plan after relocation had occurred. For many families this inadequate information exacerbated the worries and concerns they already possessed. In addition to this worry a lack of information makes families feel unimportant in the

decisions made with regard to their relatives. Cummins and Dunt (1990) link a lack of information in the initial stages of planning for deinstitutionalisation to the negative attitudes that families frequently express in the pre-resettlement phase.

Another enduring concern for families who are involved in the process of deinstitutionalisation is the issue of permanency. While institutions are often viewed as permanent (lifelong) placements for their family members, community services are seen by some families as transitory and impermanent. Correspondingly, long-term security of funding is also a critical issue for families who often do not believe that funding will be on-going and long-term (Booth, Simons & Booth, 1990; Conroy & Bradley, 1985; Ford & Barlow, 1994; Frohboese & Sales, 1980; Lord & Hearn, 1987; Spreat et.al., 1987).

Staffing of community services is another area that causes persistent anxiety for families of children and adults with an intellectual disability. Whereas institution staff are usually seen as experienced and well trained, community service staff are often seen as being well meaning but too young and inexperienced for the level of responsibility that they often carry.

Frohboese and Sales (1980) contended that conceptualizing parental concerns was useful in developing intervention models and techniques for assisting parents who experience difficulties in accepting the deinstitutionalisation of their sons and daughters. Many other researchers have asserted the need for policy makers and planners of deinstitutionalisation programmes to include families' views and opinions as an integral component of the planning process (for example Booth, Simons & Booth, 1990; Conroy & Bradley, 1985; Ford & Barlow, 1994; Grimes & Vitello, 1990).

Few researchers have investigated the development of specific strategies designed to assist families involved in deinstitutionalisation. Larson and Lakin (1991) compiled a list of ways of facilitating parental satisfaction with the deinstitutionalisation process. The list was compiled through a review of all the (then) available research literature in the area of family involvement in deinstitutionalisation and by identifying every suggestion made by individual researchers with regard to facilitating family involvement in this process. Larson

and Lakin highlighted the need to: acknowledge parental concerns before the move; facilitate parental involvement in the deinstitutionalisation process; and involve parents in ongoing quality assurance efforts.

A practical attempt to promote the positive involvement of families in the deinstitutionalisation process in Canada has been the development of a family involvement resource booklet that suggests some practical strategies that families can implement when faced with this transition (Farlow, 1988). This booklet does not, however, provide suggestions for policy makers, planners and disability service providers in order to ensure that such professionals are able to involve families positively in issues related to the delivery of services to people with an intellectual disability.

Despite the fact that there is a significant body of research literature that has focused on the issue of family involvement in deinstitutionalisation, a gap in knowledge and understanding in this area remains. Much of the research reported here has highlighted families' views prior to- and following resettlement with the notion of parental satisfaction integral to such research. Little research has sought to fully understand families' experiences as they have experienced their relatives' transition from institutional to community based services. It has not been common for deinstitutionalisation research to be concerned with the decision-making processes that families engage in as they traverse the unfamiliar terrain of service delivery change. Furthermore, earlier research has almost exclusively focused on the views and experiences of parents (or siblings fulfilling a parental type role). Little attention has been paid to the important roles that adult siblings can play within families involved in the process of deinstitutionalisation.

Research on out-of-home placement

The previous section of this chapter focused on deinstitutionalisation and family involvement in deinstitutionalisation processes. The research in this area is about parents, who at that time, chose institutional placements, often acting on professional advice. In more recent years, professional opinion has swung from advocating such placements for children with an intellectual disability to

advocating that they should be cared for in the family environment (Blacher, Baker & Feinfield, 1999).

While it is tempting to make the assumption that exploration of what makes families seek out-of-home placements (care arrangements) is no longer necessary, current research shows that this continues to be an area which requires on-going attention. In a recent Australian study Llewellyn, Dunn, Fante, Turnbull and Grace (1999) found that 25% of the 167 families participating had already sought or were considering placement for their children with high support needs. In the case of this study out-of-home placement was defined as being when a child with a disability was living away from the family home for more than 70% of the time in a week. The out-of-home placement options included foster care, the child living with another relative, or the child living in residential care or a children's hospital. A New Zealand study by Bray, Moss, Forrester and McConnochie (2005) that explored the needs of 53 New Zealand carers of family members who had complex support needs reported that 43% of the carers surveyed had *"seriously considered full-time out-of-home placement for the disabled person they cared for."* (p.28) Seventy-nine percent of the people being cared for were sixteen years of age or younger.

These significant findings highlight the continuing concerns of some families who feel unable to cope with supporting a family member with a disability at home despite current policy and practice which encourages such caring practice. It is clear that some families will seek out-of-home placement at some point. Nancy Rosenau (2001) made the following statement:

> While one family finds a child's needs too great, or their lifestyle too restricted, another family with a child with identical labels is doing well. The disability alone is not the reason for non-family life. We must look beyond the child for an explanation. (p.31).

This statement suggests why it is important to understand the factors, contexts and situations that contribute to families' decisions to seek out-of-home placement. This need for greater understanding is particularly critical when current policy and services are based on a philosophy which supports family-based and/or community models of care. It is also important to understand what kinds of services most appropriately meet the needs of people with disabilities and their

families in order to reduce the likelihood of the maintenance of institutional facilities, or the development of new ones (Rosenau, 2001).

Factors that contribute to families' decisions to seek out-of-home placement

Bromley and Blacher (1989) conducted a study which sought to determine the factors that may contribute to the delaying of out-of-home placement of American children with severe disabilities. The study sample consisted of 63 parents who had made the decision to place their children in alternative care outside of the family home in a period ranging from 1 to 24 months prior to taking part in the study. Fifty-eight of the parents who took part were mothers. Data were collected during in-depth interviews in the parents' homes, through the completion of family data sheets which sought demographic information about the family and the placed child, and through the administering of a 21-item scale. The scale was titled the Factors Preventing Placement Scale and was developed specifically for use in this study. The scale was designed to reflect factors hypothesized by the researchers as serving to delay or prevent placement. Bromley and Blacher asserted that this approach was in contrast to other out-of-home placement studies which commonly conceptualized factors that may influence placement decisions, rather than those factors that may contribute to families' decisions to continue caring for their children in within the family home environment.

Bromley and Blacher (1989) found that most families who eventually seek out-of-home placement attempt to care for their relative at home for as long as possible. They also found that families were reluctant to consider alternative options for extended periods of time. This refutes the notion that families who eventually do seek out-of-home care are not concerned for their family members with an intellectual disability.

The availability of formal social support that met the needs of families was also a factor that delayed placement decisions. Bromley and Blacher concluded that internal or cognitive factors such as feelings of attachment or guilt rather than external factors were found to be the most salient influences on the delaying of out-of-home placement. In their view, this finding highlights the need for cognitive

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factors such as attachment and guilt to be further explored in family and out-of-home placement research.

Blacher (1990) extended this research further through a study involving parents who had sought permanent placements for their children with severe disabilities out of the family home. The parents were interviewed three times with each interview being held at intervals of between eighteen and twenty-four months. Blacher identified that families' decision to seek out-of-home placement is a process rather than a discrete act. The actual decision to place a child out of the home is preceded by a series of steps or events. Research by Bruns (2000) confirms this view. Bruhns conducted qualitative research with five parents who had sought out-of-home placement. She found that all parents described a similar progressive decision-making process that eventually saw them seek out-of-home placement. Furthermore, research with 54 New Zealand families of children with high support needs (Carpinter, Irwin & Rogers, 2000) also concluded that no one event is the catalyst for out-of-home placement. Carpinter et al. stated: *"The general pattern appears to be that over time the child's needs increase and the general capacity to meet their needs decreases resulting in a situation that is no longer sustainable."* (p. iii).

Bromley and Blacher (1991) reported that parents' perceived daily stress and burden related to caring for a child with an intellectual disability was the most influential factor in predicting out-of-home placement. The child's level of functioning, as well as behavioural problems were also influential predictors. The availability of appropriate support services were only moderately influential to the decision to seek out-of-home placement. Further to this point researchers have emphasized the importance of creating a range of family support options to ensure that all families feel able to access a formal support system that meets their specific support needs (Herman & Thompson, 1995; Llewellyn, et al., 1999)

Blacher, Hanneman and Rousey (1992) explored whether particular child characteristics may significantly influence out-of home placement. Blacher et al. found that children with more significant intellectual disability were at increased risk for out-of-home placement. They found that the risk increased further if children had accompanying physical disabilities. Behavioural issues also contributed to the likelihood that a child would be placed out of the home. Despite

these findings Blacher et al. concluded that the differences between those who seek out-of-home placement and those who do not extend well beyond child characteristics. That is, even if two different families each have a child with a similar disability profile one family might seek out-of-home placement while the second family may not. Other factors besides the child's disability influence the decisions that families make about out-of-home placement.

Hanneman and Blacher (1998) conducted longitudinal research designed to examine predictors of attitudes, or behavioural intentions regarding placement, and actual out-of-home placement for children with severe or profound intellectual disability. In using a longitudinal approach the researchers were able to explore in greater depth the processes that led to out-of-home placement. In this American study of 100 families Hanneman and Blacher considered the following variables associated with the consideration of, or the actual placement of a child with an intellectual disability: characteristics of the child (age, gender, ethnicity, health and appearance); sociodemographic characteristics of the parents (education, occupational status, age, and the number of children in the household); the quality of the home environment and family and child adaptation; the degree of perceived stress on the family and caregiver; and sources of social and financial support.

Hanneman and Blacher found that those parents who felt strongly that the burdens of caring for a child at home were reducing harmony in the household were more likely to be considering placement seriously. Furthermore, parents who were more concerned about their child's level of intellectual disability were also more likely to be considering placement. However, if the mother felt that she was coping well with the demands of caring then placement was less likely to be considered. Interestingly, this study suggested that support resources outside of the family were not significantly associated with the variation in the seriousness of consideration of out-of-home placement. The findings generated through this study accentuate the impact of parents' cognitive processes on consideration of out-of-home placement and suggest that ensuring the availability of family support services will not always ameliorate problems and stresses associated with caring for a disabled family member.

Adams, Wilgosh and Sobsey (1990) sought to understand and learn more about the experiences of 18 Canadian parents caring for their children with severe disabilities at home. The findings of this qualitative study indicated that a child with severe disabilities was the most significant impact on the "life-world" of the mothers who took part. Most mothers reported that their life and life plans had been influenced and dominated by the needs of their child with a disability. The study also found that parents have on-going stress and anxiety related to caring and that the child with a disability has a strong impact on other family members. This finding is similar to that reported by Beckman (1991) who, in a comparison of mothers' and fathers' perceptions of care-giving, found that mothers were responsible for increased care-giving requirements and experienced greater stress than fathers. These findings stress the gendered nature of care-giving, an issue explicated by Eva Kittay (1999) and Robyn Munford (1989).

In her book *Love's Labour* Kittay, the parent of an adult daughter with an intellectual disability and philosopher, states that:

> The call for sexual equality has been with us for a very long time. But until relatively recently, the demands of even the most farsighted women have assumed very traditional and gendered arrangements of dependency work. (p.188).

This statement resonates with Munford's (1989) research in the area of care-giving that identified the ways in which patriarchal systems structure and control the lives of women who care for people with an intellectual disability. Munford explored the issue of power in two key sites: the household and the organisation. Exploration of women's experiences of providing unpaid and paid care revealed that their care work was devalued. Munford linked this devaluing of care work to a societal tendency to devalue the people with an intellectual disability being cared for.

Studies have confirmed that parents' perceived daily stress is a strong influence on out-of-home placement decisions (Beckman, 1991; Bromley & Blacher, 1991; Kobe, Rojahn & Schroeder, 1991). Concern for family relationships in general, and the wellbeing of siblings in particular, have been identified as critical to out-of-home placement decisions in a number of studies (Bromley & Blacher, 1991; Hanneman & Blacher, 1998; Llewellyn et al., 1999). However, little research attention has been

paid to understanding how parents and other family members have adjusted to the out-of-home placement of a family member with an intellectual disability (Baker & Blacher, 2002).

The impact of out-of-home placement on parents, siblings and people with a disability

Baker and Blacher (2002) have recently attempted to address this issue through a study designed to explore post-placement adaptation of 106 families with a disabled family member living in a residential facility. The study included the families of children under the age of fifteen, as well as families of adolescents and adults who had an intellectual disability and/or mental illness and who had moved to one of three large residential facilities. The focus of the study was on ascertaining whether families viewed placement outside of the family as a better or worse alternative to caring for their family member at home.

Findings generated through this study showed a contrast between the experiences and views of families who had placed children under the age of fifteen outside of the family home and those families who had sought residential placement for their children who were over the age of fifteen (young adults) and adults. Families of children under the age of fifteen visited their children more often, reported the highest stress and care-taking burden prior to out-of-home placement but reported the lowest marital adjustment to and advantage from placement. Families of young adults and adults over the age of fifteen reported more positive outcomes and expressed more positive views toward out-of-home placement. This difference in views relating to out-of-home placement is perhaps due to the fact that a move from the family home after the age of eighteen is more in keeping with typical life cycle developments for young adults.

Baker and Blacher's study provided some interesting insights into the experiences of families who seek out-of-home placements. When asked about disadvantages caused by placement the families often talked about these from the perspective of the child, young adult or adult that had been placed outside of the family home. In most cases they perceived the family member with a disability as being disadvantaged through a loss of contact and sharing of experiences with the family.

About half the families in this study had the view that siblings experienced some disadvantages after their brother or sister was placed out of the family home. For example, siblings were reported to miss their brother or sister and the role they had previously played in their daily activities.

Some parents worried about not being able to fulfil their parental role and were particularly concerned that they were not able to instill their own family's values in their child. Of the 106 families who took part in this study about one third expressed feelings of worry and guilt about the decision they had made and the impact that the decision would have on their family member. Interestingly, about one half of the families reported that they were worried about the impact removing a disabled child from the family home would have on non-disabled siblings. That is, parents worried more about the effect of out-of-home placement on non-disabled siblings than on their disabled children. Thus, while out-of-home placement undoubtedly reduced stress for some parents it resulted in increased stressors in other areas of their lives.

The positive impacts on family life were frequently reported as being an improvement in family relationships and increased family harmony. Many of the participants in this study commented on the general reduction in stress and the fact that the household was not continually in crisis.

Baker and Blacher concluded that exploration of the impact of out-of-home placement on families in general and on siblings in particular is a relatively unexplored area. A focus on the relationships between people with intellectual disability and their siblings is becoming more pertinent as people with disabilities are increasingly outliving their parents and becoming more reliant on the involvement of other family members, usually siblings. One of the most important areas that Baker and Blacher highlighted was the emotional response to out-of-home placement the families reported as being expressed by their family member with a disability. These feelings included rejection, desertion, loneliness and anger. Morris (1997) asserted that the emotional impacts on those experiencing out-of-home placement, that is people with disabilities themselves, are deserving of greater and more intensive exploration.

Research has addressed an important question linked to the impact of out-of-home placement on children living outside of their family home. Baker and Blacher (1993) interviewed 62 families who had placed their children in residential care facilities about the level of involvement that they maintained with their child. Baker and Blacher defined family involvement as the way a "family continues to think, feel and behave toward the child who is placed." (p.368). Over a two-year period family involvement with and attachment to children placed in residential facilities decreased only slightly. Interestingly, Baker and Blacher identified that the opportunities for family involvement offered by the facility in which their child was placed were significant in determining the level of involvement a family would maintain. This finding suggests that services have a critical role in facilitating on-going family involvement in the lives of children (and adults) who reside out of the family environment.

Family involvement in the life of children and adults with an intellectual disability was studied by Baker, Blacher and Pfeiffer (1996). The involvement of families of 163 children and adults with an intellectual disability using residential services were explored through the use of staff and family reports. Staff and family were found to have very similar views of the level of family involvement that was occurring for individual children and adults. In this study there did not appear to be a lessening of family involvement over time. Families who exhibited higher levels of involvement with their family member with a disability were found to: live closer to the residential facility; have an expectation that their family member would return home; and have a family member with a lower level of intellectual disability. Baker et al. contend that while family involvement in community based residential (and vocational) services is sought in principle, there has not yet been adequate consideration of what positive family involvement in such services is, nor how such involvement could or should be facilitated.

It is important to acknowledge the significant body of research literature on families and caring. A review by Winder and Bray (2005) provided an overview of findings of recent research on informal or unpaid (usually family) carers of children and adults with a disability. Winder and Bray concluded that while families want to care for their relatives with a disability, they require improved supports and services in order to provide care in a manner that minimises family stress. Further

to the preceding point, services need to include a focus on carers, as well as on the person with a disability. American researchers Cole and Meyer (1989) attempted to determine what services and resources families of 166 children with disabilities found to be useful in assisting them to maintain caring in the home environment. Cole and Meyer constructed what they referred to as a "wish list" and asked parents to select those resources that they felt would be most useful in assisting them to maintain care of their child at home. Greater spousal support was the item on the wish list that parents ranked most highly. Parents then selected the following external items as having the greatest potential to benefit them in their caring efforts: payment for medical and dental expenses; evening and weekend in-home childcare; funding for home help; access to professional consultation for behavioural issues; access to a physician knowledgeable in disability issues; funding for transportation and special equipment needs; access to respite care; and access to community based recreational facilities.

Families' perceptions of their resources for caring for children with an intellectual disability were explored by Herman and Thompson (1995). Similarly to findings presented by Cole and Meyer (1989), 233 American parents in this study who were caring for their children in the home environment felt that they had inadequate amounts of time, discretionary income and access to child-care resources. Families who felt more positive about their ability to care for their children were found to have more well-developed social support networks and a greater level of income. Herman and Thompson contended that these findings suggest the need for greater flexibility in the types and amounts of services that are designed to meet the needs of families caring for disabled children in the home environment.

The issue of family wellbeing has been explored in recent literature. Cummins (2001) explored the quality of life of people caring for a relative with a severe disability within their family. This review of qualitative and quantitative research concluded that data indicates that primary caregivers are at considerable risk of high stress, clinical depression and a low quality of life. Baxter, Cummins and Yioloitis (2000) highlight the difficulty of isolating problems of the child with a disability from problems experienced by the family as a whole. The experiences and needs of family carers have recently been explored in a document commissioned by the British Department of Health (Ward, 2001). Under a section

labeled emotional support the following point was made. *"So often the psychological demands of caring are underestimated in comparison with the tasks of physical care. The emotional needs of all members of the family need to be recognised and supported."* (p. 21).

Dyson (1993) provides a different perspective on family well-being within families of children with disabilities. This researcher concluded that the quality of the family relationships that existed within families that included a child with a disability had the biggest impact on stress. That is, the way the family functioned had the effect of reducing or increasing the presence of stress within the family.

A focus on family functioning and relationships within families including children with disabilities was also pursued by Mirfin-Veitch, Bray and Watson (1997) in the New Zealand context. Mirfin-Veitch et al. concluded from a study that included 12 parent-grandparent pairs that the presence or absence of support from grandparents within such families was largely determined by the history and quality of their family's relationships. Furthermore, through a review of the literature relating to stress and coping in families of children with disabilities Scorgie, Wilgosh and McDonald (1998) identified family cohesion as being integral to the coping ability of such families. Families who have "warmth" and a "we are in this together" approach are more able to manage successfully the pressures associated with caring for a disabled child in the family environment.

Methodological issues related to obtaining information about family decision making in the area of out-of-home placement have been raised. Many studies in the area of out-of-home placement involve parents telling their stories some time after they have made the decision to seek out-of-home placement and after their disabled family member has made the transition from the family home. Researchers have raised concerns about the accuracy of memory in parental report (Bromley & Blacher, 1991) and the possibility that parents may try to justify their prior decision making processes (Cole and Meyer 1989). Blacher (1990) also contended that retrospective studies are more likely to result in out-of-home placement being seen as a discrete act rather than a gradual process. Baker and Blacher (2002) raised the issue that families who have sought out-of-home placement because they believe it will be more advantageous for them, are more likely to report more favourable family impacts related to out-of-home placement.

Siblings of adults with an intellectual disability

Both research on deinstitutionalisation, and research on out-of home placement have begun to recognize the importance of considering the roles and experiences of siblings of people with disabilities. The final section of this review focuses on the role of siblings within families that include a family member with an intellectual disability. This review focuses primarily on current research literature in the area of the relationships evident between adult siblings with and without an intellectual disability. It also highlights current issues related to this area – most notably the increasing need for adult siblings of men and women with an intellectual disability to assume care and/or decision-making roles in the lives of their brothers or sisters.

After having been virtually ignored in the research and policy literature as sources of support for adults with an intellectual disability (Krauss, Seltzer, Gordon & Friedman, 1996), adult siblings have gained increasing research attention over the past decade. This increased attention can be attributed to the fact that adults with an intellectual disability now experience a greater life expectancy and increasingly outlive their parents (Bigby, 1996; Braddock, 1999). This means that siblings may be expected to assume responsibility for their brother or sister with an intellectual disability. Understanding the perspectives of adult siblings as potential future care or support providers, and describing their current roles in the lives of their brother or sister with an intellectual disability is an important agenda for future policy development (Griffiths & Unger, 1994; Stoneman & Berman, 1993).

Secondly, a focus on siblings is an obvious outcome of the recognition that families (not just parents) play a central role in the lives of adults with an intellectual disability. Research indicates that families often constitute the most consistent and long-term relationships that people with an intellectual disability experience and therefore, the roles fulfilled by individual members need to be better understood.

Sibling relationships between children with and without disabilities

A great deal of information exists in the area of sibling relationships amongst child siblings with and without disabilities. Much of this research focuses on what parents , and in a smaller but growing number of studies, non-disabled siblings perceive as the positive and negative implications created by the presence of a child with a disability in the family (Gallagher, Floyd, Stafford, Taber, Brozovic & Alberto, 2000).

It has been common for researchers working in the area of sibling relationships to highlight the heightened awareness and understanding of difference that siblings of children with disabilities often experience (Burke & Montgomery, 2000; Harry, Day & Quist, 1998). However, research has also focused on the benefits that a child with a disability can bring to family life (Bray, Shelton, Ballard & Clarkson, 1995). Connors and Stalker (2003) conducted a two-year study of Scottish disabled children and their non-disabled siblings with the aim of fully including the voices and perspectives of children. Twenty-six disabled children aged between 7 and 15, along with 24 of their non-disabled brothers and sisters were interviewed about their daily lives. When questioned about their relationship with their disabled siblings most children who participated in this study described their relationship in positive terms. In Connors and Stalker's view this finding could be interpreted as challenging stereotypes of disabled children including their potential for reciprocal relationships.

Many parents have, however, expressed concern about the wellbeing of their non-disabled children. This is particularly common in family situations where parents are expending a great deal of time and energy caring for a disabled child in the home environment (Burke & Montgomery, 2000). Parents feel guilty about not being able to expend the same amount of time and energy on their non-disabled children (Evans, Jones & Mansell, 2001). Furthermore, parents have also expressed concern that their non-disabled children feel uncomfortable about having friends home because they feel embarrassed by their brother or sister with a disability. This concern has been found to be particularly pertinent when the disabled sibling has behaviours that are challenging for the family (Evans et al., 2001).

Concern for the well-being of siblings has resulted in a strong focus in the literature on support groups and strategies designed to assist children with disabled siblings to cope with the extra practical and emotional demands that they frequently experience (Burke & Montgomery, 2000; Evans et al., 2001; Lindsey & Stewart, 1989) This focus on support is particularly relevant given that research has consistently shown that concern for non-disabled siblings is one factor that is frequently influential in terms of families' decisions regarding out-of-home placement for children and young adults with disabilities (eg. Blacher; Llewellyn et al., 1999). This particular issue was discussed earlier in this chapter during the section on out-of-home placement.

Siblings relationships between adults with and without disabilities

As mentioned in the introductory paragraphs to this section, the relationships existing between adults with an intellectual disability and their non-disabled adult siblings have only recently been the topic of in-depth disability research. For this reason such relationships are not well understood. However, a number of studies have begun to identify important information and issues related to sibling relationships in adulthood.

In a longitudinal study of families that included an adult with an intellectual disability still living at home, Krauss et al. (1996) explored a variety of aspects of sibling relationships and expectations regarding future care-giving roles. One hundred and forty non-disabled adults participated in the study that identified that siblings generally maintained regular and personal contact, provided emotional support, and felt knowledgeable about the needs of their brother or sister with an intellectual disability. In cases where siblings had firm plans regarding the future care of their brother or sister with intellectual disability, 36% reported that they intended for their brother or sister to reside with them when their parents could no longer fulfil the caregiving role.

The study identified several factors that differentiated those siblings who were intending to provide long-term care for their brother or sister, and those who were planning to obtain residential care within the community based system. The first of these factors was gender. Findings indicated that sisters were more inclined to be

planning to co-reside with their sisters (rather than their brothers) with an intellectual disability. The second factor was level of intellectual disability. Co-residence was more likely when the adult with a disability had lower support needs. The third factor was current frequency of shared activity. If siblings enjoyed a high level of contact and shared activity they were more likely to be planning to live together in the future.

Krauss et. al contended that their study highlighted the inevitability of intergenerational transmission of care-giving but also the diverse ways that siblings will assume this responsibility. Further to this point Krauss et. al asserted the need to consider the impacts of this transmission of responsibility on the current community-based service system. For example the ability of the community-based system to respond to the additional demand for residential services needs to be considered. Unlike their parents, many siblings may not be able to care for their brother or sister on a fulltime basis, or may not choose to do so.

Orsmond and Seltzer (2000) extended the exploration of the gendered nature of sibling relationships. Using the same group of sibling participants as included in the aforementioned study by Krauss et al., Orsmond and Seltzer focused on the differences and similarities in how adult brothers and sisters negotiated sibling roles, relationships, and future care-giving expectations. A key finding of the study of 245 siblings included that sisters provided more care and companionship for their sibling with an intellectual disability than brothers provided. Interestingly, brothers of brothers with an intellectual disability had the most positive feelings about their siblings, but they had the fewest worries about future care. Brothers of sisters with an intellectual disability showed the opposite pattern. Orsmond and Seltzer interpreted this finding as having negative implications for women with an intellectual disability who may be at risk of reduced support if their most involved sibling is a brother. They also contended that there is a need for disability support services to recognize that future family involvement in services will inevitably involve siblings and therefore attention needs to be paid to considering the needs of adult siblings who fulfill care-giving or decision making roles.

Australian researcher Christine Bigby (1996) conducted qualitative research in the area of succession planning or planning for the future by elderly parent care-givers

of 62 adults with an intellectual disability. Bigby was interested in ascertaining the extent to which elderly parents plan for their disabled child's future when they will no longer be able to provide care. The research produced interesting findings related to the roles expected to be assumed by non-disabled siblings. In the situation of "key person" succession plans – that is, plans which were characterized by the planned transfer of responsibility from parents to a nominated person – eighty eight percent of the nominated key people were siblings. Specific expectations of the siblings were determined by the nature and quality of the family relationships and parents' informal networks. Where a person with a disability had more than one sibling it was common for one person to be expected to assume key person responsibility. Bigby also found that siblings were not involved in succession plans when a poor relationship existed between them and parents. The high level of expected sibling involvement in the care and/or necessary decision-making in the lives of adults with an intellectual disability indicated in this study provides further evidence of the need to understand the relationship between disabled and non-disabled siblings.

The need to consider the roles of siblings is furthered highlighted in the situation where non-disabled siblings fulfil legal roles for their disabled brothers or sisters. Siblings may become welfare guardians of adults with an intellectual disability. A recent New Zealand study (Bray, Dawson & van Winden, 2000) found that while the majority (75%) of welfare guardians were parents, 18% were siblings. Similarly to parents, non-disabled siblings frequently held a high degree of control over a range of aspects of their brother or sister's life.

While research and personal accounts have often included the views of younger people with disabled siblings, it is difficult to find similar literature including adult sibling accounts. Jacqueline Irving (1994) provided her perspective on this specific sibling relationship through her narrative account of her life with, and feelings toward, her older brother who had a disability. While Irving is clear that she loves her brother and feels proud of what he has achieved in his life, she holds a very negative view of the impact that his disability has had on her family. In particular she highlights the enormous physical and emotional pressures that were placed on her parents, firstly as they struggled to care for him at home, and then after he had been institutionalised against their wishes. She also talked of the bitterness and

resentment that her older sisters had toward their brother whom they perceived as taking up all of the family's emotional and financial resources. Even as adults, her three sisters refuse to have any kind of relationship with their brother with a disability for this reason. Irving's personal story provides a contrast to many sibling accounts and/or sibling research which has frequently identified the positive aspects of this specific family relationship.

Researchers have identified family members as comprising the only, or the most consistent social contact experienced by individuals with an intellectual disability living in community based residential services. Blacher and Baker (1992) asserted that despite this knowledge "researchers and policymakers have not paid much attention to the family's continuing role in the life of a member placed out of home" (p.35). They went on to say that the few studies which have explored this area have focused on counting the number of visits made by families rather than on the more important issue of the "content or contribution" of involvement. Blacher and Baker suggest that in order to facilitate meaningful family involvement in the lives of adults with an intellectual disability service providers need to be active in promoting a range of options that show families how they can relate to the service setting in which their relative is living.

The transition of adults with an intellectual disability from the family home into community based residential services, and the resulting impacts on family relationships was explored by Seltzer, Krauss, Hong and Orsmond (2001). Data for this study were collected from 461 families over an eleven-year period (1988-1999). Interviews were conducted with families where there was a mother between the age of 55 and 85, and who cared for a son or daughter with intellectual disability at home at the time the study commenced. This longitudinal study involved interviews with families occurring at intervals of eighteen months apart. A total of eight interviews have been conducted with families to date. Additional interviews with the "most involved" sibling (as designated by the mother) occurred at the time of the third and sixth interview.

The findings of this study showed that mothers and siblings of adults with an intellectual disability who moved from the family home during the time the study was being conducted were more anxious about the future for their family member

than mothers and siblings whose family member stayed at home. This is a significant finding in that it highlights that even families who make proactive decisions about transition from the family home continue to worry about those decisions. Siblings of the adults who moved from the family home maintained their usual level of involvement with their brother or sister and in some cases increased the frequency of their visiting directly after relocation had taken place. This pattern of involvement mirrored that which was reported by mothers of the adults with an intellectual disability who had moved from the family home. Seltzer et. al concluded that community based service providers should focus on facilitating sibling involvement because it is likely to be the longest lasting of all relationships, and therefore the most constant of all support that the adult with an intellectual disability is likely to experience.

New Zealand researchers O'Brien, Thesing and Capie (1999) explored the presence of "intimate connections" (close friendships) in the social networks of 54 people with an intellectual disability. They found an interesting comparison between staff's perceptions, family's perceptions, and the perceptions of the people with an intellectual disability themselves in terms of who were close friends in their lives. Staff indicated that they perceived staff to be the most intimate friendship for 41% of the focus people in the study followed by the person's sister (24%) and then their mother (22%). In contrast, the family member nominated the focus person's mother (55%), brother (56%) and sister (55%) as being the most intimate friends a person had. A further contrast was seen in the perceptions of the people with an intellectual disability themselves who classed their sister (89%) as their most intimate friend followed by other people living in the house (55%). O'Brien et al. commented that it appeared that each group nominated close friendships with people who reflected their own status.

Research that explores the issue of sibling relationships from the perspective of children and adults with an intellectual disability themselves is uncommon. While most sibling research approaches this topic from the perspective of non-disabled siblings, or from the perspective of parents, British researchers Davies and Jenkins (1997) provide an insight into the way disabled adults view such relationships. In a study of self-identity Davies and Jenkins found that young adults with an

intellectual disability can sometimes feel intense frustration when their siblings attain goals that are important but seemingly unreachable for them.

At a glance it appears that the issue of sibling relationships between brother and sisters with and without disabilities has been comprehensively explored. If one takes a closer look at this field of study, however, there are some significant gaps. Consideration of the relationships and related issues that exist between disabled and non-disabled adult siblings has occurred only recently. The focus on sibling relationships between children with and without disabilities has occurred in conjunction with the emphasis on family systems approaches to family research (Turnbull & Turnbull, 1990) and the notion that all children (including children with disabilities) belong in families.

In contrast, a significant number of today's generation of adults grew up in the context of institutionalisation being perceived as appropriate for many individuals with an intellectual disability. Family relationships within many families including a member with a disability were eroded by the removal of the disabled person from the family home. Deinstitutionalisation sometimes has the effect of enabling families to become re-involved in the life of their disabled family member. It is an expectation in many deinstitutionalisation processes that families will take a decision-making role regarding issues relating to resettlement. Some families need time and support in order to be able to pick up such roles again.

Research that includes an emphasis on adult sibling relationships is also necessary in order to better understand the experiences of and issues for families who have cared for their family member at home, or who have utilized community based intellectual disability services. It has always been the case that many families have always cared for their family member within the home environment. In the past it was common for disabled men and women to have a shorter life expectancy – that is, most did not outlive their parents. The life expectancy of men and women with an intellectual disability has now increased to the point that they are increasingly outliving their elderly parent caregivers. This means that the next generation of family, siblings, are having to assume care and/or decision making roles for their disabled siblings.

Heller (1998) commented on current trends in providing support for families of adults with an intellectual disability. According to this prominent family researcher an issue currently of particular significance relates to the role of siblings. *"As parents die, siblings are often expected to take over the responsibility, yet many are unprepared for the role and have rarely been included in family training efforts."* (p.22).

Heller elaborated with the following comment.

> As families are expected to take on greater roles in providing care, siblings may face greater difficulties than parents in assuming such roles. Given the vital role of siblings, the challenge to service providers is to form a partnership with them to support their ongoing involvement with their brother or sister. (p.22).

In a recent article Australian researchers Dew, Llewellyn & Balandin (2004) ask us to consider a number of issues they identify as critical to meeting the needs of the "new generation" of sibling carers and their families. After reviewing the literature relating to siblings who have a brother or sister with an intellectual disability. Dew et.al. contend that future research should explore the relationships that exist between non-disabled and disabled siblings including whether non-disabled siblings feel love and responsibility for their family member.

Implications for this study – why this research is necessary

The aim of this doctoral research was to examine issues that may influence the decisions that families make with regard to the deinstitutionalisation of their family members with an intellectual disability. While there is a significant amount of research in the area of family involvement in deinstitutionalisation, such studies frequently fail to address the complexity of families' responses to this major process of social change.

Australian ethicist Jayne Clapton (2003) contends that *"when considering the ethical decisions that impact on the membership of future societies it is critical to seek insight and wisdom by looking to past actions."* She went on to say that *"remembering the past is critical to understanding current and future decisions."* Whilst Clapton's comments were made in the context of a consideration of the impact of biotechnology on

people with an intellectual disability and their families, they have resonance within this doctoral research.

This doctoral research had the aim of providing an original contribution to this significant body of research by providing an in-depth exploration of the experiences of families. In doing so it had the aim of highlighting the complexity of families and the need for planners, policy makers and service providers to understand the heterogeneity of families and to recognize that meeting families' needs may mean that individual families require an individual approach in order to achieve positive involvement in deinstitutionalisation.

While families have been included as participants in a significant number of deinstitutionalisation studies, few studies have involved an in-depth exploration of the impact of this process on families or the decision-making processes employed by families in this situation. This thesis attempted to contribute new information that may be used to facilitate more positive family involvement within the process of deinstitutionalisation. It also has wider relevance to family involvement in intellectual disability services in general.

The research was also necessary because it considered the needs of New Zealand families involved in deinstitutionalisation. Despite what I might know about empirical research evidence available to support the positive outcomes of deinstitutionalisation, for the group of parents with whom I was working deinstitutionalisation was something new and unfamiliar. To many of them it represented a huge life change for their family members that they, for all kinds of reasons, believed to be unnecessary and potentially detrimental. This view was supported by Stancliffe, Emerson and Lakin (2000) in an editor's introduction to a journal edition dedicated to deinstitutionalisation research. Stancliffe et al. stated:

> There is still a need to try to build support for deinstitutionalisation among constituencies to whom it is a novel or threatening idea. We cannot assume that politicians, family members or the public will be informed about past success at institutional closure. Among those who may never have heard of Penhurst, St Nicholas or Darenth Park, or those from jurisdictions where deinstitutionalisation is a relatively new policy, it remains important to provide local, current evaluations. (p.11).

The literature reviewed for the purposes of this chapter also showed a strong link between the current policy and practice of out-of-home placement and the need for further information relating to how and why some families make the decision to seek permanent residential placements for their disabled children and young adults. The current study makes a contribution to this important area by examining the possible influences that may most strongly dictate the decisions that families make.

Finally, research that has analysed the involvement of siblings in the process of deinstitutionalisation is limited. Studies that have analysed family involvement in deinstitutionalisation have frequently mentioned the role of siblings but with a focus on siblings as surrogate parents (O'Brien et al., 1999; Tuvesson & Ericsson, 1996;). That is, siblings' views and experiences are sought in the situation where parents have died or are unable to take an active role in decision-making. Few studies have explored the dynamics and decision-making that occurs in families which include parents and adult siblings or other relatives who are all involved with the family member with an intellectual disability. This research aimed to explore the interpersonal relationships and dynamics that occurred within families and between family members as the process of deinstitutionalisation progressed.

This research was also intended to highlight the importance of sibling relationships between adult siblings with and without an intellectual disability – another area which has had a lack of research attention. Researchers, policy makers and disability service providers now agree that this relationship requires urgent attention as supporting sibling relationships may be a critical aspect of achieving positive family involvement in intellectual disability services. American researcher Victoria Damiani (1998) in her review of the literature relating to responsibility and adjustment in siblings of young children with disabilities stated that "...*future responsibility, whether real or imagined, can be a key factor in the cognitions and therefore emotional responses, of family members.*" (p.6).

Research in the area of family involvement in issues concerning their family members with an intellectual disability is and will continue to be relevant. Orlowska (1995) highlighted the significance of families in the lives of people with an intellectual disability and linked this significance to a "growing emphasis on the

importance of parents' views and participation in the planning and delivery of services on both formal and informal levels." (p.437). Fujiura (1998) extended this position still further after researching the demography of family households of families including a member with a disability:

> As a consequence of its size and composition, the family must be central to all deliberations involving disability policy. What adversely impacts the family may, in the end, adversely impact all components of the disability support system. (p.225-235).

It is against this backdrop of research literature that my research commenced.

CHAPTER FOUR

METHODOLOGY

An introduction to qualitative research

This doctoral research was undertaken within a qualitative research position. Denzin and Lincoln's (2000) description of the term qualitative research provides a sensible starting point for elaborating on the theoretical and paradigmatic approach that has been taken in this research.

> Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world into a series of representations including fieldnotes, interviews, conversations, photographs, recordings and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret phenomena in terms of the meanings people bring to them. (Denzin & Lincoln, 2000, p.3.).

The word "bricoleur" may be used to describe the multiple tasks and roles of the qualitative researcher (Denzin & Lincoln, 2000). Bricoleur means a "jack-of-all-trades" or professional "do it yourself" person (Denzin & Lincoln, 2000, p. 4) and thus would seem a useful term for articulating the fact that qualitative researchers often are required to utilize a range of strategies, methods or empirical materials in order to address the research question under study (Becker, 1998).

According to Denzin and Lincoln (2000) qualitative research is a set of interpretive activities that privileges no single methodological practice over another. Furthermore, qualitative research cannot be defined as having a singular theory or paradigm or distinct set of methods or practices of its own. Grbich (1999) supports this view and describes qualitative approaches as being complex and varied, thus allowing the researcher to study a situation from a range of positions and perspectives. This complexity and variation makes it critical for researchers who describe their work as "qualitative" to provide details about the particular

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philosophic frame of reference that they use to access, analyse and interpret the data in their study.

It is clear that it is not enough for qualitative researchers to simply come up with a good research question, to collect data and, subsequently, to say what that data means. To undertake these tasks without identifying the framework within which the design, collection and interpretation have occurred creates the potential for the researcher to be criticized for providing an interpretation based on his or her own preferences and possibly limited perceptions (Grbich, 1999).

Furthermore, to simply label a particular study as "qualitative" does not acknowledge that significant diversity exists among qualitative researchers in terms of the way that they approach research questions. Some researchers , such as Patton (1990), take a methods-based approach to qualitative research whereby they emphasize the methods and strategies commonly associated with qualitative studies. Qualitative researchers who ascribe to a methods-based approach are of the view that the researcher can participate in and document the world with minimal intrusion (Grbich, 1999). Such researchers hold to a positivist position with the belief that "reality" can be captured through careful application of qualitative techniques and can be reported on objectively.

The next section of this chapter describes an alternative approach to qualitative research, an approach which prioritizes the issue of paradigm over that of method and explains the significance of the researcher's paradigm position.

The importance of paradigm

It is becoming increasingly common for qualitative researchers to take a paradigmatic approach to qualitative research. In this approach the researcher articulates his or her particular way of seeing the world. This worldview has, in turn, theoretical and methodological implications for the research being undertaken (Grbich, 1999).

The term paradigm can generally be taken to mean "the basic belief system or worldview that guides the investigator, not only in choices of method but in

ontologically and epistemologically fundamental ways." (Denzin & Lincoln, 1994, p.105). A paradigm is then an interpretive framework from which a researcher can approach the topic that they wish to explore.

> The researcher must understand the basic ethical, ontological, epistemological, and methodological assumptions of each paradigm and be able to engage them in dialogue. The differences among paradigms and perspectives have significant and important implications at the practical, material and everyday level. (Denzin & Lincoln, 2000, p.162)

Guba (1990) contends that a paradigm is characterized by the way an inquirer responds to three questions that relate to their planned inquiry. The first question relates to the ontological position that a researcher takes. That is, how does the person view the nature of reality? The second question is linked to epistemology – what is the nature of the relationship between the knower and the known? The third question relates to methodology – how should an inquirer seek knowledge? These ontological, epistemological and methodological premises represent a basic set of beliefs that guide each researcher in his or her research activities. The research paradigm within which they work is determined by each researcher's answer to questions of ontology, epistemology and methodology.

Lincoln and Guba (2000) identify interpretive paradigms current in qualitative research as: positivism; post-positivism; critical theory; constructivism and participatory. Lincoln and Guba's articulation of the ontological, epistemological and methodological premises underpinning each of these alternative inquiry paradigms has guided the descriptions presented here.

The positivist paradigm

Positivists believe that there is an apprehendable reality, and that the findings produced through research can be objective and true. Positivists primarily use quantitative methods to achieve verification of research hypotheses but their belief in an objective reality discoverable by replicable methods is frequently evident in qualitative studies .

The post-positivist paradigm

Proponents of the post-positivist paradigm would contend that reality is apprehendable but only imperfectly and probabilistically and thus research findings are "probably" true. A wide range of methodological approaches are taken to arrive at such findings including, in some circumstances, qualitative methods.

The critical theory paradigm

Critical theorists believe in historical realism – that is, they ascribe to the notion of a reality shaped by social, political, cultural, economic, ethnic and gender values. Findings generated within this paradigm are acknowledged as subjective and value-mediated and dialogic and dialectic methodologies are used to generate knowledge.

The constructivist paradigm

Constructivists are relativists. That is, they believe that realities are present in the form of multiple constructions, based on the social experiences of those who hold them. Research findings within the constructivist paradigm are subjectivist and created (or constructed) by the process of interaction between the researcher and the research participants. Methodologies used within this inquiry paradigm are qualitative and hermeneutic or dialectic in nature.

The participatory paradigm

The participatory paradigm has recently been added to Lincoln and Guba's table of Alternative Inquiry Paradigms. This addition was made as a result of the work of Heron and Reason (1997) who contended that the participatory/cooperative research approach represented an important inquiry paradigm in its own right. Those ascribing to the participatory paradigm believe in a participative reality – that is, a reality that is both subjective and objective and that is co-created by mind and given cosmos. Inherent to the participatory paradigm is critical subjectivity and a focus on practical knowing and co-created findings. These are achieved through

the application of a methodology based on political participation, collaborative action, primacy of the practical and language appropriate to the context within which the inquiry occurred.

These descriptions of current alternative paradigms of inquiry have been included in this thesis as a way of introducing the paradigm (set of beliefs) that has guided me throughout the conducting of this study.

Various approaches to constructivism

When I wrote the original application seeking funding for this study I asserted that it would be conducted within a constructivist paradigm. Schwandt (1994) defined what he refers to as everyday constructivist thinking in the following way.

> In a fairly unremarkable sense we are all constructivist if we believe that the mind is active in the construction of knowledge. Most of us would agree that knowing is not passive – a simple imprinting of sense of data on the mind – but active; mind does something with these impressions, at the very least forms abstractions or concepts. In this sense, constructivism means that human beings do not find or discover knowledge so much as make it. We invent concepts, models, and schemes to make sense of experience and further, we continually test and modify these constructions in the light of new experience. (Schwandt, 1994, 125-126.)

As the study has developed over the past four years, thinking and analysis within a constructivist paradigm has retained its relevance. However, while Schwandt's "everyday constructivist thinking" provides a valuable overview of the basic principles of this paradigmatic approach, there are a number of specific constructivist viewpoints that can be taken. These specific constructivist approaches include: radical constructivism; social constructionism; feminist standpoint epistemologies; and a constructivist paradigm (Schwandt, 1994).

While these specific approaches to human inquiry are underpinned by "everyday constructivist thinking" they subscribe to alternative interpretations or applications of constructivist thought in particular areas. I have drawn on the work of Schwandt (1998) in order to provide a brief summary of each of these constructivist approaches, before discussing in greater depth the particular constructivist approach selected for use in the current study. I have attempted to demonstrate

their points of difference from the specific constructivist approach (a constructivist paradigm) taken in this study by describing how I would have designed and conducted this study had I been applying these alternative constructivist viewpoints.

Radical Constructivism

Radical Constructivism is closely associated with the work of psychologist Ernst von Glaserfeld (1991) who was particularly concerned with epistemological questions – the nature of knowledge and what it means to know. In von Glaserfeld's view knowledge is actually an activity or process rather than being a specific product that exists independently from the knower (Schwandt, 1998). Therefore, the validity of a knowledge claim is achieved if the claim is able to be used to achieve a goal, and knowing is possessing the ways and means of acting and thinking that enable people to achieve their goals.

To this end, if I had taken a Radical Constructivist approach to the current study I might have designed a study that had the capacity to allow me to implement one or more of the conclusions drawn from the findings generated by this study. I would have had the scope to "test" the validity of my study by checking to see if a recommendation or "claim" did result in a situation whereby study participants were more able to achieve a stated goal.

Social Constructivism

Social Constructivism is also underpinned by a rejection of the notion of an objective base for knowledge claims and is concerned with examining the process of knowledge construction. This approach, which is often associated with the work of Kenneth Gergen (1985, 1995), differs from radical constructivism in that it is concerned with understanding the shared, social constructions of meaning and knowledge.

> Contrary to the emphasis in radical constructivism, the focus here is not on the meaning-making activity of the individual mind but on the collective generation of meaning as shaped by conventions of language and other social processes. (Schwandt, 1998, p.240).

This approach is predicated on the assumption that how we understand the world is generated through interchanges (relationships) that occur among people. For this reason knowledge claims are only valid within a particular context or community where the conventions of language and other social processes are shared.

If the current study sat firmly upon the tenets of a social constructivist framework the emphasis on individual experience, choice and decision-making may not have been so pronounced. Rather the study would have focused more clearly on how families (as a collective group) involved in deinstitutionalisation interacted with other collectives, for example, those involved in implementing the process of deinstitutionalisation. In other words, analysis would have focused more on families' collective reactions to deinstitutionalisation rather than on the individuality and heterogeneity of families.

Feminist Standpoint Epistemologies

Feminist Standpoint Epistemologies are concerned with portraying the lived reality of women's lives (Schwandt, 1998). Feminist researchers who ascribe to feminist standpoint epistemologies are of the view that women's life experiences are not represented by current conceptualizations of social life. For this reason it is necessary to focus on the social construction of gender and to treat gender as a specific analytic category. Discourse analysis is a methodological approach used frequently to achieve the goals of feminist standpoint epistemology. Furthermore, feminist theorists and researchers are often concerned with the material or economic conditions of women's lives and therefore often combine analysis of discourse with political and economic research. Finally, it is also common for feminist researchers to include a strong focus on the social construction of the research relationship within their work.

My own research unquestionably shares a close bond with feminist standpoint epistemologies given my focus on the role of women, usually mothers and sisters, within the context of the deinstitutionalisation. This bond is also intensified through my interest in and the importance I attach to the social construction of the research relationship within my own work. Having said this, if I were to ascribe to

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this specific approach I would have needed to approach my research topic and shape my research questions with a clear focus on gender from the outset – I did not do this.

A "Constructivist Paradigm"

A "Constructivist Paradigm" is the fourth specific constructivist approach identified by Schwandt who describes this approach as a "wide-ranging and eclectic framework". Egon Guba and Yvonna Lincoln's "constructivist paradigm" was developed as a result of earlier work they termed naturalistic inquiry (Lincoln & Guba, 1985). Guba and Lincoln use the terms a "constructivist paradigm" and constructivism interchangeably when describing their particular constructivist approach (Guba & Lincoln, 1989). Their "constructivist paradigm" was proposed originally as an alternative to the positivist paradigm of inquiry.

Lincoln and Guba (1994) define the constructivist paradigm in the following way.

> The aim of inquiry is understanding and reconstruction of the constructions that people (including the inquirer) initially hold, aiming toward consensus but still open to new interpretations and information as sophistication improves. The criterion for progress is that over time, everyone formulates more informed and sophisticated constructions and becomes more aware of the content and meaning of competing constructions. (p.113).

Guba and Lincoln's constructivist philosophy is idealist, pluralistic and relativist (Schwandt, 1998). That is, this approach is based on the assumption that reality is a construction in the mind of the individual and furthermore, that there are multiple and often conflicting or contradictory constructions that are all meaningful. Similarly to those who ascribe to feminist interpretations of constructivist thought, Guba and Lincoln contend that the observer (researcher) cannot be seen as distinct from the activity of inquiry. This means that the findings of a particular inquiry (study) are themselves a creation or construction of the inquiry process - the researcher's reconstruction of a particular event. The reconstructions (findings) themselves are achieved through a dialectic style process of iteration, analysis, critique, reiteration, reanalysis which eventually results in a joint construction shared by the inquirer (researcher) and research participants. While I accept the notion of a joint construction, I question the term consensus. Consensus in my view

denotes shared understanding and agreement between researcher and research participants. While I believe that I eventually constructed findings that were viewed as trustworthy and authentic by participants, I am not sure whether the term consensus would be applicable in this situation. I will discuss this issue, and my views in relation to it, in greater detail later in this chapter.

The application of a "Constructivist Paradigm" in this study

My doctoral research has involved the application of constructivist thought according to the work of Guba and Lincoln. Guba and Lincoln's constructivist paradigm appeared to match my own worldview, and consequently, the research questions that I wished to pursue through this doctoral research. I wanted to understand how families interpreted and responded to a major process of social change. The fact that my research was planned to occur over an extended period of time appeared to support my choice of paradigm for this particular piece of research. I would be able to explore and chart the process over time of the development of participants' constructions (their interpreted experiences, attitudes and beliefs regarding deinstitutionalisation).

In order to demonstrate the constructivist framework underpinning my research , I have chosen to articulate critical aspects of Guba and Lincoln's "constructivist paradigm" further, and have linked them to the conduct of my own study. It is intended that in doing so the reader receives both a greater depth of information about constructivism as it is interpreted according to Guba and Lincoln and the theoretical and paradigmatic components of the current study. The remainder of this chapter on methodology describes a constructivist approach to: the nature of knowledge; knowledge accumulation; authenticity and trustworthiness, and values. Furthermore, these paradigmatic components are explored in terms of how they presented themselves, and were addressed within this study.

The nature of knowledge

Constructivism seeks to use individual constructions and re-constructions of a particular phenomenon in order for the researcher and research participant to develop a co-construction of experience. With regard to this research I gathered

families' stories in order to work toward developing an understanding of why families respond to deinstitutionalisation in the diverse ways that they do. Each time a family or individual told their story, they had a chance to further reflect on that story through the process of checking their interview transcript. They could further develop their construction of events at this point, or choose to leave it as it was.

However, because I interviewed people more than once over a period of time they had the ability to reflect on their earlier constructions, for example their attitude toward or response to plans for deinstitutionalisation. I believe it was this repeated interviewing that allowed participants to develop more informed and possibly more sophisticated understandings of their earlier constructions of deinstitutionalisation. This provided the context for interrogating present constructions. If I had not been involved in conducting research with these families they would not have had to confront their previous and often contradictory views and actions as the deinstitutionalisation process progressed. An example of this can be seen in the fact that some families who were strongly opposed to deinstitutionalisation during the first interviews were incredibly positive by the time of the second interview. How families reconstructed this acute change in attitude became an important focus for this research.

It is important to mention here how the application of constructivist thought in the current study differed in one area from that proposed by Guba and Lincoln. Guba and Lincoln include the aim of achieving consensus between the researcher and the research participant as one aspect of taking a constructivist approach. As I referred to earlier in this chapter (refer p.81) I did not achieve nor have the intention of achieving consensus either between myself and individual participants, or between the families who participated in this study. I do believe however that a reconstruction of a range of family experiences of deinstitutionalisation was achieved.

I suggest that one of the strengths of this study is that it highlighted the complexity and diversity of families' experiences within a specific context – the major process of social change referred to as deinstitutionalisation. I believe the term consensus suggests that all participants would have had to agree with my reconstruction of

family involvement in the process of deinstitutionalisation. That was not the intention of this research. Rather my analysis and reconstruction of the experience of deinstitutionalisation reflects the diverse views of the thirty-five families who took part in this study. It also reflects my own views and interpretations of this process that have been shaped by both my personal and professional experiences of disability and family.

Knowledge accumulation

The constructivist approach of this thesis sought to generate increasingly informed and sophisticated reconstructions of a particular phenomenon. This study was conducted in an area that has been the subject of a great deal of research exploring the issue of family involvement in deinstitutionalisation. The originality of the present study was the focus on understanding families' responses to this major social change and, subsequently, on illuminating their decision-making processes related to this change. I was committed to striving to understand why families reacted and responded in the way that they did. This approach differs from simply describing how families reacted which has been the focus of much of the previous research in this area. As I was not personally involved in the process of deinstitutionalisation being implemented at Templeton Centre I sought to understand families' experiences vicariously – another feature of the participant-researcher relationship inherent to constructivist inquiry.

Authenticity and trustworthiness

While researchers who ascribe to positivist paradigmatic approaches might judge "quality" by applying their standards of rigour such as internal and external validity, reliability and objectivity, a constructivist is concerned with concepts of trustworthiness and authenticity. Authenticity and trustworthiness are concepts that provide an alternative way of exploring issues of rigour in research. In using these concepts as a means of assessing quality the researcher must confront the enduring debate about how to assess the presence or absence of trustworthiness and authenticity within qualitative research. Authenticity and trustworthiness were qualities that I believed were integral to my relationship with participants and to the process of reconstructing my research findings.

Janesick (2000) suggests that qualitative researchers should replace the concepts of validity, generalizability, and reliability with "qualitative referents". It is Janesick's view that the terms validity, generalizability and reliability are all terms from the positivist paradigm and therefore efforts to replicate such concepts within qualitative research are misguided.

> I think it is time to question that trinity and the use of psychometric language, and in fact to replace that language with language that more accurately captures the complexity and texture of qualitative research. (p.393).

Families participating in the present study had different views and attitudes toward their family members with intellectual disabilities, toward the notion of deinstitutionalisation and toward the community based disability system. This meant that my reconstruction had to, as much as possible, reflect the diversity of those views and experiences. Families may not share the experiences or views of some of the other participating families but my reconstruction needed to be perceived as authentic by the participating families. I believe this authenticity was achieved by providing an account that enabled individual families to understand the reactions, responses and decision-making of other families involved in the same process but not necessarily experienced in the same way by them. What I wanted to achieve was a reconstruction of families' experiences that was viewed as authentic - that is believable and understandable, by the families who took part in this study, and by other families who may be involved in similar processes in the future.

Patti Lather (1986) provides one way of looking at the notion of authenticity and trustworthiness. Lather provides what she refers to as a re-conceptualization of validity "in the hope that it will aid those of us who work within openly ideological research programs to focus more of our energies on how to best establish data credibility." (p.90). In Lather's view researchers need to design qualitative studies to incorporate the following components:

- Triangulation - inclusion of a variety of methods, data sources and theories within a single study.
- Reflexive subjectivity - discussion of how the researcher's assumptions have affected and been affected by the data.

- Face validity – incorporation of a process whereby participants provide feedback on emerging analysis and conclusions.
- Catalytic validity – discussion of how the research has led to insight and/or activism on the part of the research participants. (Lather, 1986, p.97).

While I believe that I addressed these components to varying degrees in the current thesis, I have chosen to use the "blueprint" for assessing authenticity put forward by Sears (1992). Sears proposes that three questions are integral to assessing whether authenticity has been demonstrated in qualitative research.

> The test is not to remain objective but one's capacity to be empathetic. Proper questions are, Have you immersed yourself in the world of the other? Have you portrayed the richness and complexity? And have you treated your informants/characters with respect and understanding. (p.149).

If this is one standard by which to judge authenticity and trustworthiness then I believe that I have gone some way toward achieving this quality within the current study.

Have I immersed myself in the world of other? My relationship with study participants occurred over an extended three- to four-year period during which repeated interviews, conversations and exchanges took place. This relationship began and continued throughout an extremely emotional period in their lives. It was my aim to understand their "lived experiences" during this time. I did this by treating every participant's story as important to the eventual process of creating a reconstruction of families' experiences of deinstitutionalisation. I attempted to understand participants' responses, reactions, and actions rather than to judge them as effective or non-effective, or as well reasoned or ill-conceived. I stayed the distance and upheld my early promise to families – that is, the promise to tell their stories regardless of the choices they may have made for their sons and daughters with intellectual disability. I believe that I immersed myself, as much as possible, in the world of other – in this case the families and individuals who chose to participate in this research.

Have I portrayed the richness and complexity of the lives of my research participants? As I argued earlier in this chapter, the richness and complexity of families was the focus of the study and a significant interest of mine as I entered this study. The findings generated through the study have served to highlight the notion that all families are different. The complexity and heterogeneity of families is at the heart of this thesis and is the quality that enables the data to be translated into research findings with meaning.

Have I treated my participants with respect and understanding? As a qualitative researcher working within the constructivist paradigm I am of the opinion that values must be at the heart of all researcher/research participant relationships. My personal and professional values mean that I take the position that a research relationship must exhibit elements of reciprocity, and that a critical feature of such a relationship is respect. The importance with which I treat the issue of respect for research participants is demonstrated through the inclusion of a discussion of methodological issues in Chapter Nine of this thesis.

Values

The above issues are extended further in considering the role of values in constructivist research. As one aspect of ensuring the trustworthiness and authenticity of the research, the researcher's own values are seen as formative within the research and therefore necessary to explicate early in the research process. Some qualitative researchers have described this process of one of locating oneself within the context of the research.

I was confronted with the need to take ownership of my own values very early in the research process. I was in the position of asking families of people with disabilities to talk to me about their experiences of deinstitutionalisation at a very difficult time in their lives. They were families who had, for a range of reasons, chosen to seek institutional care for their relatives in the past. They were also families who were concerned about the impact of deinstitutionalisation, and who were in some cases, openly and actively opposed to change. What were my values? In the first instance I was a researcher representing a research institute that promotes research and education in the area of disability and that advocates for

community integration and disability rights. Given that this was my professional context it was clear that some families may not automatically trust me as a person who could reconstruct their stories in a way that was meaningful to them.

A common situation in the early phases of this research was for families to ask me "what I thought about deinstitutionalisation". I perceived this to be a question about my values. I decided that I had to answer this question with as much honesty as I could, without being disrespectful to the views of the person asking me the question. In most cases I talked about deinstitutionalisation in terms of what I had seen in my local community, and in terms of the experiences of people with disabilities that I knew and worked with in the community environment. This gave participants a clear picture of my values – that is, my belief that all people with disabilities should have the right to live in, and to be part of their local communities. However, I was careful to acknowledge my (real) empathy toward families' concerns and that I was very committed to understanding their concerns. Furthermore, I was also committed to producing research that could have an impact on ensuring that positive family involvement would be a feature of major changes in service delivery in the future.

The issues covered here are integral to conducting research underpinned by "a constructivist paradigm". They relate to the thinking that informs the research process, and the interaction that exists between researcher and participant. The next part of this thesis outlines the process implemented to conduct the research. According to Denzin and Lincoln (2000), *"Strategies of inquiry put paradigms of interpretation into motion."* (p.22).

I describe the strategies of inquiry used to set up this study and to collect and interpret data in Chapter Five - Method. I have chosen to keep methodology and method as two separate chapters in order to achieve greater clarity for the reader. However, given that I have taken a paradigmatic approach to this study it may be clear that my own worldview assumes that methodology and method are inextricably linked within the endeavour of qualitative research.

CHAPTER FIVE

METHOD

A research design describes a flexible set of guidelines that connect theoretical paradigms first to strategies of inquiry and second to methods for collecting empirical material. (Denzin & Lincoln, 2000, p.22)

The context for this research

It is important to provide the context within which this research developed. When I commenced this doctoral research I was employed as a researcher with the Donald Beasley Institute in Dunedin, New Zealand. The Donald Beasley Institute is an independent organisation involved in research and education in the area of disability, with a specific focus on intellectual disability. I had worked on a range of research projects during my time with the Donald Beasley Institute, and had developed a special interest in family research.

In the mid-1990's we began taking note of plans for the deinstitutionalisation of Templeton Centre believing it was important to conduct a thorough exploration of the closure process due to occur. In 1997, the Donald Beasley Institute was successful in securing funding from the Health Research Council of New Zealand to document, describe, and analyse the closure of Templeton Centre. In my role as researcher with the Donald Beasley Institute I had been responsible for the development of this research application to the HRC, under the supervision of the Director of the Institute – who later became one of my thesis supervisors.

The HRC research took place over a period of four years and had the general aim of providing families with an opportunity to articulate their views, experiences and understanding of the process of deinstitutionalisation. Specific goals for the HRC study included:

- To identify the major variables affecting families' historical decisions to choose institutional services for people with an intellectual disability.
- To understand the reasons for families' current concerns regarding the deinstitutionalisation and eventual closure of Templeton Centre.
- To document families' experiences of the period of transition from one model of service delivery to another.
- To determine families' expectations and evaluations of service quality for people with an intellectual disability and how these expectations and evaluations are formed.
- To evaluate processes aimed at ensuring families' involvement during the closure of Templeton Centre and the development of new models of service delivery in the community from the families' own perspectives.
- To identify changes in the concerns and aspirations of families as the process of service delivery change is accomplished and to determine reasons for these changes.

As is clear from the stated research goals, families' views and perspectives were integral to the HRC research. However, while data gathered from families have always been the key component of the HRC study, the design of the HRC study also incorporated the views and experiences of other individuals involved in implementing the process of deinstitutionalisation. Data gathered through interviews with such individuals and organizations were referred to as key informant interviews. Historical data and data obtained from media representations of the Templeton closure were also collected.

Given that I was part of the research team that gained funding from the HRC to conduct a study of the Templeton Centre closure I then made the decision to seek permission to pursue my doctoral research within the context of the study. This seemed to be an appropriate decision given that I had been responsible for developing the research proposal in the first instance, and because the study reflected my research interests. We approached the HRC with the request that I be granted permission to conduct my doctoral research as part of the funded study. The HRC approved this request. I then made an application to the University of Otago to be accepted as a candidate for the degree of Doctor of Philosophy, an application that was approved in 1997.

Ethical Approval

After research funding was secured, and I had been approved as a candidate for the degree of Doctor of Philosophy, I undertook the process of gaining ethical approval. The HRC study was assessed and approved by two registered Ethics Committees prior to commencing. The study received ethical approval from both the Otago Southern Regional Health Ethics Committee and the Canterbury Southern Regional Health Ethics Committee. At the time ethical approval was sought both these committees were administered through the Dunedin and Christchurch offices of the Southern Regional Health Authority (SRHA). These Ethics Committees are part of the New Zealand system of ethical review of health and disability research. Multi-centre approval was required because I planned to recruit research participants in Otago and Canterbury. In this situation ethical approval must be sought from all relevant accredited ethics committees in localities from which participants are to be recruited. As part of the ethical approval process the fact that I was intending to use aspects of the data for my PhD was discussed and approved.

What is the difference between this doctoral research and the HRC study?

The present thesis reports on data gathered from the thirty-five families who participated in the HRC study. The data were used to explore specific questions central to this thesis:

- What factors influenced families' earlier decisions to choose institutionalisation for their disabled relatives?
- Who and/or what influences the decisions that families make about transition from institutional to community based services?
- How do siblings interpret the experience of institutionalisation and deinstitutionalisation?
- How do families experience the impact of the transition of their disabled relatives from institutional- to community based disability services?

These questions illustrate the strong links between the HRC study and the focus of the doctoral research. The present study focused on a defined topic area that was

less expansive than that explored in the HRC study. The doctoral research had a particular emphasis on how families made decisions about institutionalisation and deinstitutionalisation, and specifically sought to explore the experiences of siblings, and the roles they fulfilled during such processes. Family relationships and functioning within the context of this complex process of social change - deinstitutionalisation - were studied by focusing solely on data collected from families during the HRC study. All research methods described below were used to conduct this doctoral research and were ethically approved according to the process described earlier in this section.

Why is this research about families?

The decision to conduct this research on families was based on several considerations. The first of these considerations was the views and suggestions of the families of Templeton Centre residents. In preparation for the HRC research proposal a group of families were consulted about what they thought would be useful and appropriate research. As a disability researcher I was convinced of the need to conduct New Zealand research on deinstitutionalisation. However, it was important to establish whether this view was shared by families as one of the groups most directly affected by institution closure.

As I referred to in the introduction of this thesis, a meeting took place in a Christchurch home with a small group of families during 1995. The families were all members of the Templeton Centre Parents' Association (TCPA), an organisation that historically had fulfilled a variety of functions for Templeton families. The families who were consulted were all members of the TCPA. The reason that the TCPA was approached to take part in this consultation was that they were a visible and accessible group of parents. At that stage it was impossible for me to talk to parents who may not have been members of the TCPA because I did not know who those parents were. While it is important to acknowledge that the comments and views of this group may not necessarily have been representative of the diverse range of families involved in the deinstitutionalisation of Templeton Centre, this group did agree that there was a need for independent research into family experiences of deinstitutionalisation.

The people attending this meeting felt that families had not had the opportunity to have their experiences, views or opinions heard. For this reason the group supported a research approach that would incorporate, as data, the concerns and aspirations of families. Consultation with this group also alerted me to the need to conduct the research in a way that would incorporate the families' experiences around the time of their earlier decisions to seek institutional care for their family member(s) with an intellectual disability. Issues related to meeting the needs of individual family participants became a critical focus of this research. This consultation process was independent of the recruitment of participants that occurred later in the research.

A second consideration built into the design of the study was the available research literature on family involvement in deinstitutionalisation processes. As detailed in Chapter Three, a significant body of research has explored family involvement in institution closure. While families have been credited with exerting some of the early pressure to close institutions, the research literature has more consistently highlighted family resistance to the process of deinstitutionalisation. After exploring the literature it was clear that there was a need for research that sought to understand the reasons for family resistance, and the decision-making processes that families employed when faced with a major change in service delivery for their disabled family member. It was also evident that little attention had been paid to generational issues within families and, in particular, how different family members responded personally to deinstitutionalisation.

A third consideration that shaped the focus and design of this doctoral research was my previous research experience with families of children with disabilities (Mirfin-Veitch & Bray, 1997; Mirfin-Veitch, Bray & Watson, 1997). This earlier research explored the issue of support within families that included a child with a disability. In particular, support relationships that existed between parents and grandparents of disabled children were studied. This research found that grandparent provision of support (or lack of provision of support) could not adequately be explained in terms of grandparent acceptance or non-acceptance of a grandchild with a disability. This finding departed from most of the available literature at that time which tended to explain grandparent support as an issue determined by "how well" a grandparent had adjusted to or accepted the fact of

their grandchild's disability. However, this New Zealand research suggested that the availability of support within families was dependent on the type of family functioning, intergenerational relationships, and patterns of helping behaviour that had existed within families prior to the birth or diagnosis of a child with a disability. It was at this point that my research interest became centred on the complexity of families, and more specifically, on how this complexity interacts with issues related to disability. The complexity and heterogeneity of families remained a constant theme within this doctoral research.

Asking families to take part

This research began at a time of great emotion and anxiety for many of the families of Templeton Centre residents. Many families were angry and upset about the proposed changes, while other families were simply confused about what the closure of Templeton Centre would mean, in real terms, for themselves and for their disabled family members. As families were already feeling excluded and ill informed about some (or all) parts of the deinstitutionalisation process it was important to me to ensure that all families felt included and well informed about our intention to conduct this research regardless of whether or not they wished to be involved as participants.

The most obvious way of contacting all families was through the Templeton Centre database. In order to achieve this it was necessary to ask for the assistance of Templeton Centre management and administration staff. Of paramount importance was maintaining the privacy and confidentiality of Templeton Centre residents and their families.

An information pack detailing plans for the research was prepared and then distributed to all individuals identified as next-of-kin by Templeton Centre administrative staff. This package was accompanied by a letter from the (then) Templeton Centre manager who assured families that the research team had not had access to families' personal information and that the distribution of study information had been handled entirely by Templeton Centre staff (Refer Appendix 1). Also included in the information package was a form that was referred to as the next-of-kin questionnaire (Refer Appendix 2).

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By completing and returning the next-of-kin questionnaire families indicated their intent or willingness to participate in the research. If families did not want to take part they simply did not respond to the information package and at no time was their identity revealed. This was seen as the most appropriate way of ensuring that all families were informed about the study but did not feel pressured or coerced to take part. This feeling of pressure or coercion may have occurred, if for example, an organisation such as the Templeton Centre Parents' Association had been used to distribute information. This was recognised as a particular risk for families who may have held views about deinstitutionalisation that were at odds with the collective, public position taken by the TCPA at the time, which was to oppose the complete closure of Templeton Centre.

The next-of-kin questionnaire had a second purpose. As well as a method for signalling participant interest, the questionnaire was also used to facilitate a process for selecting a sample from the total population of possible participants. When the information was posted to the parents/next-of-kin of 455 Templeton Centre residents there was no way of predicting just how many people would be interested in taking part. It was possible, however, that more families may have wished to participate than would be able to be included within the study. With this point in mind the next-of-kin questionnaire was designed to generate basic information necessary for selecting a manageable study sample, which reflected the diversity of Templeton Centre residents and their families

Sample selection was based on a number of specific criteria that would allow the aims of the study to be achieved. These criteria included that: each person electing to take part in the study must have been involved in, or be familiar with, the original decision to seek institutional care for the family member with an intellectual disability. They must also have been involved in the (then) current decision-making regarding resettlement and the change in services for that same person. While those selected for the study all assessed themselves as meeting these criteria, it became clear upon commencing the research and getting to know individual participants that their level of information about or involvement in these issues was sometimes scant. What was usually true of people who wished to take part in this study was a strong view, or a strong emotional reaction to the planned deinstitutionalisation process.

The next-of-kin information served the important function of allowing me to get a sense of the people most closely affected by the planned institution closure – the men, women, and children with an intellectual disability themselves. Demographic information sought about the person with intellectual disability included: age; gender; date of admission, length of stay; level of disability (as perceived by the study respondent); and relationship of respondent to the person with an intellectual disability (eg. sibling , parent, cousin, grandparent). It also asked the person filling out the participant interest form to provide details of "other" family members who wished to be part of the interview process. This information provided me with the earliest data from families.

Families and individuals were selected, as much as possible, to reflect the diversity of Templeton Centre residents and their families. The selection process described above was also essential because I did not have the resources to include all families of Templeton Centre residents. It was very important to me to acknowledge the support of those families who were interested in but unable to be included in the study. Families in this position were kept informed of the progress of the study as it proceeded and received research reports on study findings that they were invited to provide feedback on.

What do I mean by "families"?

It is important to explain my use of the term "families" in this research. In contrast to most deinstitutionalisation research, rather than focusing solely on the views and experiences of parents the active participation of a broad range of family members was sought. A focus on families rather than parents was necessary for two reasons. First, it was clear that some Templeton Centre residents would no longer have parents alive or that other family members may have taken over the responsibility of being involved in decision-making relating to provision of care. Equally as important to me was the notion that not only parents but rather entire families may be affected by major changes in service delivery. An important aspect of this research was the exploration of such impacts from the perspectives of different family members. The interactions that occurred between individual family members were an important focus in this research. To pursue this focus the inclusion of "other" family members (and not just parents) was necessary.

Who were the participants?

After choosing a sample and completing informed consent procedures, the study commenced. Thirty-five families took part in the research from a total number of sixty-five families who wished to participate in the study. Within the thirty-five families who participated in the study, sixty-five individual family members participated in interviews and provided information necessary to meet the aims of this study. As was anticipated prior to the commencement of this study, parents of Templeton Centre residents, rather than other family members comprised the majority of participants.

Forty-three of the sixty-five individual participants were parents or step-parents. Fifteen couples participated in joint interviews while four fathers and nine mothers participated in individual interviews. Thirteen sisters and seven brothers who had a family member with an intellectual disability living at Templeton Centre participated in interviews. Finally, one grandparent, one niece and one aunt talked about their views and experiences related to the deinstitutionalisation of their family member. In summary, eighteen of the participating family groups included other parents as well as other family members (e.g. sibling, grandparent, niece, aunt). Five of the eighteen family groups did not include parents.

While it is important to reiterate that the men, women, and children who were being resettled from Templeton Centre were not active participants in this study, it is relevant and necessary to provide some information relating to the people with an intellectual disability who were the focus of families' contributions to this study. The families provided information about thirty-six people with an intellectual disability who were soon to be resettled from Templeton Centre (one family had two family members living at Templeton Centre).

The diversity of the characteristics of the final sample is reflected in the contents of Table 1, Table 2 and Table 3 that provide information relating to Templeton Centre residents' age of admission, the date of their admission and their gender.

TABLE 1: Residents' age of admission to Templeton Centre

Age (yrs)	0 - 4	5 - 9	10 - 14	15 - 19	20 +
No. N = 36	5	16	6	7	2

TABLE 2: Residents' date of admission to Templeton Centre

	1950-1959	1960-1969	1970-1979	1980-1989	1990-2000
Fulltime admissions N = 32	4	9	9	10	0
Shared care admissions N = 4	0	0	1	1	2

TABLE 3: Residents' gender

Male	23
Female	13
N =36	

One component of the next-of-kin questionnaire sought information pertaining to the level of disability experienced by their family member as perceived by the family. In this initial information gathering process nineteen families described their family member as having a severe disability, thirteen families described their family member as having a moderate disability, and three families described their family member as having a moderate to severe disability. One family did not provide any information on this issue. Upon getting to know this family it became clear that they did not believe their family member had an intellectual disability at all.

Collecting data for the study

The research interview

The research interview was the primary strategy implemented to collect data for this study. Research interviewing now commands an extensive research literature of its own (Fontana & Frey, 2000; Kvale, 1996; Limerick, Burgess-Limerick & Grace, 1996; Oakley, 1986; Schuerich, 1995). While qualitative researchers commonly employ the strategy of interviewing to collect data, it has been less common for the inter-personal issues associated with interviewing to be described or explored in research reports. It is my view that considering and in some cases analysing the inter-personal issues and exchanges that occur during the research interview is critical to achieving authenticity through explicating interpersonal context issues within the research environment. I have included further information pertaining to this point in Chapter Nine of the thesis.

Feminist researcher Ann Oakley made the following statement regarding interviewing in feminist research. *"Interviewing is rather like marriage: everybody knows what it is, an awful lot of people do it, and yet behind each closed front door there is a world of secrets."* (p.31). Oakley contends that researchers are usually concerned with documenting how many interviews were conducted in a particular study, how long they were, and what questions were asked. Conversely, Oakley believes that researchers are less likely to comment on: the social/personal characteristics of the interviewers; interviewees' feelings about being interviewed; interviewers' feelings about the interviewees; hospitality; interviewees' attempts to use interviewers as sources of information; and the extension of the interviewer-interviewee interaction into more broadly based social relationships.

These are all facets of the research relationship that interested me as I pursued my doctoral research. The "mythical" objective interviewer/interviewee relationship was not a feature of my research experience, nor did I intend it to be. I was confronted with very clear messages relating to how some interviewees felt about being interviewed – one could not assume that voluntarily consenting to participate meant that an individual was entirely comfortable with the research process. If I am to be brutally honest I would have to admit to "liking" some participants more than

others. I was offered and accepted incredible hospitality from many participants (eg. meals, and in one case an overnight stay). Equally, I reciprocated with providing information relating to a broad range of issues on the disability spectrum. Finally, my relationships with some participants developed into more broadly based social relationships whereby my life events were sometimes acknowledged by participants (eg. the birth of my first child) and significant life events of participants were acknowledged by me (eg. family weddings and other special events).

Limerick, Burgess-Limerick and Grace (1996) explored the issue of power relations in the research interview. Like Oakley did ten years earlier, these feminist researchers concluded that existing models for conceptualising the research interview were inadequate. In particular, the assumption that the interviewer is automatically the most powerful person in the interviewer-interviewee relationship is too simplistic. Limerick et al. contend that the power relationship shifts between interviewer and interviewee at different stages and times during an interview. These authors use the imagery of the interview being like a "gift" to illustrate the exchange that takes place between interviewer and interviewee. Limerick et al. make sense of the need to re-examine the research interview in greater depth by explicating the importance of the research interview.

> Interviewers are a critical source of data for many research questions. The quality of the research interpretation and analysis depends on the quality of the text generated in the interview. The text generated in an interview depends on the relationship between the interviewer and interviewee. Understanding this relationship is essential to research based on interviews. (p.459.)

The issue of researcher-participant relationship became a strong focus and concern for me as I conducted this study.

How the research interview was used in this study

Data used to develop this thesis derive from interviews conducted with research participants at three distinct points in the deinstitutionalisation process: prior to their family member with an intellectual disability making the transition from Templeton into an alternative model of residential service; 1-3 months following

the resettlement of their family member; and one year following the resettlement of their family member. While this timeline was intended to be rigidly adhered to, the reality was that these timelines were sometimes altered to meet the needs of individual families, or because the critical contact had not been made. I was largely reliant on families to inform me as soon as their relative had been resettled from Templeton Centre. If they forgot to do this I sometimes missed the intended timing for the second interview so this was undertaken later than planned for.

The interviews ranged between one and three hours in length and took place in a location of the participant's choice. Usually this was the participant's own home or, in a few instances, their place of work. In one instance, a participant chose to be interviewed in my office as he did not want to discuss the issues relating to his family member with an intellectual disability in his own home environment.

All interviews were taped with the consent of each individual participant. Only one participant did not have her interviews taped and in this case an alternative method for dealing with her interview data was developed. In this case we had an un-recorded interview. I then wrote complete notes as my reconstruction of this interview which I then submitted to the participant. She then had the opportunity to contribute or to change this account and to signal when she was happy for it to be included as data for the study. More comprehensive details of the reason for this adaptation to the intended research process is provided in Chapter Nine as part of a discussion of methodological issues encountered during this study.

The audio-taped interviews were transcribed, checked, and returned to the research participants who then had the opportunity to change, correct, add or delete any information. This process represented an additional dialogue between myself and the research participants. It also represented an opportunity for participants to reflect on their own contributions to the study. While this process is common practice in qualitative research I came to see the process as significant to the constructivist framework that underpins this research.

The research interviews were unstructured but assisted by the use of an aide-memoire to ensure that similar topic areas were raised with each participating individual or family group (Refer Appendix 3). "Unstructured interviewing can

provide a greater breadth of data than other types, given its qualitative nature" (Fontana & Frey, 2000). It was common for families to have a particular topic or issue that they were particularly concerned about or focused on. The unstructured interview approach provided the scope to pursue the issues and topics that families perceived as important.

Following a more structured interview format may have led to a situation where this study failed to capture "families' lived experiences" of the process of deinstitutionalisation. I also believe that an unstructured interview format was appropriate for the sensitive nature of the topic explored for the purposes of this doctoral research. One component of this study is about how the families responded to the fact that a member(s) of their family has an intellectual disability. The study was also about a process of major social change – social change which challenged the way that the families who participated in this study had constructed disability and disability services within their own lives. Providing an interview environment in which families had the scope to explore institutionalisation and deinstitutionalisation as it impacted on their lives was critical to meet both families' needs as participants and, more pragmatically, my needs as a researcher.

The first interview represented a chance to get to know families and to begin to establish the level of relationship critical to conducting longitudinal research in this sensitive area. The first interview included: a discussion of families' past decisions to seek out-of-home placement (institutionalisation) for relatives with an intellectual disability; how they perceived the service that their family member had received at Templeton Centre; contextual information relating to how long families had been aware of the possibility that Templeton may close; family reactions to the announcement of the planned closure; how they planned to approach the resettlement of their relative from Templeton Centre. Also critical in this first interview was the time spent talking with families about their family member with an intellectual disability and how they perceived that person.

The second interview commenced with a discussion of the views, perspectives and opinions that the family had shared during the first interview. This served the dual function of reminding families of the information they had shared during the previous interview, and of highlighting the ways in which families' attitudes may

have changed or stayed the same during the period that had lapsed between interviews. Topics that were critical in the second interview included: family decision-making relating to the planned resettlement of their relative; who and what influenced their decision-making; families' experiences of the actual transition from Templeton Centre into a new disability service; and their views of the new disability service.

Essential to the third interview was a reflection on the process in which families had been involved as they had made the journey with their family member with an intellectual disability from Templeton Centre to a new model of disability service. Included in this reflective process was the opportunity to discuss how and why attitudes had changed or, in a few cases, had not changed. The third interview also served the function of giving families the opportunity to articulate what were critical aspects of the process of deinstitutionalisation and the way it was implemented for the families involved. This area of questioning aimed to generate information that could be used to develop strategies for positively involving families in major changes in service delivery for people with disabilities in the future. Finally, this third interview phase gave families a final opportunity to discuss their family member with an intellectual disability – the most important figure in the process they had just undergone – and to reflect on how that person had been affected by resettlement.

The progressive and repeated interviewing that occurred as part of this study fitted with a constructivist framework. As each interview occurred participants had the chance to reflect on their earlier comments, and to make sense of their current thinking about the major process of social change within which they were immersed. The process of repeated interviewing also enabled some participants to reflect on their own views and perceptions (constructions) of their family member with an intellectual disability.

It is important to note that the three interview stages that occurred as part of this study did not occur at neat, pre-determined intervals. All families participated in their first interview during a two month period during July and August 1997. After the initial interview, and despite carefully laid plans, the second and third interviews took place according to a rather haphazard timeline. This was largely

due to two reasons. First, families chose for their family member to be resettled from Templeton Centre within their own personal timeframes – that is, some families had relatives in a group of the first people with an intellectual disability to move from Templeton Centre while other families refused to consider the possibility of their family member moving until well into the resettlement process. I had made a commitment to follow families' journeys regardless of how fast or how slow that journey turned out to be.

Secondly, the Templeton Centre deinstitutionalisation process took over a year longer than had originally been planned by those individuals and organisations responsible for the process. The delay was due in part to the strong resistance to, and lobbying against closure by some families. It was also due to the fact that the network of community based services necessary to meet the needs of the men, women and children who were leaving Templeton Centre took longer to achieve than was anticipated initially.

It is important to note here that while I conducted the majority of interviews, the volume of interviews required for the purposes of this study meant that I needed assistance. A Donald Beasley Institute research assistant was employed to work on this project to help with administrative tasks and to conduct some interviewing. I was directly responsible for this researcher who received training and direction from myself relating to how to conduct the interviews. She provided feedback on the interviews directly after conducting them and I read and coded all interview transcripts (more detail relating to this coding process is given later in this chapter). I remained the primary contact for all families, regardless of who conducted the interviews with them. In summary, I worked exclusively with 23 families, the research assistant worked exclusively with seven families and we shared interviewing responsibility for five families.

More than just interviews

Data from this study were also generated in other ways. Most particularly, my contact with families between formal interview stages provided me with important, additional information for the study. I received letters and telephone calls from individual family participants. Such contacts usually had the purpose of conveying

details of an event or situation that families perceived as critical to understanding their experience of the process of deinstitutionalisation. I included this information in the particular person's data file.

Families also sent me written information which usually had the purpose of illustrating to me how they were informed about deinstitutionalisation and the resettlement of their relative. This information was also critical to my own knowledge, understanding and analysis of the families' stories as it provided the context within which families constructed their own understandings of the process of deinstitutionalisation – the understandings which they had chosen to share with me in the interview setting.

Analysing the study data

Constructivism has been described as having a hermeneutical/dialectical methodology (Lincoln & Guba, 2000). Kvale (1996) defines hermeneutics as being "the study of the interpretation of texts." (p.46). This doctoral research is based on unstructured interviews conducted with families of people with an intellectual disability who were being resettled from institutional to community based disability services. The "text" (interview transcripts) therefore provided the focus for the hermenuetical style interpretation process inherent to constructivism.

Kvale proposed that the research interview *"is a conversation about human life, with the oral discourse transformed into texts to be interpreted."* (p.46).

> During the analysis of interviews, it is common to read an interview through first to get a more or less general meaning. One then goes back to certain themes and special expressions, tries to develop their meaning and then again returns to the more global meaning of the interview in light of the deepened meaning of the part, and so on. (Kvale, 1996, 48).

As is common within the discipline of qualitative research, the process of data analysis was ongoing throughout this research. From the time I conducted the first interview for this study I was beginning to develop my own ideas, understandings and constructions of the families' stories. Each interview I undertook was shaped by previous interviews because of the fact that each time I talked to families my own views and perceptions were further developed. As a researcher, it was

impossible for me to disregard this previous knowledge as I met with each new participant. The most critical aspect of beginning to develop an analysis of families' experiences of deinstitutionalisation was getting to know their stories very well.

After each interview I wrote field notes. These field notes contained my impressions of the interview – how the interview had felt for me as the interviewer and how I believed the participant responded to me. I also noted some of the non-verbal exchanges that took place within the interview setting. These non-verbal cues and signals became very important to me both in terms of my analysis of particular families' stories, and also in terms of how I responded to participant needs within the interview setting. During this field note process I also began to record some of my first impressions (analyses) of families' interactions with the process of deinstitutionalisation.

The recording of field notes was, in my view, one of the very first components of a thorough and rigorous analysis process. The second aspect of the analysis process was that of checking each interview transcript before it was returned to each participant. Because I did not conduct the transcription process myself it was vitally important that I checked each interview to ensure that it was transcribed accurately. There is some debate over whether it is imperative that the person who conducted the interviews (and who will be conducting the analysis) should perform the transcribing. I believed that it was more time and cost efficient to use an experienced transcriber who could provide sensitive and accurate transcriptions in the area of family and disability research. I believed however that it was my responsibility to ensure that the transcriptions were as accurate as possible before they were returned to participants. I listened to each interview with the transcript in front of me and made sure that what was recorded as written data matched the dialogue that occurred in the interview setting.

As well as ensuring that participants were receiving an accurate representation of the discussions they had with me, this checking process was also a vital part of the analysis process. Listening to the interviews soon after having conducted them cemented each participant's story in my mind. It was an extremely effective way of "getting to know" my data. This process of becoming increasingly familiar with

each participant's story was integral to developing a coding schedule – the next step in my analysis process.

The development of a coding schedule or framework is one of the most frequently used methods for approaching the analysis of qualitative data. Coding of qualitative data occurs whether one is taking a "by-hand" approach or a "computer assisted" approach to exploring coded concepts within the data. I took both a "by-hand" and a "computer assisted" approach to coding my data. After conducting the previously described process of getting to know families' stories as well as I could through listening to and reading the interview transcripts, I began to note the concepts, themes and patterns that I saw as emerging from the data. These concepts, patterns and themes became the coding schedule for the data. The coding schedule was also determined by the topic areas used to guide each interview. I then explored each interview transcript with the coding schedule as a reference, highlighting sections of the interview transcripts that matched the codes I had developed.

After conducting this manual coding process I developed a coding schedule for the interview data. A Donald Beasley Institute research assistant who was involved in the Templeton Centre research entered the data into the qualitative research computer software package NUD.IST developed at La Trobe University, Melbourne, Australia by Lyn Richards and Thomas Richards. NUD.IST is an acronym for non-numerical unstructured data, indexing, sorting and theorising. The use of computer software packages within qualitative research have been critiqued by some researchers who believe that using such packages can result in the contributions of research participants becoming de-contextualized. That is, in the process of coding data the participant's "story" is lost and, consequently, so is the researcher's ability to develop a sophisticated understanding of that person's experience. I am of the view that qualitative research software such as NUD.IST can be very helpful but **only** if researchers view such software as a data management tool rather than an analysis tool. Computer software packages such as NUD.IST, the package used in this study, are only useful and effective if the researcher is thoroughly conversant with the qualitative data before he or she begins to enter them into the computer. Eben Weitzman (2000) in his discussion of software and qualitative research made the following statement:

Simply put, software can provide tools to help you analyze qualitative data, but it cannot do the analysis for you, not in the same sense in which a package like SPSS or SAS can do, say, multiple regression. Many researchers have had the hope, for others it is a fear – that the computer could somehow read the text and decide what it all means. That is, generally speaking, not the case. Thus it is particularly important to emphasize that using software cannot be a substitute for learning data analysis methods: The researcher must know what needs to be done and do it. The software package provides the tools to do it with. (p.805).

I chose to use NUD.IST as a data management tool as I had a large enough data set to justify the time required to enter the data onto the computer. I was conducting multiple interviews with multiple participants – NUD.IST represented a logical way of storing my coded data. NUD.IST coding printouts provide all the information relating to a particular code which can be useful say, for example, when exploring the contrasts and similarities existing between participants on a particular issue. The coding printouts were also useful in identifying when I had perhaps been over emphasizing or under emphasizing the presence of a particular theme or concept.

The degree of decontextualization that occurs through the use of NUD.IST is researcher driven – that is, the researcher makes the decision as to how much context they include with a particular comment or reflection on an issue of interest. I wish to be extremely clear that my use of NUD.IST did not lead me to abandon my "complete" interview transcripts. In fact, the reverse is true. My analysis process involved constant and thorough examination of both my complete interview transcripts and my computer generated coding printouts. Reading a complete transcript sometimes led me back to my coding printouts and exploration of the coding printouts sometimes led me back to the complete transcripts. I never lost sight of the fact that I was the analyst and the computer software simply a useful way of managing and working with a large quantity of narrative data.

At the point that I felt confident that I had rigorously explored the data for similarities and themes, and that I had also recognized the many contrasts and differences amongst families' stories, I began to write about my ideas. These concepts and ideas became the analyses that form the basis of this thesis. I wrote three reports for families during this period (Mirfin-Veitch, Bray & Ross 1998;

Mirfin-Veitch, Ross & Bray, 2000; Mirfin-Veitch & Bray, 2002). Please refer to Appendix 4,5 & 6 for complete copies of these reports. I referred to these reports as preliminary reports on the findings and they represented both an effort to keep families informed of my progress in a somewhat lengthy research process, as well as a method of checking my analysis with them to that point. Families were extremely positive about the findings presented in these reports and their feedback gave me confidence to further develop my analysis of these early ideas and concepts. These ideas and concepts form the basis of findings presented in the following chapters of this thesis.

CHAPTER SIX

INSTITUTIONALISATION

Introduction

This first findings chapter focuses on families' past experiences of seeking out-of-home placement for their relatives in an institutional facility. Specifically, critical elements of decision-making related to institutionalisation are explored, including the impact of such decisions on parents and siblings.

The first phase of interviews with families covered a range of areas associated with the process of deinstitutionalisation. A component of these initial interviews that emerged as very important for families was the story of their earlier decisions to choose institutional care for their relatives with an intellectual disability. The decision made in earlier times to choose institutional care was not always the first issue or topic we discussed in the interviews. However, it consistently emerged as the most significant aspect of these discussions. Learning about the experiences and decisions that led up to the institutionalisation of a family member provided me with a great deal of insight into the individual context of each family. The story of institutionalisation was, therefore, the natural starting point for the analysis and, consequently, the starting point for presenting the findings related to this research.

The journey towards institutionalisation

The families taking part in this study were all different. The great diversity in families is reflected in their differing views toward their family members with disabilities, toward the plans for deinstitutionalisation and toward the process they experienced as change and transition to community placement began to occur. These and other related issues will all be explored in later findings chapters of this thesis. While the diversity among families taking part in the study was clearly apparent, they did nevertheless, share a consistent story of the experiences that had led to the decision to seek permanent out-of-home care in the past.

The first interview with families involved an exploration of the events that had occurred and the decision-making that families had engaged in when they had sought hospital based services for their relative in the past. In exploring these issues I was able to identify and interpret this shared experience which described the journey each had made toward seeking institutional care. The shared story presented in this chapter is based largely on the experiences, recollections and reflections of parents. For this reason the term parents is used more frequently than the term families throughout this section. The experiences, views and reflections of adult siblings are explored toward the end of this chapter.

The decision to use Templeton Centre was never a "spur-of-the-moment" decision for parents, nor was it something that they planned to occur at a specific point in the life of their son or daughter with an intellectual disability. A number of factors were common to families who chose to use institutional residential services on a permanent basis for their children. Through my analysis of study data I have identified these common factors as: a commitment to maintaining the family unit; the search for community based services; challenges to caring; the influence of professionals; and the catalyst for out-of-home placement.

A commitment to maintaining the family unit

Parents had a strong desire to have their children live within the family and to be cared for by the family for as long as possible. Templeton Centre was a service option that many parents refused to consider when their children were young or were first diagnosed as having a disability. Furthermore, when challenges to families' abilities to cope occurred, Templeton Centre continued to be actively resisted by many parents for a very long time. Almost without exception parents talked about the importance of keeping their family together and caring for their relative with an intellectual disability at home for as long as possible.

One mother said:

> I had that little boy and I need to look after him, he's my responsibility, he's got no one else and he's not going to that dreadful place [Templeton Centre].

And another:

> He said to me, by the time that child's seven you'll have put him in a home and I said oh never. I said he'll never leave his home...

A third mother made the following comment:

> We did realize that sooner or later he would have to go though we put it off as long as possible because you know, he's part of the family.

To seek the services of Templeton Centre, at this time, was seen as representing a breakdown in the family unit that parents clearly wished to avoid. Many families who took part in this research reported feeling unfairly judged by today's parents and professionals involved in the disability field who respond negatively to out-of-home placement. More particularly families were affected personally by the assumption that they did not love or care for their children but rather abandoned them to an institution. The opportunity to talk about their earlier decisions to seek permanent out-of-home placement was a unique experience for some families and they reported this as a factor influencing their decision to participate in this longitudinal study.

The search for community based services

Parents were serious in their efforts to locate alternative disability support services in the community for their sons and daughters. As parents struggled to keep their sons and daughters at home they often tried a number of options. However these options were perceived as failing to meet the needs of the person with a disability, and the family's needs as a whole. Parents often talked about the difficulties they experienced in "matching" their sons and daughters with the available services.

The quotes used to illustrate families' stories of searching for an alternative to Templeton Centre were all made by mothers.

> Yeah the strain was certainly beginning to tell on me. Definitely. Because at that time there really wasn't any support at that time from anybody. Anywhere. There wasn't any relief or respite care or anything like that. No. So I guess the strain was definitely beginning to tell on me, which is why she went there in the first place.

> Well I almost felt as though I got the third degree. Because they didn't want this handicapped child who was also a crippled child, they didn't want the stigma of someone who was intellectually handicapped ruining their little kindergarten and it was terrible...

> Well it was the only place [Templeton Centre]. In those days and still is as far as I'm concerned.

> There was nothing else...Templeton was the only place we felt comfortable, well as comfortable as circumstances allow, it certainly wasn't something that was easy.

This difficulty in finding community based services hastened parents' moves toward using Templeton Centre services. The manner in which families began using institutional services occurred predominantly in two ways. First, it was common for families to send their son or daughter to Templeton Centre as a form of respite, at first sporadically and then more frequently as the families' needs became greater.

One mother said:

> ...and he started going to Templeton on a daily basis because there just didn't seem to be anything for him...then we got the six week thing for him and then it kind of grew from there.

Another mother's comment highlights the ambivalence that families experienced when contemplating the institutionalisation of their son or daughter.

> I didn't feel very happy about her going to Templeton. Certainly not. But I felt she had to go somewhere and that seemed the only option at that stage. So that's what happened.

A small group of parents who took part in the present study revealed that they did not experience Templeton Centre as a respite provider. These parents talked about making a decision about permanent out-of-home placement when their children were very young. In this situation the child's break from the family was usually, swift, complete, and sustained over a long period.

Challenges to caring

Parents, particularly mothers, faced intense and sustained pressure as issues associated with caring for their sons and daughters increased over time. A number of factors contributed to families' feelings of being unable to cope. Pregnancy and the birth of other children into the family was frequently cited as an event which could upset the delicate balance of the household. Two different mothers described their feelings of pressure and an inability to cope as they cared for their disabled children at home.

> It was a matter of balancing things. There was no such thing as family life. It was a fulltime job, frustrating, and the most important thing was [son with intellectual disability].

> Well [non-disabled daughter] is 22 months younger than [son] and I must admit that when I found I was pregnant with her that I really panicked and it didn't really help when I took [son] to the Plunket nurse where we were living and when she found out that I was pregnant she said 'Oh I can't believe it, how on earth are you going to cope' and that really did not help. That was terrible in fact...I really panicked when I was in [maternity hospital] and I do remember they put me on sedation, I just couldn't imagine how I was going to cope when I got home – because [son] actually took up more time than [new baby].

Meeting the physical needs of their family member became an issue as children grew bigger and parents became older. Both parents and siblings identified the provision of personal care as becoming increasingly difficult over time. Despite these problems, parents tended to cope with issues related to providing physical care for their sons and daughters more easily than those related to behaviour. Parents often felt powerless to deal with difficult behaviour and felt that such behaviour had a detrimental effect on the entire family. Parents were particularly concerned about their other children whom they felt were prevented from inviting friends to the family home. Parents themselves reported feeling increasingly isolated from their own social support networks.

Throughout this period in families' lives there remained for most of them a resistance to seeking permanent out-of-home placement for their relatives with intellectual disabilities. However, it was during this time when challenges to caring seemed overwhelming that many parents initiated an association with Templeton

Centre as a respite care provider. Many mothers had never had a break from caring for their child until they began to use Templeton Centre for short-term respite. Furthermore, as services in the community failed to meet families' needs, Templeton Centre became more critical to families as their only respite option. Parents who found it increasingly difficult to cope viewed the institutional service as crucial to their ability to continue to care for their children. The increased use of Templeton Centre as a provider of respite care facilitated a gradual acceptance of permanent out-of-home placement in the institution.

> We started out with short stays, just a break that's right. It was such a relief for me to have a weekend you know, without [disabled son], because he literally lived with me 24 hours of the day.

A sense of inevitability present in many families' stories became evident at this stage. Families struggled to delay the use of Templeton Centre for as long as possible but at the same time they described having a sense that they were delaying the inevitable. Families felt that they would not be able to care for their child in the long term primarily because they perceived that the community based service system could not meet their needs. It is interesting to note that this perception was held by parents who institutionalised their children in the 1970's, 80's and early 1990's, as well as by families who sought institutional care during the 1950's and 1960's. During this period of delaying the inevitable families "got used to the idea" of having their relative live away from the family environment on a permanent basis.

The influence of professionals

Contrary to an enduring perception that health professionals (such as general practitioners, paediatricians and/or psychologists) made decisions for parents regarding out-of-home placement, the role of health professionals reported by families taking part in this study may be more accurately described as "facilitators". Parents who were resistant to the idea of permanent out-of-home placement often were given "permission" to begin to think about Templeton Centre as a service option by health professionals who knew both their child and their family circumstances. While a few parents reported that professionals had been very assertive in their advice to parents, it appeared that it was more likely for

professionals to give validity to what families, particularly mothers, were feeling. The following comment made by a mother illustrates this point.

> I mean when [paediatrician] said to us - when he told us about [son] and what life would be like, he said when you want care outside of the home you go and get it. He said, don't hesitate. I said oh yeah sure, not believing that we would ever do it or need to but [mother] was sort of a bit more realistic perhaps and decided that, you know, the time had come.

Parents were reassured that their feelings of stress and inability to cope were to be expected and that they should not feel guilty about seeking additional help. Mothers' poor mental health and its impact on the rest of the family was often observed and raised by health professionals. It was also common for general practitioners to recognize the acute level of stress that some mothers were experiencing and to arrange respite in those situations. One mother recounted how a psychologist had helped her to see the needs of individual family members. His assessment of her family situation enabled her to consider institutional placement for her child.

> Only from the psychologist really, he helped us because he sort of put the whole thing in focus on the family and said there's not just one member in the family, there's – we had my mother living with us as well, so there was grandmother and my husband and [non-disabled son]. So that – each had to have a space and also myself. So that really was the turning point and I realised well that's how we've got to look at the family unit and not just concentrate on one member of it.

The catalyst for permanent out-of-home placement

Individuals with intellectual disabilities usually remained at home until an event occurred within the family that altered the balance of family life. For many families, the birth of additional children signalled a change in the ability of mothers to cope. The ill health of another child or elderly family member was a frequent catalyst for change, and in some families the health problems of mothers compromised the ability for a person with an intellectual disability to be cared for within the family environment. A mother said:

> Yeah I got really sick, that's what happened and then I just couldn't cope any more and it got to the stage that I was just so ill.

Almost all parents who participated in this study attributed their decisions relating to the future care of their child with an intellectual disability to their perception that their other children were "suffering" as a result of parents', particularly mothers', efforts to provide care within the family environment.

The mental health status of mothers determined to a large extent the timing of a transition into permanent out-of-home care at Templeton Centre. Mothers who had struggled for many years to enable their children to remain within the family usually chose to utilize Templeton Centre services when they felt they were no longer able to cope emotionally with the demands of caring for their disabled son or daughter as well as the usual demands of family life. In some cases other family members, friends, or professionals articulated what parents had difficulty admitting to themselves.

> We had him home for quite a long time, but it was just bedlam with the baby and [son with an intellectual disability]. I was heading for a nervous breakdown, so was my husband and the doctor suggested that – I can't remember how old he was when he went away to begin with, could have been about seven...

During an interview one father turned to his wife and said:

> You just cracked up one Saturday didn't you?

This comment illustrates clearly a strong theme to emerge from this study – the decision to institutionalise a son or daughter with an intellectual disability rested squarely on the shoulders of mothers. A mother's inability to cope determined the passage into institutional care. This issue is discussed in greater depth in a later section of this chapter.

Every single parent who took part in this research described the decision to choose permanent out-of-home placement for their son or daughter with an intellectual disability as the hardest and most painful decision of their lives. One mother described the stress she was under trying to manage to fulfil her family's needs, but she still felt upset at the thought of her daughter leaving the family environment.

But what happened was she was frustrated, she was not tired enough I think and in the night she would stand up and shift the whole cot with her body and then unlock the door or something. And kept everybody awake, he [husband] had to go to work, I had to be the person to manage the whole family, the kids have to go to school, it went on for a while, I can't remember how long, but my doctor rang [Templeton Centre medical superintendent] and he said is the woman mad, she should have – the child should be long, long away, so I got a place at Templeton straight away – which I hated!

Parents talked about a great sense of sadness, and in some cases an enduring feeling of guilt and failure when they felt they could no longer care for their children. These long held and very personal feelings intensified when parents were confronted with the announcement of plans to deinstitutionalise Templeton Centre.

Three different mothers made these comments:

...seven when he went to Templeton. I was devastated because [son] had to be at Templeton on the Friday and [non-disabled daughter] started school on the Monday. I thought it was the end of my world. I get very emotional about it, sorry.

Yes, she had made the break and I didn't really want her to come home because it is much harder to put her away again.

Oh it was terrible, it still makes me emotional and I think I – oh I cried for weeks and weeks after that.

One father described his sense of loss upon institutionalising his son:

It was earth-shattering, it really was...Oh man, it scared the living daylights out of me. I walked in there and there was all these people sitting in front of a television set, obviously not seeing what was on telly...No, no it really fazed me, and that would have been one of the most traumatic times in my life. It was sort of like the realisation that you'd failed, you know.

The actual transition from the family home to the institution was made much more difficult for parents when they were told by institution staff that they should leave their child and not return to visit for at least six months. Many of the families who participated in this study reported that this had been their experience. The guilt and hurt was compounded by the fact that they really did feel like they were abandoning their child to the unknown. It seems that almost all families who were

given this advice heeded it and did not visit their child for a very long time. Given this common practice it is not surprising that family relationships and involvements were critically damaged. One sister's comment illustrates the way in which institutionalisation impacted in a negative way on the lives of many families. A sibling provided her perception on how her brother's transition from the family home into institutional care had been handled.

> Things that I remember my family saying was that they couldn't have contact with him when he first went out there for six months, so she couldn't go and see him, he couldn't see her and they both fretted which I think was a barbaric way to handle it back then.

Another distressing occurrence for parents was that the advice and information that they tried to give institution staff on the day their son or daughter moved to Templeton was dismissed as unimportant or was ignored completely. The rejection by institution staff of their knowledge of their children illustrated to parents very graphically that they no longer had the most important standing in their son's or daughter's life. A mother made the following comments as she described leaving her son at Templeton Centre for the first time.

> I think that's the only thing I really remember about that day. Apart from being really upset. I tried to tell them how he loved water and taps and things and they said, whatever he will do has been done here before.

> ...I sat up all night sewing little names on all his clothes and everything and I was just told – you know, take them away, he'll be having institutional clothes.

The shared story of institutionalisation presented here reflects the experiences, views and perceptions of parents who chose to take part in this study. All the families taking part in this research willingly and openly talked about the decision-making process that occurred in considering and, at a later date, actively seeking out-of-home placement for their sons and daughters with intellectual disabilities. Throughout this story two themes were significant and deserving of individual presentation at this point. These themes were mothers' roles and the consideration of siblings.

Mothers' roles

A central and powerful theme to emerge from this research relates to the role of the mother in families that included sons and daughters with intellectual disabilities, and who took part in this study. Regardless of the time period in which a person with a disability began to use institutional services on a permanent basis, mothers had provided the care necessary for their sons and daughters with intellectual disabilities to remain in the family home. Mothers fulfilled the emotional and physical needs of their children and were without exception committed to the well-being of their children and to doing everything possible to ensure that their child could remain at home for as long as possible. Mothers described the enormous physical and emotional stress associated with caring for sons and daughters with intellectual disabilities.

> ..oh he took my time up fully.

> I couldn't have him out of my sight. I couldn't have him out of my sight. If he disappeared you didn't know what he was going to do. He was hyperactive, dreadful. I had to watch him all of the time. Very, very difficult really, very stressful really and I felt at the age of eight it was either him or me...

> [Son] never slept either, never stopped and it was very difficult for us to have people here...he would march from this room to that room yelling day and night.

> ...he was three going on four and he wouldn't sleep, and wherever he fell asleep I would lay down with a pillow and put my arm over him and the minute he woke up I knew he would move. He'd only sleep ten minutes at a time, so that's all the sleep I got.

> I had three children, four children then, three others and I was just about beside myself and the Doctor said well I'm afraid it's either [daughter] or you, one of you will have to go. That is why we decided to put her into Templeton.

> I decided I couldn't handle it anymore really.

As children grew older, behaviours that were manageable when they were small often became increasingly difficult for the whole family to cope with. It was common for mothers and/or now adult siblings to report that fathers began

working long hours leaving mothers to cope with the tasks associated with caring for their child with a disability and the usual demands of family life. The stress and pressure that mothers had to deal with was enormous.

> Well he was almost uncontrollable and unfortunately my work took me all over the country and my wife was on her own a lot – but however it got to the stage finally that she couldn't control him at all and it became necessary that something had to be done.

> ...this is the second time I've been married and [daughter] when the break up happened, [daughter] didn't handle it too well and she was uncontrollable. My ex-wife couldn't control her, so she finished up at Templeton.

These passages illustrate that family coping with caring for a family member with an intellectual disability was really determined by mothers' ability to cope. Therefore, if a mother was unable to continue to care for their son or daughter because of emotional or physical exhaustion (or both), institutionalisation became their "fault".

Five mothers reported that their husbands had a negative response to their child with an intellectual disability. Some of these fathers went so far as to completely reject their sons and daughters with intellectual disabilities. The propensity for fathers to leave their families was not linked to the decade in which their child with a disability was born. The following quotes about fathers relate to situations that occurred from the 1960's until the 1990's. That is, the fact that one could expect more liberal or inclusive attitudes regarding disability in more recent years did not prevent some fathers from reacting negatively to their child's disability. Four different mothers described their husband's reactions to the diagnosis of their child's disability.

> ...my first husband didn't want anything to do with [son], he said you had him, you look after him and it was a very difficult time. I was on my own for a while and when I met [new partner] he gave me the strength to say we could help this poor boy.

> Well a month after the diagnosis [husband] left because he couldn't cope with it.

My husband walked out on me.

[My daughter's] father's family said they do not have retards in their family and that was it basically. They have nothing to do with her at all. [My daughter's father] won't acknowledge her.

A grandmother participating in the study reported that her daughter's husband left the family after their child was diagnosed with an intellectual disability.

And of course I think it did help break up the marriage. The father walked out. He took no further responsibility for either of the children...

As mothers were the major care providers it was also evident that mothers took responsibility for making the final decision about when to seek permanent out-of-home placement or shared-care on a formal basis at Templeton Centre. Fathers often took a central role in describing events and challenges to family functioning that had occurred while their son or daughter was being cared for at home. However, it was clear that mothers were seen as responsible for making the final decision to seek out-of home placement, even if this decision was usually made at a time when they were suffering from mental and/or physical ill-health.

It was common for mothers to express feelings of guilt and remorse about this decision and in the context of the announcement to deinstitutionalise Templeton Centre, to question whether they had made the "right" decision in the past. This discomfort with their decision was made worse for some mothers when their husbands or their other children reacted negatively to their need to seek out-of-home placement for the child with a disability. The following passages indicate that fathers did not always engage with the crisis of institutionalisation in the same way as mothers. It is evident that both these fathers reacted negatively to the fact that their children had been institutionalised and one could conclude that their reactions would have heightened the difficulty that the mothers had in coming to terms with their decisions.

Well I knew there was something wrong and in a way I was relieved to hear it. My husband was the one it affected most. He just wouldn't believe it and as time went on and [son] became more difficult to handle he still wouldn't accept it... and it was when [son] was about seven that I just felt I couldn't go on. I just rang my husband at work one day and said look I can't have [son] home today...I just said I can't have him home...But the unfortunate

thing was that my husband just couldn't accept it. And even when [son] went to Templeton, the children and I took him up. [Husband] just withdrew from anything for months, years. It was the beginning of the end of his life I feel. He got cancer and he died. [Husband] was in an orphanage when he was a boy and I think the thought of his son being in an institution was more than he could cope with...He did come and visit him once or twice with me but it just changed his whole life. He became a different person.

I don't think he coped very well at all. His weekends used to be taken up with [recreational activities] or whatever his given thing was at the time and I think his life basically carried on. I shouldn't say in denial of the whole thing, you know he just sort of let things flow over him. It didn't seem to have the same effect on him as it certainly had on me

It is important to note, however, that there were a small number of exceptions to these findings relating to the role of mothers. In the situation where fathers were parenting alone they reported very similar experiences and feelings to those expressed by mothers relating to the decision to seek permanent out-of-home placement for their son or daughter. One father described his feelings after seeking institutional care for his son.

It was earth shattering, it really was. I took him out there, I dropped him off and I went home and I don't know how many days I cried for, but you know.

Consideration of siblings

A second major theme related to the crisis of institutionalisation was the consideration of siblings. As mentioned previously in this section, parents frequently identified concern for other children in the family as a significant component in their eventual decision to seek permanent out-of-home placement for their child with a disability. A great deal of this concern related to the fact that they felt that their other children were: forced to assume too much responsibility at a young age; unfairly disadvantaged in terms of the amount of time their parents were able to spend with them; embarrassed by their disabled sibling; and, isolated from their friends as a result of that sibling being cared for at home. The following comments made by four different mothers elucidate the concerns they had for their non-disabled children.

> In the early years? I think it affected my other children quite badly. I think they missed out on an awful lot. In particular I think I spent too much time in the early years looking after and being with [son] -because he needed that special time - that there was never enough time for them...

> As they grew older of course, we did notice it, they didn't want to bring their friends back because he [disabled sibling] wouldn't behave... they didn't want to bring friends home when [disabled sibling] was carrying on like that. So we never have people to the house much.

> What really brought it to a head one day was one of our children, there was a great commotion and [my daughter] said this is ridiculous. Mum can't go on like this. So it was an indication that the family was feeling.

> And the children at school used to be teased about – why isn't your brother at school, why isn't he like other children.

More frequently expressed were parents' feelings of guilt and worry about the lack of time and attention they believed they were able to give to their non-disabled children. Parents, particularly mothers, reported feelings of inner tension and conflict as they struggled to balance their need and desire to spend a great deal of time with their disabled child, and to also provide an adequate level of time, care and support to other children in the family. At the time of being interviewed for this study, often many years following the institutionalisation of their disabled child, parents continued to express concerns regarding the possible impact of their attempts to care for their disabled child within the home on other children in the family.

A father commented:

> Well we were so busy with [daughter] the rest of our children – they were very, very good, always good with [daughter] but we didn't realize how much it was affecting them until after she moved to Templeton, our [non-disabled daughter] was at [local school] by that time and one of the teachers over there had taken a great interest in her and said that they had noticed the difference, noticed there was something wrong with her and we didn't realize what an effect it was having on their lives.

A mother talked about how she had failed to recognize the needs of her other children when she was caring for her son with an intellectual disability within the family environment.

Because this was another thing that they brought home to me, did I realize the effect that [son] and I were having on the other three children. I knew that, but I was too tired, I was so engrossed in doing everything for [son with an intellectual disability] that I was too tired even to watch the other children to see what was happening, As long as they were fed, they were clothed, they were clean – everything else, that was the main thing. But psychologically I wasn't helping at all – and [son] didn't care whether it was me doing this for him. Now I can look back, but I didn't think anyone could look after [son] like I did.

Parents did report that their non-disabled children frequently acted as carers and reflected on how this level of responsibility at such a young age may have had an impact` on them. Two different mothers made similar comments regarding this issue.

One mother said:

I should have given him up sooner because my daughter didn't have a childhood and then at eleven and twelve when other children were developing into other things, she went back to playing with dolls. So she missed out on being the little girl, she was always Mum's right hand.

The second mother said:

… I mean from the moment that [non-disabled daughter] could get around she fetched and carried for me…[son with an intellectual disability] used to beat her up all the time. So it makes me wonder why she is so nice to him now. But no, she's always been extremely good to him but it certainly wasn't easy for her…

While parents identified that they felt uncomfortable with the level of responsibility that the non-disabled children were forced to assume, they also believed their non-disabled children did gain in a positive way from their family experiences.

[Non-disabled daughter] was bright and she grew up actually surpassing him and she was doing things for him. So she learnt to look after him. She grew up very quickly but I think the good thing about it is that she's become a very tolerant person And is also quite sensitive to the needs of others. So there is a plus. It's not all grim.

They had an assembly one day and they asked children to stand up if they had anything special to talk about and I got a ring from the headmaster

because my children stood up and said that they had a very special brother and that he taught them a lot about giving and loving...

However, as some families told their story an interesting contradiction became evident. While many parents identified their concern for other children as a catalyst for out-of-home placement, it was clear that siblings in a number of families did not react positively to the institutionalisation of their disabled brother or sister. Parents reported that in some instances other children in the family had been openly opposed to their decision regarding out-of-home placement.

[My] oldest son will never forgive me for deciding to [institutionalise my son with an intellectual disability], it just caused a tremendous void between my oldest son and myself...

Oh yes, oh when we put her into Templeton they thought it was dreadful and [non-disabled daughter] – that's the next girl...She said you can't do that, you want to keep her at home and we had to try and explain to her that well [disabled daughter] was high school age, other boys and girls went to boarding school, and that's what she was doing but they [other siblings] still felt she shouldn't be in a home, she should be here. But of course now they all realize.

Non-disabled siblings' views and experiences of institutionalisation

The findings presented above have related to parents' perceptions and experiences although this study was not confined to the views of parents alone. Other family members were also included in this study to explore the impacts of institutionalisation and deinstitutionalisation on the family unit as a whole. Of particular interest in this study were the views, experiences and reflections of the now adult siblings of Templeton Centre residents. The importance of the information gained from this group of participants gained greater resonance when it became clear how much parental decision-making regarding institutionalisation had been influenced by the real or perceived impact on non-disabled siblings.

Some now adult siblings talked about how they thought their parents and other relatives reacted to the fact of a family member's disability. A sister who was able to meet her brother only after the process of deinstitutionalisation had commenced elaborated on how she thought her brother's disability was perceived in her family.

I think it was a secret, a lot of our family don't know about it. So I think it was very much hush, hush. There was a lot of stigma attached to it back then, in fact my older sister still hasn't been able to tell her own children about and when I told my own daughter a few years ago she was really angry I hadn't told her sooner. That's how we grew up, thinking that it was hush, hush that we had a half brother out at Templeton.

I think it was probably – it was done in the 60's when the time was – I know there was a lot of pressure on my mother – a lot of pressure on her and I think there was a lot of – probably a lot of sadness – oh a tremendous amount of sadness surrounding it, and the guilt and everything else of having someone – of bringing someone into the world that was handicapped.

So what was it like to be the brother or sister of a child with an intellectual disability? Some of the stories recounted by the now-adult siblings who participated in this study confirmed the fact that they did assume extra responsibility within the context of family life. The following passage provided by a sister provides insight into everyday life within her own particular family.

Yeah. It was chaotic – I'm the oldest so I felt like I had a lot of responsibility – you know when I look back I think I had a lot of responsibility that I may not have had if he hadn't been handicapped…we had to lock all the doors of the house because he used to break all the windows. He just used to throw things at the windows all the time. I don't know how many windows that Mum and Dad had fixed. In the end the insurance company wouldn't pay for any more and he also used to lock himself in rooms. The house we lived in was a big old villa…and all the doors had Yale locks on them and when we moved there we just used to snib them back and not use them, but I always remember one day, I was in standard four, and he locked himself in my bedroom from the inside and there was no key for any of these doors and I was really upset. I can't remember why, I don't think it was that it was my room, but we couldn't get him out and in the end Dad smashed the lock out of the door, and it was just awful and after that they took all the locks out of the doors… It was just a weird sort of family life I suppose, because we even had to lock the bathroom door so until we were tall enough to open it we had to get someone to open the door before we could go to the loo and things like that.

The siblings who took part in this study told stories that were very similar to the stories of the journey toward institutionalisation recounted by parents and presented earlier in this chapter. They described the stresses and tensions apparent between their parents and within the context of family life. In particular they frequently talked about verbal fighting between their parents as symbolizing

everyday life in their home. While it was uncommon for parents to identify the deterioration in their relationship with their spouse as one reason for seeking out – of-home placement, siblings did identify fighting and/or tension as a significant characteristic of family life. The following comments were made by siblings from four different families.

A brother said:

> ...but I imagine it was quite a stressful time, there were always arguments and things at home. [Brother with an intellectual disability] would cry a lot, endlessly cry and cry and that was quite hard for Mum who was home alone.

A sister told a similar story:

> ...Mum seemed constantly fraught. She was really on edge all the time. And she seemed – when I remember, she seemed to shout all the time, she probably didn't but that's how it seemed. And Mum and Dad used to fight all the time, they blamed each other all the time. It was just yucky...I don't know this but I suspect it – Mum and Dad had a sense of being to blame or that they'd done something wrong and that's why he was like that. There really wasn't any support much.

And another brother said:

> It got the stage where it was atrocious, you know, I mean something had to be done. Because basically it caused major problems between my parents.

One brother described how the multiple stressors of divorce and institutionalisation compounded the problems within his family.

> ...I think there was a lot of stuff going on in our family around that. Like Mum and Dad separated and divorced when [brother with an intellectual disability] was really young and he took twenty-four hour care, and us kids. I remember being left to our own devices really...and with the divorce, that was quite full on for the family. [My brother] sort of aligned himself with my Dad and I didn't align myself to anybody. And [my sister] aligned herself to Mum. You know it was one of those messy stages in life.

The previous passages indicate that frequent fighting between their parents had just as much, if not more of an impact on siblings, as children and adults, as the

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presence of their brother or sister with an intellectual disability in the family home. However, having said that, it does appear that most of the siblings perceived that it was the challenges associated with caring that led to the breakdown in relations between parents where this happened.

Given that parents almost without exception cited concern for their other children as a reason for seeking institutional care for their child with an intellectual disability, the inclusion of siblings in this study allowed an insight into how they actually felt about their brother or sister when they were children and were living in the family home. One sibling made it quite clear that it was not her brother that she was embarrassed about but the way their family functioned at the time. Hers was a family that was under tremendous pressure and her parents fought frequently.

> I loved him, like it was kind of how it was, but the set up at home was embarrassing, I suppose he was a bit embarrassing but not really, it was just living in that weird household.

A sister from a different family described how she viewed her brother with an intellectual disability.

> ...I didn't really think of him as totally different. I just accepted him as part of the family and when people would come to play after school, they would ask me what's wrong with him, and I used to gloss it over. He didn't seem too different to me. He was just [my brother]. It's just the way he was.

A brother's comments also highlight the finding that siblings appeared to be cognizant of difference but did not accentuate it within their perceptions and descriptions of their siblings with an intellectual disability.

> I think if I can recall I regarded him as a regular brother and he was important and different but not worthy of having been removed from the family.

Reflections like these illustrate the unconditional love that siblings felt for their disabled brothers or sisters despite the difficulties that were caused, wholly or partly, by their presence in the family home.

All of the siblings that took part had stories and views of their own relating to the decision to seek out-of-home placement for their brothers and sisters with intellectual disabilities. Some now adult siblings had vivid memories of the institutionalisation of their brother or sister. In some cases they described the impact of this momentous family event with a rawness that was missing from their parent's stories.

One brother recounted the following story of what happened when his mother received a phone-call from someone who informed her that her son with an intellectual disability could go to live at Templeton Centre.

> I remember the phone-call – it's one of those things that you remember for no reason. I was just playing around at home – I was playing in the living room and Mum just burst out crying on the phone. I don't know if she was - I can't remember if she ever said why she cried, but it was a very emotional time... But I think – it's only what I think, but I think it was probably a combination of things, sort of having someone she had cared for as if they were an infant for so long, for six years, the possibility of having him taken away, even though she knew that perhaps – at the time, because it was just so stressful and everything else, that it was the best...

A sister said:

> Oh yeah, because we had him up until he was five. We were used to looking after him and that. So it was pretty horrendous for them having to put him in an institution.

It appeared that some siblings were cognizant of the fact that their parents had tried to shield them from the difficulties and tensions within the household.

One brother said:

> Mum and Dad always, were good for me in that they tried to make sure that I grew up independent of what was happening with [brother with an intellectual disability] and things...I think I was shielded from a lot of that...

Siblings who had a younger brother or sister go to live at Templeton Centre could describe their recollections of and feelings about their brother or sister going to Templeton Centre for the first time. Not one sibling who participated in this study

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reported feeling happy that their brother or sister had moved out of the family home on a permanent basis.

A sister told the story of taking her brother to the institution for the first time.

> And I remember when we took him up there and Dad didn't come and I don't think I was aware that he was really so against him going. I found that out later I think. So Mum drove us up there and there were all of us in the back of this little Ford Prefect but the thing I remember most – I remember when we left him there and yeah I just felt really upset – like I'm starting to feel upset talking about it...So the whole thing was like oh horrible nightmare stuff.

Another sister recounted how her brother's institutionalisation affected her mother and father.

> And when we came home without him it was the first time I'd ever seen Mum cry. She wasn't one to sort of express her emotions really, and neither was my father, but she really cried. I know she said to me later that she cried for a week. I can't remember that but I know that it really upset her...[my father] didn't react terribly visibly. He never did, about anything. So stiff upper lip I guess.

This same sister elaborated on how witnessing her mother's grief enabled her to understand how hard it must have been to seek institutional care.

> But I think I felt more for Mum in seeing her cry. It made me realise how much he was part of her, you know, how much she loved him. And to have to give up one of your own children because you can't cope is sort of, you know, it really is like a failure I guess, to her.

However, siblings did acknowledge that family life was indeed less fraught after institutionalisation but in many cases it appeared that the immediate stress of caring was replaced by an immense and enduring sadness for their mother. Siblings were definitely aware of the difficulty parents had in making the decision to institutionalise their child with an intellectual disability.

When asked whether his mother talked about the decision to institutionalise his sibling with an intellectual disability one brother made the following comments:

Yeah, in terms of the pain of it. Just in terms of [the pain of the decision] – not in terms of should we have done something different.

I know that it was hugely traumatic for my mother… It was very traumatic for my mother. And as long as I can remember I can remember my mother expressing great sadness about the terrible time she had with having to send [her son] to Templeton.

You know it's such a hellish, hard choice separating altogether from your child and living fairly stressfully like that and looking back I know full well, she felt extremely – she couldn't reconcile it either.

It was common for siblings to never have had the opportunity to establish a relationship with their brother or sister with an intellectual disability. If they were younger than their sibling they were often not old enough to have developed a relationship before institutionalisation occurred. A sister and a brother from two different families provide insight into how it feels to have a sibling that is largely unknown to them.

The sister said:

No [brother with an intellectual disability] is older than me and I think I was one or two when he left the family. So I don't remember that event. My older brother certainly does. That was a really big thing for him.

The brother said:

…I was only five when he actually left home. Whether or not – my memories are what my mother had already described or my sister has always described him… of what I actually remember I have no idea.

One sister talked about the experience of her brother coming home for brief, infrequent visits:

And I was a little bit, slightly scared of this brother who moved around erratically. Well he was my brother, but I had no real connection to him because he was not in my daily life and yet I knew there was a lot of sadness surrounding him.

Another sibling from this family described the formality of his brother coming home for very infrequent visits. His recollection was that his brother, who had

entered the institution aged five, returned to the family home twice during a ten year period.

> Oh total mystery, total, total foreigner. Couldn't, you know, really communicate. Somebody who was locked into themselves. We didn't [go to] get him. I think my father got him and bought him to us. And yeah, we all got dressed up for it, it was all very, it was quite strange. It was quite acted out. It was not a normal thing. It was like suddenly having a martian in your home and you were on your best behaviour.

Other siblings described how difficult they found it to "return" their brother or sister to the institution following a visit home.

One sister described her difficulties:

> As a teenager emotionally I used to find it a lot more difficult. I used to find it really hard taking [my sister] back to [Templeton Centre] because I'd often go with Mum or Dad and take [sister] back after a weekend home and she would be crying and sometimes so would I.

Siblings who took part in the research often held the view that their mother was the parent who took greatest responsibility for providing the care for their brother or sister with an intellectual disability. While the adult siblings who took part in this study were supportive and understanding of their parents' decisions to seek out-of-home placement in the past, some continued to struggle with the notion of institutionalisation and with the fact that their brothers and sisters had lived such vastly different lives to their own.

A sister said:

> I used to as a wee kid feel very, very sad about him being out there. I hated going out, I thought it was a terrible place and I thought how lucky we were to have Mum at home with us and he had nobody out there. I've got horrible memories of the whole thing and looking back it was probably the only decision back then, particularly because she had remarried. It might have been different if Dad had been a different sort of person and I think there was a stigma.

A brother provided powerful commentary that elucidates his feelings about his sibling's life at Templeton Centre.

I regarded him as a regular brother and he was important and different but not worthy of having been removed from the family. But looking back it's a deep kind of thunder, it's the incredibleness of him leaving at four and a half and there's just been this – why was he? – he's been isolated and coping on his own ever since then.

A sister from a different family described a similar sense of sadness.

I feel sad talking about her life, although [my sister] doesn't feel like it has been a bad life, but I feel like she hasn't had much of a life.

Some parents obviously tried to portray Templeton Centre in positive, "idyllic" terms in the hope that siblings would better accept the decision to institutionalise their brother or sister. Such presentations seemed to confuse some children. A sister talked about how she had interpreted her mother's account of what an institution would be like.

..but the day that she came and told me that [my sister] was going out to Templeton, they said this is a lovely place, it's a big farm and it's run like – they have their own gardens and they have animals, I just remember going up to my bedroom and lying on the bed and visualizing [my sister] in a paddock full of hay, or wheat or a field like that and she was sitting in the middle of it crying and I thought, she can't go. This is just too horrible, but anyway she did go there when she was three...But what a dreadful thing, I can't bear to think of her out there.

A few siblings were able to reflect on their own responses and reactions to the institutionalisation of their brother or sister at the time it occurred. It was common for them to feel that they had not paid as much attention to what had occurred for their brother or sister as they now believed they should have.

An older sister said:

Yes I know that they were upset, I know that my mother cried, but you know, I think I was too selfish at that age and sort of running around with my own life, that I put that kind of thing into the background. I know they were distressed and that they loved her, and it was a big wrench and I think it was a very courageous thing to do really. And it was the sort of done thing in those days and she was an embarrassment...

She went on to express feelings of guilt as she believed she had been the reason for her parent's decision to institutionalise her sister.

No, no, I knew she was a problem and a worry, but didn't really understand. It's amazing how when you're within an environment you accept what you're told, especially the young and I didn't discard the dreams I had for her, but they were separate from the real [sister with an intellectual disability] that was around. So I think when I was 16 was it, 15 [sister] went to Templeton...I think now looking back, that my mother decided that [sister] was going to cause trouble for me, which I feel very sad about. I suppose I was just getting to the age of wanting to go out and do things, and I think perhaps the fact that I 'd stopped bringing any friends home and didn't talk about [my sister]...

Other siblings expressed similar feelings. Sisters from two different families made the following comments:

So yeah, I grew up quite guilty, and you know. It was quite hard living with [brother], especially after Dad died. Because my brothers were older and there was only Mum and us girls at home.

Oh I hated it. Hated it. I couldn't believe he was there. I felt guilty – I remember swimming one day, a hot day years ago. I must have been nine or ten and thinking what does he do out there when he gets hot. Things you think of when you're a kid you know. I remember I was rapt when they got the swimming pool out there.

Two siblings who participated in this study described feeling embarrassed, not because their brother or sister had an intellectual disability, but rather because he or she had been sent away from the family to live in an institution. The siblings were from different families.

The following comment from a sister articulates this point:

With some people I worried about what they thought of me because [my brother] was the way he was when I was a kid, but there was more a feeling of being embarrassed by the fact that he'd gone to Templeton Centre. People seemed to make judgements more about that, and then when mum went back to work – that was like about the end!

As a child this sibling perceived that fact that her brother had been required to leave the family home as carrying more of a stigma than him remaining at home. Added to this was the unusual occurrence, in her world at least, of her mother returning to work. These two issues combined to make her feel as if her family was very different to other families in her local community.

A brother talked of his ongoing difficulty with trying to locate his brother within his family.

> I've got one brother and one sister and I never actually bothered to tell people that there's [my brother] out at Templeton, because I didn't know – there's always an explanation needed and I didn't quite know. We didn't really know what was wrong with him, it was sometimes difficult to – it was like an addendum and you just forget about the addendum.

The final passage used in this chapter illustrates the intense emotion that a significant number of siblings expressed when talking about their brothers and sisters who had been institutionalised. The following thoughts and reflections were expressed by a male sibling of a man who had been institutionalised from the age of five and had resided at Templeton Centre for close to forty years at the time this interview took place.

> ...I mean why him and not me? A lost brother, yes I don't quite know what the sadness is, but it's something quite deep and quite sad. And since piecing the history together over the last nine months and getting clear about the chronology of family events from his birth onwards, I see now even more, and having my own children – I see now even more strongly than I had at any other time in my life – the massive dislocation of having someone removed from a family situation at such an early age. When I think about my own children going out of the family, I just about – it's something I can hardly think about. You know, a five-year old coping on their own. So there's a lot of feeling around it. Yeah, there's a tremendous amount of feeling there and it's quite emotional...

The intensity and rawness of this man's account completely dispels any notion that removing a child with an intellectual disability from the family home does not have significant and enduring effects on other family members. The intensity of these feelings seemed to be highlighted by the issue of deinstitutionalisation. Similarly to parents, siblings were also confronted with long-held and painful memories of the past.

Summary

The present chapter has illuminated the intensity of emotions that both parents and siblings experienced before, during and after the institutionalisation of a child or brother or sister with an intellectual disability. Central to this chapter has been the presentation of a shared journey toward institutionalisation – a journey characterised by a series of events that progressively weakened a family's ability to care for their family member within the environment of their family home. Integral to this consistent construct of the journey toward institutionalisation was the finding that parents assessed the decision to seek institutional care for their son or daughter as the hardest and most painful decision that they had ever had to make. Almost without exception parents discussed their early resistance toward the idea of out-of-home care and correspondingly, their efforts to cope with caring for their disabled son or daughter as well as with the other demands of everyday life.

Highlighted in this chapter were two issues that were found to have a strong influence on parents' decisions to seek institutional care. The first influence was that of mothers' roles. Mothers were found to provide the vast majority of care for their sons and daughters with an intellectual disability. Consequently, decisions to choose institutional care were found to rest squarely on the shoulders of women. If mothers were unable to continue to care for a disabled child due to physical or mental ill health, the resolution to this difficulty appeared to be institutionalisation. For this reason mothers who participated in this study sometimes felt guilty that their inability to cope had led to the decision to seek out-of-home care for a child with an intellectual disability. Fathers' reactions to such decisions determined how "bearable" such decisions were for mothers. That is, if fathers understood and supported their need to seek help mothers were better able to accept the decision they had felt forced to make.

The second issue that influenced parents' decisions to seek institutional care for children with an intellectual disability was that of consideration of other siblings. Parents revealed that they worried about how their efforts to care for a disabled child within the family home impacted on their non-disabled children and, consequently, parents' perceptions that this was having a negative impact on their

non-disabled children contributed to their decisions to seek out-of-home care. The present study provided the adult siblings of brother and sisters with an intellectual disability the opportunity to discuss the impact of institutionalisation on their lives, and the lives of other family members. Whilst siblings were aware of the stresses and difficulties that contributed to their parents' decisions to seek institutional care for their brother or sister, it was common for siblings to talk about the negative impact of having a brother or sister removed from the family environment. Most difficult for siblings to accept was the fact that their brothers and sisters had been forced to experience such a vastly different life to their own. Siblings commented on the experiences that they believed their brothers and sisters had been denied or deprived of, for example parental love and affection at a young age. Such insights were not usually found to be a feature of parents' discussions of the impact of institutionalisation. Furthermore, the now adult siblings revealed that they had worried about their brothers and sisters even when they were still children, and continued to question the appropriateness of institutionalisation during their adult life.

CHAPTER SEVEN

DEINSTITUTIONALISATION

Introduction

Chapter Six developed a construct presented by parents to explain their own journey – a journey that encompassed caring for a child at home to seeking institutional care for that same child. The previous chapter also provided information about siblings' responses to the institutionalisation of their disabled brothers and sisters. Information from siblings has not typically been presented in research relating to the field of deinstitutionalisation. The purpose of chapter six was to highlight the importance of focusing on families' earlier decisions to seek institutional care in order to better understand their later reactions and responses to deinstitutionalisation.

An assumption could be that if the families participating in this study shared a similar journey toward institutionalisation they might also share similar responses and reactions to deinstitutionalisation. This assumption does resonate in the data to a certain degree. Many families who participated in the current study shared the common emotional responses such as uncertainty and concern about deinstitutionalisation. However, their reactions and subsequent decision-making showed a greater degree of diversity than commonality. The complexity of families, a central theme within this thesis, was highlighted by the fact that as families converged in their similar stories of institutionalisation, their responses and reactions to deinstitutionalisation diverged.

This chapter explores the range of responses that were evident both within and between families and the decision-making processes that families entered into with regard to deinstitutionalisation and the resettlement of their relatives with an intellectual disability into community based services. Chapter Seven is comprised of four parts. The chapter begins with the presentation of findings relating to families' initial responses to plans for deinstitutionalisation. This section elucidates families' fears and concerns, as well as their hopes and aspirations for their relative's future. The second section of the chapter focuses on understanding how

families made decisions regarding the resettlement of their relative, including the role of siblings in family decision-making. The third section focuses on the actual transition from institutional to community based services and identifies important criteria for families when selecting a new service and provides findings relating to families' evaluations of the new services. The chapter concludes with an exploration of the development of a sheltered village service option for people with an intellectual disability involved in the deinstitutionalisation of Templeton Centre.

Findings presented in this chapter are based on data collected during Phase One interviews (interviews conducted prior to the resettlement of their family member) and Phase Two interviews (interviews conducted 1-3 months following resettlement).

Initial responses – what did families really feel about plans for deinstitutionalisation?

During the interviews that were conducted during Phase One families were asked to talk about how they felt when they realized that Templeton would indeed be closed, and that their relatives would be resettled into community based services. In the ten months that passed between the preliminary announcement in November 1994, to the official announcement of the planned closure in September 1995, it was clear that some families had clung to the hope that Templeton Centre would not close, or at least not completely. A great deal of individual action had been taken by some families in an attempt to ensure that Templeton Centre would remain a service option for their disabled relatives. The Templeton Centre Parents' Association had emerged as a strong opponent of the complete deinstitutionalisation of Templeton Centre.

The realization in September 1995 that Templeton Centre definitely was closing constituted a huge disappointment for some families and instigated a new round of collective action against deinstitutionalisation. At the same time, families were beginning to become engaged in the information being released by the Crown Health Enterprise (CHE) and the Southern Regional Health Authority (SRHA) about deinstitutionalisation. They were also attempting to understand how the process would impact on the everyday lives of their relatives and on their own lives.

It would be accurate to say that at this early stage the majority of families who took part in the study described themselves as having reacted negatively to the Templeton closure announcement. It was also common for families to express that they were shocked that the announcement had been made and that plans for closure had been formalized. Such responses could be perceived as somewhat contradictory given that in the same interview many families identified that they had known that the closure of Templeton was inevitable and for some, for an extended period of time.

The following comments from different parents were provided in response to the question, How long have you known that Templeton Centre was likely to close?

> Long before that, perhaps a couple of years it had been bandied about.

> Oh the Parent's Association have been having meetings about this for some years.

> There's always been uncertainty about it and we've just – for perhaps the last ten years have known that it's going to close.

> It's always hung over our heads, always.

> I couldn't put a specific year on it. I know it's been in the pipeline for quite a long time.

The comment below, in my view, illustrates the position of many families in an honest way. This father's response indicates that while families may have known that plans for closure should have been taken seriously, it was easy for families to take an "it will never happen" approach to deinstitutionalisation. Many parents had a certain awareness of the likelihood that Templeton Centre would be deinstitutionalized, but had chosen to ignore such awareness because they had not received any formal notification of closure.

> Well of course it has been talked about for years, so I suppose in a way we thought, oh it'll probably never happen.

None of the families whom I interviewed for this study, regardless of their knowledge of the likelihood that Templeton Centre would be closed, had explored alternative service options for their relatives in preparation for deinstitutionalisation.

Exploring families' fears

In analysing the data that was generated through this study it became clear that families were able to articulate their fears for their relatives with an intellectual disability very clearly. My question regarding families' fears generated a far greater volume of material than that related to their hopes and aspirations for their family member in the future.

When I began interviewing families for the purposes of this study I quickly became aware of the depth and intensity of fear that many families felt about deinstitutionalisation and the resettlement of their relatives into community based services. As identified in Chapter Six almost every family who participated in this study reported that the earlier decision to choose Templeton as a residential service was due, at least in part, to the fact that they were unable to access a community based service that could meet the needs of their relative. Many families had experienced repeated disappointments when trying to access services. Therefore, because of their previous experiences families were understandably very anxious about the outcome of deinstitutionalisation. Families reported that what they had needed in the early stages of this plan was to receive assurance that services that were now available could provide adequate care for their relatives. Many people believe that this assurance was never given and that their concerns remained unanswered during the early phases of the process of deinstitutionalisation.

It was common for families to be frightened of the impact of deinstitutionalisation per se. Families' fears were pervasive and were based on their past experiences of attempting to care for their family member with a disability at home. Many families had not considered that service options might now be available to their relative and therefore had no real knowledge of currently available disability support services. A theme related to this issue that emerged from the data was perceptions of many families that their relatives were incapable of living in the community environment. One sister, who later became a great advocate for community living, talked about how she felt when she first became aware that her brother would be moving into the community.

> A bit frightened for him. I couldn't imagine where he could be placed. I couldn't think of anywhere else that would look after somebody like him.

Another sister provided her view that deinstitutionalisation was an unrealistic goal for people with an intellectual disability. This woman's words echoed the perception that a significant number of families involved in this study held – that Templeton Centre was the only service option suitable for their relatives who had an intellectual disability.

> And this is the irony of this Templeton Centre closure, now they're saying that these people should be integrated into society. If they were able to live in society, that's where they would be, they wouldn't be in Templeton.

Like this sister, quite a number of the families and individuals who took part in this study had very negative and outdated views of people with an intellectual disability. These views extended to their own relatives and provided a rational basis from which to articulate their fears. Their arguments were underpinned by the premise that no matter what you do or say you cannot change that fact that people with an intellectual disability are restricted by their impairment. One father articulated his perspective on the concept of normalization, and on people with an intellectual disability in general.

> Of course the normalization programme was introduced by the IHC - they dropped that word, I don't think they realized how it was being construed – but as I have always said it doesn't matter what is done for the IH [people with an intellectual disability] they will never be normal, they'll always be different. I think what is not there at birth can never be put there as far as their brain is concerned so it doesn't matter what environment they are brought up in, it won't make a great deal of difference – it doesn't matter whether you go to China and get a group of handicapped Chinese together. Virtually no different, apart from appearance, from a group here. So you know you could be on cloud nine and believe anything, but the reality is that what they haven't got at birth can not be put there.

This father was committed to retaining institutional facilities on the old Templeton site. His son eventually went to live in a sheltered village that was set up on part of the original institution site. For families who exhibited similar attitudes to this father it was almost impossible for them to accept the concepts and philosophies driving deinstitutionalisation.

Linked to their previous experiences of non-existent or unsuccessful services, families were hugely concerned about the perceived impermanence of community based services. Parents reported that when their relatives went to live at

Templeton Centre, they were told that the Centre would be a "home for life". Many people, who had often struggled to find the best possible option for their relative, found this assurance to be a huge relief. To now realize that Templeton Centre would not be their relative's home for life was very traumatic for many families. This realization was especially troubling for some of the older parents who were worried that they might become responsible for looking after a son or daughter who may not have lived at home for many years. While this was never an intention of the proposal, for some families a fear of being expected to care remained for a considerable period. Families believed that they were losing a service that had met their relatives' needs when no other service had been able to. One very elderly mother was still clinging to an assurance she had been given by a Templeton staff member over fifty years earlier.

> ...he gave me an assurance, this is what makes me so mad that they're closing down Templeton. Because I had an assurance from [Doctor's name].

However, another parent acknowledged that the change necessary to achieve deinstitutionalisation was challenging to deal with – perhaps because of such assurances that had been given in the past.

> Well like anything new, after you get into a set of things that are going on through your life it's the change you know, that rocks you at first. Here we were promised if we put our child in Templeton he'd be cared for.

One mother who had a daughter aged in her twenties living at Templeton Centre reflected on how plans for closure were having an impact on older parents.

> I think it has put a lot of stress on those. Also the older ones who were told years ago to leave their child there and we would look after it. You have to go away and have – you see this is it, you can't trust anything anymore can you?

One elderly mother worried more about the impact on her non-disabled children if the closure of Templeton Centre resulted in families being expected to care for their relatives with an intellectual disability. Her comments highlight two points. First, this mother obviously believed that her son might be returned to her care if Templeton Centre closed. Second, she was adamant that her other children should not have to take on the responsibility for caring for their brother.

> Yes, because they didn't say that they'd [Templeton Centre residents] would still be looked after for life and we wondered if we'd have to have him at home, because just Templeton was closing, nothing as to what was going to happen to them, and well, just parents are getting so much older. And it wouldn't be fair for his brother or sisters to have to look after him. Wouldn't be fair at all. Wouldn't want that.

From the outset, the deinstitutionalisation of Templeton Centre and resettlement of residents into the community was presented as a "quality of life" decision. The SRHA and the CHE were always careful to point out that the planned closure of Templeton Centre was not about money but was, instead, a move intended to improve the lives and lifestyles of people who have disabilities. Despite this, almost all families remained unconvinced that the plan was not financially motivated. Most families continued to believe that the deinstitutionalisation of Templeton Centre was a direct attempt to cut costs, and believed that the long-term security of their relatives was being compromised by this decision.

> I'm still squarely of the opinion that the dollar is at the centre of this whole thing…

> I wouldn't think it would cost all that much to upgrade Templeton. I think it's money, it comes down to money, a lot of it. I'll be surprised if it's not.

Families who were opposed to the closure of Templeton Centre, and who clearly believed the deinstitutionalisation process represented an attempt to reduce the costs of caring for people with an intellectual disability, seemed genuinely confused as to why the government would pursue a service option that was going to be more expensive to fund.

> I can't understand why they can't see that it is not the most cost effective way of doing things.

Despite realising that deinstitutionalisation was not going to result in any reduction of costs, one brother remained mistrustful of the motivations driving the process.

> Well I think people thought it was going to be a cost cutting exercise…I mean that is an amazing thing in a way, it is going to cost them much more than keeping people at Templeton. It's got to. It's not very often the government does this. You don't very often get a government pushing the community to spend more money. You know the government's usually cutting costs. Here they were advocating spending more money, when nobody knew that we were advocating it. No one was saying look we've got to close Templeton down. You know, the parents weren't saying it.

Uncertainty, mistrust and fear were common themes. One mother was asked if she saw anything that could result in a positive outcome for her son if he was resettled from Templeton Centre. She replied in the following way.

> Brigit I wish I could tell you that. You see we have just been. Templeton was a stable place beyond doubt. The shock just about killed us. We had nightmares – nightmares about what was going to happen to [son]. Now we are forced to accept that Templeton is going to close. We feel very uncertain. Scared. Financially, what about when they run out of money.

This mother's statement raises several issues including her view that all stability would be removed from her son's life, as well as from her own life, as a result of the closure of the institution. She also raised a common perception that the community based service system would not be as financially secure as the institution. One might perceive this mother as giving a very emotional response but my awareness of this family's story of institutionalisation meant I was able to comprehend the level of fear they were feeling. This family had experienced a history of unsuccessful services for their son. Their disappointments had occurred both within institutional and community based service settings. In recent years, this family felt as though they finally had achieved a relatively settled existence following their son's move to Templeton Centre. To contemplate upsetting the fragile balance they had achieved in their son's life was extremely distressing for this family. This same mother reflected further on the impact of a loss of stability that she saw as an inevitable result of resettlement.

> I couldn't sleep at night. It really was quite a nightmare, it was constantly on our minds and it was just terrible. Especially as you are aware, most Templeton parents are not young people. If you have to use a new service you have to keep an eye on it. As you grow older the last thing you want to lose is the stability.

Families perceived that planners and policy makers involved in the process of deinstitutionalisation did not listen to their views and concerns. Families also believed that unless such people knew their relative personally the information that they were trying to convey had little relevance and did not address their very real concerns.

> Yeah we were angry, everybody, all the parents were angry but we were frustrated because no one would listen.

One of the biggest worries that families expressed related to the personal safety of their relatives. A significant number of people talked about feeling concerned that their relative did not have the necessary personal skills to act appropriately in the community or to ensure their own safety.

> But I don't really like the idea of [brother] being in the community situation. I mean he's the sort of guy that would go and walk into a shop and like the look of a magazine or a bag of lollies or something and just pick it up and walk off with it.

Concern about whether or not their family member would be accepted by the community was mentioned by a significant number of people. Families generally saw the community as a hostile environment, and an environment that displayed no concern for vulnerable people. Such concern is understandable given that many families had, in the past, experienced situations where their relatives had been denied services, and had been excluded from the community.

> Some of those kids [people with an intellectual disability], and I don't know that, you know, the people out and about are going to cope, or if they will even accept them…

Families also worried about their relatives' ability to protect themselves from those people in the general community who may try to take advantage of them. An extremely small number of families mentioned that they were worried that their relative may cause harm to others.

A significant area of concern expressed by the majority of families who participated in this study related to the issue of staffing of the new community based services. Many families felt that Templeton Centre staff had the necessary training and backgrounds in order to be able to work most effectively with people with disabilities. Families feared that staff in the community based services would not have the same level and type of training.

> He won't get the care he had out at Templeton, because they do look after him and they're trained for it, the nurses. These people that are going to take over I think they're only in it for the money.

> Oh my son has got to have special, specially trained people because of his – the autistic persons need different handling and it's supposed to be 24hour care. You can't leave them to fend for themselves. It's out of the question.

...we are deeply concerned for [our son] and others who are severely handicapped with special needs about the ability of this new health regime to deliver the level of expertise and skills that are going to be required – always have been required for these types of people...

Even families who were positive about the resettlement of their relatives felt that the success of the move relied on the quality of staff employed to work in the community. Such families feared that the success of deinstitutionalisation would be compromised by the appointment of poorly trained staff, or staff who did not have the appropriate personal qualities to work effectively with people with an intellectual disability. A father who described himself as being thrilled when he heard of the plans to resettle his son said:

But then it's that fear now, that it's got to be the right person, the right place, the right staff.

One issue that was raised by a small number of families and individuals was that of having to wrestle with their own feelings of guilt. While most families directed their feelings of anger and fear outwards, some families reflected on their own role in the institutionalisation of their family member resulting in feelings of guilt about their earlier decision. One mother said:

Because the first time we heard that come over the radio [we felt] guilt, that my god, perhaps she shouldn't be there.

Feelings of guilt were more commonly expressed by families later in the process of deinstitutionalisation after witnessing their relative's successful transition into the community. At this earlier stage their comments usually reflected the fact that they now questioned their earlier decision to seek institutional care for their son or daughter.

Another fear that became apparent during Phase One interviews was that of a fear of responsibility. It is significant that the fear of responsibility was articulated by a small number of siblings. Two sisters from different families indicated that their fears were centred on the impact that an increase in the level of responsibility for decision-making would have both for themselves, and for their elderly parents.

[This] responsibility that hasn't been ours is suddenly coming back to us again, coming back round to Dad again who's seventy-five.

Well early on I was quite worried I suppose. I was worried about Mum, how much she would end up having to take on and I was worried about the fact that she was so worried and I guess I worried about how much I might need to take on.

A third sister's comments reflect a certain level of bitterness about a perceived expectation that families would become involved in the decision-making integral to deinstitutionalisation, regardless of whether they had experienced an on-going relationship with their relative over the years.

Suddenly they want the families to be involved again. Yet I feel the families have been kept at arms length for the last generation. You can't suddenly expect them [to say] – hey, hi brother.

This sister's comment highlights the fact that deinstitutionalisation forced many parents and siblings to begin to re-establish and maintain different relationships and roles with their relatives with an intellectual disability.

Positive reactions to plans for closure

The previous section has discussed the fears held by families who had relatives involved in the deinstitutionalisation of Templeton Centre. Many of the families that held such fears were opposed to the resettlement of their relatives. This was not the case for all families involved in this study. A significant number of families and/or individuals did not respond negatively to the idea of resettlement for their relatives. These people felt that the opportunity to live in the community might be a beneficial one providing all the necessary supports and services were firmly in place. The following comments were provided by parents and siblings from different families.

As far as [my daughter] is concerned, I'm quite happy. She shouldn't be there, she should be out in the community.

Well I was a bit concerned and then Healthlink South put out all their written things and somebody came and talked to us and said that none of [our children] would be moved until there was at least the same quality of services out in the community. So that made me feel a bit better because I would like [my daughter] to be closer to us.

I have no problems and I think a lot of the people fighting the closure of Templeton don't understand that there's going to be a better life, or better environment for them…

There are some wonderful people involved in this resettlement programme, and I think it's going to be wonderful for them really. I think they're going to get more opportunities for a normal life.

During an interview that took place with a husband and wife they were asked how they felt when they learned that Templeton Centre would close and their son would be moving into a community based service.

We were actually, both of us, quite secretly overjoyed that it was going to happen… we've always thought [our son] would have done better in the community.

When this same couple was asked whether they had expressed their view to other Templeton Centre parents they responded in the following way.

Wife: Well we…
Husband: We didn't voice an opinion
Wife: But we kind of thought well that will be quite nice.

This rather hesitant endorsement of deinstitutionalisation illustrates two points. First, this family was not opposed to the major change in service delivery planned for their son. Secondly, they were conscious of the need to not be too vocal about their support of the plans for closure. Both husband and wife were members of the Templeton Centre Parent's Association (TCPA) and acknowledged that their own positive view may not necessarily be shared by other families. They felt that by expressing a positive attitude toward deinstitutionalisation they would be perceived as disloyal by families who had negative attitudes toward the closure of the institution.

Other families and individuals who looked forward to deinstitutionalisation also reported feeling as though they had to hide their true feelings from other families, and in a small number of cases, from staff working in the institution.

Yes – that was one of the things that sort of persuaded me to start doing something, because I thought "oh I'd rather be in at the beginning than in at the end" and I might have mentioned that to the unit manager [at Templeton Centre] and she said "well I don't think that's a good attitude, because that's scaremongering"… so I thought "oh yes, I won't say any more about that then". But I mean it was a natural thing to think wasn't it?

In saying that she would rather be in at the beginning than at the end this sibling was articulating the private view of many families who took part in this study. She believed that her sister would receive greater choice in terms of a community based service if they began the process of transition as soon as they could. When she expressed this view to a staff person within the institution the staff person chastised her for holding this view because it might scare other families into believing that they also had to become active in the search for a community based service for their relative. At the time this exchange took place Templeton Centre staff were, to a large extent, uncertain and frightened about their employment futures.

Exploring families' hopes and aspirations

During the Phase One interviews I asked families to tell me their hopes and aspirations for their relatives with an intellectual disability. All families, regardless of their view of deinstitutionalisation were able to identify at least one hope or aspiration for their relative following resettlement. An interesting aspect to this finding was that even families who were opposed to deinstitutionalisation and the resettlement of their relative into community based services, held aspirations for that person.

While some families projected their own hopes on to their relative *"[I hope] that they have a sheltered village and [my son] gets to stay there*, all families expressed the overriding hope that their relatives would experience ongoing happiness and quality care. How happiness and quality care could ultimately be achieved, however, was perceived differently by different families.

Some families had thought in greater depth about what a transition to smaller residential services in the community could mean for their family member, and their hopes and aspirations reflected this. Often families hoped that they would experience a greater level of involvement with their relative after resettlement.

> ...We're hoping that we'll have better contact aren't we. More involvement, with [our son's] day to day thing. I don't mean being there every night and ringing up every night, but we're hoping that we'll have a little bit more involvement.

When asked about their hopes for their son's future one couple had very specific aspirations for their son. This was surprising to me as it seemed to contradict the

conversation that had gone before which centred on their very negative view of deinstitutionalisation. While the couple were proponents for retaining the institution, they shared hopes for their son that were unlikely to be achieved at Templeton Centre. Their son was in his thirties and had left the family environment and gone to live at the institution when he was about seven years old. The father said:

> If he had a one-to-one relationship – even start to read. I know it sounds unlikely.

The mother continued:

> I mean his music ability, he loves music, he used to sing beautifully and in tune when he was a little boy. He lost a lot of that and now he sort of sings in a funny way, but he does love his music and that could be brought out more, who knows.

Another mother hoped that her daughter would experience increased privacy and control as a result of her move from institutional to community based services.

> Well one of the hopes would be that she will have some privacy, and be able to have her things around her without other people coming in to destroy them all. That's what I would hope, that she got to feel that that was her home. And as an adult person, she still relates to us as a family, but that that is her special place.

Interestingly, siblings were also found to have given a great deal of thought to what could be achieved through the resettlement of their brother or sister. Several siblings described their hopes and aspirations in a way that reflected their lifelong struggle to gain a real understanding of their brother or sister's intellectual disability. Often siblings hoped that their brother or sister would experience a greater ability to communicate – to display their potential.

> Rainman – that sort of revelation about the potential locked in – inside [my brother] that could come out with the right help – so he gets as much out of life as possible, even though he is locked inside himself…My greatest fear is that it just goes on like it is [at the moment]…

A sister who was very involved in supporting her parents to make decisions about the future of her sister with an intellectual disability had hopes and aspirations for both her sister and herself.

The number one thing is that she is looked after and loved and no one is hurting her and she's comfortable in her own mind…I'm hoping that I'll be able to go into these houses and just call in and say hello, because I would never go out to Templeton just on the off-chance.

This sister elaborated further:

My hopes for my sister are that she will have a more intimate home environment where she lives with other people that she likes, and she is cared for by people who care about her and who have some energy for her and who love her. Especially, I mean I know it will be a job but that [the staff] will like what they are doing and that we can visit as a family, and where we can drop in… on our way in and out of town…and that we can have a relationship that is easy and talk about things that are good or things that are not so good. That staff can feel supported, because we're all staff people working in environments ourselves so we know what that feels like, but that staff would see that we support them.

The hopes and aspirations that this sister held displayed a holistic quality. They encompassed herself, her sister, her family, and the staff who would support her sister in the future.

"Seeing the other side" – Family decision-making and deinstitutionalisation

When I began working with families for the purposes of this research I was interested in gaining an understanding of how families were intending to progress toward the resettlement of their son or daughter from Templeton Centre into a residential service based in the community. In particular, I was focused on establishing whether or not they were planning to actively seek alternative service options for their relative, or whether they were planning to remain inactive, despite the fact that the process was taking place around them. It is important to remember that at the time that the Phase One interviews were conducted families had been given formal notification that Templeton Centre would indeed be closed. Families could no longer ignore the unsubstantiated rumours about closure, because a formal deinstitutionalisation plan for Templeton Centre had been developed and made public.

At the time I began interviewing families for this research the general perception amongst the wider community was that all families who had relatives living at Templeton Centre were committed to the facility remaining open. This perception was certainly accurate for a significant number of families whom I interviewed. The

level of opposition that families felt toward the deinstitutionalisation of Templeton Centre could, in part, be ascertained by whether or not they planned to actively engage with the process of service coordination for their relatives – that is to start looking for a service in the community.

By the time that I commenced Phase One interviews all Templeton Centre residents had undergone a needs assessment process. The needs assessment formalized each person's support and service needs. Once this process had been completed families had been told that they should contact the service coordinator who had been assigned to their family member. This process was designed to make families feel as though they were in control of the process. What happened in many cases, however, was that families used this control to stall the move toward resettlement for their family member – that is, they purposely did not contact their service coordinator. Families who took this approach were clear about their intention to "do nothing". The following comments illustrate this point.

> Probably sit on the fence for a while and see which way the wind blows.

> I need reassurance that while Templeton will close, nothing terrible is going to happen because [my son] is not going to move until we find something as good as Templeton or better.

> We're still saying that [our son] is not going to shift from Templeton until a suitable place is found. And that is our position.

Other families had a different view. Their inaction was not intentional, but rather they did not know how to start a process that would lead them toward they eventual resettlement of their family member. Their comments highlighted their lack of information about the process of deinstitutionalisation, what role they were expected to take within that process, and what options were available to their relatives in the community. Families reported that they would have started the process of transition of their relative from Templeton Centre into community based services a great deal sooner if they had known where to start to locate potential services. The following comments reflect this view.

From day one if we could have found something we'd have been out like billy-o.

Tell us where to go and we'll have a look at it.

Now I just want it to happen…I would like to get it rolling.

We sit and wait, yes, we sit and wait.

One brother's comments illustrate the frustration felt by some individuals and families as they waited for progress to be achieved in terms of the resettlement process.

Sometimes I feel like I should just push it through, and I should go up to them and say hey [my brother's] got resources, he's got money. I could just go and buy a house and I could get together with some other people and say hey, let's hire some really good people, put some money up to get a joint exercise and get some really nice people to look after him – you know, if I had initiative like that but that's all dream time. No – I just sit back and let the process happen and it's taken so long hasn't it. It's just taken years and years and it's interminable.

While this man was clearly feeling frustrated about how long the process of resettlement was taking for his brother, I became aware that two issues combined to complicate the situation for this family. First, the man's elderly father was the primary decision maker regarding resettlement and he was opposed to the closure of Templeton Centre. Second, the father was also unclear about his role within the process. In short, he was waiting for a service coordinator to approach him rather than taking the step of initiating contact with a service coordinator himself. This resulted in a situation whereby the brother did not want to offend his father by assuming control of the situation. He was also aware of the fact that it was perhaps his father's last decision-making role in the life of his son with an intellectual disability and he was being careful not to usurp his father's authority.

Other siblings described the complexity of supporting a parent to make decisions about the future care of their relative. A sister articulated her sense of confusion about whether or not she and her father were taking the best course of action. To respect her father's position this sister had agreed to support her father's decision to remain inactive with regard to choosing a community based service. Nevertheless, she said that in supporting her father's wishes she felt that they may

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be compromising the choice of service that would be available to her brother in the long term.

> And the problem about sitting on the fence is, which Dad and I were talking about yesterday, is that because we're messing about we're going to lose choice. And we're going to end up with something we didn't want because everyone else is going to have the choice.

This issue of achieving the greatest choice of community based services was certainly a significant factor in the decision-making exercised by families who participated in this study. This issue is discussed in greater depth later in this chapter.

One couple who participated in this study talked about their hope that they could achieve greater choice for their daughter through taking a slow and measured approach to identifying an appropriate service. Their daughter had very high support needs and frequently was aggressive towards those who lived and worked with her. This couple's anxiety about being able to access an appropriate support service understandably was high but they still refused to support what they saw as the radical approach of some families opposed to the closure of Templeton Centre.

> Int: So what are your plans from here?
> Parent: Probably from going to meetings and seeing some radical thoughts and seeing some radical people who were jumping up and down and holding placards, there's not – I mean there's nothing we can do and there's no need to. You're not going to get anywhere by shouting and asking questions with things like that. And we'll just float on quietly and see where we go…or what they come up with. At least we've got the right to say yes or no we hope. And that if we're not happy with what they come up that perhaps [we can say] we can have a wee look at this again.

"Should I stay or should I go": Understanding family decision-making

During the course of conducting the Phase One interviews I talked with several families who had already moved from being opposed to the resettlement of their relative, to being positive about resettlement and actively engaged in the process of identifying a suitable community based service. I was interested in trying to establish what might have influenced such dramatic changes to families' views.

Several families discussed the impact of having the opportunity to observe people with an intellectual disability actually living in the community setting. One strategy

that was employed during the process of deinstitutionalisation as a way of providing more information to families was the opportunity to visit community based services that had been established to facilitate the resettlement of people with an intellectual disability following the closure of another South Island institution.

Families described vastly different reactions to this opportunity. When I asked families what had influenced them to think more positively about their relative's resettlement a number of families reported that having the opportunity to visit a residential service operating in the community was a valuable experience. Actually seeing people with an intellectual disability living in a community based home enabled families to visualize how their relative might fit into a similar environment.

> Probably when we went to Dunedin and looked around the community housing and we had the opportunity… well we looked at it from a personal view first didn't we, because we thought, well yeah [our son] could fit into that house.

> I think having been in Dunedin and having had contact with the other homes that are actually in operation and how [our daughter] could fit into a scene like that.

However, not all families interpreted the opportunity to view other existing community based services in a positive way. Some families believed the people with an intellectual disability living in the community services were not comparable with their own relatives. That is, these families held the view that their relatives were more disabled and had higher support needs than the people living in the services they were shown. Despite the fact that he had not actually visited any community based services one father said:

> There may have been one or two with very mildly handicapped people. Half a dozen [community based residential services] working in some parts of New Zealand, and we have had a Templeton group of parents go down to Dunedin I think… and have a look at how some of those have been settled in the community. I'll guarantee that they have been the more mildly handicapped people. I haven't heard anything about the more severely handicapped ones being satisfactorily placed on a long-term basis in the community.

This perception that deinstitutionalisation and community living might be possible for "other" people with an intellectual disability was quite pervasive among families who initially were opposed to the closure of the institution.

The reflections of one couple probably go some way toward explaining why for some families even seeing community based services working effectively in the community did not help them feel more comfortable about resettlement. The couples' comments illustrate that it is difficult for families to put aside their deep rooted fears about the care of their relatives with an intellectual disability.

> Husband: Yeah, we went to Dunedin, we all thought it was wonderful, but the closer we got back to Christchurch on the bus that night...
> Wife: ...everybody thought it was wonderful, great, and the next minute...

These comments serve to illustrate the nervousness and ambivalence that some families felt when faced with having to make decisions about the future care of their relatives.

Similar to the function served by families having the opportunity to visit community based services, information that was distributed by other disability focused agencies and organizations played a part in assisting families to shift their thinking in relation to deinstitutionalisation. One mother described how information that she received from a service coordination agency helped to influence her to change her approach to the resettlement of her son in a more positive manner.

> And some of the information that came through to us that could've come from Lifelinks or somebody like that, that set out their priorities – like the charter so to speak. And you could see that this was going to perhaps be better than what [my son] had had. I'd always said that I wouldn't object to him going out if what he was getting was better than what he had at Templeton.

Many families became motivated to be active participants in the process of deinstitutionalisation being implemented at Templeton Centre simply because they believed they would achieve greater service choice if they acted early in the process. Often families continued to harbour doubts and fears but these were overridden by their pragmatism about service availability.

A sister's belief that her brother would have greater choice in the support services he could potentially access illustrated her ambivalence towards deinstitutionalisation. Moving out early would give her brother the option of returning to Templeton Centre if his resettlement was unsuccessful, but at the same time, her vision for her brother's future was a positive one.

... I had this theory that if he moves out as one of the early people out, Templeton will still be there if it doesn't work initially... So to be in early you've still got [Templeton] there as a back-stop. But I try - I really don't think about that very much, I'm sure it's going to work. I'd love for him to be like somebody in their own home, happily inviting you in, you know.

Other families were quite resentful of the perception that those who made decisions regarding the resettlement of their relatives early in the deinstitutionalisation would achieve better service outcomes. A parent justified his reasons for not being forced into making a decision about his son's resettlement.

I thought I'd see what happens, rather than rush in, because there's been a few scare tactics you know - if you don't get in first you'll not get the best!...When the time comes I'll definitely make a move. I won't do it now... when the situation arises I will deal with it.

Some families identified that staff both within the institution, and within the newly developed community based services were instrumental in some cases in helping families to have the courage to move toward resettlement. When asked why they had made a very quick decision about their daughter's placement one couple replied:

It's just that we thought it was for the best. And we were impressed with [manager of community based service], weren't we.

Another parent talked of the dual influences of a staff member who had worked with her son for many years in the institutional setting, and of her daughter for helping her to come to terms with her son's resettlement.

Well I suppose this lady, the one I'm mentioning. She said to me, it's be great for [your son] to go into the community. She said I'm all for it and she has convinced me, she did convince me...My daughter was very keen on the move out... she said oh I think [son] will have a different life altogether mum you know. And that help me to see the other side. And then I realized that all his needs were written down – yes, I thought it could be a good idea.

This woman's daughter explained how she had managed to influence her mother's view from being extremely opposed to the closure of Templeton Centre, to embracing the notion of resettlement for her son.

Well I guess information gradually, but also just starting to look at what something else might be – I remember saying to her "you know at Templeton there have been a lot of things that may be could have been done that haven't been done, and I don't know but it's possible in an environment where there's a small number of people that there could be more done for him." I don't know – but anyway she started to see that.

The role of siblings in family decision-making

As illustrated by the previous quote it was clear that in a significant number of families siblings played an important role in influencing their parents to view deinstitutionalisation as something other than an inherently negative transition. While the end result may have been similar, siblings had different motivations for trying to shift their parents' thinking, and consequently their actions with regard to deinstitutionalisation.

Siblings often appeared to respond personally to the plans for deinstitutionalisation by reflecting on their family history, and on their own relationship with their brother or sister with an intellectual disability. Sometimes they described their attempts to (re)establish their relationship and commented on the emotional affects of such a process.

One sibling described how he felt he had been conditioned to view his brother with an intellectual disability negatively when they were both children.

[Brother] practically didn't exist as a person then. He was a nothing. See the attitude – and I think I was influenced by the attitude – was that [brother] only deserved to be in a place like Templeton.

This sibling continued to agonize over the decisions his parents had made in the past and to berate himself for not becoming more involved in his brother's life. He described how the events of the planned deinstitutionalisation had motivated him to learn more about the reality of his brother's life and the decisions that his parents had made in the past regarding institutionalisation.

Well [my brother] means a lot to me. It's a bleak and moving area and it's something I find quite difficult to get a proper understanding of because I don't have any very vivid memories of him. I certainly have memories, but they're only for very much the early part of my life… It's like a big gap and there's something that's a bit of a mystery as to what that gap is. I've been exploring it in the last nine months and just getting clear about the dates,

how old he was when he left, and options that my parents had, sending him to Templeton, and trying to get an understanding of it. Because for me when I visited him, particularly in the 70's when I started to make a more regular practice of visiting him – it was always an emotional experience and I thought, "a lot lies here which I don't fully understand". It was very emotional at the time and I'd often cry and just feel terribly sad.

A sister who participated in the study also described a situation whereby her unresolved feelings toward her brother with an intellectual disability, and his removal from the family home, were experienced sharply and unexpectedly.

> ...and a friend of mine who knew about [my brother] asked me if I would talk about what it was like growing up with him and I said I would. And I started talking and I just found – I shook like this was such a shock, sitting there talking and I started shaking all over and I couldn't stop and then I got really upset and it was just awful, and I hadn't realized how deeply upset I was and I'd never really acknowledged that and it's probably affected a lot more about me than I'm even aware of now I think.

It is difficult to offer a conclusive analysis of this response. One possibility is that this sister was upset about the fact her brother had an intellectual disability, and that her recollections of coping with his difficult behaviour on a daily basis overwhelmed her. A second possibility is that this sister confronted her own unresolved feelings about her brother's removal from the family home, a removal that resulted in an on-going and unresolved tension between her mother and her father. My position is that her emotional response to talking about her brother was most likely to be caused by a combination of both of these realities. It is clear, for this sister at least, that having a brother with an intellectual disability who was institutionalized as a child had had a lasting emotional impact on her life.

During Phase One interviews it was common for siblings to reflect on their relationships with their brothers and sisters with an intellectual disability. A sister described the process of getting to know her brother again. Her comments echo the sentiment of other siblings who participated in this study in that she articulates a strong connection to her brother even though they were separated for over thirty years.

> I've had far more to do with him since I've been living in Christchurch, which is only four years, than in many, many years. And he responds really, I mean it's like we were never separated. He's really loving, and he's really happy to see me and he recognizes me and knows who I am, although he doesn't ever name me. And he knows I have contact with Mum. Mum is like you know, really special [to him].

In contrast with the previous two examples, this sister had a very open relationship with her mother with whom she had frequently discussed the emotional impact of her brother leaving home to live in an institution. Her attempts to re-establish her relationship with her brother had been affirmed by her mother and by other members of her family.

It was common for siblings to take a pragmatic approach to deinstitutionalisation – they understood that change would occur and that their brother or sister with an intellectual disability would be required to move into community based services. Siblings with this pragmatic approach believed it was important to help their parents accept the reality of the situation.

> But no – I really started saying to her from the word go, look this is probably going to happen. In fact I tried to paint a fairly rosy picture of it [deinstitutionalisation] really because I thought it was going to happen and really you've got to look at the positive side and try to influence it in a way that we can get what's best for [brother] out of it you know.

Another sibling in this same family was also motivated by her view that good information would be gained by staying calm and by focusing on the proposals and consultations that were being presented to families.

> Well Mum was really upset, so I didn't get upset. I guess I thought well we have to wait and see what proposals there are and what is actually going to happen. Because I think that the parents were panicking…they had this opportunity for consultation but I could see that a lot of the parents at Templeton were getting quite radical. I had a sense that they weren't really listening to what was being proposed.

The influence of the siblings in this family was pronounced. The elderly parent who was making decisions relating to the resettlement of her son changed her view from being a vehement opponent of deinstitutionalisation to someone who chose a service and supported the transition of her son from Templeton into the community at a very early stage in the process. This mother was supported in her decision-making by two of her non-disabled adult children who made her aware of the potential for positive outcomes for her son with an intellectual disability. She also accepted her non-disabled children's view that she would have a greater degree of service choice if she resettled her son sooner rather than later in the process.

It was clear that in some situations it was siblings who could be quite open with a parent and challenge them to look more positively at the plans for deinstitutionalisation. This is quite possibly an approach that no other person involved in trying to implement the resettlement phase of deinstitutionalisation could take. A mother described an exchange with her non-disabled daughter during which her daughter alerted the mother to her general resistance to change.

> Well everyone says you have got to be positive. I just got a lecture today about this. Even my daughter said, "you're just so negative – you know you don't like change. Look how you didn't want [disabled daughter] to go to [new school], now look what you say about it.

This mother confirmed that she had been opposed to a change in school environment for her daughter but after experiencing the transition had realized that she had worried needlessly. Her daughter's comments reminded her of her previous experience.

Some siblings reported that they had experienced an alteration or readjustment to their own thinking that had the effect of enabling them to embrace the notion of deinstitutionalisation themselves. One brother talked about how his own perception, and subsequent approach to this issue changed after a discussion with his wife.

> Well what I heard initially, that they were going to be put into the community - that was quite a long time ago, I was cynical about that because I thought this is a cost saving measure...And I thought I wonder if they really will deliver on quality of life. What I'm looking for is quality of life, I don't care what happens – and I'd be surprised if they could do it on quality of life, because there would have to be a major change to the funding – or that is an absolute priority I would have thought. However, increasingly, and particularly through discussion with [my wife] and her thoughts on the matter I see – don't prejudge what this is all about. Though this may be just a shortcut to save money, it could be an opportunity for something better. And it's all very simple – I can summarize it very simply, if it's going to be an improvement on his present position, change is – I would be absolutely for it. So I'm not interested in the closure of Templeton Centre, I'm only interested in the well-being of [my brother].

Another sibling described how she had thrown herself into the lobby to retain Templeton Centre, even to the point of taking a petition about the closure of Templeton Centre to her place of work for colleagues to sign. Over time she also changed her view and supported her elderly mother to choose a community based

service for her brother. This made him a member of one of the first groups of people to leave Templeton Centre. When asked what influenced her change in view she could not articulate how or why her change in thinking had occurred – just that a change had occurred gradually over time.

> Not really no. I think I must have gradually got more optimistic in things I was telling her were happening. And she really did come on side. She believed what I was saying. I think it's really important that she's positive... You tend to start thinking about the positives rather than the worries, the negative parts. And you think, oh yeah, he'd like that if he could do that.

Her role in the decision-making relating to her brother's resettlement had been formalized to the degree that she now received all the relevant information, as did her mother.

> Yes they did send out some information. But Mum would often get it confused and not interpret it in the way it was supposed to be interpreted.

A third sibling described how the negative response of other families who had relatives involved in the closure of Templeton Centre had the effect of allowing her to see the positive aspects of transition.

> Some of the people that were aggressive, some of the parents [were] so anti closure, because we had a few members of parliament out, and they gave them such a hard time. I hated that, that goes against everything in my nature. I didn't like that type of behaviour and I looked at some of these people and I thought you're not here because you care about your child staying at Templeton, you love the fight, you love the politics involved in it and that is not me... and I also started to realize, listening to the politicians and thinking about the government and the country, that it was going to happen, and I felt that it would be better to move with it, instead of standing up and fighting, so I decided that I thought it would be a good idea and that I would work along with [my sister] towards it.

A small number of siblings felt guilty that they were not involved in the decision-making relating to the resettlement of their brother or sister. A sister who lived in another city described how she felt about the fact that she had no real role in the decision-making that occurred with regard to her brother's resettlement.

> Yeah, that I'm not doing enough, that sums it up, yeah. And also the residual feeling – perhaps I'm taking on my mother's pain as well – because it's not mine, I mean he wasn't my child, he was the lost brother kind of thing, no not the lost brother, that's very dramatic, but that sort of sense of a gap and the sad event that caused the gap.

In contrast, another equally small group of siblings were resentful that they were being expected to assume responsibility for the decision-making related to their brother or sister's resettlement. In one case, a sister who was making decisions about her brother's transition from institutional- to community based services felt that her mother was abdicating responsibility in this matter.

> Yeah, [my mother's] kept out of it. She's quite willing for me to just handle it all. As I say, from my point of view – I'm a mother, he's her child, no matter what the situation or condition or state he's in. It appears to me she only has those maternal instincts when she is with him. When she's away from him, well you know, it's not something to be thought about and so [she thinks] she can sort of – "oh let them deal with it.

It was clear that siblings felt, in some situations, that their ability to have a voice in the decision-making related to their brother or sister was compromised by the views and approaches of their parents. These situations occurred in families where parents did not appear to be comfortable sharing the decision-making process. A brother described the dilemma he found himself in when his own and his father's opinions diverged.

> ...my father's into a sheltered village...And I'm not – that doesn't tell me enough about [my brother] really. I keep coming back to what is best for [my brother] and if out there [Templeton Centre] is a sheltered village, it's not good enough. And I have a little difficulty – I need to know what is meant by a sheltered village...I just reserve on that because I don't really know what they mean.

A mother's propensity towards privacy left a sister feeling as though she could not have any active role in decisions relating to her brother's resettlement.

> Well it's, in our situation it's quite awkward because my mother's a very private person and I think the first decision is with her. So I couldn't have liked to have been involved if it was a threat to her.

This study has shown that many of the adult siblings who contributed to this research did perceive themselves to have important roles in the lives of people with an intellectual disability. Significantly, siblings highlighted the importance of their being available to advocate on behalf of their brother or sister, and to ensure that the support and services they received continued to be delivered to a high standard.

Two different brothers said:

> But it's my job to make sure that the powers that be and the decision makers keep their word [about] looking after the care of my brother.

> ...my key concern for my brother is getting his needs met. So whether that is at Templeton in a sheltered community, or living in a home, a high needs facility in Christchurch. My concern is [my brother] getting his needs met.

A sister elaborated on this issue further:

> I see my role as a legal guardian and those of my brothers and sisters – that we will need to continue [to be] vigilant on my sister's behalf because she's always going to be vulnerable to where she's living and who she's living with.

Even before Templeton Centre residents had made the transition from the institution into a new support service based in the community, siblings were reflecting favourably on the way the process of deinstitutionalisation had an impact on their relationship with their brother or sister. Siblings acknowledged that the process had enabled them to reconnect with each other as family.

> Well funnily enough we've got to know him far more lately than previously.

> And I see the change as being positive. It's certainly been positive for us as a family to talk and think again, where [our sister] is at and what her needs are.

These quotes provide a stark contrast to the sense of dislocation expressed by a sibling at the conclusion of Chapter Six. Reflections on the process of deinstitutionalisation suggest that families were beginning to experience a sense that their relatives with an intellectual disability were being (re)located back into their lives and their family environment, if not their family home.

Transition – experiencing life in the community

The previous section has highlighted the roles that various family members played with regard to the decisions that families made during the process of deinstitutionalisation and the resettlement of their relatives. While it was necessary for families to accept and experience some positive feelings toward change, they still needed to base their decisions about suitable services on tangible qualities or

characteristics. Such qualities and characteristics were components that families perceived as being critical to the delivery of a quality service to their relative with an intellectual disability. The following section of Chapter Seven is focused on how families selected a community- based service for their relatives, as well as on the actual impact of transition on the families of those involved. The findings presented in this section are based on an analysis of the interviews that were conducted as part of Phase Two of the research which involved interviews conducted 1-3 months following resettlement.

"But it's just so hard to choose": Selecting a new service

As I indicated in the previous section, families were divided about when to initiate the move of their relative into community based services. Many families who had relatives involved in some of the earliest moves from Templeton Centre had chosen services early because they were positive about the opportunities that resettlement could offer their relative. It was common for this group of families to also believe that by making their decisions quickly they would be afforded with greater choice. Other families who were not as positive about the plans for resettlement also agreed with the notion that to move early would afford them with increased options. Contrary to this, a significant number of families resented the feeling of pressure and were adamant that they would take as much time as they needed to decide on the best possible option for their relative. Some of these families were delaying any decisions until they were completely sure of all the service options that would be available to people with an intellectual disability affected by the deinstitutionalisation of Templeton Centre.

Quality staffing

Although families had different views about when to move, almost all families taking part in the study highlighted a number of common areas as being important as they explored and selected a new service for their relative. Almost all families taking part in this study reiterated the fact that the success of the new model of service delivery for their relatives would be determined by the quality of staff working in the community based houses. While families were united in this opinion, they had differing views as to what constituted "quality" staff.

Some families believed that if the needs of their relatives were to be met then staff should be registered nursing staff.

> I would have preferred registered [nursing] staff on each shift.

Many families wished to see as many former Templeton Centre staff as possible working in the new community homes as they saw them as experienced and suitably trained.

> I was keen to have somebody that was going to employ psychopaedic nurses, which limited a lot of the other [providers].

Other families were positive about the fact that there were going to be "new" staff employed to work in the area of supporting people with an intellectual disability. Such families tended to believe that attitudes and values, not nursing qualifications, were the most important characteristics for staff to possess. As families went through the process of selecting services sometimes the knowledge that a particular individual was involved in a particular service (usually at a management level) encouraged families to choose that service.

> We went to see [manager of disability support service] and we were most impressed with him.

Track record of service provider

The "track record" of service providers was also an important area to consider for many families. Often families were inclined toward a particular service because they had prior knowledge of that service, had seen it in operation, and liked the way they did things. For families who were concerned about the stability and long-term financial security of services, the fact that a service had been operating in the community for some time was seen as positive.

> ...so we haven't got much fear that way. The [disability service provider] – well I selected them because I had visited their homes before... So I had been in quite close contact and was pleased with what I saw and the standards they were maintaining and I thought it's in very good hands in the long term.

And the main thing is the number of people and the ratio of staff...and also a Trust that has some track record – that hasn't just started.

Community based services that included a number of homes, not just one or two homes, were seen as more financially secure and as having the ability to share resources such as transport and staff. Not all established services, however, had the kind of "track record" that families were attracted to. Not surprisingly, families were resistant to using services that had not met the needs of their relative with an intellectual disability in the past.

Number of clients

The number of clients that individual homes were planning to provide care for also had an influence over the decisions that families made. Once again, families were divided in their opinions. Some families firmly believed that smaller five or six bed homes would better meet the needs of their relatives. These families felt that smaller homes would contribute to a greater sense of family and individual attention for those living in the home.

> ...but we had in our minds we really didn't want [our son] to – we wanted him in a smaller situation...we decided that we liked these smaller group homes.

Other families were attracted to services that provided for a greater number of clients in each home. They perceived there was a higher staff/client ratio in these homes that would enable greater opportunities and individual attention for their relatives.

> We had come very early to the decision that we wanted [our daughter] to be in a house with more people, maybe because there would be more staff.

Proximity

Many families were hopeful that their relatives' new home could be in close proximity to their own homes. After many years of having to make the trip out to Templeton Centre families were often excited by the prospect of being closer to their relative.

We didn't particularly like the area that it was in. It was a long way for [my daughter] from the other side of Christchurch and I really felt that was important – that wherever [my son] was that it was going to have to be reasonably accessible for my daughter.

While a home would be considered more positively if located conveniently, families did not usually base their eventual decisions regarding service choice on the issue of proximity alone.

Home's appearance

Like proximity, the "look" of a home was important to families but never took priority over issues such as staffing or the track record of a service. An attractive home was a bonus but did not deter families from ensuring that all their other requirements of a quality service were met.

On a less positive note a small number of families selected a particular community based service because they felt they had no other options available to them that time. This was the case for families with children who were seeking a shared care arrangement based in the community early in the deinstitutionalisation process. For these families there was only one choice in terms of a service provider. This was disappointing to families who felt that the one service available to them did not possess all the characteristics that were important to them. Two mothers who both had children with an intellectual disability who received regular respite services through Templeton Centre explained their situation – a situation that was characterized by little or no choice.

> Yes I didn't have a choice. There were no other places that were offering respite care that you could have at one house. I mean respite care was all around the place and I wouldn't do that to [my daughter]. I want her to have her own room and her own environment.

> Well I did feel that we were not being given any choice, so in that respect we as parents had to make sure that [disability service provider] from the outset was a good carer in our eyes for our kids because that's the only one around.

"Making the move": Leaving Templeton Centre

The day that their relatives left Templeton Centre to begin a new life as part of the community was a significant one for families. After relying on the Centre to provide care for their relatives, often for decades, families had different responses to the transition.

It seemed that families who had relatives involved in some of the early moves from Templeton Centre felt disappointed in the way Templeton Centre staff responded to the resettlement process. One mother described the day that she collected her son from Templeton Centre and drove him to his new community based residential service. Despite arranging the pick-up time with Templeton Centre staff, when she arrived she found her son standing outside his "villa" waiting for her. His belongings had left Templeton Centre on a truck at nine o'clock in the morning. He had waited outside the villa from that time until one o'clock when his mother arrived. He had nobody waiting with him and neither staff nor residents came to bid him farewell.

> ...I wanted to take him to the house. I wanted to be there when he got there, so I would take him. So his belongings left at something like nine o'clock in the morning. When I got there at one o'clock he was still standing outside. How I didn't cry my heart out I'll never know. I still think about it and I just think you poor little bugger. He was still there with a cardboard box under his arm. All he had in it was his insulin...they didn't even leave him with his walkman. And I drove up and he was just standing outside, all on his own and that's all he had, he had nothing else with him and he'd been there since nine o'clock. And I just went – and nobody came out, nobody did anything – I felt really awful.

Other families felt that although they had chosen for their relative to go into a community based service they were grateful and wished to acknowledge the care that Templeton Centre had provided. Many families felt that the long-term relationship they had had with Templeton Centre staff was eroded in the period directly leading up to their relative's move from the Centre and that they were not able to have the kind of parting with staff that they would have liked. This may have been due in part to a lack of clarity relating to the role Templeton Centre staff were able to assume. One mother described her sadness that Templeton Centre staff who had played a special part in the life of her son were not able to share her excitement and positive feelings about the move. This mother wanted a particularly special staff member to have the opportunity to see where her son was moving to

And I said to her, I'd just love you to see this place. She was really thrilled that [my son] had got in there, she felt it was ideal for him. And he was getting quite, there's quite a few rough ones out [at Templeton] so she felt it was time he got moved out before he got hurt, because there's a few violent ones where they are. She was really thrilled and I said to her I really would love you to come and have a look and she said I will once he's left and it's been confirmed but I'm not allowed and that's a shame. Whether it's political or it's union or it's hospital policy – I didn't like to ask her. I mean they're an employee and they've got to work there so they've got to do what they're told.

As the deinstitutionalisation process progressed and more people left the Centre, families reported that they felt that Templeton Centre staff had responded positively to their relative's move from the Centre. Families also commented that Templeton staff were sometimes involved in helping individuals to "get to know" their new homes. This did not seem to be a feature of early transitions from Templeton.

Individuals often left Templeton Centre and arrived at their new home to find that their rooms were not ready and that confusion reigned. While families often talked about the lack of organisation in the new homes on the day of the actual move, not all families perceived the lack of organisation in a negative way. Families were aware that the transition from Templeton Centre to the new service occurred on one day and that packing someone's belongings, including their bed and furniture and ensuring that they were all in place by the end of that day was incredibly difficult.

> And you know for the next couple of days I spent quite a bit of time there, running back and forwards and sorting [my son's] stuff for them. Just doing anything I could to be useful, because I felt so sorry for the staff. They were all there and anxious to do something but all they could do was cook up food.

Some families who chose to be actively involved in their relative's move often took great delight in the party atmosphere that occurred. Witnessing the excitement of those moving was a very positive experience for families and reassured them of the positive aspects of the move.

> Oh yes, because there's such a happy atmosphere. And the opening day – when they all arrived, they had balloons everywhere and all sorts. Just lots and lots of flowers everywhere. It was just like a big party.

Families who were involved in the actual "settling in" on the day of transition did so because it was important to them to ensure that staff knew about particular routines that their relative was used to. They also wanted to support their relative and staff on this very busy and important day.

Other families chose not to be involved in the actual transition process for equally valid reasons. Some families believed that their relative needed time to bond with the staff in the new service and that the "bonding" process may be undermined by their presence. The following comments made by three different mothers illustrate this point.

> No [disability service provider] did that because they were all in one villa and we discussed it with [manager of new service]. Because [my son] is so attached to me, we decided that I would stay away for a couple of days and let him settle in to his new environment.

> We thought well it might be better [to stay away] until she settles. Well it's worked anyway.

> No I wasn't [at new home when son arrived]. No I chose not to be. I thought it was important to be there with his new staff, not with his mother.

Other families chose not to be present on the day of transition because they believed that they might "get in the way" of staff as they worked to ensure that everyone settled into the new home.

Almost all families reported that they had a high level of contact with the new service in the period directly following their relatives' move from Templeton Centre. This contact was almost always initiated by the families and was a way of reassuring themselves that everything was going well for their relative.

> I am visiting twice a week at the moment. The first night everyone moved in it was pretty chaotic. I visited three days in a row to satisfy myself that everything was going OK for [my daughter].

Sometimes families were involved in addressing incidents that had occurred in the new service and many said that they had a greater knowledge of their relatives' daily lives as a result. A number of families reported that they felt a heightened sense of responsibility for their relatives because they had a greater awareness of issues affecting their lives. These families had felt unable to be involved in issues

relating to their relatives' daily lives when they lived at Templeton Centre. Families said that the high level of contact with the new service decreased as they felt satisfied that their relative's needs were being met.

Families also identified several other factors that enhanced (or would have enhanced) the process of transition for themselves and their relatives. Being able to visit the new home with their relative prior to any transition occurring was viewed as being very important. Having the opportunity to meet with the staff and clients of the new service was also valued by families. The compatibility of their relative with other members of the home was very important to families and they often found it distressing to have to make a decision about a particular service without any information about who else would be living in the home.

> ...so I came back home and that move was going to take place on the 18th of December and even then they couldn't tell me who was going in to the house. This Privacy [Act] was something to do with it. She said well do you mind us telling [other parents]. I said no I didn't mind. I suppose she was getting the approval of other parents. So that was a wee bit difficult. You had to make a decision not knowing who was going to live in the place.

"The positives outweigh the negatives by about 9 to 1": Experiencing the new service

While families talked of the problems or difficulties they faced during and soon after the transition of their relatives from Templeton Centre into the new service, most families were very positive about the changes in their relatives' lives.

Families' level of satisfaction with the community based residential services that they had chosen for their relatives appeared to be determined by the type of relationship they had with staff working in that service. Families who were positive about the transition that their relative had made usually identified the relationships they had developed with management and direct care staff in the new services as being particularly rewarding. Many comments were made and examples given of the way the new services responded to the needs of their relatives.

When families perceived that they had open and effective communication with management and staff in the new service they were accepting of early problems and issues that arose as their relative settled into their new home. It appeared that

once families had made the decision to go through the process of resettling their relative they were fully committed to "making things work." Some families felt their relatives experienced difficulties as they adjusted to a new way of life, and as the new service learnt how to respond to their needs. Typically problems were associated with the management of specific health needs or with the appropriate management of behavioural issues.

Despite this, families did not appear to perceive early problems as confirmation that deinstitutionalisation would not be successful. It was clear that families who had experienced some difficulties after their relative had moved that they expected and accepted "teething" problems as long as they felt that they were acknowledged openly and resolved quickly.

> Mother: And I mean the little incidents that have been are just…
> Father: Are just that, incidents. They're not accidents or major provocations like they were in the past. Little things in the past used to turn into big things. Well now little things – through a couple of phonecalls can be nipped in the bud and handled and dealt with.

Families who felt positive about the service they had selected for their relative soon after resettlement felt that having a good relationship with staff helped them to address problems more efficiently. These families also appreciated the fact that they heard the "good things" that were happening in their relative's lives rather than just being notified when problems were occurring.

> And one thing that I do like is we hear positive things. We used to hear a lot of negative things. You'd only hear if he did something bad, whereas now we hear – the majority of it is good things isn't it?

Families felt informed about their relative's daily lives and that they had a closer relationships with their relatives after experiencing the transition into community based services.

For many families a process of getting to know their relative again could be attributed, to a very large degree, to the move from Templeton and into the more accessible environment of the new community based home. While many families had reported in the early stages of this study that they felt "indebted" to Templeton Centre, the relationships they were developing with their relative's new services were more reciprocal. They were consulted about aspects of their relative's care,

and felt that their presence in the home during visits was welcomed as an important part of creating a family environment. While a significant number of families reported that they felt more responsible for their relative after they had moved from Templeton Centre into a new service in the community, not all these families saw this as an unwelcome change. Some families saw the increased involvement in their relative's life as being a reflection of the relationship they were developing together.

Two or three families who found themselves heavily involved in their relative's resettlement processes felt uncomfortable with the level of responsibility they felt they were being forced to assume. Some families found themselves being called to the new service to give advice, or in some cases, to take control of an incident involving their relative. This was acceptable once or twice but when families felt that little progress was being made in terms of responding appropriately to their relatives' needs then they began to feel less positive about the service. It was these families who commented on the lack of training that they felt some staff had when they commenced working in the new community based services.

However, for most families problems and challenges that arose around the time of transition were addressed quickly and appropriately. For other families problem areas took a little longer to sort out but a satisfactory outcome was achieved.

In situations where families felt that they did not have effective and open communication with staff and when they did not perceive staff as having the appropriate experience or characteristics to provide quality care for their relative, attitudes towards community based services became more negative. Three families who participated in this study reported in Phase Two of the study that they did not feel that transition from Templeton Centre into a new community based service had been successful for their relatives. This small group included two families who had held positive views about the opportunities that resettlement could provide at the outset of the study. These earlier views were reversed as they experienced what they perceived as poor quality services in the community. The third family comprising this group had always expressed negative views toward the plans or deinsitutionalisation and had struggled to find a community based service that they felt met their relative's needs. They subsequently experienced the breakdown of this placement.

Changing attitudes toward deinstitutionalisation

When I commenced this research, families, regardless of whether they held positive or negative views of the planned deinstitutionalisation process, all expressed concern about what was to happen when Templeton Centre closed down. Families were worried about, or had questions regarding the impact of deinstitutionalisation on their lives and on the life of their relative. Some families were concerned about certain aspects of the proposed resettlement of their relative but believed that community based residential services could offer their relative increased opportunities. Other families had a high level of concern about all aspects of the plan to deinstitutionalize Templeton Centre and were opposed to any transition of their relative from the Centre.

It became evident within the study that families' attitudes changed over time. Because I interviewed families prior to the move of their relative from the institution (Phase One) and again soon after the move of their relative into alternative services based in the community (Phase Two), I was able to identify changes in the views expressed by families, and describe the range of positions held by families by the time of Phase Two of the study.

Through the process of analysis it became clear there were five different ways that families described their journey from first learning that deinstitutionalisation definitely would occur, to experiencing the transition of their relatives into community based services.

"We always thought it would work."

As I identified earlier in this chapter, not all families taking part in this study were opposed to deinstitutionalisation. As the title of this section suggests, families who believed that their relative would have more opportunities to experience a new way of life were largely positive about resettlement. While these families, like others, expressed concern about certain aspects of the proposed community based services, they explored and selected services very early in the process. They felt that they would have greater choice in terms of the services available if their relative moved quickly. Families who were positive about the possible benefits of

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community living continued, generally, to be positive after their relative had moved.

As one mother said:

> But it just makes you wonder if he'd been out five years earlier, he'd just be five years further ahead.

"We're quite happy - as long as it continues."

The title of this section was chosen because it denotes the sense of ambivalence displayed by another group of families who approached the plan to deinstitutionalize Templeton Centre with a sense of resignation. They accepted that Templeton Centre would close and that their relative would be required to move into a new service. They believed that the lobby to achieve an alternative facility on the Templeton site would not succeed, or that even if it did their relative would not meet the criteria for such a service. These families were not convinced that resettlement could offer their relatives greater opportunities but (similarly to those families who did feel positive about community based services) they believed that entering the process of exploring and selecting services early in the process would ensure greater choice. When I revisited these families after their relative had been resettled they were pleased and surprised at how well their relative was doing in the new service.

One parent said:

> Well all I can say is that it's been a long and painful process. Probably it would have been painful however it was done. But the outcome I feel is for the betterment of residents' lives.

"Oh I had really grave doubts... "

One mother's statement highlights the fact that about half of the families who took part in this study talked about having a complete reversal in their attitude toward deinstitutionalisation after they had experienced the resettlement of their relative into a new community based service.

Oh I had really grave doubts... and I can't really believe that I was so un-accepting toward what really has turned out to be a marvellous move for him.

Many families taking part in this study were strongly opposed to any change in service for their relative when I first met with them. However, these same families accepted the transition of their relative into new services (often very reluctantly) for a number of reasons. Again, the fear of having a reduced choice in the services available to them was one reason, as was the impact of the change occurring within the Centre on their relative. Coupled with the knowledge that their relative would not be eligible for a "specialist" service, families often felt forced to become involved in selecting a new service for their relative. Often younger family members supported older parents to make these decisions. Interestingly, families who displayed a high level of opposition to the closure of Templeton Centre prior to resettlement, were some of the most positive after their relative's transition had occurred.

As one mother said:

> Parents told us how their family members had changed since they'd been in these homes but I still wasn't convinced. I think you have to see it, with your own family, before you are convinced.

" I said it would all come down to the staff and it has."

Two families who originally had felt positive about the opportunities that a move from Templeton Centre could create for their relatives reported feeling disappointed with transition. These families attributed their feelings of disappointment to the fact that some staff working in the home they had selected did not meet their expectations of quality staff. Furthermore, both families did not feel that they had been successful in achieving any change in staff attitudes or behaviour and subsequently that their relative's needs were not being met.

Almost all families taking part in the study felt that the success of deinstitutionalisation relied on the quality of staff that had been selected to work in the community based services. When I revisited families directly after resettlement of their relative the quality of care provided by staff was always a key discussion point. Those families who remained positive about the resettlement process usually assessed the staff working in their relative's home very highly. In the case of the

two families who did not see their relative's transitions as having been positive, their criticisms and concerns related to staff, in particular how staff interacted with their family member.

A sister said:

> The residents seemed neglected while the staff were always outside drinking coffee and smoking. My prediction that staff would have a major impact on whether or not [my sister's] resettlement would be a positive experience was proving to be correct.

"I don't understand why they are doing this."

One family maintained the strongly negative view toward deinstitutionalisation that they had expressed during my first interview with them. Their fears about transition were realized when their relative's first community based service placement broke down completely. The insecurity and on-going issues related to this situation obviously contributed to this family's feelings of negativity. Feelings of upset and powerlessness were heightened when there appeared to be no obvious solution to the problems being experienced by their relative.

Other families who had experienced the breakdown of an initial placement, or who had experienced significant problems in the early stages of their relative's transition, continued to feel positive toward the process of deinstitutionalisation if the issues were addressed quickly and efficiently.

Two important issues were raised by many families taking part in this study regardless of their position on resettlement. A significant number of families reported a continuing resentment at the way the process of deinstitutionalisation had been handled. Additionally, some families continued to worry about the long-term security of the community based service system. It became clear through the conduct of this study that families were frequently unaware of how community based services were funded to care for their relatives with an intellectual disability. There was also confusion over whether or not their particular community based disability service was a charitable trust, or a profit generating business.

Pursuing the option of a sheltered village: the development of Brackenridge Estate

Of the thirty-five families who participated in this study, ten families had relatives who did not move into the community but instead were eventually resettled in a "specialist facility" developed on a small corner of the original Templeton Centre site. These families had retained serious concerns regarding the ability of the available community based services to meet the needs of their relatives. Some of these families had such serious concerns that they felt that the only acceptable service alternative to Templeton Centre would be a specialist facility created along the lines of a sheltered village. A sheltered village can be defined as a model of service delivery that provides housing and all other facilities required to meet the needs of a group of people with an intellectual disability on a single site. Most of these families also felt that to create such a service on the existing Templeton Centre site was the most sensible and cost effective option.

When the Templeton Centre Parents' Association (TCPA) first presented this idea to the then Southern Regional Health Authority (SRHA) they were told very clearly that a "sheltered village" would not be a service option available to individuals affected by the deinstitutionalisation of Templeton Centre. However, this statement did not deter a small and committed group of families who continued to lobby for the development of a village style service alternative. Their vision was to have the option of using a service that could meet the needs of three main groups of people: those with challenging behaviour, those who were medically fragile, and those with multiple physical and intellectual disabilities. Members of this lobby group felt that the community based service system could not offer their relatives the level or type of service that they required. A significant number of families supported the views of this group and delayed any decision-making regarding services for their own relatives in the hope that this lobby would be successful.

In 1998, four years following the original announcement for closure, the Health Funding Authority (HFA) announced that a facility would be developed on a small area of the original Templeton Centre site. This announcement followed several years of intense lobbying and political activism by a group of parents committed to achieving this option. Similarly to families who experienced a transition process when their relative moved into a new home located within the community, families

of individuals making the move to Brackenridge were also immersed in a process of change.

The pathway into Brackenridge was not the same for all families. Some families had believed that a service like Brackenridge was the only possible option for their relative. From the time that the announcement to close Templeton Centre was made, these families made it clear that the only service that they would accept for their relatives would be a "sheltered village" style service.

A number of families who were proponents of a sheltered village style service had relatives who had been part of an assessment process. This assessment process was put in place to establish who would be eligible to use this kind of service. A number of families had relatives involved in this process and who were assessed as clearly meeting the criteria for Brackenridge.

> They just approved it. We didn't – there were no hassles or no problems...no we weren't told to go and check [the new community based services out]. We were given the option of Brackenridge. That was the first option given to us, so we didn't look anywhere else.

Other families learned that their relatives had not met the criteria for this service. Some of these families entered a review process in the hope that a further independent assessment would result in the original decision being reversed. A reversal did occur for some families.

> And after [our daughter's] assessment we sat with our fingers crossed and hoped that maybe her assessment might take her that way.

Another grouping of families apparent among those in this study made the decision to choose Brackenridge after spending time exploring other service options. These families had the ability to make a choice between Brackenridge and other services because their relatives had been assessed as meeting the criteria for Brackenridge. Even though places in Brackenridge were assured for their relatives, these families were keen to look at other services in the quest to find a service that best met their relatives' needs. Most of the families in this category eventually chose Brackenridge because there seemed to be no other alternative that provided services of the level and type that they believed their relative required. Conversely, a few families chose not to use Brackenridge despite the fact that their relative with an intellectual disability had met the criteria to gain entry to the service.

The relative of one family began using Brackenridge services after experiencing difficulties with their first community based service placement. This person had moved later in the deinstitutionalisation process and had reduced options to try to resettle into other services by this stage. This person's family experienced a great deal of distress in trying to resolve the difficulties related to resettlement.

Most families committed to the notion of a service like Brackenridge had relatives who required a high level of support. Many of these families were particularly concerned about issues of safety and security and believed that a facility like Brackenridge would provide a safer environment than any other service alternative. Obviously, these families were greatly relieved when they were informed that Brackenridge was available to their relative.

Oh I think we're just very grateful she's in a safe place.

Despite this relief, families who had relatives making the transition from Templeton Centre into the newly developed Brackenridge reported feeling the same kinds of emotions and of experiencing similar concerns as the move approached and then took place to those reported by other families who had experienced the transition from Templeton Centre. After finding that their daughter had been assessed as meeting the criteria for Brackenridge services one couple described how they were feeling. It is important to note that this couple hoped desperately that Brackenridge would be available to their daughter.

Well it was a bit like going into the unknown.

This nervousness and ambivalence mirrors that experienced by families who were positive about their relative making the transition into community based disability services. It appeared that any change created an emotional response in families regardless of their position on deinstitutionalisation.

Like families who had relatives who moved into new homes in the wider community, Brackenridge families were focused on the importance of quality staff. Individual families had specific views on what they saw as quality staff and they identified areas related to staffing that they had concerns about.

One mother explained:

That was perhaps one of our major concerns, wasn't it, that for a lay-person to see what [our daughter] is about, with changing staff you don't see that consistent pattern. So within the staffing of Templeton that was consistent, they could see the changes in [our daughter's] attitude, behaviour and they could pick perhaps that we have a problem starting to brew up. That was our major concern with changing staff, and perhaps more lay people – were they going to notice?

Brackenridge families also enjoyed developing positive relationships with staff working in their relatives' homes as they saw these relationships as being central to continuing to experience an open and effective communication regarding their relatives' needs.

The day that their relative made the actual transition from Templeton Centre to Brackenridge Estate also progressed along similar lines to the transition process described by others. Homes not being finished and being rather disorganized was a feature described by many. Despite this, most families saw this situation as being unavoidable and not the fault of Brackenridge staff. Similarly to other families, Brackenridge families seemed to accept that problems would occur around the time of transition.

A parent articulated this point with the following comment:

You know, it'll have its good points and bad. For a time, I mean it's a new thing. You can't expect something like that just to be a hundred percent, be all things to all people. So of course it's going to have its ups and downs...

Families who had relatives moving into individual homes on the Brackenridge Estate did not appear to view Brackenridge as one large service. They talked about the homes that their relatives were living in as separate entities with lives of their own. Most families made comparisons between houses relating to their suitability for their relatives in much the same way that families utilizing services in the wider community had done when discussing why they had selected one particular service provider over another. Finally, families had different views on what Brackenridge Estate meant to them. Some families held the view that Brackenridge was a community based service just like any other. This was illustrated through the "separate homes – separate identities" perception that many families had. A small number of other families were open about the fact that they valued Brackenridge because they saw this service as having characteristics very similar to Templeton

Centre. These families did not perceive Brackenridge to be a community based service and assessed their relative's life as being unchanged from that previously experienced at Templeton Centre.

One mother said:

> Her life hasn't changed too much really.

Families who had relatives who made the transition to Brackenridge Estate were as diverse as all the other families participating in this study. They had different concerns, different perceptions of "quality" staff and made different choices among homes within the Brackenridge service. Overall however, all these families reported that they generally felt positive about their relatives' transitions from Templeton Centre to Brackenridge.

As one parent said:

> We are delighted. I mean I'm sure his quality has improved one hundred percent. The fact that he's involved in cooking food, and has his own room, the staff seem to be there because they want to be there. He's having a much fuller life.

Despite families' positive reports about Brackenridge, in comparing their accounts of transition with families whose relatives moved into disability services based in the community there appears to be one main difference. The families who selected Brackenridge for their families did not describe the achievements and personal gains that their relatives with an intellectual disability had made since moving into the new facility. They sometimes commented on the fact that their relative was more involved in the cooking of food, or that they had their own room, but they did not celebrate the new achievements or set milestones in the same way as other families did. The sense of greater opportunity and the ability to reconnect with their family, which was a strong theme in the stories of families who had relatives in community based disability services, was not echoed by Brackenridge families.

Summary

Chapter Seven has presented information relating to families' interactions with the process of deinstitutionalisation implemented at Templeton Centre. Once again the complexity and heterogeneity of families has been revealed through the different ways that families chose to engage with the process. The official announcement of the plan to close Templeton Centre and resettle adults and children with an intellectual disability into community based services was met with outright opposition from some families, and a strong sense of concern by others.

Most families who took part in the present study reported that they had been aware that Templeton Centre would probably close sometime in the future, however none of these families had chosen to explore any other service options for their family member with an intellectual disability. Understandably perhaps, families knew little about community based services for people with an intellectual disability and based their views of the availability and/or suitability of such services on experiences they had had in the past. This contributed to some families being adamant that their family member was unable to live outside of the institutional environment. Deinstitutionalisation was, to such families, an unrealistic goal and one that was unnecessarily risky.

Importantly, some of the families who chose to participate in the present study held positive views of the opportunities that deinstitutionalisation may provide their family member with an intellectual disability. Families displaying such views were found to perceive their family member as having the potential to change and to develop. All families held the aspiration that their family member with an intellectual disability would be happy in the future although it appeared that those families more positive about the resettlement of their family member were more specific about their hopes for the future. Some families hoped that the transition from the institutional to a community based environment would result in the family member having greater privacy and being treated with respect. Furthermore, some families aspired to achieving better contact with their family member with an intellectual disability and a situation whereby the whole family would benefit from an enhanced relationship with that person.

Central to the current chapter was an exploration of the factors that appeared to have an influence over family decision-making. A range of factors contributed to

families' propensity to make decisions leading to the resettlement of their family member with an intellectual disability. Siblings were found to be particularly important and influential within the process of decision-making that occurred within some families. Depending on the relationship that siblings had with their parents, siblings often facilitated the process of changing parents' attitudes towards deinstitutionalisation and community resettlement.

When examining the actual transition from the institution to community based services it was evident, for some families, that becoming (re)involved in their family members' lives meant that they began to take back some control and power as parents. After relinquishing parental responsibility to the institution, families were being consulted by community services in a way that acknowledged them as being "experts" in relation to their family members' needs and behaviour. While some families embraced this new role, other families were frightened and/or resentful of this heightened responsibility.

Findings presented in Chapter Seven illuminate families' experiences of becoming more informed about deinstitutionalisation, and in some cases, coming to understand their changing attitudes towards this major process of social change.

CHAPTER EIGHT

COMMUNITY LIVING

Introduction

This chapter presents the views of families on community living for people one year after the transition from Templeton Centre had occurred. While Chapter Seven focused on families' experiences of deinstitutionalisation soon after the transition of their relatives had occurred, the present chapter explores the families longer-term realities of community living. The findings presented here are based on interviews conducted during Phase Three of the study. The Phase Three interviews were designed to provide an in-depth understanding of families' experiences of and attitudes toward resettlement one year after their relatives had moved from Templeton Centre. By this stage families had had time to reflect on their journey from deinstitutionalisation to community living. In the last section of the chapter I consider factors that became evident across the study that seemed particularly salient in the families' experiences of deinstitutionalisation.

One year on: Families' views of community living

In Chapter Seven I provided a discussion of the variations in families' responses and reactions to the resettlement of their relatives during Phase Two of the study. Phase Two interviews were conducted directly following the transition from Templeton Centre into alternative residential services within the community. In explaining the sometimes subtle and sometimes conflicting differences in families' views I intended to highlight the complexity and heterogeneity of the families who were involved in this study. In the following section of this chapter I have once again attempted to elucidate the contrasts and the similarities between families who had relatives involved in this process of deinstitutionalisation.

Identifying positive change

Perhaps the most significant finding generated through Phase Three of this longitudinal study was that the analysis of interviews conducted at this stage of the

research confirmed the views that had been expressed by the families during Phase Two. The families who expressed a positive attitude toward their relatives' resettlement within interviews conducted during Phase Two of the study, continued to describe positive experiences, and to hold favourable views at the time of the concluding interviews. Families who were not positive about resettlement in Phase Two continued to report concerns in the Phase Three interviews. However, families were able to provide more detailed information about their impressions and experiences of the new model of service being delivered to their relatives. Consistent with a constructivist approach, this third interview gave families the opportunity to reflect further on their constructions and reconstructions of deinstitutionalisation over time.

Families who expressed favourable views toward deinstitutionalisation and community living provided information that suggested that their expectations of their relatives continued to be challenged, albeit in a positive way during the first year following resettlement. An elderly mother reflected on how her thoughts and attitudes had changed after witnessing first-hand the major achievements of her son during his first year of community living.

The mother said:

> No, I didn't think he could do it, but he managed very well, and he was a pleasure to have around.

Both large and small goals that families had previously not considered for their relative were achieved and surpassed by bigger steps toward a more independent life. Supporting a family member with an intellectual disability to travel out of Christchurch for a holiday or to attend a family occasion was a commonly held "large" goal. Other families reported that they valued seeing their family member "out-and-about" in the community shopping or attending local events as rewarding goals. When commenting on the overall impact of deinstitutionalisation the following comment was made by a sibling:

> I think he has benefited and developed tremendously.

Families positive about the outcomes of deinstitutionsalisation typically reported that they felt excited about the potential for achievement that transition into community based services offered their relatives with intellectual disabilities.

One sibling said:

> Quite amazing really. It's opened my eyes quite considerably. It's been good for all of us because we didn't really have a brother and now we have. It's fascinating and each time you go [to the siblings community residence] now you sort of wonder, well what else has he been doing and what else is he up to and what else is he going to do.

This sibling's comment extends the findings presented in Chapter Seven whereby deinstitutionalisation began to allow people to see their family member as having family membership. This was not always possible in the past when siblings did not know how to incorporate their brother or sister into their thoughts or conversations about their family.

Some families felt so re-connected that their relative began to visit the family home again – something that had often not occurred for many years. One elderly mother described her feelings when her middle-aged son visited the family home after four decades away.

> They flew down and [my daughter] took me out to the airport to meet them and walking down the stairs, he was holding [my other daughter's] hand with one hand. In the other he was holding a big bunch of flowers for me. That was one of the kind things they did at [the new service], they suggested to my daughter that he got flowers for me and I thought that was lovely.

This mother's strong emotional response to this gesture was understandable. She had felt forced to institutionalise her son when he was a small child and had, consequently, never experienced him assuming the role of an adult son. This mother acknowledged that it was the actions of the staff of her son's new community based service provider who illustrated to her how her son could participate in family life in a new way. Once again, the sense of dislocation associated with institutionalisation and highlighted within Chapter Six seemed to be replaced with a sense of their relatives being relocated back into family and community during the first year of community living. A couple described their delight that their other children were becoming more involved in their son's life and articulated why they thought this change had occurred.

> They can sort of see such a change and they – there was a stage when they sort of kept away because [our son] was so different, but now they want to talk you know which is quite touching.

However, the fact that their son's visits to the family home have become such well-attended events meant that this couple had devised a strategy for spending time alone with their son.

> Sometimes I say to [my husband] well we won't tell [he's coming home] so we can have him to ourselves.

For families who previously had held no expectations for the ongoing development of their relative, witnessing that person's personal development during the first year in their new service was an enlightening experience. A mother explained:

> He cleans his teeth, he helps himself out of the pantry what he'd like for breakfast. If they offer him some sort of breakfast cereal that he doesn't want he will get up and show them what he does want. Never had the opportunity before – they say he's very easy.

For this family, the fact that their son was considered easy to manage was a very positive change for them. In the institutional environment he had been considered to be someone with very significant behavioural problems.

Another mother reflected on the changes she had witnessed in her son:

> He's talking more, although he's hard to understand and he's more independent and he sort of gets on with other people better – he can communicate with other people better than he used to be able to.

A third mother commented on the differences she had noticed in her daughter since making the transition from institutional to community based services.

> Oh yes, I think she's much more independent and she doesn't now want to be treated as a child and to be told what to do all the time. She likes to make her own choices, especially about clothes and what she's going to do.

Families who were positive about community living often could not wait to see what the future held for their relative and sometimes suggested new goals their relative could work toward. However, other families who were positive about deinstitutionalisation and had seen a rapid escalation of their relative's skills and achievements during the first year of resettlement were wary of having too many expectations. They reported that they were happy with "where things were at" and that they did not expect to see too many more significant changes in their relative in the future. A mother who had reported that her son had rapidly acquired new

skills directly following his resettlement in the community was asked whether her son had continued to make such gains during his first year in the community.

> No he's leveling out I think, he's just more relaxed. I don't think we're going to see a lot more but who knows. Who knows? You don't know do you? But I mean I'd be happy if he stayed as he is because I do think he's improved so much.

Replicating the findings presented within Chapter Seven, families continued to make the comment that they could no longer just "drop in" at their relatives' homes. Previous experience had shown families that they should not assume automatically that their relative would be home. This was not perceived as a negative outcome of deinstitutionalisation – rather it signaled to families that their relative was enjoying a full and varied social life. Two or three families reported that they did not have the same regular arrangements for visits home as their relative was often involved with other activities and outings and liked to be able to join in with those as they arose. While these families were sometimes disappointed that they did not get to see their family member quite as frequently as they had in the past, they were extremely happy to see that person taking part in the community in a way they never had before. A father provided a snapshot of his son's life, and subsequently how he and his son's community based service worked together to ensure flexibility.

> A couple of the staff took [son] and one of the other residents down to Queenstown for show weekend. They took him jet-boat riding and out on the Earnscleugh to the farm and everywhere. He had an absolutely marvellous time. In general if it is not convenient for us to have him home every weekend – like we do normally have him home for the weekend from Friday we pick him up about 4 o'clock and take him back late Sunday afternoon. If it is not convenient [to have him home] he always seems to be doing something there and sometimes – like this week they rang and said don't pick him up on Friday night because he is going to a birthday party, so it's all very flexible.

This finding that people who had been resettled from Templeton Centre were typically enjoying varied social and recreational experiences addressed an issue that families had raised frequently during earlier interviews. Many families felt that their relatives had received quite a high level of access to recreational and leisure activities whilst living at Templeton Centre. During their initial interviews some families had questioned whether such a level of activity would able to be replicated in the community environment. During the Phase Three interviews I asked

families' opinions on this issue. Families who reported a positive attitude toward deinstitutionalisation identified their relatives as being involved in a high level of activity in addition to their vocational or day programmes. One mother described her daughter's reluctance to come home as she always seemed to have something on - a situation that contrasted with her need to come home frequently when the young woman resided at Templeton Centre.

> Well she's been there a year now isn't it? Just over a year I think. Yes – it seems to be working out really well…She's really happy and I notice that she doesn't want to come home now as much as she used to, because she's too busy and I mean that's really good. Because actually I'm really pleased about that, because when she was at Templeton she'd come home and she'd always make sure before she left that she had a date for coming home again, but now I'll send her a fax and say when are you coming home?

People with intellectual disabilities who had been resettled from Templeton Centre were participating in a range of regular activities, for example, sport, as well as many spontaneous outings. Living in the community environment appeared to make it easier for people to access regular community events such as concerts or other special events.

One year after the resettlement of Templeton Centre residents into community based services families continued to report that they found it much easier to visit their relatives at their new homes than it was to visit the institution. One reason for this improvement was that the new homes were usually in closer proximity to them – that is, they were in the city rather than at Templeton Centre on the outskirts. The second and more important factor was that the community based homes provided a more relaxed and relaxing environment both for the people who lived there, and for their families who came to visit.

One mother said:

> I think the most positive thing for us is [that] I can go and visit and when I go to visit I can sit down and he's not trying to rush me away [from the house like he did at Templeton Centre] and he'll take my hand and show me his bedroom. It might be every time I go but that doesn't matter.

A father from a different family echoed this point:

> One thing I like about [my son's home], you walk in there and you feel as if
> you are walking into a family home. You don't feel as if you are walking in
> where there's people working...and I think that's the key to have a relaxed
> feeling about the home and well if you have a relaxed feeling you don't have
> so many behaviour problems.

A common, early concern held by families was the fear that their relative would
fret for Templeton Centre. Families believed strongly that their relatives' long-term
associations with Templeton would mean that they would experience real
difficulty adjusting to a transition into alternative services. In the early stages of the
process of deinstitutionalisation families that most strongly opposed the closure of
the institution often emphasized their view that people with an intellectual
disability were being cruelly wrenched from Templeton Centre - the home they
were familiar with and enjoyed. These families worried about the impact of such a
move and reported concerns about behavioural issues, stress or depression that
they suggested may occur as a result of resettlement.

It appears, however, that almost all the individuals who moved from Templeton
Centre settled happily into their new homes. The problems that families had
predicted did not, for the most part, eventuate. Those men, women and children
who had previously lived at Templeton embraced their new lifestyles with very
little trouble and did not, according to the families who had positive attitudes
toward deinstitutionalisation, appear to be concerned about the loss of their "old
lives". In fact, many families told stories that seemed to confirm that their relatives
were more concerned about having to return to Templeton than they were about
leaving. After being asked by her parents if she wanted to return to Templeton
Centre, a woman who had lived there for many years replied emphatically:

> No – [Templeton is] not my house.

Two or three families reported that their relative was initially very reluctant to go
anywhere in a car or van. While other reasons for this reluctance are also possible,
some families and community service staff attributed this to the fact that the person
was worried that a ride in a vehicle would result in them returning to Templeton
Centre. After a period of days, weeks, or occasionally months, the aversion to
vehicles was reported to have gone away as the person realized that they were
going to stay at the new home.

Having ascertained that it was clear that most people who left Templeton Centre did not "look back", it is important to make it clear that this did not mean that people did not need time to settle into the routine and rhythm of their new home. As discussed as part of Chapter Seven, many people needed time to settle into their new service and most families accepted this transition process as inevitable.

Families' interactions with disability support services

Similarly to the two previous phases of the research, the issue of the residential and other staff involved in the community services continued to be a significant focus of families' interview comments relating to the deinstitutionalisation process. Families were concerned about the relationships that they had with staff in the new services, and about how well they perceived individual staff as meeting the needs of their relatives with intellectual disabilities. One mother provided her view of what factors contribute to a quality staff-family relationship within disability support services.

> Well I think it's important they keep contact up with the family. I think it's also important for the family to listen to staff.

Families commonly linked the quality of the relationship that they perceived as evident between their relative and the staff who worked with that person with the quality of life enjoyed by that person. Consequently, the issue of staffing continued to be a topic on which many families focused.

A mother elaborated on her relationship with staff:

> Very good. And [the Manager], he's just at your disposal really - any time at all you could ring him and just have a chat with him. Any time at all. And he's so helpful and considerate and he treats the residents at his own level. He is really very good.

Earlier in this thesis I explored families' perceptions of disability service staff. For most families, it appeared that over time their preoccupation with the formal training qualifications possessed by individual staff decreased. In particular families became less concerned with whether staff were registered nurses, and instead placed increasing value on how staff interacted with the people they were paid to support. A brother linked the importance of staff to whether or not deinstitutionalisation would be a success for individuals .

What is the key to this in my opinion is good staff caring for them. And while one can – and this is an issue which one can never, I suppose, be one hundred percent guaranteed that the quality of care is good – but in my heart of hearts I think that [my brother] has very good care there. And for the talks that I've had with [the disability service staff] about [my brother's] behaviour, and the development that has gone on in [my brother], the lid was really on him in Templeton and worse than that, the treatment was pretty severe.

An elderly mother had noticed how people were treated more as individuals within the community based setting and had made the connection that this must result in an improved context for care and support.

They're more independent. I can't say the care is better but I'm sure it must be, and the individual attention they get – each one is considered on his own merits really.

Another family described their joy that the individual characteristics and qualities possessed by their son were being noticed and enjoyed by staff supporting him in his new home.

Do you remember the time we were there and [staff person] was making scones and [son] wanted to go into the kitchen and she said oh [son's name] out you go, I'm baking, and he just roared with laughter, He went, he left the kitchen and he roared and roared and of course all the other residents started to laugh because they could see the funny side of it... and [the staff person said] he's like that when he gets told come on, out you go, I'm busy and she said he just makes the whole house happy. Nobody appreciated his laughter before.

Despite all the positive things that families had to say about staff they continued to articulate the need for quality support staff to be available within the community based service system. It was common for families to recognize that some staff on some occasions required a greater level of training or experience in order to respond appropriately to some situations.

In most cases it gets down to the degree of commitment and experience and knowledge of the staff on how to deal with these people – some of whom can be very difficult [and who can have] severe behaviour problems or illnesses and so forth which require special expertise to look after.

Linked to this concern was the recognition that staff turnover could become a real problem for community based intellectual disability services.

A sister said:

> There's been a huge staff turnover. Lots of different staff members. I don't just know why...yes I think it's a bad sign, but I don't just – I haven't had the opportunity to be in the right place at the right time to actually ask why.

One or two families worried about staff burnout – a problem that they saw as directly related to the high rate of staff turnover in the home in which their relative lived. These families expressed a critical need to address this issue in order to secure a more settled staff environment and consequently, a better environment for people with intellectual disabilities living in the home.

One family described why the sudden loss of a staff member upset them. They were saddened that they did not get the opportunity to thank the particular person for her role in supporting their son. They credited this person as being responsible for making their son's first year away from Templeton Centre a success. It was also distressing on a personal level for them to learn that a person they perceived themselves as having a close "personal-type" relationship had left the community based service without talking to them first. This finding suggests that families have high expectations of staff and can also develop personal attachments to them. Families need to remain cognizant of the fact that disability support staff often fulfill paid caring roles and are not always able to act as "surrogate" family. Conversely, disability support staff often underestimate families' reliance on them as the person who knows their family member best, and who therefore can assist them to feel secure in the knowledge that their relative is happy and well cared for.

It was clear that families particularly valued staff who were prepared to meet them half way in the quest to establish or re-establish relationships with their relatives with intellectual disabilities. One family, for example, recounted the story of inviting the staff in a particular community residence not only to bring their relative out to meet them on a family outing but also all the other people who lived in that home. The staff embraced this idea and everyone enjoyed a day of relaxation and fun. This reciprocal quality of relationship was very important to families who felt supported by the new service in their quest to make their own transition – a transition in the type of relationship they had with their family member. As always, the quality of communication between families and the community based service staff and management was the major indicator of

families' level of satisfaction with the new service. One mother summed up her position on this issue with the following comment.

> I said I don't want to interfere – I just want to be kept informed.

A sibling attributed his desire to visit his brother more frequently than he had whilst his brother had been living at Templeton Centre in large part to the way he was able to interact with staff in the community based service.

> It's easier and it's also such a height of standard...I'm really wanting to reinforce some of the really good things there. Like one of the staff members there, I hold him in very high regard so for me it is interesting just to meet and talk with staff members and I just want to show I care...

Negative views of community living

In Phase Three of the study three families reported negative views about resettlement that were similar to those that these families expressed during Phase Two interviews. Two of the three families had originally been positive about the opportunity for their relative to move into the community environment but had reported negative views during Phase Two interviews. One family had been negative about the plans for deinstitutionalisation from the commencement of the study. In Phase Three interviews, all three families stated dissatisfaction and disappointment with the way that the transition from Templeton Centre to new services in the community had occurred for their relative. There were two major reasons for this dissatisfaction. The first was related to an absence of positive communication between the family and the new service. When families felt that their concerns were not acknowledged or responded to they tended to hold a more negative view toward the new service. One woman, who was her sister's sole family decision-maker, articulated the problems she experienced in communicating with her sister's disability service.

> My continuing relationship with the manager and staff [at the disability service] is taking time to become one of confidence with each other. I am very conscious that the staff are aware of the dissatisfaction I expressed when [my sister] was distressed, and although her behaviour is now stable and the attitude of staff is much improved, there is still an attitude of mistrust between us..."

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The woman's description of her relationship with staff is actually a very circumspect one. The level of her mistrust of staff was so acute that she wished to remove her sister from the disability service. Her sister, however, refused to be moved and the woman did accept her wishes. However, despite the fact her sister remained living at the community based service, this sibling continued to hold very strong negative attitudes toward deinstitutionalisation based on her own experience of her sister's transition.

> Now it is over a year since [my sister] has been resettled from Templeton Centre into her new home in the community. After my very positive hopes for my sister's future, her first year in community based services has been fraught with a great deal of disappointment, stress and tension. I have spent a lot of time, sometimes intentionally and many times just going over and over again all the reasons why the move for [my sister] has at this stage failed. What I must stress is that it has not failed from [my sister's] perspective and perhaps this should be my only criteria, but it was me who asked to move her and the facts and implications of her move will stay with me all my life.

The second reason I identified as contributing to families' negative views toward deinstitutionalisation one year following resettlement was related to the suitability of placement. When families had felt forced to make a decision regarding service choice they tended to hold more negative views. Tension was heightened if the family had felt that the placement was not a suitable one for their relative. If families entered into a relationship with a new service when they held such views it was unlikely that those views would change. Two of the three families referred to here had felt that they had no other service options available to them at the time they chose the particular service that their relative moved to.

One mother who was negative about the outcome of her daughter's transition described her feeling of shock when staff working in her daughter's new community based service communicated their discomfort with the way this mother had been interacting with them. This mother had originally been very positive about the opportunity for her daughter to make the transition from the institutional environment. Her attitude altered dramatically within weeks of her daughter's resettlement. She had written a comprehensive list of concerns about the way her daughter's support was being delivered and communicated these concerns to staff and management of the service. Due to her worries this mother visited her daughter's home regularly.

> And I said to [disability service staff] well how do you think it's going and [one of the staff] looked me in the eye and said well some of the staff think you're looking at everything they're doing...and that you just charge in when she's having personal care and I was just so shocked because nobody had said anything about having any problems with me. I mean I hadn't been consciously doing that. I mean I was there a lot, especially for the first couple of months because nobody knew [my daughter] and [my daughter] was there on alternative weeks, so by the time somebody started to get to know [my daughter] she was gone again...

This experience highlights the importance of effective communication between families and the disability service staff to whom families have entrusted the care of their loved ones. Contributing to the heightened feelings of this mother was the fact her daughter was a child. This mother cared for her daughter at home every second week and, understandably, had very high standards and expectations relating to her daughter's support. She wanted her daughter to be loved and "parented" within the group home environment - a goal that was probably not achievable in the type of residential service within which she had been resettled.

This mother stated:

> [My daughter] is still a child and needs a warm family home where the staff are capable of being her stand-in parents when I'm not there.

The placement had been the single service choice for this mother at the time her daughter had made the transition from Templeton Centre. It was the only service available that would accommodate this mother's wish to care for her daughter at home on alternate weeks.

This same family reported that staff without a nursing background had sometimes expressed to them their personal discomfort about having to perform medical tasks or procedures that they did not feel they had the training to perform with confidence. This family was now very dissatisfied with their child's community based service after having expressed positive views about deinstitutionalisation during the early stages of the project.

The mother described her daughter's situation within her community based service in detail:

> At least two of the staff informed me that they did not know how to give suppositories. One of them was willing to be shown how. These staff

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persons work alone on night shift at times. I conclude therefore that [my daughter] is medically unsafe as a staff person who does not know how to administer suppositories would not know how to give an enema for seizures either.

It is important to emphasise here that the differences between families who had a positive experience of resettlement and those who were profoundly disappointed by the process of deinstitutionalisation were acute. This difference, in my view, highlights the importance of working with families on an individual level in order to strive to ensure that their concerns are addressed and their hopes and aspirations for their relatives with intellectual disabilities are met.

Independent service coordination: "But it would have been harder for me without that moral support"

During Chapter Seven I referred to the role of service coordination within the process of deinstitutionalisation as I identified some of the factors that influence family decision-making relating to the resettlement of their relatives. This section of Chapter Eight will describe this particular aspect of the deinstitutionalisation process in greater detail and in doing so I draw on findings generated from data collected during all three phases of the study.

Independent service coordination was set up to ensure that every Templeton Centre resident had a representative who would work toward helping them achieve the best possible arrangement of community based services. Because it was most common for families to be involved in the decision-making regarding resettlement into services (rather than the person him or herself), service coordinators were intended to be a resource or support for families as they negotiated their way through the process of deinstitutionalisation. Originally it was intended that families should initiate contact with an independent service coordinator themselves when they felt they were ready to engage with the process of discussing resettlement options for their family member. When families failed to initiate such contact an alteration was made to the planned process and service coordinators were given the ability to contact families directly in order to try and create some movement and momentum with families. Families' reactions to both the intended, and the altered process are discussed in the following section.

The findings indicate that families had mixed responses to the introduction of independent service coordinators into the deinstitutionalisation process. At the time service coordination was introduced it was common for families to be feeling angry, concerned and/or anxious about the planned resettlement of their relatives and the subsequent closure of Templeton Centre. As previously mentioned, at this early stage families were expected to approach the service coordination service when they felt ready to take this step. It became clear that not all families were aware they were responsible for making the first approach to the service coordination service. Consequently some families who were waiting and willing to hear from a service coordinator could not understand why they had not been contacted. One brother highlighted his incomplete knowledge of service coordination at this early stage in the process by asking me a question.

He said:

> Do they contact us or do we contact them?

When I replied that the process called for families to make the first contact with service coordinators the brother articulated why he did not think he could do so.

> Well a couple of things really. The first is I don't know what they do. The second thing is I don't know what they can offer me, and the third thing is I'm quite happy with what is going on at the moment.

It is also important to make clear that at this early stage most families who participated in the current study were aware of the intended process but continued to refuse to make contact with service coordination. To do so, in their view, would be the catalyst for beginning the transition of their relative from Templeton Centre into community based services. At the time of the Phase One interviews a significant number of families were reluctant to take this first step. A sister who, at the time of the initial interview, was opposed to deinstitutionalisation responded quite angrily when I asked her about service coordination.

She said:

> Oh apparently you don't get any choice, they contact you anyway.

At the time, this sister's comment was in fact correct. This change in approach was a turning point in the process for many families. Having the opportunity to talk about their relative's history, and to ask questions specific to that person was, for some families, the first time they could look at the prospect of resettlement in a way that made sense to them. Families frequently were reassured by the support and advice of their service coordinator to the point that they decided to actively pursue a transition from Templeton Centre for their relative(s). Many families also valued highly the presence of independent service coordination because in these tenuous early days, they saw this independent role as providing an additional "safety net" which would ensure that the community based services continued to provide high quality care for people with intellectual disabilities.

One mother made the following statement:

> She was just superb so whatever her role is, I hope she keeps in it.

A second mother said of her daughter's service coordinator:

> She's a pusher – she pushes for things. And makes sure I know what I'm entitled to.

It is important to acknowledge that independent service coordination was not received positively by all families. A number of families who were contacted by service coordinators resented what they saw as an intrusion and as unnecessary pressure at an already difficult time. These families were those committed to retaining institutional services and who at that point would not accept any discussion of the resettlement of their relative.

During the Phase Two interviews I encouraged families to expand on their experiences of service coordination and to articulate their views of how they perceived this service contributing to the new model of service delivery in the future. A number of families, particularly those who were opposed to resettlement at the time they initially met their service coordinator, talked about having to set boundaries around the relationship. It was common for families to say that they did not appreciate the efforts of "pushy" coordinators.

A father said:

> We're going to have to make a decision about community placement in two
> or three months [but] we're not going to be pushed back against a bloody
> wall and have to make snap decisions.

This man's wife recounted how she had made their feelings known to the coordinator.

> She's aware of that. I said to her we won't be pushed into it. I said I'm still
> happy to work with you, but just get it clear now – I've only spoken to you
> two weeks ago and you're telling me all this is going to happen.

As this mother's comments suggest, a less then positive beginning to a family/service coordinator relationship did not mean that it would not develop positively over time. Some families talked of getting to the stage where they felt very comfortable with the relationship they had with their coordinator who they now perceived as a valuable source of support for both them and their relative.

Service coordinators helped families to see the possibilities that were available to their relatives with intellectual disabilities. Because many families were naturally apprehensive about the resettlement of their relative from Templeton Centre they were appreciative when their coordinator showed them a range of options. Central to families' concerns with the process of deinstitutionalisation per se was the perception that they had no choice over what was occurring. When a service coordinator took the time to discuss and to show them a range of service options families were more confident about making choices and decisions. It also showed families, many of whom had sought the services of Templeton Centre because they believed there were no other services available to them, that the community based service system had developed to the point that their relative could successfully be included within it. One mother described the very personal relationship that she had with her son's service coordinator.

> She's lovely really and she has a handicapped son of her own. He's living in
> the community. She took me to see where he's living and she said the
> change in him was absolutely dramatic since he went to the community.
> And I suppose she helped set my mind at rest.

The quality of the rapport that coordinators were able to establish with families was vitally important throughout the process of deinstitutionalisation. Families' views of service coordination were largely dependent on the personal characteristics of individual service coordinators, and on the relationships that they established with them. One couple talked about their son's service coordinator and agreed that the following statement summed the person up.

Well, he always listens to your concerns.

In some cases coordinators obviously had concentrated on building a positive relationship in the first instance rather than on identifying new services. When the relationship was more firmly established the progression to talking about potential services and the transition process itself occurred more naturally. A sibling reflected on the role her sister's service coordinator had played for her.

My service coordinator was excellent. She explained everything to me clearly and kindly and gave me confidence in my decision. The knowledge that she would stay with [my sister and I] indefinitely, would keep regular checks on [my sister] and would act as an arbitrator and friend in any situation that arose was a great comfort to me.

Some families experienced a succession of different coordinators. This was due in part to the fact that as the process of deinstitutionalisation progressed some logistical difficulties associated with allocating coordinators arose. Assigning individual people with individual coordinators was a sensible idea until those individuals started moving into new homes in the community. The early system meant that every individual living in the new home could have a different coordinator - a situation that quickly became recognized as problematic. It was difficult for staff in the community homes to accommodate this system. A new system was then slowly implemented whereby each home had one service coordinator which meant that families were faced with a change in coordinator. Sometimes families felt they were losing a person with whom they were comfortable and they were not always happy with this loss.

The same sister who made the previous comments about what the role of service coordinator meant to her said later:

It was at this time that [my coordinator] told me she would no longer be with [my sister] and me. I was very disappointed and wondered if this would be the beginning of a series of letdowns.

Another mother described her experience:

I was told then that I had a new coordinator, but she never contacted me so I just let this part of the arrangement slip sideways.

While most families were reporting positive experiences of resettlement soon after their relative had moved from Templeton Centre, it was common for families to continue to report that the presence of a service coordinator continued to be welcome in case "something went wrong." Families who were not yet convinced of the stability of the new model of service delivery continued to believe that an independent group was a necessary "watchdog".

A niece who participated in this study said:

[Our service coordinator] quite often just checks up [about] how we feel and how things are going and do we have any complaints, but every time it's the same old boring no, no, good as gold. She said to me, one day I'm going to ring up and you're going to shock me and I said what? She said you'll have something to moan about.

During Phase Three interviews the emphasis that families placed on the presence of independent service coordination changed. After accepting the resettlement of their relative(s) into community based services most families reported that, in the first instance, they would always address problems with the individual staff involved, or with the service manager. Families felt comfortable with the relationship that they had established with direct care staff and with management. For these families using a service coordinator to address issues would be an option of last resort in instances where they were not receiving responses or actions that were satisfactory to them. A mother described her relationship with the service coordinator who had been assigned to her son.

Oh definitely, I haven't had to contact her at all. Now and then she just rings up to see if I'm happy with everything.

It is important to acknowledge however that a few families said that they would approach their service coordinator first if they had a problem with their relative's new service. Families in this situation either did not feel comfortable with staff or

did not like to be perceived as difficult or complaining. For them, having access to a service coordinator to raise issues on their behalf eliminated their discomfort. The fact that some families relied on their service coordinator to resolve problems raises issues associated with the loss of the independent service coordinator role.

Towards the completion of Phase Three interviews for this study the role of independent service coordination was withdrawn as a new national system of needs assessment and service coordination was implemented. For some families this was a disappointing development in the deinstitutionalisation process. Although most families had high quality relationships with their relative's service providers, it was common for families to continue to value the ongoing relationship that they had with their service coordinator. Even in cases where families reported that they only engaged their service coordinator to address issues in situations of last resort, many continued to value the opportunity to talk and discuss their relative with their coordinator. A significant number of families were unpleasantly surprised to learn that service coordination, in the form they were familiar with, would not continue in the long term. Whilst describing the role of service coordination in her daughter's life one mother signaled her awareness that service coordination in the format that they had become used to would not be available in the long term.

> What do I see their role as now? Just to keep an overall eye on things to make sure that [my daughter] gets what she needs. I think they're organizing Lifestyle meetings as just another avenue of communication I think, which I guess if there was a real problem I could actually go to them and say can you sort it out. But I don't know if anybody knows how long they're going to be around, as far as you know, years ahead or anything.

The loss of service coordination was more distressing for families who relied on their service coordinators to take a more active role in the communication that occurred between themselves and their relative's service provider. These families had to develop their own strategies for communicating with service staff and managers and for having issues addressed.

Overall, the role of independent service coordination was assessed by families to be a valuable one in the process of deinstitutionalisation that occurred at Templeton Centre. One of the critical aspects of this role was that it afforded families the opportunity to have one-to-one contact with an individual who got to know them and their relative. This created a situation whereby families could have

their questions answered in a way that was relevant and appropriate. Before the introduction of service coordination, families had often struggled to gain information that was relevant to their individual family circumstances and relevant to the specific needs of their relative.

Impressions of the sheltered village service option

In Chapter Seven I included the experiences of ten families who had chosen for their relatives to make the transition from Templeton Centre to Brackenridge. Brackenridge is a sheltered village located on the original institution site. By Phase Three of the study it was clear through analysis of the data that families who used Brackenridge focused on similar issues in terms of the positive and negative aspects of the service that they had chosen for their family member to that of families who had resettled their family member into the community based service system. Similarly to families' descriptions of the aspects that they appreciated about their relatives' new homes in the community, one brother made a comparison between how he felt when he visited Templeton, and how he now felt when he spent time with his brother at Brackenridge.

> It's a lot more homely and it's a lot more – it's more individual to [my brother] in that he's got his own room, his own space and those sorts of things. So as a place I feel like it's more of a home for him rather than Templeton which – he's been there since he was six and even before that on short stay…It's more like a home for him I think, yes it makes me feel good when I go there.

This sibling also elaborated on how the change in environment had enabled him to interact with his brother on a more personal level. He identified the opportunity for privacy as being central to the enhanced relationship.

> There's a lot more opportunity for privacy, so often when I go there I'll sit down and talk with him in the day room and then I'll pick him up and take him down to his bedroom and plonk him on the bed and we'll put some music on and look around and I'll talk to him and stuff – which I find easier to do than – I used to do that at [Templeton] as well but I'd take him from the dayroom through to the dormitory where his bed was and there were all the other beds in the room. So I think that's enhanced. It makes it easier to have that sort of relationship and I think that's one of the biggest things – the ability to have privacy.

An interesting point to note is that while this brother recognized differences in the environment between Templeton and Brackenridge, he continued to use terms to

describe the physical layout of the home that were common to the institution. For example, what families who had relatives living in community based services would call a lounge or sitting room, this sibling continued to refer to as a dayroom. This suggests that he had not changed his perception of his brother's living situation in the same way as families whose relatives had moved right away from the institutional environment.

A mother's comments highlighted this point to me during an unrecorded conversation that we had one year after her daughter had moved from Templeton to Brackenridge. When I asked her what was different between the two environments she said that Brackenridge had much more pleasant surroundings as it was new and well appointed but that in actual fact it was not too different to Templeton. She justified this observation with the comment that a replication of Templeton services was, in actuality, what families who chose that option wanted. Conversely, other more politically oriented families who lobbied for the development of sheltered services were careful to make the point that in their view Brackenridge was a community based service like all the other residential options available to Templeton Centre residents making the transition from Templeton Centre. Such families were aware that it was more "politically savvy" to highlight the similarity rather than the difference between community based services and the sheltered village type option. The mother I spoke with, however, had played no part in the politics of achieving a sheltered village and was very honest about the fact that all she cared about was not upsetting the delicate balance of her daughter's support. Achieving a placement that was as close as possible to Templeton Centre was, in her view, the most effective way of maintaining the status quo that had ensured her daughter's care for over twenty-five years. The following comment made by this mother during a recorded interview reflects the view of Brackenridge she shared with me.

> So as far as our contact with [our daughter] goes, or her response – [it] really hasn't changed. But yes, it's more pleasant to visit.

Overwhelmingly, the quality of the relationship that existed between individual families and the staff who worked in the individual houses that make up the Brackenridge complex determined the extent of families' satisfaction with this service. This was true for all families who experienced the process of deinstitutionalisation that occurred at Templeton Centre.

Families who were committed to the development of a service like Brackenridge had always talked about their concerns regarding the level of training and experience that staff in the new community based services would possess. It was the view of these families that it was more likely that a service like Brackenridge would seek staff with backgrounds more in keeping with the experience and training that Templeton staff had. In actual fact, the staff who were eventually employed to work with people at Brackenridge had a range of experience and backgrounds. Some staff had transferred from the institutional environment while others came with little or no experience in the disability area.

One mother identified that there had been problems between ex-Templeton staff who had been successful in securing positions within the new service at Brackenridge, and those staff who had come from the community environment.

> There has been a problem in the house between the new ones and the Templeton ones. Us and them kind of thing that [the manager] has just started to break down and some of the Templeton ones made it difficult for her earlier on and she came and talked to us and I think it's good if families are aware of those things.

A father reflected on the care of his son within Brackenridge and reported a situation whereby the inexperience of staff had become evident.

> It has been OK, just a few things we have had to have words about. I think some of the new staff – while they have been of the right attitude and they are very caring they are just very inexperienced and sometimes this shows through.

Interestingly, just as families using community based services changed their views on issues related to what constitutes "appropriate" staff, so too did Brackenridge families after experiencing their new service. While nursing skills remained important to a significant number of families, the personal qualities and characteristics of staff became increasingly important to many. Some families even commented that the creation of a balance of staff who had had previous experience in the institutional setting and those who had non-institutional backgrounds was positive as it decreased the chances of institutional practices dominating the everyday running of the service. A mother explained why she thought such a mix of staff was necessary as she attributed some problems that were occurring to the presence of ex-institution staff in one of the homes.

She said:

> Some of it has been inherited from the staff from Templeton – just the way they [are with the] residents and there's a domineering type of person-almost excluding [parents].

This type of comment could be perceived to contradict what parents, like this mother, campaigned about when they lobbied for a service like Brackenridge. Central to the argument made by such parents was that the quality of service offered by Brackenridge would be enhanced by retaining staff with an institutional background. It is possible that two different approaches to supporting people were highlighted by the different backgrounds of staff working at Brackenridge and that families began to recognise the benefits of a less institutional approach.

Families reported similar concerns to those whose relatives had been resettled into community based services when questioned about worries they had with Brackenridge. One mother reflected on the staff changes that seemed to occur regularly within the individual home at Brackenridge within which her daughter resided.

> There's still unfortunately the staff changes. Seems to be changes there, they don't seem to be able to get people to stay.

Like other families who used alternative services, the views of Brackenridge families were diverse with regard to the role that the development of Brackenridge had played in the deinstitutionalisation process. Most of the ten families whose relatives were able to access Brackenridge continued to see the development of this service as something that had prevented the resettlement of their relative from being a complete disaster

A mother said:

> She's happy there and I feel we can relax a bit now. If she's got to go there permanently at least we know she's going to be happy there.

Another couple talked about what Brackenridge had meant to them:

> Well we only had one option [presented to us]. We were notified for a placement in Dunedin and as we said well Dunedin was twice as far to go as

Christchurch and we had no other options to take or to look at. So Brackenridge was our God-send really. It was [our daughter's] God-send.

A father reflected on the relief that he and his wife felt upon learning that their son had been accepted into Brackenridge.

> Well I suppose from our point of view it was a bit like winning lotto really – [for our son] anyway. In so much as there was a certain criteria of people that were eligible for the thing and he actually won a place in it. I think he is better off where he is, in my view, than out there in the community as such. I might be short changing him by saying that.

The final sentence of this quote hints at some level of ambivalence in terms of whether their son could have made the adjustment to life in the community had they chosen for him to have that opportunity.

One brother who participated in this study reported that he now thought that his sibling could have adjusted to a different model of service. This view was at odds with his parent's view that their son could only live in a service such as Brackenridge and would be unable to be supported within the community based service sector.

While Brackenridge was seen as a "necessary saviour" by many opposed to the closure of Templeton Centre it is clear that this specialty service was not immune to the issues and problems that are common within intellectual disability services. This section concludes with the comments made by a father who was adamant that his son would move into Brackenridge after leaving the institution. While he championed Brackenridge throughout the interview, he also talked at length about some of the problems that were occurring for his son within the new environment. Most significantly, his son's "perceived persona" had followed him from the institution resulting in staff having a certain, largely negative, view of his behaviour. This father believed the way his son was perceived to be unfair and based on previous one-off actions that had not been repeated. I have included this father's comments here as I perceive them to capture his ambivalence, not only about the service option he ultimately chose for his son, but also about his son's disability.

No, a lot of people used to go to Templeton and they would see teenagers and adults sitting in a pool of their own urine on the wooden floor, and the physical disabilities as well as the mental disabilities. They would say what a dreadful place! There was nothing wrong with the place essentially. It's the disabilities that are the shocking things and they're dealing with it the best they can after all for goodness sake. So I hope no one goes to Brackenridge and says oh what an awful place because it's a very good place. But I do think they need to be grouped with their own level of disability with others. They've been punished in life already by being disabled. Let's not keep on punishing them by putting them with inappropriate other people so that there is conflict every day of their lives. They don't deserve that.

Reflections on the process of deinstitutionalisation

One of the aims of this doctoral research was to learn more about families' experiences of deinstitutionalisation. It was anticipated that this might allow some conclusions to be drawn about how to best support families through similar processes. Because a significant number of families in the present study reported concerns and problems prior to the resettlement it may seem possible that they would have clear thoughts about how the process could have been implemented differently to ensure that their needs and the needs of their family member were met. In reality, despite families having been through a lengthy resettlement process, it frequently was difficult for them to be very clear in stating what would have improved their own experience of deinstitutionalisation.

Families acknowledged that there were difficulties in implementing a process in ways that might suit everyone. Some families also acknowledged the inconsistencies in their own feelings and responses as the deinstitutionalisation process progressed. Nevertheless, they often found it more difficult to articulate what would have constituted a "better" process for their family The issues that were articulated include matters of trust, accessing information and the challenge of understanding and accepting new ideas and values in relation to disability.

Developing trust

Many families felt that a consistent message about the aims and intended outcomes of deinstitutionalisation had been lacking from the process. As I talked with families, particularly in the early stages of the research, it was clear that many families did not understand that deinstitutionalisation was intended to result in positive outcomes for the people most closely involved in the process – that is

people with intellectual disabilities themselves. Most families originally had viewed deinstitutionalisation as being solely a cost cutting exercise. During Phase Three of the research participating families were able to reflect on this view and they acknowledged that it had made them suspicious of the motives of those involved in planning and implementing the process. Many said that their belief that financial concerns were driving the deinstitutionalisation process meant that a "them and us" situation was created and that this oppositional sense had become very hard to shift.

One father said:

> We didn't trust them, I suppose it was them and us.

In terms of trust, some parents felt that their own views were being challenged by professionals who had no relevant experience. A mother articulated angrily why she was resentful of the way that deinstitutionalisation had been presented to them.

> I think that parents...a lot of parents have been sick of being told by other people what they thought we needed and I still object to that. Every now and then it crops up, by people who have never lived with children such as we have, and will never live with them, but because they have read the right book or [have gone] to university [that they have said] this is what we need. I think that is basically what gets up people's noses. Once we are told we don't know, we are just the parents and who are we to say what the needs of our children are. In the very beginning this was my biggest issue – that I was continually told what was right for us by people who had no idea or concept.

Linked to this was the resentment felt by families that the closure of Templeton was pre-determined, a "fait accompli" and therefore the submission process was simply a pretence of consultation. One mother elaborated on how she saw the process of deinstitutionalisation as having evolved.

> I think the whole thing was based on a mistrust from the beginning, so they came in with an agenda and the parents were determined to fight it, so that wasn't a good base to start from, and that continued for quite a number of years, even though we did a whole consultation programme and we had a lot of contact with parliamentarians and the Minister of Health who said express your concerns in the consultation, that's what it is all about. We spent hours putting in submissions from parents and then they took no notice of them in the option given – [and] one option they [families] did

want was cluster housing or sheltered village or whatever you call it. And so I think the whole fight was confrontational then.

Alongside the fact that families resented what they saw as a situation that had been decided and that was not open for genuine debate, they were critical of what they saw as a lack of a transparent and accessible plan. Families believed that they would have felt more comfortable with the notion of deinstitutionalisation and the subsequent resettlement of their relative if a clear plan had been presented to them. A father who had been positive about the opportunities that deinstitutionalisation had the potential to offer his son right from the outset of this study, remained critical of the way the process had been handled.

> Well looking at it from the Health Funding [Authority]– the people at the Health Funding [Authority] – they're not business people... A lot of these people would have come from the hospital services or social welfare backgrounds and, they had quite a turnover of staff – [and] they were all well meaning. [But] the decision-making process was abominable and they didn't have clear agendas, and they certainly didn't have a blueprint that this is what we are going to do and this is how we are going to do it which would have been the logical thing when you set out to do this project. So we had ridiculous situations arise and indecisions and changes of mind and so forth. From my point of view is was not a very business like operation at all.

These findings suggest that families did not, at the beginning of the process, see themselves as having a role in the way that the new model of service delivery was developed to meet the needs of the men and women with intellectual disabilities who were leaving Templeton Centre. It is possible that if families had felt genuinely involved in the planning process they would have felt more positive about deinstitutionalisation.

The difficulties in accessing information

The ability that families had to ask appropriate questions of appropriate people was compromised by the fact, as described in Chapter Seven, that those involved in the planning and implementation of the deinstitutionalisation of Templeton Centre had confusing and complicated roles. The frequency with which key staff and key roles changed made it difficult for families to identify with a consistent person as having responsibility for certain aspects of the process. This in turn heightened families' feelings of mistrust as they saw themselves as having been forced to commit to a process when key staff did not display the same level of commitment to see it through to completion.

There was almost unanimous agreement that the kind of large public meetings that had been held early in the process were not useful for conveying important messages relating to deinstitutionalisation. While there was recognition that such meetings were an obligatory step in the process of communicating plans for deinstitutionalisation, they did not fulfill a useful role in developing effective communication between families and officials.

A father said:

> Public meetings were always a disaster. But they are necessary to give information but for anybody to try and sell the idea to a great [big] group of parents who were for a large part older rather than younger and for a large part highly suspicious that this was a cost cutting exercise. Trying to sell the idea in public like that is useless. I don't know how they could go about it better. But I think offering choices and then they feel empowered by having a choice.

Because such meetings commonly were dominated by the contributions of a few very vocal people, the perception that all families were opposed to deinstitutionalisation became entrenched.

A father said:

> The public meetings were dominated by a few big gobs, I could give you a list of a dozen or so who just shouted others down to get their point of view across. Most of the middle of the road people who would possibly have liked to have explored it further were just too scared to stand up and shout them down.

Families resented that they could not gain appropriate answers to important questions in these forums at a time when these forums seemed to be the only place to ask questions.

A brother elaborated on these issues:

> As I said I attended a number of meetings. The large meetings, you know the hundred, oh scores of people and strong feelings were expressed. Well, in my opinion it was a complete and utter waste of time. I was never an outspoken advocate of the Templeton model, not at all. I was just there because my father wanted support, not that he was an unspoken advocate either. I don't know that he ever spoke at these meetings, but we just wanted to see and hear what was going on. But I don't recall any support for a

change. And I'm really bothered why. I suppose all those who had seen the light were not bothering to go to those meetings and those people who were clinging to the old models were there…

What may have made a positive difference for families would have been the inclusion in the process of a contact for families. This person would have been required to be an independent person who could answer families' questions relating to the individual circumstances of their family and the individual needs of their family member . Families were without such a person throughout what I believe to be a critical time in the process of deinstitutionalisation– the early phase of the planning process. One mother's comments illustrate this point:

> They told me a lot of irrelevant information. But then what was irrelevant to me may not have been irrelevant to someone else so I think that they needed to give you all of it and I knew eventually that I'd have to make a decision if the right home came up but I was a bit of an ostrich, I stuck my head in the sand and thought well when the crunch comes I'll make a move. Really the best thing they could have done for me was to send me that information straight away and give me a support person.

Independent service coordinators fulfilled a critical role later in the process but because they were introduced later in the process families had already suffered an extreme level of anxiety and concern. One mother described her early experience with a service coordinator that left her with little faith in the process during the early stages of deinstitutionalisation.

> I had somebody in the beginning, right way back before I'd even gone and looked at Dunedin or anything but that person didn't follow-up. The person left me cold and I found out later that she'd actually [changed her job] but she hadn't handed my son's file over to anyone else to follow-up…I think at that stage I could have been followed-up by [subsequent service coordinator] who was really excellent, who said I'm not here to push you - I'm here to ask you what you want and I'll go out and see if I can find it. Now I never once had that said to me in my first two years.

This same mother went on to reflect on the idea of having personal contact with a service coordinator or family advocate type person early in the process of deinstitutionalistion.

> That's my personal feeling because I'd gone to Dunedin. I'd done all that with a lot of strangers and I'm not shy as I say, I'm used to getting up and speaking to big crowds, but I got there and I thought this isn't right for me so why ask any questions and I didn't – I sat back. Then I went to all the different ones in Christchurch and I kept thinking they're all talking about

their different places, none of these are right for me either so I sat back again...it wasn't until [service coordinator] came on board that [deciding on a community based service] happened.

This mother's point of view is interesting as the same services were available to her son after the service coordinator began working with her as she had been exposed to prior to having access to a service coordinator. Her earlier comment about the service coordinator needing to ask the right questions of her has resonance here. It is possible that it was not so much that the services were wrong for her son but that this parent had not been able to see what was right about them. It appears that gentle questioning and support from a respectful service coordinator allowed her to see the possibilities of the range of community based services available to her son.

The journey toward accepting deinstitutionalisation

A number of families described feeling horrified at the suggestion that their family member could live in a different environment to that provided by Templeton Centre. Many of these families said on reflection that this feeling of horror was caused by the fact that families had little or no knowledge of an alternative – they did not and could not conceive of what the future might hold. One brother articulated the sense of uncertainty common to many families.

> So for me the lack of knowledge is the crux of it and I think people respond badly to uncertainty. But unfortunately [in the deinstitutionalisation process] there was always going to be that – because if you look at the result compared to the start, then obviously there's a lot of uncertainty to get there on both parts.

Some families said that visiting the alternatives made a difference for them, however most families admitted that seeing other people living in community based settings did not change their views. They simply saw these examples as people and places not representative of the changes that their family member was being subjected to. They also did not believe that the men and women that they saw in community based services had comparable levels of disability to their own family member.

The process of deinstitutionalisation is by its very nature a difficult one. Any major change in model of service delivery is difficult for families to contemplate and

accept. In a situation where proposed changes have not been initiated by families themselves anxieties and worries are heightened significantly. For this reason it is not easy to say, with absolute conviction, what would have made things better for families. Families themselves acknowledged that this was a process that had to be worked through, and in many cases be experienced before they could relax and begin to enjoy the many positive outcomes for their family member.

As one mother said:

> No, I think that I probably was the doubting Thomas who had to see it actually happen before I believed it could happen.

Another mother reiterated the need for families to be able work through the process at their own pace in order to ensure their comfort with their ultimate decision-making.

> I think everyone has got to be comfortable with their own decision on this. I mean my decision was that [my daughter] shouldn't be at Templeton and should get out of there as fast as possible. There were a lot of people who didn't think that way. I don't know, I think whatever decision they make they have got to be comfortable with themselves really.

This mother's comments highlight the fact that Templeton parents were not a homogenous group for whom a single strategy to encourage their positive involvement in deinstitutionalisation would be effective.

The emotional strain placed on families who had relatives involved in the deinstitutionalisation of Templeton Centre cannot be underestimated. A sibling reflected on the personal toll that lobbying for a sheltered village alternative had taken on his father and more particularly his mother.

> I think also it's just such hard work to try and work for the whole – and I think Mum and Dad – well Mum especially has just been trashed with it and she's had enough of that. So I think she just picks off specific projects now, but in saying that, if she didn't have something she'd be terrible as well. I think even though she would deny it, she needs to have – she has to have something on the go and something to sink her teeth in...

It is important to provide the perspective of those families who did not report any complaints regarding the way the process of deinstitutionalisation implemented at Templeton Centre had occurred.

One father said:

> I think it has been a good process. It's been interesting from my point of view to watch and to talk to parents who had extreme views about the disestablishment of Templeton and this start up of community services. But in most cases the kids seem to be doing much better. The parents are amazed at how well they are doing – the extension of the new and different things they never did at Templeton. It's been pleasing to see. There have been some – not failures – but disappointments for some along the way where things haven't worked out but they've been few and far between really I think. From what I've heard from people it's been 90% positive.

Coming the full circle: Families' views of deinstitutionalisation

The concluding section of this chapter contains quotes from families when I asked them to describe what the closure of Templeton Centre and the resettlement of their relatives into community based services had meant to them. The responses highlight the heterogeneity of families, and the different practical and emotional issues that were important to individual members, and the concerns that continued to linger for some families. However, overwhelmingly, these comments do provide a sense of the importance that families attached to their relatives being (re)located back into life within family and the community. The quotes all come from different parents and siblings. None of the quotes included here were expressed by families who had relatives who moved into the sheltered village on the old Templeton site.

> The situation he is in now is more friendly and [is] providing a better level of service than he was getting at Templeton, particularly over the last few years. We hope he's got a lifetime placement there. I suppose it is a hope for most parents.

> I'm quite happy about it now. Yes I wasn't happy about it at the beginning. I wasn't happy about Templeton closing and I felt that I wasn't sure how [my son] would cope with the move but I did my best to make it easier for him.

> Yes very much. Extremely so, yes. Well there was a degree of the unknown, and had I foreseen what later transpired – the only thing that concerned me in my sense that this was the right thing [was my father] and as it happens my father is completely of the view that this was the best thing...So he's very relieved and pleased.

It's been a positive thing although I still think that the group housing on the Templeton site would have done the same thing, but then he wouldn't have had all the access to all the community things that he has now.

Oh help yes. I didn't think it would end up like this. It's been nothing but positive. It's been absolutely wonderful. No question at all, but when we first – we could never dream that it was going to end up where we're at now.

One elderly mother summed up what her advice would be to other families who were facing the prospect of deinstitutionalisation and the resettlement of their relatives into alternative intellectual disability services in the community.

She stated emphatically:

I would say go ahead and do it, it's wonderful.

Whilst expressing positive views about the sheltered village facility, families who opted for their relative to be resettled into Brackenridge were not found to reflect on the process of deinstitutionalisation in the same way as families whose relatives had moved into the community environment. Families whose relatives were living in the community after many years in an institution appeared to be able to reflect on their earlier fears, how those fears had been addressed, the excitement of opportunity, and the joy of seeing positive outcomes for their loved ones. The families who selected the sheltered village Brackenridge as a service provider for their relatives expressed relief at having achieved, in their view, the most appropriate service provider, and valued the improved physical environment but they did not appear to experience the change, development or opportunity that pervaded the accounts of the families who had selected community based service options.

Summary

Chapter Eight has presented the views and perspectives of families one year following the resettlement of their disabled family member from Templeton Centre, into alternative disability services. It appears that many families who participated in this study held the view that deinstitutionalisation had facilitated a process whereby their family member with an intellectual disability had been relocated back within the family environment. Families continued to talk

knowledgeably and excitedly about the new life their family members were leading since leaving the institutional environment. Particularly emphasized by families was the perception that community based residences were real homes. Consequently, visits were more enjoyable both for the person with an intellectual disability and for their family.

While families' perceptions of what constituted "quality staff" show considerable diversity, the present findings suggest that as families altered their perceptions of their family members, they experienced a corresponding change in view about what characterized quality staffing within community based services. Specifically, as families became aware that their family members perhaps had greater skills and abilities than they had previously believed them to have, their perceptions of quality staff seemed to become more centred on the personal characteristics of staff, rather than on their professional qualifications. While acknowledging the positive attributes of many community based service staff, families reported concerns about the issues of staff burnout and the associated high rate of staff turnover.

Three families continued to express negative views toward deinstitutionalisation one year after the resettlement of their family members with an intellectual disability. Whilst all these families had very different individual situations, their dissatisfaction with deinstitutionalisation was founded on similar issues. Firstly, positive communication had been absent from these families' interactions with community based services, and secondly, it appeared that the service they had selected, or in two cases felt forced to select, was not suitable for their family member.

Families who reported on the process of deinstitutionalisation during Phase Three of the present study appeared to have benefited greatly from the introduction of independent service coordination. From somewhat shaky beginnings, independent service coordinators frequently became an important factor in influencing families' decisions with regard to their family member's transition from Templeton Centre. It could be assumed that this was because independent service coordinators provided families with a personalized contact who was "legitimate" within the formal process of deinstitutionalisation. Independent service coordinators were also important because they got to know both the families and their family member with an intellectual disability – such personal contact was vital for a significant

number of families who found the confidence to make decisions once they had the support of an informed and empathetic person.

The ten families who chose to utilize the sheltered village service Brackenridge spoke positively about their relatives' transitions from Templeton Centre. These families valued the ability to have some privacy when they visited their family members. Equally important to this group of families was the improved look and condition of the physical environment that their family members were now living in. In contrast to families whose family members had moved into community based services, Brackenridge families did not, for the most part, report that their family member had changed in any way, or that they had changed the way they thought about them. Brackenridge families were almost unanimous in their belief that the availability of a sheltered village option was what had prevented the closure of Templeton Centre from being a complete disaster for their family member, and themselves.

Finally, Chapter Eight illuminated families' reflections on the process of deinstitutionalisation. Families themselves emphasized that it is difficult to be prescriptive about how to more positively involve families in a major change in service delivery such as deinstitutionaliation. This is due in large part to the heterogeneity of families and the fact that every family's individual situation is different. Despite this difficulty families tended to focus on several issues as deserving of attention when considering family involvement in the process of deinstitutionalisation. First, families need to feel they can trust both the motivations for such a process, and the individuals who are involved in the implementation of the process. Secondly, families need to be able to access relevant information in accessible formats. Lack of knowledge and understanding about the process of deinstitutionalisation serves to exacerbate families' feelings of fear and uncertainty.

CHAPTER NINE

DISCUSSION AND CONCLUSIONS

Introduction

The purpose of the final chapter of this thesis is to discuss the findings generated by this doctoral research on family involvement in deinstitutionalisation. As the previous eight chapters have illustrated, the thesis has explored the views, perceptions and experiences of thirty-five families who had family members with an intellectual disability involved in a process of deinstitutionalisation. Multiple interviews, as well as other additional contacts occurred with families over an extended period. This resulted in the generation of a large and diverse body of information. The process of deinstitutionalisation explored in this study was centred on the closure of Templeton Centre, a large hospital-based facility that provided residential care to adults and children with an intellectual disability. The closure of Templeton Centre and the subsequent resettlement of residents into alternative, community based services provided an opportunity to explore families' interactions with a changing disability support system while such a change actually was occurring. As a result, I experienced the privilege of being able to learn from families as they experienced an intense period of change in their own lives, and in the lives of their family members.

Chapter Nine has the purpose of discussing the findings presented in chapter's six, seven and eight of this thesis in five separate but inter-related sections. In the first section of the chapter I provide some answers to the research questions that underpin this study. Included in this first section is a discussion of how the answers that I have put forward relate to the literature reviewed in Chapter Three of this thesis. The second section of this chapter has a focus on understanding what the answers to the research questions may mean from a theoretical position. In particular, I discuss the notion of a constructivist paradigm and specifically, how I have used the ideas expressed within this paradigm to theorise the findings of this study. The third section of the chapter illuminates the methodological issues

arising through this work. Constructivism is also presented here as a useful way of interpreting the various methodological and ethical issues that I encountered during the conduct of the present study. The fourth section of this chapter identifies the limitations of this research. The fifth and final section of this chapter suggests some implications for policy, practice and future research in the area of family involvement in deinstitutionalisation and other areas of disability service delivery.

Some answers to the questions asked in this study

This doctoral research was based on four central research questions.

What factors influenced families' earlier decisions to choose institutional care for their disabled relatives?

This question was integral to the study and was found to be an issue critical to families and one that they discussed in great depth and detail. Families who participated in this study were found to share a common story – a story that described similar experiences of caring for their family members with an intellectual disability at home. This shared story culminated in these families making the decision to seek permanent out-of-home placement at Templeton Centre, for that person. With regard to the placement decision the present research is supportive of the findings of a study by Blacher (1990) that identified the decision to seek out-of-home placement as a process rather than a discrete act. The purpose of presenting families' journeys toward institutionalisation in Chapter Six of this thesis was to identify the elements of such a process from the retrospective perspective of families themselves. It also provided a framework from which to approach the issue of deinstitutionalisation in accordance with the view of researchers Lord and Hearn (1987) who contended that understanding the factors that contributed to families' decisions to seek institutional care is critical to understanding their later processes around deinstitutionalisation.

Integral to the families' journeys toward institutionalisation in the present study was a desire by families to have their relative live at home for as long as possible and an initial reluctance to consider alternative care arrangements outside of the family home. Such reluctance has been identified in other out-of-home placement studies (Bromley & Blacher, 1989) and refutes the notion that families who

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eventually do seek out-of-home care do not love their family members with intellectual disabilities and want to institutionalise them to avoid their care. At the time they made the decision to institutionalise their child the parents who took part in this study did not perceive that community based disability or family support services were available to meet their needs. This is not to say that such services were not available at the time that they were caring for their family member at home but rather that in their experiences available services were not successful in meeting their needs. Bromley and Blacher (1991) reported that the availability of appropriate support services had only a moderate influence on the decision to seek out-of-home placement. However, other researchers have emphasised the importance of creating a range of family support options to ensure that all families feel able to access a formal support system that meets their specific support needs (Herman & Thompson, 1995; Llewellyn et.al., 1999)

In terms of the decision to institutionalise their son or daughter, the issue of family wellbeing was highlighted in this study through the finding that families reported experiencing increasing pressure on family life over an extended period of time. In a recent review Cummins (2001) explored the quality of life of people caring for a relative with a severe disability within their family. This review of qualitative and quantitative research concluded that primary caregivers are at considerable risk of high stress, clinical depression and a low quality of life. These issues were identified and described by the families participating in the present study as factors contributing to their eventual decisions to seek out-of-home placement. Other studies have confirmed that parents' perceived daily stress has a strong influence on placement decision (Beckman, 1991; Bromley & Blacher, 1991; Kobe et.al., 1991).

Additional factors that emerged as important to the findings of the present study were the role of the mother, and the consideration of siblings in decision-making related to out-of-home placement. I am cognizant of the difficulties that fathers undoubtedly faced with regard to the fact of their child's disability, and to subsequent decisions to seek institutional care for that child. However findings highlighted the specific role that mothers appeared to play in relation to decision-making about out of home placement. Mothers were the major care providers and, therefore, appeared to be responsible for making the final decision to seek out-of-home placement to an institution. Often mothers made the decision to institutionalise their child with an intellectual disability following a crisis in their own mental health. This finding corresponds with the work of Hanneman &

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Blacher (1998) who reported that out-of-home placement was less likely to be considered if the mother felt she was coping well. The current study showed that mothers carried the emotional responsibility for making the decision to institutionalise a child and, as a consequence, the mothers frequently reported long held feelings of guilt. This finding also resonates with the work of Munford (1989) who highlighted the ways in which patriarchal systems structure and control the lives of women who care for people with an intellectual disability. In the situation of decision-making about institutionalisation I contend that women were being oppressed and controlled by a dominant ideology that reinforced their own belief that they were solely responsible for the care of their children. In the context of this dominant ideology mothers accepted the responsibility for making a decision that impacted on all members of their family because of their understanding that it was a mother's duty to be the family's primary caregiver.

All parents who participated in this study identified that their concerns for their other non-disabled children had influenced their decision to seek out-of-home placement. Concern for family relationships in general, and the wellbeing of siblings in particular have been identified as critical to out-of-home placement decisions in a number of studies (Bromley & Blacher, 1991; Hanneman & Blacher, 1998; Llewellyn et.al, 1999). However, little research attention has been paid to understanding how siblings perceive(d) the impact of removing a child from the family home to be cared for in another environment. In the present research the now adult siblings reported that at the time they had specific understandings, views and emotional responses to the fact that their brother or sister with an intellectual disability had left the family home to live permanently in an institution. This issue is further discussed later in this chapter.

The indicators that family placement decisions are influenced by factors such as family stress experiences continues to have relevance despite the fact that current policy and services are based on philosophies which support family-based and/or community models of care. In a recent Australian study Llewellyn et.al. (1999) identified that 25 percent of the families participating had already sought or were considering out-of-home placement for their children with high support needs. This significant finding highlights the fact that some families continue to feel unable to cope with supporting a family member with a disability at home despite current policy and support arrangements that are intended to encourage such caring practice. It is clear from such research, even in a context that claims to

provide family support, that some families will seek out-of-home placement at some point. Some of the ideas presented here have previously been published in a refereed journal (Mirfin-Veitch, Bray & Ross, 2003). Appendix 7 contains a complete copy of the paper.

Who and/or what influences the decisions that families make about transition from institutional to community based services?

The second major question underpinning the present study was concerned with establishing who and/or what influenced the decisions that families made about the transition of their relatives with an intellectual disability from institutional to community based services. An important finding in this research was that while the families shared a similar journey toward institutionalisation, they were found to hold diverse views toward the prospect of deinstitutionalisation and the resettlement of their relatives into community based services. In the present study more families reported that they opposed institution closure than were supportive of the proposed plan for community placement. Willer et al. (1979) contended that family opposition to deinstitutionalisation is caused by having to revisit their painful, earlier decisions to institutionalise their relative with an intellectual disability. The discussion of institutionalisation provided earlier in the present chapter lends weight to the supposition that families are affected in an on-going way by the decision to institutionalise a family member with an intellectual disability. In her study Funnell (2001) also found that institutionalisation created long held emotional difficulties for parents, siblings and for people with an intellectual disability themselves.

It is clear from this research that when exploring the issues that influence family decision-making it is important to consider the emotional responses that families have to plans for deinstitutionalisation. Exploration of the emotional responses of individual families can provide a context from which to understand the decisions that families eventually make about community placement. Whilst all families who participated in the present study reported that they felt concerned and anxious about the impact that deinstitutionalisation may have on their lives, and on the lives of their relatives, some families were positive or, at the least, cautiously optimistic about the opportunities that an alternate model of service delivery could offer their family member. However, the families who were positive toward deinstitutionalisation were not confident about expressing their views publicly as

they believed they would be treated with contempt by families who opposed plans for the closure of Templeton Centre. Media reports at the time of the closure of Templeton Centre focused almost exclusively on the views of the parents and other members of the community who were opposed to deinstitutionalisation. This led to a perception by the general public that all families were opposed to closure.

Families who participated in this study, regardless of whether or not they had positive or negative views toward planned closure, frequently mentioned the difficulties they had experienced with community based services in the past that had contributed to their nervousness about the impact of deinstitutionalisation. Cummins & Dunt (1990) reported that it can be difficult for families to accept that their previous experiences with regard to lack of community based services may not be well founded in the present context. Also, as Cummins and Dunt say, accepting community placement means that the earlier advice the parents had from professionals should now be disregarded. All this was evident in the present study, and accepting the ideologies associated with deinstitutionalisation meant, for some families, questioning whether they had made the best decision for their family member in the past.

The fears that families expressed regarding deinstitutionalisation frequently appeared to be driven by the way they had constructed the identity of their family member with an intellectual disability. As discussed earlier in the context of institutionalisation and in the context of resisting the offer of community placement, the families highlighted the deficits they perceived their family member to have. This view, coupled with a lack of knowledge about alternative constructions of disability, and how this linked to disability support in the community meant that families could not see how it was possible for their family member to make a successful transition from institution to the community.

A significant number of researchers have reported that families who have relatives involved in deinstitutionalisation processes frequently are suspicious of policies prompted by the new and unfamiliar ideologies of care which envisage their family members living in ways that they do not perceive as realistic or possible (Booth et al., 1990; Conroy and Bradley, 1985; Cummins and Dunt, 1990; Grimes and Vitello, 1990; Lord and Hearn, 1987; and Tossebro, 1996). In the present study, families' evaluations of their relatives have often been formed by their interactions with medical professionals who have characterized the person with a disability as

having little or no potential to develop in any significant way. I hypothesise that it may have been important for the families themselves to maintain a construction or identity for their family member that allowed them to continue to justify their earlier decision to seek institutional care.

Just as most of the families expressed fears with regard to the possible impact of deinstitutionalisation, they also expressed hopes and aspirations for their family members' futures. An interesting aspect of this issue was that it was not only families who were positive toward the idea of closure that identified hopes and aspirations. In a few cases families who were extremely opposed to institution closure talked about what they hoped their family member could achieve through the experience of being resettled from the institution to the community based environment. If families were able to identify even one hope or aspiration for their family member the opportunity was created for resettlement to have the potential to be seen as a positive development.

Most research in the area of family involvement in deinstitutionalisation focuses on documenting any changes in family attitudes prior to, and following the resettlement of a relative with an intellectual disability (for example, Booth et al. 1990; Conroy & Bradley, 1985; Tossebro, 1996). A major concern of the present study was identifying how families made decisions regarding deinstitutionalisation and, linked to this, who and/or what influenced such decisions.

The present context of families' lives, along with their past experiences, engendered emotional responses that made it difficult for individual families to make decisions in support of community care for their family members with an intellectual disability. However, the present study also identified a number of other factors contributing to families making a decision that their relative's future should be outside of the institutional environment. Such factors included: the ability for families to engage with current community based services; contact with service coordinators; and the presence of a family member, usually a sibling, or another trusted person who presented a positive view of an alternative to institutional living. Sometimes all of these factors were present within an individual family's situation, and sometimes only one of these factors may have prompted families to take the first step toward choosing a community based service. The factors identified here all had the potential to help the individuals responsible for making decisions about the resettlement of their family members to challenge the

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perceptions that were making them oppose community resettlement and to feel confident and supported enough to embrace the change.

It has not been common for deinstitutionalisation research to focus on the identification of factors that influence how families' may come to accept deinstitutionalisation as a reality in their lives. As well as identifying what influenced families' first steps toward accepting deinstitutionalisation as an achievable goal for their family members with an intellectual disability, I was also able to determine the practical considerations that families made when they had progressed to the point of selecting a community based alternative to institutional services. These practical considerations were, in order of importance: perception of quality staffing; track record of service provider; number of clients in the residence; proximity to the family; and the residential home's appearance. These findings also provide important information for those involved in implementing deinstitutionalisation processes or indeed other major changes in service delivery, and/or who provide community based disability services in general. The practical considerations described by families indicate very clearly the issues that motivate families to feel secure about a disability service provider. While it is undeniable that different families will have different ideas about each of these issues, they provide a starting point from which planners and service providers can begin to facilitate positive relationships with families who have relatives with an intellectual disability.

An interesting finding generated through this study related to the ways in which the families exercised control over the deinstitutionalisation processes whenever they had the opportunity to do so. Specifically, despite the fact that some families were pro-closure, they deliberately did not engage with the process of service coordination because they felt they were being forced to accept a process that they had not had the opportunity to influence during the initial planning stages. I interpreted this action as a response by families to an initial lack of information or personal engagement with the process. Conversely, however, other families were held up in their decision-making because they lacked information and understanding about the processes with which they were supposed to be engaged. Both these contexts point to the need for people involved in implementing major changes in service delivery to be careful to interact with families on an individual basis and to ensure that communication is clear in its content and intent.

How do families experience the impact of the transition of their disabled relatives from institutional- to community based disability services?

The question previously discussed related to how families made decisions about the resettlement of a family member from institutional to community based services. This third central question related to how the families who participated in the present study experienced the reality of transition. As mentioned earlier, the issue of how families' attitudes toward deinstitutionalisation change, or for some remain unchanged, has been a significant focus of a great deal of research. Conroy and Bradley (1985) considered theirs to be the first study to document families' feelings and concerns before and after resettlement, and therefore the first to document families' changes in attitudes during the process of deinstitutionalisation. Conroy and Bradley found that although families were satisfied with institutional care prior to resettlement, the same families were found to be equally satisfied with community based services following resettlement.

This change in attitude from negative to positive toward deinstitutionalisation has been a feature of studies that have since collected data in the pre- and post resettlement phases (Booth et al., 1990; Conroy and Bradley, 1985 ; Cummins and Dunt, 1990; Grimes and Vitello, 1990; Lord and Hearn, 1987). The present research was consistent with such findings and at the conclusion of the study only three families from a total sample of thirty-five families were negative about the impact of deinstitutionalisation in the lives of themselves and their relative.

It was common for families who held favourable views with regard to the impact of deinstitutionalisation to be positive about the perceived change in their relative's general well-being, happiness and skill development. Some of these families had emphasised what they viewed as the deficits that characterized their family member during Phase One of the study. However, after experiencing the transition from institutional to community based services it was common for these same families to begin to present more information about their family member's personality, individual characteristics and personal achievements. This finding may be connected to Bogdan and Taylor's (1989) exploration of the social construction of humanness. In studying close relationships between disabled and non-disabled people Bogdan and Taylor identified that the key to the success of such relationships was that the non-disabled people attributed qualities of "humanness" to the person with a disability. In particular, the non-disabled people

attributed thinking to the other person, saw individuality in the person, viewed the other person as reciprocating, and had defined a social place for them. Bogdan and Taylor concluded by saying that these perceptions of others enable non-disabled people to define disabled people as "like themselves" despite the differences that may exist between them.

In the present study the move into community residences provided the opportunity for families to get to know their family member with an intellectual disability within the context of their daily life. This may have enabled families to begin to see the "humanness" of that person again. In using the term humanness I do not mean to suggest that families who did not choose to resettle their relatives in community based services did not love or care for their family member with an intellectual disability. However, their descriptions or constructions of their family member tended to emphasise deficits and limitations and did not include the attributes that Bogdan and Taylor identified as being integral to what it means to be human.

Equally as integral to families' positive evaluations of deinstitutionalisation was the sense that as a result of community placement their family member with an intellectual disability had been relocated back within the family, and that the family itself had regained an important position within that person's life. This was an important progression from earlier discussions with families about institutionalisation. This finding links strongly with Funnell (2002) who highlighted the centrality of familial love to developing an understanding of how institutionalisation and deinstitutionalisation impacts on families.

It is important to discuss the issue of transition as it occurred for families who had made the decision that their family member with an intellectual disability would make the transition to Brackenridge. As explained earlier in the present study, Brackenridge was a "sheltered village" style facility that was developed on the former Templeton Centre site. It was clear from this research that families who chose Brackenridge experienced feelings of fear and insecurity about their family member's transition. This was despite the fact that these families were adamant that a sheltered village was the only model of service that could meet the needs of their family member. After achieving such a service it could be reasonable to assume that these families would have no concerns about resettlement.

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I was able to identify one key difference between the transition experiences of those families who chose community based services for their family members with an intellectual disability and those families who chose Brackenridge. Families who had family members who made the transition from Templeton Centre to Brackenridge did not, to any great extent, alter the way they viewed that person. Whilst they commented on the improved physical environment, and in some cases, greater accessibility to their family member, they did not tend to focus on how transition had allowed them to get to know that person again. Further to this point, throughout their participation the Brackenridge families did not focus very much at all on the individual or personal characteristics of their family members with an intellectual disability, a feature that was very strong in other families' descriptions of the impact of deinstitutionsalisation.

How do siblings interpret the experience of institutionalisation and deinstitutionalisation?

The fourth and final key question posed in this study was "how do siblings interpret institutionalisation?" My commitment to including the views and perspectives of siblings proved important to gaining a more complete understanding of the way in which families make decisions relating to their relatives with intellectual disabilities. Because other research on deinstitutionalisation has more commonly focused on the role of parents, the important role that siblings can play in this process has frequently been overlooked.

As previously noted, this research identified that it was extremely common for parents (and more particularly mothers) to make decisions about institutionalisation based on their concerns for the wellbeing of their non-disabled children. Specifically, parents worried about: not spending enough quality time with their non-disabled children; their non-disabled children having to assume a level of responsibility for the care of their brother or sister that was not typical in other families; family life being limited by the sibling with an intellectual disability; and non-disabled children feeling unable to have friends home because of the presence of the child with an intellectual disability.

An interesting aspect of this research was that while the now adult siblings usually understood and supported their parents in the earlier decisions that they had made

regarding institutionalisation, very few of the siblings viewed themselves as being the reason that their brother or sister left the family home in the first place. When asked, most siblings attributed the institutionalisation of their disabled sister or brother to the fact that their parent(s) could no longer cope with the stress and pressure associated with caring for the person at home, and the fact that there were no community based service alternatives at the time placement was sought. Some of the siblings recounted stories told to them by their parents regarding incidents that occurred involving them and their brother or sister that highlighted the fact that they had experienced difficulties and frustrations. Very few siblings recounted similar incidents from their own perspectives and most viewed their brothers and sisters with an intellectual disability positively. This finding is similar to that of research by Connors and Stalker (2003). Connors and Stalker questioned children about their relationships with their disabled siblings and found that most children described their relationship in positive terms.

In the present study siblings reported that removing a child with an intellectual disability from a tense and stressful family context did not immediately restore peace to a household. In fact, the reverberations of removing a child from the family home sometimes had the effect of creating an enduring sense of sadness in many families. The now adult siblings of men and women with intellectual disabilities appeared to continue to try and make sense of the dislocation that had occurred within their family. Many struggled with the sadness caused by their brother or sister going to live in an institution while at the same time recognizing that the stress and difficulty of caring for a child at home had caused real problems within their family. Siblings often described the negative impact of the removal of a disabled child from the family environment.

Strong and long lasting memories for siblings were of family visits to the institution during the time their brother or sister was a child living there. Many siblings remembered such visits to be sad, and sometimes disturbing for them. Central to siblings' feelings on this issue was the feeling of guilt that they were experiencing a completely different life to that of their brother or sister in the institution. That guilt sometimes stayed with siblings into adulthood. Siblings' discomfort with visiting their brother or sister in the institutional environment sometimes meant that they visited less frequently over the years and, consequently, often did not have a well-

developed relationship with their family member, or a real understanding of their daily life.

The movement of people with intellectual disabilities from the institutional setting into a range of community based alternatives was, for many families, the catalyst for a rekindling or reconnecting of family relationships. It became clear through the interviews conducted with siblings that the process of deinstitutionalisation resulted often in an increased understanding and awareness of men and women with intellectual disabilities by their families. The process of decision-making that families had been, to a certain extent, forced into frequently had the impact of enabling the family member with an intellectual disability to begin to be psychologically relocated back into the family. This happened because the deinstitutionalisation process provided an opportunity for change and development in the lives of people with intellectual disabilities. While change and development may have occurred within the institutional environment, it was not usually as evident to families, nor were they an integral part of a process as they were in the case in deinstitutionalisation.

Interviews with the now adult siblings of men and women with an intellectual disability revealed that they frequently had their own private, and long-held thoughts and views relating to the institutionalisation of their brothers and sisters. Despite this, it was clear that siblings did not, in most cases, blame their parents for the difficult and painful decisions they had previously made. The adult siblings who took part in this research were incredibly supportive and understanding of their parents and the decisions that they had made regarding the institutionalisation of their brother or sister. They were also very worried about the impact of the planned deinstitutionalisation process on their parents and wanted to protect and support them through it. A significant number of siblings felt that their parents had not received appropriate support or information in the early stages of the process of deinstitutionalisation and continued to feel angry about the level of stress and anxiety that their parents had been required to work through.

The siblings who took part in this research displayed a variety of roles in relation to their level of involvement with the decision-making that occurred for their brother or sister with an intellectual disability. A small number of siblings followed the lead of their parents with regard to decision-making. Some were already fulfilling a decision-making role in partnership with their parent(s). Others took a lead role in

the decision-making that occurred in relation to their brother or sister but still considered the wishes of their parent(s). A few siblings were in the position of being the only family decision maker in relation to their brother or sister with an intellectual disability. Orsmond and Seltzer (2000) contended that disability support services need to recognize that future family involvement in services will inevitably involve siblings who fulfill care-giving or decision-making roles. Furthermore, Bigby's (1996) research identified that older parents of adults with an intellectual disability had high expectations that their non-disabled siblings would be involved in the care or decision-making, providing further evidence of the need to understand the relationship between disabled and non-disabled siblings.

This research has shown that the adult siblings of people with disabilities often play an integral part in facilitating the movement of their brothers and sisters with intellectual disabilities from institutional environments into disability services based in the community setting. Most of the siblings who took part in this study felt that they needed to help their parents negotiate the often anxiety-provoking process of considering a change in model of service delivery. Anxiety about the transition of a family member with an intellectual disability was expressed by both parents and siblings in a study by Seltzer et al. (2001). This point was particularly pertinent within families where parents were quite elderly. Some siblings reported that they felt that the methods used to communicate and disseminate information were not accessible to their parents. Usually their concerns regarding accessibility related to the language and terms used in correspondence, and the use of large public meetings that made it impossible for families to have individual concerns addressed.

In situations where parents shared a decision-making partnership with their adult children, decisions were made about resettlement more quickly and more positively. In such cases it was evident that siblings played a significant role in helping their parent(s) to understand more about the process of deinstitutionalisation in general and community based services in particular. If siblings asserted a positive view of what the future could hold, their parents were more likely to follow their lead and embrace the notion of resettlement as well. A significant number of families whose family members were amongst the first to move from Templeton Centre were families in which siblings played an active decision-making role. Their support of the proposed changes in service delivery made it easier for parents to take the initial step toward resettlement.

Many siblings were surprised and delighted to observe the changes in their brother or sister with an intellectual disability that occurred after they had been resettled from Templeton Centre. Siblings appeared to embrace very quickly the notion that life in the new model of service delivery could offer their brother or sister a great deal more opportunity. A significant number of siblings became actively involved in suggesting and creating new opportunities for their brother or sister. This finding provides a response to Blacher and Baker's (1992) assertion that research needs to focus on the "content or contribution" of family involvement in the disability service by which their family member is supported.

Not all siblings reported that they saw a change in the skills or abilities of their brother or sister but almost all siblings said that they felt the new situation was better for the family as a whole. Siblings, like parents, believed that they had a greater level of understanding of, and involvement in the life of their brother or sister. They also felt that they had a more comprehensive level of communication with management and direct staff working in the new services. One thing that siblings particularly seemed to appreciate was that they were informed of new and positive developments in the life of their brother or sister rather than just learning about problematic or negative issues as had been more common in the past.

Researchers have pointed to the need to understand the perspective of adult siblings as potential or future care providers (Griffiths & Unger, 1994; Stoneman & Berman; 1993). An interesting point raised by this study was that siblings were cognizant of the need for them to take a more active role in the life of their brother or sister in the future. In particular, they were aware that as their parents became older that they would be required to take on a greater level of responsibility for their brother or sister. Some siblings had already begun to formalize this by becoming legal welfare guardians, a finding consistent with another New Zealand study (Bray, Dawson & van Wilden, 2000), while others chose to become involved in the governance of the new community based services. These findings lend support to the view of Seltzer et.al. (2001) who contend that community based disability services should focus on facilitating sibling involvement because it is likely to be the longest lasting of all family relationships and the most constant support that adults who have an intellectual disability will experience.

A theoretical framework for interpreting the findings of this research

This doctoral research was based upon the paradigmatic framework of constructivism. Specifically, I chose to utilize Guba and Lincoln's (1994) "constructivist paradigm" within the present study. This decision influenced my choice of methodology - that is, how I approached the task of seeking knowledge relating to the issue of family involvement in deinstitutionalisation and, subsequently, my approach to theorizing the findings of this study. The following quote (which can also be found on page 78 of this thesis) describes the notions upon which a "constructivist paradigm" is based, and articulates the ideas that were central to the development of methodology, method and theory within the present study.

> The aim of inquiry is understanding and reconstruction of the constructions that people (including the inquirer) initially hold, aiming toward consensus but still open to new interpretations and information as sophistication improves. The criterion for progress is that over time, everyone formulates more informed and sophisticated constructions and becomes aware of the content and meaning of competing constructions. (Guba & Lincoln, 1994, p.62).

It is my contention that these basic tenets of a "constructivist paradigm" have enabled me to theorise families' experiences of institutionalisation and deinstitutionalisation in a way that incorporates, and indeed highlights the complexity and heterogeneity of families so evident throughout this study. Constructivism assumes the relativism of multiple social realities, sees the viewer (researcher) and the viewed (participants) as mutually creating knowledge, and aims to achieve an interpretive understanding of participants' meanings (Charmaz, 2003).

Assuming a constructivist position in the present research determined, to a large extent, the methodological procedures that were used to conduct the study. For example the present study was designed to enable me to interview families at repeated intervals over an extended period of time. This time allowed me to develop a relationship with each of the families to a level that gave me an insight into the complexity of their lives. In each of the findings chapters of the present thesis the similarities evident between families involved in the process of deinstitutionalisation have been revealed, but the contrasts and contradictions both within and between families have been featured perhaps even more strongly. This

is in keeping with the constructivist's aim of including *"multiple voices, views, and visions in their rendering of lived experiences"* (Chamaz, 2003, p.275). In a methodological sense constructivism gave me the ability to "hear" families' voices, views and visions about institutionalisation, deinstitutionalisation and community living.

Constructivism influenced my approach to theorizing the findings of this study. Taking a constructivist approach to the theorization of the present study has enabled me to illuminate the competing constructions of institutionalisation, deinstitutionalisation and community living within: individual participants' constructions; within the constructions presented by individual members of a single family; and between the diverse group of families who chose to participate in the study. Through the findings chapters I attempted to reveal the meanings families seemed to attach to their lived experiences of institutionalisation, deinstitutionalisation and community living. That is, I have tried to capture families' perceptions of the emotional impact of the institutionalisation and deinstitutionalisation of family members, as well as ways in which families have responded or acted when faced with making decisions relating to the care of that person. Information gleaned from listening to and reflecting on families' stories has enabled me to present a reconstruction of families' constructions based on the meanings or interpretations that have emerged.

Phase One of this study provided me with a starting point for understanding the families' constructions of deinstitutionalisation at that time. I commenced the Phase One interviews soon after families had been told that their family member with an intellectual disability would be resettled into community based services. I quickly found that before I could understand families' constructions of deinstitutionalisation, I needed to explore their constructions of institutionalisation. All the families who participated in this study were in the position of having to engage with deinstitutionalisation because of the decision they had made to institutionalise a family member at an earlier date.

As I have previously shown in this thesis families experienced a series of events that eventually forced them to seek out-of-home placement for their family member with an intellectual disability. Their constructions of institutionalisation were formed around descriptions of these experiences and events. However, it became clear that some more underlying issues were underpinning their

constructions, for example, their notions of disability and perceptions of appropriate models of care. In Phase One of the study families usually revealed an understanding of disability as illness and pathology along with a mistrust of community based services. However, even at this stage some families showed they were at least aware of alternative models of disability and responding to disability by revealing that they were not totally opposed to plans for deinstitutionalisation. Notions of gender, and in particular the role of the mother also influenced how families constructed their stories of institutionalisation and were found to be influential. Mothers who took part in this study appeared to adhere to patriachial notions of the role of mother and as a consequence shouldered the primary responsibility for caring for their child with an intellectual disability. A statement made by constructivist researcher Kathy Charmaz (2003) supports my view that it is critical to look beyond the resources that families are perceived to have and instead seek to understand how they experience and, consequently, construct and assign meanings to their lives. In this regard Charmaz commented:

> To seek respondents' meanings, we must go further than surface meanings or presumed meanings. We must look for views and values as well as for acts and facts. We need to look for beliefs and ideologies as well as situations and structures. By studying tacit meanings, we clarify, rather than challenge families' views about reality. (p. 275).

Different ways of thinking about disability

With reference to the above quote, it is necessary to explicate the alternative notions or ways of thinking about disability that may have influenced the ways in which families constructed their experiences of disability. Firstly, families' earlier decisions to use institutional services were legitimated by the tacit acceptance of a medical model disability. As Oliver (2004) has explained, this model constructs people with a disability as "sick" and impaired and as having limited ability to exhibit independent thought and action. Furthermore, central to the medical model is the view that medical or other professionals should have primary influence with regard to the person's needs and ongoing care. These decisions typically recommended assigning disabled people to a corrective or protective environment away from mainstream community settings (Barnes & Mercer, 2004).

In contrast, families' experiences of deinstitutionalisation took place in the context of alternative conceptions of disability. As discussed in Chapter Three of the present thesis, the concept of deinstitutionalisation was motivated originally by three predominant factors: the recognition of the unfavourable conditions for people with an intellectual disability within institutions (Taylor, 2001); the principles inherent to the concept of normalization (Nirje, 1985; Wolfensberger, 1992); and the development of a community based disability support sector (Mansell & Ericsson, 1996). During the conduct of the current study the importance of these earlier motivations have become less significant as services improved and acknowledgement of the rights of disabled people extended in policy and practice. Nevertheless, these factors continued to be evident in varying degrees by families as they talked about their understandings of deinstitutionalisation. For example, in the early stages of the current research it was common for families who were resistant to the closure of the institution to argue against this major process of social change on the basis that the institution provided good enough services; that people with an intellectual disability would never able to achieve a "normal" life; and that the community based disability support sector had failed families in the past.

During the conduct of the current research alternative models of disability that encompassed a social interpretation of disability were gaining significance within disability theory and research (Barnes & Mercer, 2004). These social models of disability propose that it is the social practices within society that create barriers for people with disabilities rather than disability predominantly involving something that is problematic and inherent to the individual (Barnes & Mercer, 2004; Fulcher, 1989; Oliver, 2004). An adherence to social models of disability has become increasingly common within the New Zealand disability community and it is evident in the New Zealand Disability Strategy (Minister of Disability Issues, 2001). The New Zealand Disability Strategy conceptualizes disability as created by societies that design environments only in ways that are appropriate for non-disabled people. Some families' constructions of their family members with an intellectual disability were found to reveal notions integral to these more recent conceptions of disability. For example, families became concerned with issues such as ensuring that their family member was assured of respect, privacy and the opportunity for individual choice.

Consideration of both medical and social constructions of disability is useful to achieving a critical analysis of the ways in which the families who participated in

this study shaped their constructions of disability. Although medical model thinking retains a powerful influence in the disability arena, it was particularly dominant in the historical period when institutionalisation was accepted practice. In more recent times understanding of disability emphasise the role of social beliefs and contexts in assigning meanings to disability. This has influenced a view of disability as part of ordinary human diversity with disabled people therefore being included in ordinary community contexts. Taking a constructivist approach to theorizing families' experiences of deinstitutionalisation requires us to examine the wider social contexts that assign meanings to culturally determined significant issues such as disability, and to consider how different ways of thinking about disability may influence families' understandings of disability.

As discussed earlier in this section the families who chose to take part in this study had all been influenced at some point by a medical model of disability. Such a model highlighted what were seen as personal or persisting deficits and advocated institutional care as being the most appropriate form of support for people with an intellectual disability. However, it is also evident that while families who participated in the present study were convinced of the appropriateness of institutions, at the same time there were many other New Zealand families caring for disabled family members at home. Furthermore, during this period, which encompassed the 1950's to the 1990's, alternative, more socially orientated conceptions of disability were becoming accepted and a community based disability service system was developing.

These alternative constructions of disability may have been responsible, in part, for allowing families in the present study to eventually reconstruct their understandings of disability in general, and their family member with an intellectual disability in particular. In the case of the present study siblings were sometimes more aware of alternative constructions of disability at quite a young age. This point is evidenced by the finding that some siblings felt more embarrassed about the fact their brother or sister had been institutionalized, than by the fact of that person's intellectual disability. These findings suggest that families may align themselves with socially dominant views of disability. Also, some families may resist dominant views of disability and hold a position that seeks alternative constructs and responses to disability and its implications.

Other influences on families' constructions of disability and caring

In the present study, paying attention to the contexts within which families operate includes examination of the ways in which gender roles are interpreted and how they may have a significant impact on the ability of women to cope with the task of caring for a family member with an intellectual disability. Understanding the constructions that seem implicit in the families' views and actions with regard to out-of-home placement allows us to engage with a difficult question. As researchers we often ask, and are asked the question "why do some families seek out-of-home care whilst other families in similar situations find caring for their family member at home a manageable task?" While an important one, the preceding question could also be perceived as being a judgmental one. In my view it is not useful to question why a particular family is not coping as "they appear to have everything they need" without taking the time to learn about the context of that family's life and the context within which they live, the lived experiences of all the individuals within the family, how dominant notions of gender impact on the family, and how the family constructs their own lived experience of disability. In taking such an approach, I suggest it may be possible to gain a level of understanding about an individual family that may go some way toward answering the preceding question.

Contradictions in families' constructions

Often contradictions in a research participant's construction of a particular phenomenon are difficult to assimilate into research findings and, subsequently, to fit into a neat theoretical model that may "explain" the specific context or situation. However, constructivism encourages the researcher to identify such contradictions and to use them to gain more complex understandings of the issues under study. As mentioned previously in this section, contradictions in families' constructions of institutionalisation quickly became apparent to me as I conducted this study. For example, all parents who participated in this study revealed that they had originally been resistant to notions of institutionalisation. Furthermore, while parents later presented constructions of institutionalisation that justified their earlier decision to remove their child with an intellectual disability from the family home, a significant number of these families revealed in the same interview that they were positive about the potential benefits of deinstitutionalisation.

To me, this illuminated the presence of alternative constructions that were held by some families. As I explored these contradictions it appeared that the families who revealed alternative constructions were families that tended to be more willing to make decisions that led to the resettlement of their family member with an intellectual disability more quickly. It would seem that being able to articulate alternatives to medical model thinking may support the construction of their family member with an intellectual disability as someone with qualities of "humanness", in Bogdan and Taylor's (1989) term, and therefore with the potential for inclusion and development in mainstream community settings.

Another example of competing constructions of institutionalisation was identified in Phase One of the present study. While parents reported that they sought out-of-home placement for their disabled children out of consideration of the needs of their non-disabled children, the now adult siblings who had experienced the removal of their brothers or sisters frequently had negative views of this event. Siblings' constructions of the significance of this event commonly highlighted the fact that the grief and distress that accompanied the decision to institutionalise continued to reverberate through their family for a very long time. Another interesting point is that participation in this research presented many of the siblings with their first opportunity to put forward their own perceptions of the impact of institutionalisation.

Phase Two of the present study illuminated families' experiences of making decisions about the resettlement of their family member. As identified earlier in the present chapter families had their thinking and decisions about resettlement influenced by a number of factors. The convergence of various emotional and practical experiences supported some families to identify with more informed and sophisticated constructions of deinstitutionalisation. These new constructions of what is real or important emerged, in part, from a greater understanding of the community based services that actually were available to them, and of the individuals who could assist them with the transition that was occurring for their family member. Equally important to families' "new" constructions was the fact that they had actually seen and experienced changes in their relatives' lives following deinstitutionalisation. Subsequently, the convergence of these practical and emotional experiences enabled families to develop a more sophisticated understanding or reconstruction of their family member with an intellectual disability. This reconstruction of their family member emphasized the humanness

and potential of that person and seemed to influence whether families would develop a positive construction of deinstitutionalisation. As identified earlier in the present chapter, it was common to find that siblings assisted parents to develop these more positive constructions of the resettlement of people with an intellectual disability into community based services.

The final stage of this study, Phase Three, revealed that families whose family members had moved into community based services had even further reconstructed their stories of deinstitutionalisation. It was common to find that families now perceived the process of community resettlement as having enabled them to "psychologically" relocate their family member back within the family. Families also tended to construct their relationship with their family member as more reciprocal – that is, that they received emotional reward through their involvement with their child or sibling with an intellectual disability.

It is interesting to explore how we might apply a constructivist approach to theorising the situation for those families whose family members moved into Brackenridge, the sheltered village developed on the old Templeton Centre site. What these families were looking for was a service as close as possible to the institutional model of care. This would seem to be because their constructions of disability did not seem to allow them to consider any other model as being appropriate for their family member. Unlike other families, the early constructions that Brackenridge families revealed tended to remain unchanged throughout the period of time that I was working with them.

Families who were committed to the development of a sheltered village type service often had family members with an intellectual disability who were medically fragile, or who had the "dual diagnosis" label. These families continued to understand their family member with an intellectual disability in terms of a medical model way of thinking. Specifically, these families did not appear to reconstruct their family member with a disability in the same way as other families did – their stories continued to reflect the thinking inherent to a medical model of disability and consequently, to highlight their family member's perceived personal deficits and need for ongoing institutional-type care. Brackenridge families often revealed a belief that their family member needed to be protected from the community and the community, in some cases, needed to be protected from their family member. Families who had family members with high medical needs were

also of the view that the level of nursing care needed by that person could not be provided in the community environment.

While recognizing that many of the people that were resettled at Brackenridge had acute care needs, this was not true of all new clients to the service. Some people had not been assessed as meeting the criteria for entry into the service, but due to the strength of their family's opposition to a community based placement they were able to enter the service. Further to this point, some people with an intellectual disability who had been assessed as meeting the criteria for Brackenridge were resettled into the community based environment at the wish of their family. This erodes the assumption that only people with extremely high needs who were unsuitable for community placement used the sheltered village service. This finding begs the question, "why did some families move toward deinstitutionalisation and community living for their family member while other families fought strenuously to retain the status quo?".

A number of factors had an influence on the decision-making processes that led families to support community placement. These factors were: the ability for families to engage with current community based services; contact with service coordinators; and the presence of a family member (usually a sibling) who presented a positive view of an alternative to institutional living. It was these factors that seemed to have been rejected by families who advocated for the development of a sheltered village. On the basis of this interpretation, I suggest that these influences were not apparent in the experiences of Brackenridge families and, therefore they were not able to adjust their perceptions of their family members and their views of deinstitutionalisation. Furthermore, it seemed Brackenridge families did not choose to engage with people or with experiences that may have challenged and consequently helped them to reconstruct their perceptions and evaluations of their family member with an intellectual disability.

Exploring the lived experiences of families in order to be able to better understand the factors that influence their decision-making processes when determining the current and future care of their family members with an intellectual disability was a key focus of this study. Acknowledging that human beings experience multiple realities and competing constructions of a single issue creates, in my view, the potential for researchers and disability professionals to develop a better understanding of how and why families and individuals react to

deinstitutionalisation in the diverse ways that they do. It is also important to continue to explore the intersection of the social context within which they live and individual elements in families' constructions of disability and disability service provision for their family members with an intellectual disability.

The issue of how families construct their experiences of disability developed greater importance for me during the final stages of writing this thesis. At this time there was extensive media coverage focused on the case of a New Zealand father who killed his young daughter with an intellectual disability. The father was committed to trial but not convicted of any crime. From media reports and comment it was evident that the New Zealand public, to a very large extent, condoned the actions of this father on the basis that his actions were justified due to the nature and extent of his daughter's disability. Central to this case was the view that medical professionals had presented a very negative prognosis for the young girl's future, and that the father had "snapped" due to the stress associated with receiving such a prognosis. This case raised many issues for me. Most significantly it led me to surmise that alternative notions of disability that are generally supported by members of the disability community have not necessarily been embraced by members of the community at large. Furthermore, it appears that some factions of the medical profession may be ill-equipped to present information about disability to families in a manner that acknowledges social models of disability and that incorporates the notion of humanness. It is my view that to understand the extreme response of this father it would be necessary to determine how his individual experiences and actions interacted with socially constructed and legitimated notions of disability that, apparently for many people, made killing a baby an understandable and forgivable act.

The ideas I have presented here suggest that it may be useful to theorise issues related to disability within a constructivist framework and, more specifically, with an emphasis on epistemology. That is, we may be able to gain greater understanding of families' perceptions of their family members who have an intellectual disability and subsequently the decisions that families make regarding the care of that person by exploring the meanings they assign to their world. Ascertaining how families come to construct their understandings of disability is, in my view, critical to responding appropriately to families' needs within the context of disability support and service provision. It is possible to draw a link between the ideas I have presented here about the theorization of this research and

recent work by Nancy Rosenau (2004). Rosenau suggests that a positive way of theorizing disability in a way that is accessible for those affected by disability in their lives is to take a "relationship-based" approach to theorization – that is to illuminate the "power of feelings". Rosenau holds the view that real change or learning occurs when we experience emotional connection with the content and the content deliverer.

> The power of feelings can be put to work to change social arrangements. Beyond, or rather under, a rights-based agenda is a relationship-based agenda, and underpinning a relationship-based agenda is what it means to be human and how we know each other to be. (Rosenau, 2004, p.270).

It is also my view that paying greater attention to the way in which we access the meanings that people assign to their constructions of disability could contribute to the development of a "relationship-based" agenda to achieve more responsive supports for families as well as greater involvement and acceptance for people with an intellectual disability. In the case of the current research we could use the example of siblings' feelings of dislocation following the removal of a brother or sister from the family environment to illustrate the benefits of exploring and supporting family relationships. Siblings' stories served to reveal the emotional connections they had with their brother or sister with an intellectual disability, and the extent to which these relationships were damaged by the event of institutionalisation. Such experiences, and such harm, seem likely to strike an emotional connection with those made aware of such accounts and so, as Rosenau suggests, promote concern for a human right agenda that includes issues of disability. It is my contention that valuing family relationships may lead to an increased ability to support and promote a more socially just situation both for people with an intellectual disability and for their families.

Methodological issues

The use of constructivism in the present study has also generated useful knowledge about conducting qualitative research with families. More specifically, the following section discusses some of the methodological issues that I encountered during this study and has the purpose of highlighting the importance of recognizing and responding to participants' needs within the research process. Methodology refers to the issue of how a researcher or inquirer should seek to know. Because I conducted this research within a constructivist paradigm the

choices I made with regard to how I sought to know were influenced by such an approach. To adhere to a constructivist position the study was designed to incorporate the opportunity for me to have multiple interactions with families over an extended period of time. This type of involvement with families enabled me to understand the different constructions and reconstructions that they presented with regard to deinstitutionalisation over time. I also "got to know" the participants as people. In the process of building a social relationship with participants I became increasingly interested in how researchers become aware of the needs of research participants, and, consequently, how we might strive to address them. Reflection and analysis of the many different experiences I have encountered while conducting this project has led to the identification of some methodological issues associated with meeting participants' needs. Interestingly, the methodological issues that I encountered were found to be strongly linked to the way individuals constructed themselves, and in several cases, how they constructed me in my role as researcher.

When considering participants' needs during the process of conducting the present study I have been able to identify two ways that participants raised issues that they were having difficulty with in relation to the research process. Participants in this study were found to be either explicit or implicit in the manner in which they raised issues with me.

In the present study, when participants experienced a response to the research process that they were able to articulate clearly to me I found it less challenging to react appropriately. I found that explicit needs were largely unanticipated but were easily identified and rectified through participants' openness about what they were having difficulty with, and how I might improve the situation. Improving the situation usually required a minor adjustment to the research process.

For example, one participant who was particularly adamant that his son would never be resettled from the institutional setting would not proceed with the research until I had removed the word "resettlement" from the project title. This meant that I created a different set of consent forms and information sheets for his use. His response, however, also provided me with an important insight into his early construction of deinstitutionalisation and influenced how I proceeded with the research. I made sure that I reassured all the families who chose to take part in the study that I would maintain my commitment to presenting their stories and

providing them with a "voice" regardless of the type of service they eventually chose for their relative This reassurance became an important first step in creating positive relationships with families.

One experience I encountered challenged general assumptions about the role of the researcher as "objective" and non-disclosing. After gaining consent from, and setting up an initial interview with one couple, I arrived to find that one partner was very hostile and negative toward the research. I was uncomfortable with this and after a concerted effort to alleviate any obvious concerns I felt that it was necessary to remind the person that he was under no obligation to take part in the research. At that point he questioned me about my surname as he associated it with his favourite recreational sport. I confirmed that my family and I did share his interest and we spent a long time discussing this topic that was completely unrelated to the research. From this point on we were able to develop a positive relationship as this man was able to view me as a "real" person - he reconstructed me. It was not until I got to know this participant over time that he told me of several very negative interactions he had had with researchers in the past. This was why he had been reluctant to commit to the research initially and, to me, emphasized the importance of acknowledging the influence of previous experiences.

In other instances participants were not able to articulate their needs so clearly and this made it more difficult for me to meet their needs. Unlike explicit needs, I usually became aware of implicit needs over time. These were something that I "felt", far in advance of determining exactly what the issue was, or how to respond to it. Re-shaping my research process usually comprised part of my response but in addition I was frequently presented with ethical and moral issues to work through.

One example of an implicit need arose when I realized that an elderly father in the study was completely unaware of the role he was required to take in the deinstitutionalisation process in terms of the stated policy and intended process. He was "supposed" to be an active participant in the process of choosing an alternative service for his son, and in the resulting transition from institutional care. Over time it seemed evident that this father had no understanding of what was expected of him, thus he was unwittingly creating a double disadvantage – to himself and to his son. At the same time as I felt it was my ethical duty to share my

knowledge with this participant, I also had to explore my own beliefs and assumptions about "what it means to be a researcher" in this regard.

In a second situation I had been working with a participant for a long period of time before I learned of a past life experience that made me dramatically alter my research process for this individual. Initially, this participant appeared to be very comfortable with her participation in the research, however, after our initial interview, which I had audio-taped, I noticed that most of our subsequent interactions were by letter. As each formal interview stage came and went, I found that I would take my tape recorder out, sit it on the table, be reassured by the participant that it was fine to tape the conversation but that I would somehow feel that turning the tape on was not the right thing to do. We continued to have a lot of in-depth written correspondence and informal contact by telephone. I continued to feel that this participant was uncomfortable with the research process but when I tried to address the issue I was always reassured that everything was all right. Finally this participant told me of her very tragic and much publicized family history.

I was initially devastated by my previous actions in assuming that tape recording an interview was appropriate for the participant and felt that my research process had been deeply inappropriate given her experiences. I then realized that I could not have known, and would never have known if the participant had not chosen to tell me. I immediately altered the process for this person and from that point on we relied solely on the joint construction of written narrative accounts based on our discussions. In this way the participant could have complete control over her story, and her fear of being misunderstood and misrepresented was alleviated. Like the situation described earlier, this participant also "reconstructed" me. When I began working with her she perceived anyone who was interested in documenting her story as only interested in one aspect of it. Furthermore, she believed that people were prepared to deceive her to uncover the story. Because I was genuinely unaware of her past experiences, and upon learning of them handed control of our interactions to her, she was able to trust me enough to engage with the questions I sought to answer.

Locating this research within a constructivist framework has contributed to the issues I have identified. Guba and Lincoln (1989) contended that the close personal relations or interactions required by a constructivist methodology may result in

"special and sometimes sticky problems" of confidentiality and anonymity, as well as other personal difficulties. In other words, creating strong, on-going relationships with research participants can lead to issues that are not present in research that ascribes to the "objective" researcher model.

Constructivist researcher Kathy Charmaz (2003) emphasized the importance of paying attention to the quality of researcher-participant relationship within constructivist research.

> A constructivist approach necessitates a relationship with respondents in which they can cast their stories in their terms. It means listening to their stories with openness to feeling and experience. (p. 275).

The researcher-participant relationship is also critical to a researcher's ability to offer a critical interpretation of a particular phenomenon that is viewed as authentic. In my view, authenticity cannot be achieved without openness to feeling and experience as revealed through participants' stories.

As I have reflected on my experiences it has become increasingly clear to me that my physical and emotional responses to my interactions with participants were my most effective early indicators of how individuals were feeling about their participation in the study. I have also become aware that if I had not had the ability to have multiple interactions with the families who chose to participate in this study I would have been much less responsive to their needs within the research process. Instead of emphasizing the difficult issues that can arise in research which prioritizes the researcher-participant relationship, Charmaz (2003) commented on what she perceived as possible negative outcomes of ascribing to a research approach that utilized one-off interviews.

> ...Furthermore, one-shot interviewing lends itself to a partial sanitized view of experience cleaned up for public discourse. The very structure of an interview may preclude private thoughts and feelings from emerging. Such a structure reinforces whatever proclivities a respondent has to tell only the public version of the story. Researchers' sustained involvement with research participants lessens these problems. (p. 275).

My interactions with the participants in the present study have enabled me to develop my understanding of the notion that as researcher I am an integral part of participants' constructions and reconstructions of research, and the research

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process. The observations that I have made here resonate with recent work by Goodley and Lawthorm (2005) who explored emancipatory disability research possibilities through the exchange of ideas between British disability studies and community psychology. Goodley and Lawthom emphasise the importance of attending to matters of epistemology throughout the research process and commented, *"Our aim of epistemologically tracing research relationships aims to capture the theoretical landscape we travel in the dynamic process of research."* (p.148).

Limitations of this research

It is important to address the limitations of this study. One limitation of the study could be linked to the fact that the information related to out-of-home placement is based on families' retrospective accounts of their experiences and decision-making with regard to institutionalisation. A number of researchers have questioned the validity and relevance of data collected retrospectively. In particular researchers have raised concerns about the accuracy of memory in parental report (Bromley & Blacher, 1991) and the possibility that parents may try to justify their prior decision-making processes (Cole & Meyer, 1989). Blacher (1990) also contended that retrospective studies are more likely to result in out-of-home placement being seen as a discrete act rather than a gradual process.

Families involved in the present study made decisions regarding out-of-home placement during a period spanning forty years. Interestingly, factors contributing to, and influencing family decision-making were found to be remarkably consistent across all participating families despite the retrospective accounts reported as data here and the diverse timeframes involved. Furthermore, the findings are consistent with the findings of current studies aiming to determine factors influencing out-of-home placement (Blacher, 1990; Blacher & Hanneman, 1993; Llewellyn, et al., 1999).

Another limitation of this study relates to the fact that men, women and children with an intellectual disability who were resettled from Templeton Centre were not able to participate in the study. Whilst the present study has provided a great deal of information about how parents and siblings have experienced institutionalisation and deinstitutionalisation, the people most affected by the change in model of service delivery did not receive the opportunity to take part. Including the voices of people with an intellectual disability themselves would

have enabled the development of a more complete picture of the impact of institutionalisation and deinstitutionalisation.

Finally, it is evident that the current study occurred within a predominantly European context. Research has indicated that other ethnic groupings may assign different meanings to the notion of disability (Kingi & Bray, 2000; Huakau & Bray, 2000) and therefore the ideas presented as part of the current research may not necessarily have relevance for non-European families.

Implications for policy, practice and future research

A number of implications for policy, practice and future research have been identified through this doctoral research. The present research has generated information with the potential to be used by policy-makers, planners and service providers to achieve more positive family involvement in major changes in service delivery, as well as in the day-to-day delivery of disability support services. Important areas for future research have also been identified.

Policy and practice

In a general sense, the ideas forwarded as part of the current thesis suggest a need for policy to incorporate a focus on, and critical analysis of the support needs of families who care for children and adults who have an intellectual disability. In the New Zealand context the New Zealand Disability Strategy (2001) advocates for the need to *"Value families, whanau and people providing on-going support"* (p.29). Paying close attention to families' experiences of caring for disabled family members, including the difficulties they encounter when providing care in the context of the family environment, could contribute to the development of services and supports that are perceived as appropriate both by families and by people with an intellectual disability.

More specifically, findings generated through this doctoral study have the potential to contribute to policy development related to the issues of out-of-home placement through providing a greater understanding of families' experiences of caring for, and subsequently seeking out-of-home placement for family members with an intellectual disability. The findings related to families' decisions to institutionalise their family members with an intellectual disability illuminate the need for the

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emotional or psychological demands of caring to be recognised and reflected in the planning and implementation of family support services. Such findings provide support for Rosenau (2001) who contended that it is critical to look beyond a child's disability to determine why some families continue to care for their child at home, and other families opt to remove the child with a disability from the family environment.

In being positive and advocating the need to take a positive view of disability and disability related issues we have made it increasingly difficult for today's families to acknowledge the difficulties they may/do feel when trying to care for family members. The New Zealand Disability Strategy states: *"Disability is the process which happens when one group of people create barriers by designing a world for only their way of living, taking no account of the impairments other people have."* (p. 3). While this statement is directed toward individuals with disabilities themselves it has, in my view, relevance to the situation facing families who strive to access quality support services for themselves and their family members. Policy-makers need to ensure that today's families have a range of individualized and flexible supports available to them that enable them to continue to care for their family member within the family home or, in the case of some families, to be able to access appropriate out-of-home services that prioritise the maintenance of a close relationship between all family members.

The present study has provided some insights into how families can be supported to cope with changes to the model of care offered to their family member with an intellectual disability. The insights are relevant not just to the context of deinstitutionalisation but also to other situations when a transition is occurring for example, from the family home, or from one service to another. When approaching the issue of change it is important to remember that the families of people with an intellectual disability are families just like any other. They see their (adult) children as children just like all parents do and make decisions that are grounded in love and concern. Disability policy and practice should recognize and respect parents' emotional responses to proposed changes in service delivery to their family member with an intellectual disability. Some families will need the opportunity to work through their concerns, issues and questions with a trusted and knowledgeable person on a one-to-one basis.

Disability support services need to remain cognizant of the importance of family to people with an intellectual disability. In particular, policy and practice in the area of disability support should acknowledge the increasing presence and importance of siblings in the lives of people with an intellectual disability. This study has revealed the vital roles that siblings play in the decision-making that often occurs in relation to the care provided to their disabled brothers or sisters. Specifically, this study has shown that adult siblings frequently have a significant influence over the decisions that parents make with regard to disability support. The study has also shown that many siblings wish to take an active role in their brothers' and sisters' lives, including an involvement with disability support services. Disability support services need to respond to this issue by ensuring that siblings are considered when planning family involvement policies or strategies.

Future research

Research in the area of out-of-home placement needs to continue. A specific focus on understanding the emotional impacts of such a decision on all family members, including the child with a disability, is required.

In order to more comprehensively answer the question "why do some families choose out-of-home placement?" further research is necessary in order to understand how families' constructions of disability and disability support contribute to their perceptions of, and proclivity toward out-of-home placement. Further to this point, more attention needs to be paid to acknowledging the complexity of families, and the multiple realities of their lives. Further exploration of how social-cultural and individual elements present in families' lives intersect and subsequently influence families' constructions of disability and disability service provision is necessary.

Given that people with an intellectual disability tend to be experiencing an increased life expectancy, a more developed understanding of the relationships between people with an intellectual disability and their non-disabled siblings is becoming increasingly pertinent. The current research has contributed to a greater understanding of siblings' perceptions of their brothers and sisters with an intellectual disability. Further research should explore how people with an intellectual disability perceive the relationships they share with their non-disabled siblings.

To conclude, I hope that the ideas that have been presented in this thesis will have meaning for families who have lived with the sense of dislocation that often accompanies the decision to place a family member with an intellectual disability outside of the family home. I would like to leave the final word to a mother whose comments illuminate the complexity of emotion expressed by many of the families who participated in this research. She spoke of her son's placement in a community residential setting and said:

> No I don't think there's anything I don't like there. I just wish the whole thing had happened 20-30 years ago. I just look back and think what a lot he's missed in his life.

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APPENDICES

Appendix 1:

Letter from the manager of Templeton Centre that was included with the package of information sent to the families of Templeton Centre residents. The letter was designed to assure families that their confidentiality had been preserved.

Dear

As you are aware Templeton Centre is closing and its residents being resettled. The Donald Beasley Institute have been funded by the Health Research Council to investigate how this process affects residents' families.

Templeton Centre management have approved the study, since we believe it is important and may lead to better services in the future. Therefore we have undertaken to distribute the enclosed invitation to participate. In order to take part please contact the research team directly.

At no time will Centre staff provide any information about residents or their families to the research team without their specific consent. At this stage no names of relatives or residents are known to the researchers. They will contact you only if you contact them first. Their contact names addresses and telephone numbers are on the enclosed Information letter.

Yours sincerely,

Appendix 2:

Next-of-kin questionnaire

Next of kin questionnaire : Outline of questions to be included

1. Questions about the person who is participating in the study

Participant's name:

Address:

Telephone number:

How are you related or connected to the resident being resettled?

Have you been appointed by the Family Court as Welfare Guardian? Yes/No

2. Questions about the person being resettled

What is your relative's name?

What age is your relative who is being resettled from Templeton Centre?

Sex: M / F

Do they have a physical disability?

Do they communicate by talking?

Can they walk unaided?

Would you say their overall level of disability was: mild / moderate / severe ?

When was he or she first admitted to Templeton?

How many years in total has he or she resided there?

3. Questions to enable other relatives to participate

Are there other members of your family who wish to take part in this project and would like to be contacted by us? Yes?No

Name:

Address:

Telephone nq:

What is their relationship with the person being resettled?

Thank you for taking the time to fill in this questionnaire.

Appendix 3:

Example of interview outlines used in Phase 1, 2 and 3 of the study and an example of the aide-memoire used in Phase 1.

Interview outlines

Phase 1 Interview: original decision to choose institutional care

"tell me about what happened right at the beginning, around the time of diagnosis"

"at the time when it was decided to choose institutional care..."

who was in the family?
did different family members have different preferences?
what was the process of making the decision?
how did people say that they felt about the decision?

what 'experts' were involved?
what were their recommendations?
how did they make their recommendations?
did family members feel pressured?
how important has the decision been in the participant's life subsequently?

"now that resettlement is imminent..."

what concerns has the participant?
how well informed do they feel?
how do they feel about the community staffing?
what do they think will be the highest level of achievement for their relative in a community setting?
what are their aspirations?

Phase 2 Interview: one month following resettlement

"now that the resettlement process has gone on for at least a month..."

what all happened during the move and how was the participant involved?
how does the participant feel about their original concerns?
are there any new ones?
have they thought any more about the original decision?
what aspirations do they now have?
how do they now perceive the community-based staff?

Phase 3 Interview: twelve months following resettlement

"it has been over a year now since resettlement..."

how does the participant feel about how the process has gone?
how do they now feel about the original decision to opt for institutional care?
what sort of relationship does the informant have with staff?
how does that compare with the time of the institution?

Checklist - Parents

Description of son or daughter ☐

Birth and Diagnosis ☐

Support issues before TC ☐

Decision to use TC ☐

Templeton Centre ☐

Proposed Closure ☐

Impact on Family ☐

Welfare Guardianship ☐

Appendix 4:

Templeton Resettlement Family Experiences
project: Preliminary Report – Phase One.
Mirfin-Veitch, B., Bray, A. & Ross, N. (1998).

TEMPLETON RESETTLEMENT FAMILY EXPERIENCES PROJECT

PRELIMINARY REPORT

PHASE ONE

Brigit Mirfin-Veitch
Nicola Ross
Anne Bray

Donald Beasley Institute Inc.
1998

Acknowledgements

We would like to thank the Health Research Council for the research grant which enabled this project to be undertaken. Thanks also go to all the families who have taken part in this research.

Templeton Resettlement Family Experiences Project
Preliminary Report
Phase One

CONTENTS

1.   Introduction

At the beginning of the "Templeton resettlement family experiences project" we outlined our major aim. We wanted to give a "voice" to families who had relatives involved in the changes occurring at Templeton Centre. We planned to meet with families and to talk with them about their own experiences of how the process of moving their relative from hospital based services to community based services was being handled.

By gaining the views and opinions of families we hoped to be able to identify better ways of involving families in planned changes in service delivery to people with disabilities. As families are extremely important in the lives of people with disabilities it is critical that those organizations planning to change the way services are delivered consult with families in a manner that families find acceptable. We hope that by doing this research we will be able to suggest ways to improve the relationships and communication between those people and organizations responsible for altering services and the families who have relatives being affected by the planned changes.

This report is intended to provide a preliminary or "early" report on Phase One of the study. (Phase One is the period before a relative moves from Templeton Centre or begins to use any alternative residential service). The report will concentrate on what families have told us so far and will particularly focus on the issues families see as important as they experience the developments at Templeton Centre. These issues and other important areas will be covered in much more depth in future documents as we analyze the findings more closely and begin to piece all the parts together.

We would like to take this opportunity to thank all of you who have chosen to take part in the study. We thank you for your time and all the valuable information that you have shared with us so far. We recognize that the stories you recount are sometimes painful and we appreciate your willingness to talk with us.

To those people whom we have been unable to include in the study (due to a greater than expected number of people who wished to

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take part), we apologize for not being able to meet with you in person. We hope that you will receive some benefit from reading this brief report and hearing about the experiences of other families who have relatives involved in the process of change at Templeton Centre. We invite anyone who has comments or feedback to make as a result of reading this report to write to us with their comments as we wish to make this work as meaningful to families as possible.

We would also like to thank you in advance for your patience. Sometimes the research process seems to move very slowly. We would like to reassure you that we have not forgotten you and remain very conscious of our obligation and commitment to all those who have chosen to take part in the project. We will continue to provide information and feedback as it progresses.

This report represents the very first step in identifying areas that families see as being critical to the way they have experienced the process of deinstitutionalization of Templeton Centre and the planned resettlement of their relatives into community based services. Over time we will be able to make meaningful suggestions about how to involve families positively in any service delivery change for people with disabilities. These suggestions will be based on the views and experiences of families.

Brigit Mirfin-Veitch, Nicola Ross and Anne Bray
Donald Beasley Institute
Dunedin

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2. The research process

How did we decide who took part?

We thought that people may be interested in hearing how we got the study started, including who is taking part in the study, and how those people were chosen. As many of you will be aware, all parents/relatives of Templeton Centre residents were invited to take part in the study. We did not have access to any personal information about any individual or his or her family as the first mailout was handled by Templeton Centre administration staff. If people received the information but had no wish to take part in the study they did not contact us therefore their identity was never made known to us. People who were interested in taking part contacted us directly.

You may also recall that interested persons were asked to fill out a brief questionnaire about their relative. We called this the Next-of-Kin questionnaire. The reason that we sought this information was so that we could choose a "sample" or group of people who had relatives who represented the diverse range of ages and disabilities of Templeton Centre residents. We also wanted to be sure that we included the families of residents who had lived at Templeton Centre for varying lengths of time. While we were very pleased that so many families were interested in taking part in the study, we regret that limited resources meant that we were forced to restrict the number of people we could include in the study.

What do we mean when we talk about "families"?

You will notice that we use the word "family" a great deal when we talk about this study. We realized before we began the study that some Templeton Centre residents may no longer have parents that are still alive, or that another family member may have taken over the responsibility of being involved in decision making around their relative. We wanted to make sure that the study included the views of those "other" family members as well, of course, as the views of parents. Also, the events at Templeton Centre have often affected not only parents but entire families and we wanted to be able to understand those impacts. In some families one member took part

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in the study while in other families up to four members were interviewed.

How many people have we interviewed so far?

Our final tally for Phase One interviews stands at fifty-four. The majority of these interviews took place in July and August of last year. We interviewed individuals, couples and family groups so through these fifty-four interviews we actually talked with seventy-three people. Participants lived in various locations throughout the South Island and the lower half of the North Island.

We would like to stress that through the research we have received a variety of views of, and responses to, the process currently taking place at Templeton Centre. Our aim is to present the views of all families as accurately and as sensitively as possible while acknowledging the similarities and differences both within, and between families who have chosen to take part in the study.

3. The decision to use Templeton Centre

One of the things that we found particularly striking as we interviewed people was the similarity in parents' stories about the "build-up" to the decision to use Templeton Centre services for their sons and daughters. All parents had wanted to keep their sons and daughters at home with the rest of the family for as long as possible. Most parents had actively fought against the suggestion that their child should go to Templeton to live on a full time basis. Two factors seemed to be common during the time directly before the decision was made for a relative to begin using the hospital based care offered by Templeton Centre. The first factor was that the community appeared to be unable to provide the level of service necessary to meet the needs of the person with a disability. The second factor was that the stress levels that families (and most particularly mothers) were feeling were at crisis point. For most families, the decision to use Templeton Centre was made when a person whose professional opinion they respected said that Templeton Centre was the only option left available to them. It was common for parents to be told to "think about the rest of your family" when they expressed uncertainty about their sons or daughters living at Templeton Centre on a permanent basis.

Families have varying views on the impact of choosing Templeton Centre services for their relatives. Some parents felt that even though their son or daughter went to live at Templeton Centre permanently, family problems did not immediately disappear. Some people felt that the stress within their family actually increased as each member adjusted to the changes to family dynamics. Other people described a sense of relief within their family as the day-to-day stress of living with a relative, who may have had extremely high support needs or challenging behaviour, was removed. Whatever happened within individual families, all parents described the actual decision to choose hospital based care for their sons or daughters as being the hardest and most painful of their life.

Parents were not the only family members to take part in the study. Brothers, sisters, cousins and nieces of Templeton Centre residents also participated. Brothers and sisters of Templeton Centre residents often had clear memories of the day their sibling first went to

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Templeton. Many described the reactions of their parents and talked about their own feelings toward that event. Other brothers and sisters who were not born, or could not remember when their sibling left the family home, were still able to talk about their own parents' feelings because they had discussed this event over the years. Some brothers and sisters who took part in the study described a sense of great sadness about the very different life that their sibling had experienced at Templeton Centre in comparison to their own life at home with the family.

For families who continue to use Templeton Centre for either respite, or as a shared care facility rather than a long term care facility for their relatives, the issues are slightly different. While disappointment at not feeling able to care for their relative on a full time basis can be strong (as it is for other families) they have not had to make the difficult decision of having to seek full time, permanent care. Families in this position talked about knowing that they would have to face this decision at some point in the future. Currently the respite care provided by Templeton Centre makes it possible for these families to have a high level of contact with their relatives. With the back up of Templeton services they are able to cope with the responsibility of caring for their relative at least part of the time. Families reliant on Templeton for respite care are concerned about the implications of losing the facility.

4. Experiences of Templeton Centre services

Families had a range of feelings about the quality of service that their family member had received over time at Templeton Centre. However, despite whether families had positive views, negative views, or mixed views of the quality of service delivered by Templeton Centre they were almost unanimous in their belief that Templeton had provided them with a much needed service at a time when there were no suitable alternatives available to them. Families had often experienced a high level of stress as they tried to find a service to meet their needs. By the time they had exhausted all other possibilities, parents had often reached crisis point and Templeton appeared to be the only option left to try. For this reason most families experienced a feeling of gratitude toward Templeton staff for being able to provide relief in the form of long-term care for their relative.

We were fascinated to hear recollections of family visits to Templeton Centre. Many people visited their family member frequently, sometimes travelling long distances to do so. Other families experienced the impact of professionals' views as to how they should interact with their family member. One such view often saw families of Templeton Centre residents being advised to limit their contact with their sons and daughters so as not to upset them or disturb their routines.

Views of the standard of care being provided by Templeton Centre were dependent on how long a particular family had been using Templeton Centre services. For families whose relatives had lived at Templeton Centre for long periods of time, views of the quality of service had usually altered over time. Families frequently reported that the amount of personal contact that they had with Templeton Centre staff had increased over time therefore allowing more open staff/family relationships to develop. This also meant that families knowledge of their relatives' day-to-day life at Templeton was greatly enhanced.

A significant number of families discussed areas of the service provided by Templeton Centre that they were or had been unhappy with. A common feeling shared by these families was that of an

inability to complain. Families worried that their laying of a complaint may result in negative implications for their relative. This feeling was heightened by the families' own beliefs that Templeton was providing their relative with day-to-day care that they themselves were unable to provide. To complain would seem ungrateful.

Despite the great variation in the views of individual families taking part in this study, one feature of Templeton Centre services was seen as positive by all families. Up until the point that the announcement of the planned closure of Templeton Centre was made, families remained appreciative of the long-term, seemingly permanent nature of the care that their relative received at Templeton.

5. Announcement of planned changes for Templeton Centre

The official announcement of planned changes for Templeton Centre did not come as a complete surprise for most people. Most families reported that they had been aware that Templeton Centre services were in question for quite a long period before the official announcement was made. Families knew that the concept of deinstitutionalization had filtered through from overseas and had influenced Government policy. Hospitals and institutions elsewhere in New Zealand had begun to close and people with intellectual disabilities were living in the community. Despite this knowledge most families of Templeton Centre residents believed that their hospital would not close completely.

On 15 November 1994 the Crown Health Enterprise (CHE) and the then Southern Regional Health Authority (SRHA) made a joint announcement that Templeton Centre would be deinstitutionalized and that residents would be resettled into community based services. Coupled with this announcement was the release of a document outlining plans for the deinstitutionalization process (the blue book) This outline of the intended process referred to a proposal to utilize Princess Margaret Hospital as a location for residential services for a significant number of Templeton Centre residents. The SRHA and the CHE asked families with specific questions to contact them directly. Additionally, a series of meetings were held throughout New Zealand to enable families of Templeton Centre residents to hear "first-hand" about the planned changes. Families and other interested persons were also invited to make submissions about the planned changes to Templeton Centre services as part of a consultation process put in place by the CHE and the SRHA.

It would be fair to say that at this early stage the majority of families that took part in the study reacted negatively to the announcement. Families described feeling a variety of emotions including shock, anger, fear, and sadness at this time. Many people believed that their sons and daughters were in no way capable of living in the community environment. They were fearful of how the safety and security of their family member would be ensured. Families believed that they were losing a service that had met their relatives' needs when no other service had been able to. Often

families had seen Templeton Centre as being a "home for life" for their relatives and had valued highly that aspect of the service.

A smaller number of families (or sometimes individual family members), while concerned, did not respond quite as negatively to the idea of resettlement for their relatives. These people felt that the opportunity to live in the community may be a beneficial one providing all the necessary supports and services were firmly in place. The people who did feel more positive about the proposed changes did not always feel able to make their position known at this stage in the process.

6. Hopes, fears and concerns

Families' reactions to the announcement of the planned closure of Templeton Centre are based very strongly on the hopes, and the fears, that they have for their relatives. The Templeton situation has been, for many families, a highly emotional and stressful time. It is a situation that has been ongoing, and has had tremendous impact on the way that they live their daily lives. Many families felt that their concerns had been brushed aside and that no one really listened to their "stories" about their relatives. Particularly important to most people was the issue of why they felt that they had to choose Templeton as a residential service in the first place. We believe that listening to families' stories is an essential part of understanding families' views and perspectives on this issue.

As we stated earlier, most families reported that the earlier decision to choose Templeton as a residential service was forced upon them because they were unable to access any service in the community that could meet the needs of their relative. Many families' experiences of community based services in the past, therefore, were less than positive. Because of their previous experiences families were very anxious about the result of their relatives attempting to fit into community based services again. What they felt they needed in the early stages of this plan was to receive assurance that services that could provide adequate care for their relatives were now available. Many people believe that this assurance was never given and that their concerns have remained unanswered.

From the beginning, the deinstitutionalization of Templeton Centre and resettlement of residents into the community was presented as a "quality of life" decision. The SRHA and the CHE were always careful to point out that the planned closure of Templeton Centre was not about money but was, instead, a move intended to improve the lifestyles of people who have disabilities. Despite this, almost all families remain unconvinced that the plan was not financially based. Most families continue to believe that the situation they are now having to contend with at Templeton Centre is the result of an attempt to cut costs. They are very angry about this and feel as though the long-term security of their relatives is being compromised by this decision.

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Another huge area of concern for families was that of permanence of community based services. Many families reported that when their relatives went to live at Templeton Centre, they were told that the Centre would be a "home for life". Many people, who had often struggled to find the best possible option for their relative, found this assurance was a huge relief. To find now that this was not the case was very traumatic for many families. It was especially troubling for some of the older parents who were worried that they might become responsible for looking after a son or daughter who may not have lived at home for many years. While this was never an intention of the proposal, unfortunately for some that fear remained for a considerable period.

One of the biggest worries that families expressed related to the personal safety of their relatives. A significant number of people talked about feeling concerned that their relative did not have the necessary personal skills to ensure their own safety. They also worried about their ability to protect themselves from those people in the general community who may try to take advantage of them. A few families mentioned that they were worried that their relative may cause harm to others.

The final area of concern that we will mention here is related to the issue of staffing of the new community based services. Many families felt that Templeton Centre staff had the necessary training and backgrounds in order to be able to work most effectively with people with disabilities. Families were concerned that staff in the community based services would not have the same level and type of training. Even families who were positive about the resettlement of their relatives felt that the success of the move relied on the quality of staff employed to work in the community.

Whatever families' views, all families were united on one issue. Their concerns for their relatives were generated by the desire to have their relative cared for in the best possible way. Similarly, all families expressed the overriding hope that their relatives would experience ongoing happiness and quality care.

7. How the process has unfolded

The submission process, Princess Margaret Hospital, and the second official announcement

The announcement of the planned closure, and the call for submissions provoked a huge response. Families and other interested members of the community were invited to forward written or oral submissions to the CHE and the SRHA. These submissions were analyzed by an independent organization, Bridgeport Group, and a report was completed and released in May 1995. The report detailed that the overwhelming majority of submissions were opposed to the changes planned for Templeton Centre services. Another significant area of concern was the proposal to use Princess Margaret Hospital as a site for residential services for Templeton Centre residents.

This submission process was, from the perspective of the CHE and the SRHA, a method of consultation with families and the wider community. The CHE had included with the blue book and submission document an information sheet which stated that "consultation is not negotiation" therefore indicating that the decision to deinstitutionalize Templeton Centre would not be reversed. Despite this, however, families continued to find it difficult to accept that even though it was very clear that the decision to deinstitutionalize Templeton Centre and resettle residents in the community was not one that families embraced, the closure would still go ahead. On 15 September 1995, the SRHA issued a media release stating that a programme of deinstitutionalization would take place at Templeton Centre over the next five years. In the same media release the SRHA confirmed that Princess Margaret Hospital (PMH) would no longer be considered as a site for residential services for Templeton Centre residents. The reason given for not continuing with PMH as an option was that the SRHA and the CHE agreed with the majority of the submissions which stated that PMH was a very unsuitable resettlement option and would represent re- or trans-institutionalization of residents if it were to be implemented.

During the ten months that had passed in between the original announcement in November 1994, to the official announcement of the planned closure in September 1995 many families had clung to the hope that Templeton Centre would not close, or at least not completely. A great deal of individual action had been taken by families to ensure that Templeton Centre would remain and the Templeton Centre Parents' Association had emerged as a strong opponent of the complete deinstitutionalization of Templeton Centre. The realization that the process would go ahead was a huge disappointment for many families and instigated a new round of action against it. At the same time, families were beginning to become engaged in the information being released by the CHE and the SRHA about deinstitutionalization and in trying to understand how the process would impact on the everyday lives of their relatives and on themselves.

8.　Information flow

The issue of information flow from the individuals and organisations implementing the proposed closure to the families who had relatives involved was one that generated a great deal of comment. Families had a variety of opinions relating to how information about the proposed changes was conveyed to them and how sucessfully they had been able to communicate with all parties involved.

A great number of families felt dissatisfied with the level and type of information they received. The initial announcement of the planned closure of Templeton Centre generated a lot of attention from the media. Many families stated that they received as much, if not more information indirectly, through newspaper articles and radio and television reports, than from other sources. A great number of these families felt that it was unacceptable to have had to hear of information that had the potential to impact so greatly on their relatives' lives, and their own lives, in such a manner.

The Templeton Centre Parents Association (TPA) put a great deal of time and effort into determining exactly what was planned for Templeton Centre residents. The TPA remained committed to passing on as much information as they could to concerned parents and relatives and continued also to lobby against the complete closure of Templeton Centre. Some people felt that despite this commitment, the TPA was just as disadvantaged as they were because comprehensive information about the process continued to be extremely difficult to gain.

Throughout the early stages of the process families received written information from the SRHA and the CHE. This information was intended to make clear to families how the process would be implemented. Families did not always find that this information met their needs. Some people found that it was not written in a style that they could understand easily. Other families felt that it did not succeed in addressing the questions that they had regarding their own relatives' resettlement. This highlighted the fact that each families' circumstances were different and in many cases prepared information did not bear any relevance to their own relatives'

situation and therefore did not contain answers to the questions that they felt the most urgency about.

Another method of communication that did not work particularly well for most families were the large public meetings where SRHA and CHE representatives met with families to discuss plans for resettlement and to answer questions. Many families described how upset and angry they were after attending one of the earlier public meetings where attendance was by invitation only and security guards were present. This meeting contributed to families' feelings of negativity toward the process and set up a "them and us" situation that dismissed, for most families, any sense of partnership between themselves, and the SRHA and the CHE.

While the large public meetings did provide an opportunity for some people to vent a great deal of anger about the planned closure, they prohibited other people from being able to have their specific questions answered. Very few people felt comfortable airing their views or asking questions in that particular environment. Some families were very opposed to the closure and were anxious to have concerns addressed but because of the anger and intensity of the public meetings they did not feel that their own questions could be answered at that time. Other people felt uncomfortable that a small number of individuals appeared to speak on behalf of all families regardless of whether or not all families agreed with their views.

For people who were not completely opposed to the planned changes to Templeton Centre the meetings were even more difficult. These individuals felt completely unable to put forward their more positive views or to ask simple questions that may have helped them to come to the decision to choose community living as an option for their relative a lot sooner. Suffice to say, whatever families' views toward the process were, large public meetings were not seen as a successful way of exchanging useful information or encouraging effective communication between all the parties involved. A significant number of people felt, however, that public meetings were an unavoidable part of the process.

The changes planned for Templeton Centre and the resulting impact on their relatives created a huge need to know exactly what was

occurring at each step in the process. The ongoing and intense need for information was shared by all families. Families appeared to spend a lot of time exchanging information with each other and had well developed information networks. Many younger parents and relatives reported that they felt a sense of obligation toward older parents who often found it even more difficult to become informed about the process and what was expected of them. In these cases individuals frequently made a point of passing on any information they had to these older parents, and in some cases, of speaking on their behalf. Sometimes Templeton staff were helpful to families and could, to some extent, answer their questions. As time went on and independent service coordinators became part of the process some families felt very comfortable relying on their service coordinator for information.

The process of information delivery and communication relating to the proposed changes for Templeton Centre is an issue that almost every family felt strongly about. This brief summary does not begin to do justice to the issue but instead highlights some of the key points. This topic will be explored in much greater depth as the study progresses as families have provided us with a huge amount of information based on their first-hand experiences.

9. Needs Assessment

All Templeton Centre residents were required to undergo an assessment in order for their needs to be established prior to any resettlement in the community. The assessments were carried out by a small team of assessors and families were encouraged to have a significant amount of involvement in the process. The needs assessment process is another important issue that will be addressed in greater depth in future documents. We did feel, however, that it was important to mention some of the major points here.

Overall, families generally felt that the needs assessments were well exucuted and represented a fair portrayal of their relatives' needs. Some families found the needs assessment process quite emotionally distressing because they were forced to confront the realities of their relatives' disability documented in "black and white." Others found the needs assessments very informative because they allowed them to become aware of aspects of their relatives daily lives that they may previously have been unfamiliar with. A few people were unhappy with certain parts of their relatives' needs assessment initially but usually found that they were able to have their concerns addressed satisfactorily before "signing-off" the assessment. Families who were committed to the option of developing a "sheltered village" on the Templeton site made sure that this was listed as their preferred option for residential services for their relatives.

Most comment relating to the needs assessment process, however, focussed on the issue of when the needs assessment process was put in place. At the time that we conducted Phase One interviews many families held the view that needs assessment occurred far too late in the process to ensure that the information generated was put to the most effective use. These people felt that needs assessments should have occurred long before any official plans for deinstitutionalization were announced. This would have guaranteed funders and service providers were fully aware of exactly how many people were needing particular types of services and would have ensured the long-term success of resettlement. It was felt that if needs assessment had occurred earlier some of the gaps in services and potential problems with the process could have been identified a lot sooner. One such area that has continued to remain is the issue of

specialist services for Templeton residents who have multiple disabilities, medical fragility or challenging behaviours.

Despite the benefits that may have been achieved through implementing the needs assessments earlier, other individuals involved in the study were inclined to see things differently. Some people acknowledged that at the time that needs assessments were put in place many still felt very opposed to the plans for change. They saw needs assessments as representing a very real step toward community living for ther relative and because this was something they did not want, they were very reluctant to become involved. A number of families admitted to changing this view after they had gone through the needs assessment process but they acknowledge that, at that time, it would have been difficult to get them to move any faster than they did.

10. Independent service coordination

Independent service coordination was set up to ensure that every Templeton Centre resident had a representative who would work toward achieving the best arrangement of community based services. Families were expected to use their particular service coordinator as a resource. The service coordinator was to be someone who could advise them about service options for their relatives, and facilitate contact between residents, families and the new community based service providers.

Originally, the aim was that families themselves would take responsibility for approaching the service coordination service when they felt ready. While designed to allow families to have control over this part of the process, this approach seemed to highlight two major difficulties. Firstly, during the Phase One interviews it became clear to us that not all families were aware that they were responsible for approaching service coordination. Some families reported that they were waiting, and were willing, to hear from a service coordinator and could not understand why that contact was not being made. Secondly, when service coordination was introduced many families were reluctant to become involved. Similar to the needs assessment situation, many families believed that to even approach the service coordination service for advice would signal that they were agreeable to the resettlement of their relative. At this point resettlement into community based services was not the preferred option for most families of Templeton Centre residents.

A little later, the process seemed to change slightly and service coordinators more actively contacted families. In many ways this was a turning point for some families. People who had been undecided about the best options for the future of their relatives felt reassured by the advice and support of a service coordinator. The understanding that service coordinators were to be a permanent part of the community based service system was also seen as positive. Families believed that this would ensure that their relatives continued to be well served by the new services and would have an independent person "looking out" for them. It was after contact with a service coordinator that a number of families decided to agree to the resettlement of their relative.

However, not all families saw service coordination so positively. Some families resented what they saw as the intrusion of service coordinators, whom they had often never met, contacting them to discuss the future of their relatives. Some saw this as unnecessary pressure at a time when they were still coming to terms with the whole idea of the deinstitutionalization of Templeton Centre and the planned resettlement of their relatives.

Once again, the issue of service coordination serves to highlight the individual differences between many of the families involved in the project. The benefits of service coordination were stressed by people who became more excited by the new opportunities their relative could experience through living in the community. For people who were still very upset, worried and angry about the possibility of their relative having to leave Templeton Centre, service coordination often represented an additional pressure. The whole area of service coordination and in particular, the timing of the introduction of such a service will continue to be explored as we progress further.

11. Conclusion - "Where to from here?"

The amount of information that we have received through the Phase One interviews has been quite overwhelming. What we have documented here represents only a very small step toward understanding the complexity of families' experiences of the process of change occurring at Templeton Centre. Our aim now is to continue to work with this information in order to be able to make meaningful suggestions as to how this process could have been different for families.

All the experiences that you have shared with us will provide the basis for us to identify exactly what kinds of information, communication and consultation families may have found most useful. Your suggestions and views are not only relevant to the Templeton situation but are also relevant to any situation where existing services for people with disabilities are undergoing change. As families have the greatest vested interest in their relatives with disabilities, their opinions have tremendous value in planning for change. We hope that we will be able to put your opinions to good use through your involvement in this project.

We look forward to talking with you all again in the future as any change in service occurs for your relative or when you experience any part of the process that you feel has impacted greatly on you or your relative.

Appendix 5:

Templeton Resettlement Family Experiences
project: Preliminary Report – Phase Two.
Mirfin-Veitch, B., Ross, N. & Bray, A. (2002).

TEMPLETON RESETTLEMENT FAMILY EXPERIENCES PROJECT

PROGRESS REPORT

PHASE TWO

Brigit Mirfin-Veitch
Nicola Ross
Anne Bray

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We would like to thank all the families who have taken part in this research. We would also like to acknowledge the Health Research Council of New Zealand for the research grant which enabled this project to be undertaken.

Contents

Introduction

In 1997 the Donald Beasley Institute commenced a research project that had the aim of exploring families' experiences of the resettlement of their relatives with intellectual disabilities from Templeton Centre into alternative residential care services. When we began the project, and developed our timeline, we were guided by the deinstitutionalization plan generated by the then Southern Regional Health Authority (SRHA). This original plan suggested that all Templeton Centre residents would have made the transition into new services by March 1999. Very quickly we recognized (similarly to the families of Templeton Centre residents) that this was probably not a realistic timeframe. As a result our research has taken much longer to conduct than we anticipated. The project was due to conclude in March 2000. We have been successful in securing extra time to complete the research and we will now conclude the study in December 2000.

In 1998 we produced a preliminary report on Phase One of the Templeton Resettlement Family Experiences Project. We were able to complete this report relatively promptly because we conducted all the interviews with families prior to the resettlement of their relatives over a two month period. In producing and distributing the preliminary report we had the aim of keeping families informed of our progress as we conducted this long term project. We used this opportunity to outline the research process including how we had selected families and how the study would progress in three phases. The report also highlighted some of the critical areas to families as they prepared for the change or transition in service delivery that was being offered to their relatives with intellectual disabilities. We did not intend that it be seen as the only piece of work on families' views prior to the resettlement of their relative, nor that it be seen as a comprehensive, final report on the findings. Despite this, the preliminary report on Phase One of the project was received with great

interest. Many people have been interested in learning more about the experiences of families. We hope that this report will be similarly received.

This document is intended to serve the same function as the previous report. It is for parents and other family members who have chosen to give their time to this study. Maintaining contact with families has been a rewarding process. Conducting the study has also presented a logistical nightmare at times as we have attempted, sometimes unsuccessfully, to meet the timeframe of the research in relation to each individual's move into an alternative service. We would like to take this opportunity to thank families for their patience and hope that the experience of being involved in such a long term research project is not too frustrating. As we have mentioned before, the amount of information provided by those participating in the study is at times overwhelming but always exciting and incredibly valuable. We also hope that other people who may be involved in, or are interested in learning about the process of deinstitutionalization as experienced by families take what they find useful from this report.

This report on Phase Two of the project will outline some of the major issues related to the transition of Templeton Centre residents from Templeton and into alternative services set up to provide residential care. The report includes sections relating to: families' decisions to choose institutional care in the past; changes in attitudes toward deinstitutionalization; choosing a new service; leaving Templeton Centre; and experiences of the new service. Please note that a separate section relating to those families who have relatives using the services of Brackenridge Estate is included in this document. The decision to address the issue of Brackenridge was made in order to be able to compare and contrast the experiences of families with relatives using Brackenridge Estate and the experiences of families using other services. The final section of this report discusses the implications of Phase Two of the Templeton Resettlement Family Experiences Project.

Chapter One:
A Typical Family's Story

The families taking part in this project are all different. The great diversity in families is reflected in their differing views toward their family members with disabilities, toward the concept of deinstitutionalization, and toward the process they experienced as change and transition began to occur. While this diversity among families is clearly apparent, there is one area in which families share a common story.

In our previous report we mentioned the similarity in families' stories about the decision to seek institutional care for their relatives with disabilities in the past. During our first interview with families we had the opportunity to talk about their past experiences of using intellectual disability services, including the decision to seek permanent out-of-home placement for their relatives at Templeton Centre. The decision to use Templeton Centre was never a spur-of-the-moment decision, nor was it something they planned to occur at a specific point in time. A number of factors were common in the months or years leading up to a family's decision to seek hospital based residential services on a permanent basis. Based on the information shared with us by families participating in this project we have been able to develop an outline of a "typical family's story" which highlights the common experiences of families.

Without exception, families had a strong desire to have their family member live within the family for as long as possible. Templeton was a service option that was actively resisted by many families for a very long time. As families struggled to find a way to keep their family member at home they often tried a number of community based options which failed to meet the needs of the person with a disability, and the family's needs as a whole.

Families continued to face intense pressure as issues associated with caring for their relative increased over time. A number of factors contributed to a family's feeling of being unable to cope. Meeting the physical needs of their family member became an issue as children grew bigger and parents became older. For other families, issues associated with the behaviour or actions of their relative with a disability caused great difficulty at a time when stress within the family was high.

While families primarily made their own decision to seek institutional care for their relatives, they had often talked with a professional (usually a GP) about the difficulties associated with caring for their family member at home. Those feelings were often acknowledged and validated by professionals but families usually rejected Templeton as a service option and continued with the task of caring for their relative at home at that time.

People with intellectual disabilities usually remained at home with their family until an event or series of events occurred which altered the balance of family life. This could have been health issues experienced by one or both parents, or by other children in the family, which made it more difficult to provide care for the relative with a disability. Many families had the perception that while the difficulties associated in caring for their family member with a disability were increasing, the needs of other family members were being treated as secondary. Often the general and mental health of mothers (who were most often the primary caregivers) prompted the need for serious consideration of out-of-home placement. In a number of cases the family's inability to cope with aspects of their relatives' behaviour was the catalyst for decision making.

Every single family taking part in this research described the decision to choose permanent out-of-home placement for their relative as being the hardest and most painful decision of their lives. Families talked about a great sense of

sadness, and in some cases guilt and failure, when they felt they could not continue to care for their relative.

A typical family's story

Key points:

- Families had a strong desire for their relative to live at home for as long as possible.
- Families often experienced a succession of failed community based alternatives.
- Families faced intense pressure as issues associated with caring for their relative increased over time
- Families sought the opinion of professionals who validated that a permanent residential placement may be necessary.
- Families experienced increasing pressure on family life.
- A decision was made to seek a permanent out-of-home placement in hospital based residential services.

After making the decision to choose permanent out-of-home placement for their relative the families' decisions once again diverged. For some families a loss of close contact and involvement in their relatives' daily lives followed this decision. For other families contact remained at a high level. The relationships that families were able to achieve with staff determined how they felt about Templeton Centre. Some families were dissatisfied with the provision of care Templeton delivered to their relative but were, at the same, time grateful and felt they had no other alternative. Other families were very positive about the standard of care their relative received at Templeton Centre. This perception that Templeton Centre had provided a level and type of care that (in the families' experience) no other service could match, meant that the decision to close the Centre was a hard one for many families to accept.

Chapter Two:

"What we thought then - what we think now" :
Changes in Attitude toward deinstitutionalization

In our earlier report we stated that all families of Templeton Centre residents were concerned about resettlement. In using the word concerned we meant that all families were worried about, or had questions regarding the impact of deinstitutionalization on their lives, and the life of their relative. Some families were concerned about certain aspects of the proposed resettlement of their relative but believed that community based residential services could offer their relative increased opportunities. Other families had a high level of concern about all aspects of the plan to deinstitutionalize Templeton Centre and were opposed to any transition of their relative from the Centre.

In this report we are able to go into a little more depth in terms of the attitudes expressed by families taking part in the study prior to the move of their relative, and about how they felt soon after the resettlement of their relative. Please note that the findings discussed in Chapters Two - Five do not relate to those families who chose to use the services of Brackenridge Estate. The experiences of these families are included in Chapter Six.

A key focus of this report is to discuss the changes in families' attitudes toward the resettlement of their relative. Because we interviewed families prior to the move of their relative (Phase One) and again soon after the move of their relative into alternative services (Phase Two) we have been able to document changes in the views expressed by families.

In summary, forty-nine percent (49%) of the families who took part in this study reversed their original negative attitudes toward resettlement and reported feeling positive about their relatives' transitions During Phase Two of the

study. Thirty-seven percent (37%) of families maintained their original positive position towards resettlement and confirmed that they felt their relatives' lives were enhanced after having been resettled. Overall, a total of eighty-six percent (86%) of the families taking part in this study felt positive about resettlement during Phase Two of the study. Conversely, seven percent (7%) of the families taking part in this study felt positive about the planned changes in service delivery to their relatives' prior to resettlement but reported dissatisfaction with the results of transition during Phase Two. A further seven percent (7%) reported feeling negative about the transition to community based services both prior to and after the resettlement of their relatives'. In total, fourteen percent (14%) of families were negative about resettlement soon after experiencing their relatives' transitions.

We have also been able to talk with families in more depth about their earlier feelings. When we began to look closely at the information that families shared with us (as part of our analysis process) it became clear there were five groupings which appeared to reflect the views of families prior to, and after the resettlement of their relative.

"We always thought it would work."
Not all families taking part in this study were opposed to deinstitutionalization. Families who believed that their relative would have more opportunities to experience a new way of life were largely positive about resettlement. While these families still expressed concern about certain aspects of the proposed community based services, they explored and selected services very early in the process. They felt that they would have greater choice in terms of the services available if their relative moved quickly. Families who were positive about the possible benefits of community living continued, generally, to be positive after their relative had moved.

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"We're quite happy - as long as it continues."

Other families approached the plan to deinstitutionalize Templeton Centre with a sense of resignation. They accepted that Templeton Centre would close and that their relative would be forced to move into a new service. They believed that the lobby to achieve an alternative facility on the Templeton site would not succeed, or that even if it did their relative would not meet the criteria for such a service. These families were not convinced that resettlement could offer their relatives greater opportunities but (similarly to those families who did feel positive about community based services) they believed that entering the process of exploring and selecting services early in the process would ensure greater choice. When we revisited these families after their relative had resettled they were pleased and surprised at how well their relative was doing in the new service.

"Oh I had really grave doubts... and I can't really believe that I was so unaccepting toward what really has turned out to be a marvelous move for him".

A significant number of families taking part in the study talked about having a complete reversal in their attitude toward deinstitutionalization after they had experienced the resettlement of their relative into a new community based service. Many families taking part in this study were strongly opposed to any change in service for their relative when we first met with them. These same families, however, accepted the transition of their relative into new services (often very reluctantly) for a number of reasons. Again, the fear of having a reduced choice in the services available to them was one reason, as was the impact of the change occurring within the Centre on their relative. Coupled with the knowledge that their relative would not be eligible for a "specialist" service families often felt forced to become involved in selecting a new service for their relative. Often younger family members supported older parents to make these decisions. Interestingly, families who displayed a high level of

opposition to the closure of Templeton Centre prior to resettlement, were some of the most positive after their relative's transition had occurred.

" I said it would all come down to the staff and it has."
A very small number of families who were originally positive about the opportunities that a move from Templeton Centre could create for their relative reported feeling disappointed with the results of their relative's transition. Families in this position usually attributed their feelings of disappointment to the fact that some staff working in the home they had selected did not meet their expectations of quality staff. These families did not feel that they had been successful in achieving any change in staff attitudes or behaviour and therefore, that their relative's needs were not being met.

Almost all families taking part in the study felt that the success of deinstitutionalization relied on the quality of staff that were selected to work in the community based services. When we revisited families after the resettlement directly after the transition of their relative the quality of care provided by staff was always a key discussion point. Those families who remained positive about the resettlement process usually assessed the staff working in their relative's home very highly. Where families were less positive about their relative's move from Templeton Centre they usually had some concerns about the ability of the staff working with their relative.

"I don't understand why they are doing this."
A very small number of families continued to hold extremely negative attitudes toward deinstitutionalization. This was usually when their relative's first community based service placement had serious problems, or broke down completely. The insecurity and on-going issues related to this situation obviously contributed to families' feelings of negativity. Feelings of upset and concern were heightened when there appeared to be no obvious solution to the problems being experienced by their relative. Other families who had

experienced the break-down of an initial placement, or who had experienced significant problems in the early stages of their relative's transition, continued to feel positive toward the process of deinstitutionalization if the issues were addressed quickly and efficiently.

Two important issues were raised by many families taking part in this study regardless of their position on resettlement. A significant number of families reported a continuing resentment at the way the process of deinstitutionalization had been handled. Additionally, families worried about the long-term security of the community based service system.

Chapter Three:

"What was important to us": Choosing the new service

As we outlined in the previous section, families were divided about when to initiate the move of their relative into community based services. Many families who had relatives involved in some of the earliest moves from Templeton Centre had chosen services early because they were positive about the opportunities that resettlement could offer their relative. These families also believed that by making their decisions quickly they would be afforded with greater choice. Other families who were not as positive about the plans for resettlement also agreed with the notion that to move early would afford them with increased options. Contrary to this, a significant number of families resented the feeling of pressure and were adamant that they would take as much time as they needed to decide on the best possible option for their relative. Some of these families were delaying any decisions until they were completely sure of all the service options that would be available to people with intellectual disabilities affected by the deinstitutionalization of Templeton Centre.

Although families had different views about when to move, almost all families taking part in the study highlighted a number of common areas as being important as they explored and selected a new service for their relative. Almost all families taking part in this study reiterated the fact that the success of the new model of service delivery to their relatives would be determined by the quality of staff working in the community based houses. While families were united in this opinion, they had differing views as to what constituted "quality" staff.

Some families believed that to meet the needs of their relatives staff should be registered nursing staff. Other families believed that attitudes and values, not

nursing qualifications, were the most important characteristics for staff to possess. Many families wished to see as many former Templeton Centre staff as possible working in the new community homes as they saw them as experienced and suitably trained. Other families were positive about the fact that there were "new" staff employed to work in the area of supporting people with intellectual disabilities. As families went through the process of selecting services sometimes the knowledge that a particular individual was involved in a particular service (usually at a management level) encouraged families to choose that service.

The "track record" of service providers was also an important area to consider for many families. Often families were inclined toward a particular service because they had prior knowledge of that service, had seen it in operation, and liked the way they did things. For families who were concerned about the stability and long-term financial security of services, the fact that a service had been operating in the community for some time was seen as positive. Community based services that included a number of homes, not just one or two homes, were seen as more financially secure and as having the ability to share resources such as transport and staff. Not all established services, however, had the kind of "track record" that families were attracted to.

The number of clients that individual homes were planning to provide care for also had an influence over the decisions that families made. Once again, families were divided in their opinions. Some families firmly believed that smaller five or six bed homes would better meet the needs of their relatives. These families felt that smaller homes would contribute to a greater sense of family and individual attention for those living in the home. Other families were attracted to services which provided for a greater number of clients in each home. They perceived there was a higher staff/client ratio in these homes that would enable greater opportunities and individual attention for their relatives.

Many families were hopeful that their relatives' new home could be in close proximity to their own homes. After many years of having to make the trip out to Templeton Centre families were often excited by the prospect of being closer to their relative. While a home would be considered more positively if it was in a convenient location, families never based a decision regarding a placement on proximity alone.

Like proximity, the "look" of a home was important to families but never took priority over issues such as staffing or the track record of a service. An attractive home was a bonus but did not deter families from ensuring that all their other requirements of a quality service were met.

Choosing a Community Based Service

Key Points:

- Quality staffing.
- Track record of service provider.
- Number of clients in home.
- Proximity / location.
- Home's appearance.

On a less positive note a small number of families selected a particular community based service because they felt they had no other options available to them that time. This was the case for families with children who were seeking a shared care arrangement based in the community early in the deinstitutionalization process. For these families there was only one choice in terms of a service provider. This was disappointing to families who felt that the one service available to them did not possess all the characteristics that were important to them. Furthermore, feeling forced to choose a service also

seemed to indicate that these families would report a negative attitude toward their relatives' resettlement during Phase Two of the study.

While families had very clear expectations of what they required from a quality service, they sometimes needed some extra support to make a final decision regarding a community based service for their relative. Service coordinators were viewed very positively by many families during the Second Phase of the study. At the time when families were wanting or needing to make a decision regarding service provision service coordinators served an important function in ensuring that families saw all that was available to their relative at that time. Younger family members often played a crucial role in supporting older members of the family to make decisions, and in some cases Templeton Centre staff encouraged families to seek alternative services for their relatives.

Chapter Four:

"Making the move": Leaving Templeton Centre

The day that their relatives left Templeton Centre to utilize a residential service in the community was a significant one for families. After relying on the Centre to provide care for their relatives (often over a period of many years) families had different responses to the transition.

It seemed that families who had relatives involved in some of the early moves from Templeton Centre felt disappointed in the way Templeton Centre staff responded to the resettlement process. Families felt that although they had chosen for their relative to transition into a community based service they were grateful and wished to acknowledge the care that Templeton Centre had provided. Many families felt that the long-term relationship they had had with Templeton Centre staff was eroded in the period directly leading up to their relative's move from the Centre and that they were not able to have the kind of parting with staff that they would have liked. This may have been due in part to a lack of clarity relating to the role Templeton Centre staff were able to assume.

As the deinstitutionalization process progressed and more people left the Centre families reported that they felt that Templeton Centre staff had responded positively to their relative's move from the Centre. Families also commented that Templeton staff were sometimes involved in helping individuals to "get to know" their new homes. This did not seem to be a feature of early transitions from Templeton.

Individuals often left Templeton Centre and arrived at their new home to find that their rooms were not ready and that confusion reigned. While families often talked about the lack of organisation in the new homes on the day of the

actual move, not all families perceived the lack of organisation in a negative way. Families were aware that the transition from Templeton Centre to the new service occurred on one day and that packing someone's belongings, including their bed and furniture and ensuring that they were all in place by the end of that day was incredibly difficult.

Some families who chose to be actively involved in their relative's move often took great delight in the party atmosphere that occurred. Witnessing the excitement of those moving was a very positive experience for families and reassured them of the positive aspects of the move. Families who were involved in the actual "settling in" on the day of transition did so because it was important to them to ensure that staff knew about particular routines that their relative was used to. They also wanted to support their relative and staff on this very busy and important day.

Other families chose not to be involved in the actual transition process for equally valid reasons. Some families believed that their relative needed time to bond with the staff in the new service and that the "bonding" process may be undermined by their presence. Other families chose not to be present on the day of transition because they believed that they might "get in the way" of staff as they worked to ensure that everyone settled into the new home.

Almost all families reported that they had a high level of contact with the new service in the period directly following their relatives' move from Templeton Centre. This contact was almost always initiated by the families and was a way of reassuring themselves that everything was going well for their relative. Sometimes families were involved in addressing incidents that had occurred in the new service and many said that they had a greater knowledge of their relatives' daily lives as a result. A number of families reported that they felt a heightened sense of responsibility for their relatives because they had a greater awareness of issues affecting their lives. These families had felt unable

to be involved in issues relating to their relatives' daily lives when they lived at Templeton Centre. Families said that the high level of contact with the new service decreased as they felt satisfied that their relative's needs were being met.

Families also identified several other factors that enhanced (or would have enhanced) the process of transition for themselves and their relatives. Being able to visit the new home with their relative prior to any transition occurring was viewed as being very important. Having the opportunity to meet with the staff and clients of the new service was also valued by families. The compatibility of their relative with other members of the home was very important to families and they often found it distressing to have to make a decision about a particular service without any information about who else would be living in the home.

Chapter Five:

"The positives outweigh the negatives by about 9 to 1": Experiencing the new service

While families talked of the problems or difficulties they faced during and soon after the transition of their relatives from Templeton Centre into the new service, most families were very positive about the changes in their relatives' lives.

Families' level of satisfaction with the community based residential services that they had chosen for their relatives appeared to be determined by the type of relationship they had with staff working in that service. Families who were positive about the transition that their relative had made when we interviewed them soon after their move, identified the relationships they developed with management and direct care staff in the new services as being particularly rewarding. Many comments were made and examples given, of the way the new services responded to the needs of their relatives.

When families perceived that they had open and effective communication with management and staff in the new service they were accepting of early problems and issues that arose as their relative settled into their new home. It appeared that once families had made the decision go through the process of resettling their relative they were fully committed to "making things work." Some families felt their relatives experienced difficulties as they adjusted to a new way of life, and as the new service learnt how to respond to their needs. Commonly problems were associated with the management of specific health needs or with the appropriate management of behavioural issues.

called to the new service to give advice, or in some cases, to take control of an incident involving their relative. This was acceptable once or twice but when families felt that little progress was being made in terms of responding appropriately to their relatives' needs then they began to feel less positive about the service. It was these families who commented on the lack of training that they felt some staff had when they commenced working in the new community based services.

For the majority of families problems and challenges that arose around the time of transition were addressed quickly and appropriately. For other families problem areas took a little longer to sort out but a satisfactory outcome was achieved.

In situations where families felt that they did not have effective and open communication with staff and when they did not perceive staff as having the appropriate experience or characteristics to provide quality care for their relative, attitudes towards community based services became more negative. A very small number of families who have participated in this study reported in Phase Two of the study that they did not feel that transition from Templeton Centre into a new community based service had been successful for their relatives (14%). This group included families whose earlier positive views about the opportunities that resettlement could provide were reversed as they experienced what they perceived as poor quality services in the community. It also included families who struggled to find a community based service that they felt met their relatives' needs in the first place, and who then experienced the breakdown of this placement.

Chapter Six:
"Achieving the unachievable":
The development of Brackenridge Estate

In our report on Phase One of this study we reported that a significant number of families were concerned about the planned closure of Templeton Centre, and the ability of newly developed community based services to meet the needs of their relatives. Some of these families had such serious concerns that they felt that the only acceptable service alternative to Templeton Centre would be a "specialist" facility created along the lines of a sheltered village. (A sheltered village can be defined as a model of service delivery which provides housing and all other facilities required to meet the needs of a group of people with intellectual disabilities on a single site.) Most of these families also felt that to create such a service on the existing Templeton Centre site was the most sensible option.

When the Templeton Centre Parents' Association (TCPA) first presented this idea to the then SRHA they were told very clearly that a "sheltered village" would not be a service option available to individuals affected by the deinstitutionalization of Templeton Centre. This statement, however, did not deter a small and committed group of families who continued to lobby for the development of a village style service alternative. Their vision was to have the option of using a service that could meet the needs of three main groups of people: those with challenging behaviour, those who were medically fragile and those with multiple physical and intellectual disabilities. Members of this lobby group felt that the community based service system could not offer their relatives the level or type of service that they required. A significant number of families supported the views of this group and delayed any decision making regarding services for their own relatives in the hope that this lobby would be successful.

In 1998, four years following the original announcement for closure, the Health Funding Authority (HFA) announced that a facility would be developed on a small area of the original Templeton Centre site. This announcement followed several years of intense lobbying and political activism by a group of parents committed to achieving this option. This brief description does not do justice to the intense and protracted process that finally led to the development of Brackenridge Estate. This process will be covered in more depth in a later document.

For the purposes of this section we will focus on the experiences of those families taking part in our study (approximately one quarter) who had relatives who moved from Templeton Centre to Brackenridge Estate. Similarly to families who experienced a transition process when their relative moved into a new home located within the community, families of individuals making the move to Brackenridge were also part of a process of change.

The pathway into Brackenridge was not the same for all families. Some families had believed that a service like Brackenridge was the only possible option for their relative. From the time that the announcement to close Templeton Centre was made these families made it clear that the only service that they would accept for their relatives would be a "sheltered village" style service.

A number of families who were pro-Brackenridge had relatives who had been part of an assessment process. This assessment process (which will also be discussed in a later document) was put in place to establish who would be eligible to use this kind of service. A number of families had relatives involved in this process and who were assessed as clearly meeting the criteria for Brackenridge. Other families learned that their relatives had not met the criteria for this service. Some of these families entered a review process in the hope that a further independent assessment would result in the original decision being reversed. A reversal did occur for some families.

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Another grouping of families apparent among those in our study made the decision to choose Brackenridge after spending time exploring other service options. These families had the ability to make a choice between Brackenridge and other services because their relatives had been assessed as meeting the criteria for Brackenridge. Even though places in Brackenridge were assured for their relatives these families were keen to look at other services in the quest to find a service that best met their relatives' needs. Most of the families in this category eventually chose Brackenridge because there seemed to be no other alternative that provided services of the level and type that they believed their relative required. A few families chose to use alternative services to Brackenridge which they felt met their relatives' needs.

A small number of families that took part in the study had relatives that became users of the Brackenridge service after they had experienced difficulties with their first community based service. This seemed to happen with people who moved later in the deinstitutionalization process and may be due to the fact there were reduced options to try to resettle into other services by this stage. Some of these families experienced a great deal of distress in trying to resolve the difficulties related to resettlement. Despite this obvious distress, families in this position viewed Brackenridge in the same way as they did other services in that they assessed its suitability for their relatives in the same way they assessed other services. It was not seen as a service that, by its very nature, would meet the needs of their relatives' but an option to be considered.

Most families committed to the notion of a service like Brackenridge had relatives who required a high level of support. Many of these families were particularly concerned about issues of safety and security and believed that a facility like Brackenridge would provide a safer environment than any other service alternative. Obviously, these families were greatly relieved when they were informed that Brackenridge was available to their relative.

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many families had. A small number of other families were open about the fact that they valued Brackenridge because they saw this service as having characteristics very similar to Templeton Centre. These families did not perceive Brackenridge to be a community based service.

Families who had relatives who made the transition to Brackenridge Estate were as diverse as all the other families participating in this study. They had different concerns, different perceptions of "quality" staff and made different choices among homes within the Brackenridge service. Overall, however, all these families reported that the transition from Templeton Centre to Brackenridge had been positive for their relatives.

Chapter Seven:

"What does all this mean?": Implications of the Templeton Resettlement Family Experiences Project (Phase Two).

Achieving positive family involvement in major changes in service delivery is an important component in ensuring successful outcomes for individuals with intellectual disabilities. The Templeton Resettlement Family Experiences Project has enabled us to explore the involvement of families in a major change in service delivery - the deinstitutionalization of Templeton Centre. Deinstitutionalization represents a process of change and families found themselves experiencing changes to all that they knew and accepted in relation to the care of their relatives.

Although we acknowledge we have not been able to document the views of all families who have relatives involved in this change, we are confident that the range of experiences reported by the sample of families studied and the in-depth information that we have obtained enables us to identify a number of important implications.

We have not found any other deinstitutionalization research that has sought to fully understand the decision making processes that families engage in when they are experiencing a major change in service delivery. We believe that the findings that have been generated through this research have implications for family involvement, in general, in major changes in service delivery for people with intellectual disabilities. These broad implications are:

■ The focus on families' earlier experience of seeking institutional care (as outlined in Section One) is an important aspect of this research.

Acknowledging families' emotional needs and experiences is just one vital component in ensuring that families feel supported and positively involved in major changes in service delivery such as that occurring at Templeton Centre. Understanding the history of families' decision-making processes which led to them seeking institutional care in the past could provide the basis for helping families to work through issues that make them resistant to changes in the model of service delivery being offered to their relatives.

- All families are different and those differences need to be recognized. The deinstitutionalization of Templeton Centre has been a protracted and often difficult process. Overlooked in the process were a number of families who we identified as "moveable". Moveable families had a number of concerns that needed to be addressed quickly and in a manner that acknowledged the individual needs of their relatives. When this did not occur many families lost the confidence to progress toward resettlement. This resulted in delays that may have been avoided and a perception that all families were opposed to deinstitutionalization.

- No one family experienced their relative's transition from Templeton Centre into a new service in the community in exactly the same way. Transition processes that worked well for some families failed others. The same is true of services. Service providers that some families credited with making their relative's move a success, other families perceived as not providing quality care. It appears that the most important factor in ensuring a positive transition from one model of service delivery to another is effective communication.

As we progress toward the completion of this study we will continue to identify important areas in which families' views and experiences can shape the planning and implementation of major changes in service delivery.

Appendix 6:

Templeton Resettlement Family Experiences project: Preliminary Report – Phase Three
Mirfin-Veitch, B. & Bray, A. (2002).

TEMPLETON RESETTLEMENT FAMILY EXPERIENCES PROJECT

PHASE THREE REPORT

Brigit Mirfin-Veitch
&
Dr Anne Bray

Donald Beasley Institute Inc.
2002

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Introduction

Introduction

Interest in our previous two reports "Templeton Resettlement Family Experiences Project: Preliminary Report – Phase One" and "Templeton Resettlement Family Experiences Project: Progress Report – Phase Two", far surpassed our expectations. These reports were written with a clear focus on families – both on the families who took part in the study and on families who may be involved in deinstitutionalization in the future. We did not anticipate the level of interest from other individuals and organisations who have also been eager to read about the findings of this study as they have become available. To those families who chose to give up their time to share their experiences of deinstitutionalization we would like to extend, once again, our sincere appreciation. The information that you shared with us has certainly contributed to a greater understanding of family involvement in deinstitutionalization and has provided other families with greater knowledge about this sometimes frightening change in service delivery.

The history of the Templeton Resettlement Family Experiences Project now spans five years. The project began in 1997 after the Donald Beasley Institute was successful in gaining funding for a project focusing on families' experiences from the Health Research Council of New Zealand. The main aim of the study was to document families' views and experiences at three distinct points in the process of deinstitutionalization: prior to the resettlement of their relative, 1-3 months following the resettlement of their relative, and one year following resettlement.

As we mentioned in the previous report on Phase Two, keeping to these distinct timelines sometimes proved to be impossible as people's lives (sometimes the families' lives and sometimes the researchers' lives) got in the way. We also found that our aim of talking with a number of different members of individual families at each of these points was also difficult to achieve at times. Despite the difficulties however, the conducting of this study was a unique experience for us as researchers. We continue to appreciate the commitment that families made to this study – a protracted commitment that occurred during a difficult and stressful time for many families.

This document is presented in the same manner as the previous two reports on this study. It is intended first and foremost as a resource for families. The report coincides with the planned closure of another large New Zealand institution and therefore retains relevance for a significant number of families who have relatives involved in this new process of deinstitutionalization. This report is also intended to be used as a resource by funders, planners, policy makers, and service providers who can learn a great deal from families with regard to how to plan and deliver quality services for people with intellectual disabilities. It is clear that the positive involvement of family results in enhanced outcomes for people with intellectual disabilities themselves.

This report on Phase Three of the study will address some of the major issues related to community living for people with intellectual disabilities one year after leaving Templeton Centre. The report includes sections relating to: impressions of the new services; independent service coordination; siblings' views; and families'

reflections on the process of deinstitutionalization. We hope that this research continues to provide useful information which can be used to inform future deinstitutionalization processes in New Zealand and overseas, as well as other major changes in service delivery for people with intellectual disabilities.

Chapter One

Impressions of the new services – One year on!

> "No I don't think there's anything I don't like there. I just wish the whole thing had happened 20-30 years ago. I just look back and think what a lot he's missed in his life."

Phase Three of the Templeton Centre Family Experiences Project was concerned with understanding families' experiences of resettlement one year after their relatives had moved from Templeton Centre. Before detailing the findings of Phase Three we thought it would be useful to recap findings related to Phase Two.

A summary of Phase Two findings

The report on Phase Two of the Templeton Resettlement Family Experiences Project clearly illustrated that most families who had experienced the resettlement of their relative(s) from Templeton Centre were extremely positive about the transition. To summarize, forty-nine percent (49%) of the families who took part in this study reversed their original negative attitudes toward resettlement and reported feeling positive about their relatives' transition during Phase Two of the study. Thirty-seven percent (37%) of families maintained their original positive position towards resettlement and confirmed that they felt their relatives' lives were enhanced by resettlement from Templeton Centre. In total eighty-six percent (86%) of the families taking part in this study reported feeling positive about resettlement at the time of the Phase Two interviews

(Phase Two interviews were conducted place approximately 1-3 months following resettlement).

In contrast to the large number of families who were satisfied with resettlement, seven percent (7%) of study participants reversed an earlier positive attitude toward resettlement and expressed a negative attitude after having experienced the move of their relative from Templeton to a new service in the community. A further seven percent (7%) reported feeling negative about the transition to community based services both prior to and after the resettlement of their relatives.

Families' views during Phase Three

"I think he has benefited and developed tremendously"

Phase Three interviews confirmed the views expressed by families during Phase Two interviews. Those families who were, by Phase Two, positive about the move continued to describe positive experiences and to hold favourable views during Phase Three interviews. These interviews did not usually differ greatly from those conducted during Phase Two but often provided further details and stories about families' impressions and experiences of the new model of service being delivered to their relatives.

"It's actually fascinating - each time you go now you sort of wonder, well what else has he been doing and what else is he up to and what else is he going to do?"

Families' expectations of their relatives continued to be challenged during the first year following resettlement. Things that families had not considered their son or daughter or brother or sister would ever achieve **were** achieved and surpassed by bigger steps toward a more independent life. Many families reported that they felt excited about the potential for achievement that transition into community based services offered their relatives with intellectual disabilities. Some families felt so re-connected that their relative began to visit the family home again - something that had often not occurred for many years. Other families were pleasantly surprised to learn of their relative going on holiday or beginning new recreational activities.

For families who previously had held no expectations for the ongoing development of their son/daughter/brother/sister, witnessing their first year in their new service was an enlightening experience. These families could not wait to see what the future held for their relative and themselves suggested new goals to work toward. Other families who had seen a rapid escalation of their relative's skills and achievements during the first year of resettlement were wary of having too many expectations. They reported that they were happy with "where things were at" and that they did not expect to see too many more significant changes in their relative in the future.

One issue that families raised frequently during earlier interviews was that of recreational and leisure opportunities. Many families felt that their relatives had received quite a high level of access to

recreational and leisure activities while they were living at Templeton Centre. Some families questioned whether such a level of activity would able to be replicated in the community environment. During the Phase Three interviews we asked families' opinions on this issue. Almost without exception families felt that their relatives were involved in a high level of activity (additional to vocational or day programmes) that met their recreation and leisure needs. People with intellectual disabilities who had been resettled from Templeton Centre were participating in a range of regular activities (for example sports) as well as many spontaneous outings. Living in the community environment appeared to make it easier for people to access regular community events such as concerts or other special events.

A significant number of families commented that they could no longer just "drop in" at their relatives' home – experience had shown families that they should not assume automatically that their relative would be home. A small number of families said that they did not have the same regular arrangements for visits home as their relative was often involved with other activities and outings and liked to be able to join in with those as they arose. While these families were sometimes disappointed that they did not get to see their family member quite so frequently as they had in the past, they were extremely happy to see that person taking part in the community in a way they never had before.

"No – Not my house" – The views of people with intellectual disabilities themselves

In this report we thought it was important to comment on a particular concern expressed by families in the initial stages of this research. A common, early concern held by families was the fear that their relative would fret for Templeton Centre. Families believed strongly that as Templeton, in many cases, was the only home that their relative had known, that they would not react favourably to the move. In the early stages of the process of deinstitutionalization family opposition often included an emphasis on the fact that people with intellectual disabilities were being (cruelly) removed from Templeton Centre - the home they were familiar with and enjoyed. Families worried about the impact of such a move and had serious concerns about behavioural issues, stress or depression that may occur as a result of resettlement.

It appears however that almost all the individuals that moved from Templeton Centre settled happily into their new homes. The problems that families had predicted did not, for the most part, eventuate. Those men, women and children who had previously lived at Templeton embraced their new lifestyles with very little trouble and did not, in their families' views, appear to be concerned about the loss of their "old lives". In fact, many families told stories that seemed to confirm that their relatives were more concerned about having to return to Templeton than they were about leaving. The title of this section is the answer given by a woman who had lived for many years at Templeton Centre. When asked if she wanted to return there she replied "No – not my house."

Several families recounted that their relative was initially very reluctant to go anywhere in a car or van. While other reasons for this reluctance are also possible, families and staff often attributed this to the fact that the person with an intellectual disability was worried that a ride in a vehicle would result in them returning to Templeton Centre. After a period of days, weeks, or occasionally months, the aversion to vehicles would eventually go away as the person realised that they were going to stay at the new home.

Having ascertained that it was clear that most people who left Templeton Centre did not "look back" it is important to make it clear that this did not mean that people did not need time to settle into the routines and rhythms of their new home. As discussed more extensively in the Report on Phase Two, many people needed time to settle into their new service and most families accepted this process. This is an important message for all those individuals, families and service providers who may be involved in the process of deinstitutionalization in the future – early problems and challenges during the process of resettlement are to be expected and should not automatically be seen as evidence that the person with an intellectual disability is unhappy about leaving the institution. Just as families found this an emotional time, so too do the people who are affected most directly by this process – people with intellectual disabilities themselves. Future research must address this issue from the perspectives of people with intellectual disabilities themselves in order to determine more precisely the effects of such transitions in service delivery.

"Well I think it's important they keep contact up with the family. I think its also important for the family to listen to staff."

Similarly to the two previous phases of the research, the issue of staff continued to be a significant focus of families' discussions relating to the deinstitutionalization process. Families were concerned about the relationships that they had with staff in the new services, and about how well they perceived individual staff as meeting the needs of their relatives with intellectual disabilities. Families commonly linked the quality of the relationship between their relative with an intellectual disability and the staff who worked with that person as being directly linked to the quality of life enjoyed by that person. Consequently, the issue of staffing continued to be a topic on which many families focused.

In the Phase Two report we talked about families being very focused on the personal qualities and characteristics the men and women working in the community based services brought to their role. For most families, the preoccupation with the qualifications that staff possessed (in particular whether staff were registered nurses) decreased, and value was increasingly placed on how a person interacted with the people they were paid to support. That is not to say that families did not recognize that some staff needed a greater level of training or experience in order to respond appropriately to some situations.

Linked to this concern was the recognition that staff burnout could become a real problem for community based intellectual disability services. Several families worried about staff burnout - a problem that they saw as directly related to the high rate of staff turnover in

evidence in the home in which their relative lived. These families expressed a critical need to address this issue in order to secure a more settled staff environment and consequently, a better environment for people with intellectual disabilities living in the home.

A small number of families continued to feel apprehensive about the maintenance of financial resourcing for staff with an appropriate level of training. These families were those who continued to feel that nursing staff needed to be available to meet the health related needs of their relatives. Some families reported that staff who did not have any nursing training had sometimes expressed to them their personal discomfort with having to perform medical tasks or procedures that they did not feel they had the training to perform with confidence. A few families felt that they received assurances of a certain level or type of staffing in order to encourage them to choose a particular provider in the first place that was then not maintained over time. While this did not necessarily mean that these families were dissatisfied, in general, with the community based service, it did add a dimension of ongoing concern.

It was clear that families particularly valued staff who were prepared to meet them half way in the quest to establish or re-establish relationships with their relatives with intellectual disabilities. One family for example recounted the story of inviting the staff in a particular community home not only to bring their relative out to meet them on a family outing but also all the other people who lived in that home. The staff embraced this idea and everyone enjoyed a day of relaxation and fun. This reciprocal quality of relationship was very important to families who felt supported by the new service in

their quest to make their own transition – a transition in the type of relationship they had with their family member with an intellectual disability. As always, the quality of communication between families and the community based service staff and management was the major indicator of families' level of satisfaction with the new service.

"Yes, so this community care is definitely not all it's cracked up to be!"

An **extremely** small number of families (3) continued to hold the views that they expressed during the Phase Two interviews and expressed dissatisfaction and disappointment with the way that the transition from Templeton Centre to new services in the community had occurred for their family. There were two major reasons for this dissatisfaction. The first was related to an absence of positive communication between the family and the new service. When families felt that their concerns were not acknowledged or responded to they tended to hold more negative views toward the new service. The second reason that was identified as contributing to families holding negative views toward deinstitutionalization was related to the suitability of placement. When families had felt forced to make a decision to choose a new service they tended to hold more negative views. Such views were heightened if the family had felt that the placement was not suitable for their relative. If families entered into a relationship with a new service when they held such views it was unlikely that those views would change. Families were usually right about the suitability of particular services for their own family member.

In the light of all the positive accounts and stories of deinstitutionalization that families shared with us, we felt disappointed for families who did not get to share in such an experience. The difference between families who had a positive experience and those who were profoundly disappointed by the process of deinstitutionalization was acute. This difference, in our view, highlights the importance of working with families on an individual level in order to ensure that their concerns are addressed and their hopes and aspirations for their relatives with intellectual disabilities are met.

Brackenridge: "It became a reality, save our village."

In the previous reports we discussed the issue of Brackenridge separately. We did not feel that this was required in this report as families who used Brackenridge expressed similar things in terms of the positive and negative aspects of the service that they had chosen for their family member. Overwhelmingly, the quality of the relationship that existed between individual families and the staff who worked in the individual houses that make up the Brackenridge complex determined the extent of families' satisfaction with this service. This is true for all families who experienced the process of deinstitutionalization that occurred at Templeton Centre.

Families who were committed to the development of a service like Brackenridge had always talked about their concerns regarding the level of training and experience that staff in the new community based services would possess. It was the view of these families that it was more likely that a service like Brackenridge would seek staff with backgrounds more in keeping with the experience and training that

Templeton Centre staff had possessed. Interestingly, just as families using community based services changed their views on issues related to what constitutes "appropriate" staff, so too did Brackenridge families after experiencing their new service. While nursing skills remained important to a significant number of families, the personal qualities and characteristics of staff became increasingly important to many. This is likely to be because families developed closer relationships with staff. Some families even commented that the balance of staff who had had previous experience in the institutional setting and those who had non-institutional backgrounds was positive as it decreased the chances of institutional practices dominating the everyday running of the service.

Like other families (who used services other than Brackenridge) the views of Brackenridge families were diverse with regard to the role that the development of Brackenridge had played in the deinstitutionalization process. While many families continued to see the development of Brackenridge as something which had prevented the resettlement of their relative from being a complete disaster, a few families now thought that their family member could have adjusted to a different model of service. A small number of families expressed a level of dissatisfaction with the services that their family member received within the Brackenridge model of service. While Brackenridge was seen as a "necessary saviour" by many opposed to the closure of Templeton Centre it is clear that this service is not immune to the issues and problems that are common within intellectual disability services generally.

Chapter Two

"But it would have been harder for me without that moral support": Independent service coordination

> "Yes for the transition process he was the coordinator there. He was just excellent. Suddenly it was like another category of quality in the whole thing and someone who seemed to be very thoughtful about everything to do with this matter. It was quite a breath of fresh air actually."

In the previous two reports we touched only briefly on the role of service coordination. From the feedback we have received, it is clear that a number of individuals and organisations continue to be interested in the process of service coordination as it was implemented during the deinstitutionalization of Templeton Centre. Although this report is focussed predominantly on Phase Three of the study, we have included information relating to this issue gathered during Phase Two in order to give a fuller picture of the role of service coordination and the way it has been perceived by families.

In our report on Phase One of the study we reported that families had mixed responses to the introduction of independent service coordinators into the deinstitutionalization process. Independent service coordination was set up to ensure that every Templeton Centre resident had a representative who would work toward helping them achieve the best possible arrangement of community based services. Because it was most common for families to be involved in the decision making regarding resettlement into services (rather than the person with an intellectual disability him or herself) service

coordinators were intended as a resource or support for families as they negotiated their way through the process of deinstitutionalization.

At the time service coordination was introduced many families were feeling angry, concerned and/or anxious about the planned resettlement of their relatives and the subsequent closure of Templeton Centre. During this early stage families were expected to approach the service coordination service when they felt ready to take this step. As we outlined in the report on Phase One, it became clear that not all families were aware they were responsible for making the first approach to the service coordination service. Consequently some families who were waiting (and willing) to hear from a service coordinator could not understand why they had not been contacted. It is also important to make clear that at this early stage a significant number of families were aware of the intended process but continued to refuse to make contact with service coordination. To do so would be the catalyst for beginning the transition of their relative from Templeton Centre into community based services. At the time of the Phase One interviews a significant number of families were reluctant to take this first step.

A little further into the deinstitutionalization process service coordinators were given the ability to contact families directly. This change in approach was a turning point in the process for many families. Having the opportunity to talk about their relative's history, and to ask questions specific to that person was, for some families, the first time they could look at the prospect of resettlement in a way that made sense to them. Families frequently were reassured by the support and advice of their service coordinator to the point that

they decided to actively pursue a transition from Templeton Centre for their relative(s). Many families also valued highly the presence of independent service coordination because in these tenuous early days, they saw this independent role as providing an additional "safety net" which would ensure that the community based services continued to provide high quality care for people with intellectual disabilities.

As we also mentioned in our Phase One report, it is important to acknowledge that independent service coordination was not received positively by all families. A number of families who were contacted by service coordinators resented what they saw as an intrusion and as unnecessary pressure at an already difficult time. These families were those committed to retaining institutional services and who at this point would not accept any discussion of the resettlement of their relative.

During the Phase Two interviews we encouraged families to expand on their experiences of service coordination and to articulate their views of how they perceived this service contributing to the new model of service delivery in the future. A number of families, particularly those who were opposed to resettlement at the time they initially met their service coordinator talked about having to set boundaries around the relationship. It was common for families to say that they did not appreciate the efforts of "pushy" coordinators. However, it is important to say that a less than positive beginning to a family/service coordinator relationship did not mean that it would not develop positively over time. Some families talked of getting to the stage where they felt very comfortable with the relationship they

had with their coordinator which they now perceived as a valuable source of support for both them and their relative.

Service coordinators helped families to see the possibilities that were available to their relatives with intellectual disabilities. Because many families were naturally apprehensive about the resettlement of their relative from Templeton Centre they were appreciative when their coordinator showed them a range of options. Central to families' concerns with the process of deinstitutionalization per se was the perception that they had no choice over what was occurring. When a service coordinator took the time to discuss and to show them a range of service options families were more confident about making choices and decisions. It also showed families (many of whom had sought the services of Templeton Centre because they believed there were no other services available to them) that the community based service system had developed to the point that their relative could be accommodated within it.

The quality of the rapport that coordinators were able to establish with families was vitally important throughout the process of deinstitutionalization. Families' views of service coordination were largely dependent on the personal characteristics of individual service coordinators, and on the relationships that they established with them. In some cases coordinators obviously had concentrated on the building of a positive relationship in the first instance rather than on identifying new services. When the relationship was more firmly established the progression to talking about potential services and the transition process itself occurred more naturally.

Some families experienced a succession of different coordinators. This was due in part to the fact that as the process of deinstitutionalization progressed some logistical difficulties associated with allocating coordinators arose. Assigning individual people with individual coordinators was a sensible idea until those individuals started moving into new homes in the community. The early system meant that every individual living in the new home could have a different coordinator - a situation that quickly became recognized as problematic. It was difficult for staff in the community homes to accommodate this system. A new system was then slowly implemented whereby each home had one service coordinator which meant that families were faced with a change in coordinator. Sometimes families felt they were losing a person with whom they were comfortable with and they were not always happy with this loss.

While most families were reporting positive experiences of resettlement soon after their relative had moved from Templeton Centre, most continued to report that the presence of the service coordinator continued to be welcome in case "something went wrong." Families who were not yet convinced of the stability of the new model of service delivery continued to believe that an independent group was a necessary "watchdog' and many families were convinced that independent service coordination (in the same format) would continue in the long term.

During Phase Three interviews the emphasis that families placed on the presence of independent service coordination changed. After accepting the resettlement of their relative(s) into community based services most families reported that (in the first instance) they would

always address problems with the individual staff involved, or with the service manager. Families felt comfortable with the relationship that they had established with direct care staff and with management. For these families using a service coordinator to address issues would be an option of last resort to be used in cases where they were not receiving responses or actions that were satisfactory to them.

It is important to acknowledge however that a few families said that they would approach their service coordinator first if they had a problem with their relative's new service. Families in this situation either did not feel comfortable with staff or did not like to be perceived as difficult or complaining. For them, having access to a service coordinator to raise issues on their behalf eliminated their discomfort. The fact that some families relied on their service coordinator to have problems addressed raises issues associated with the loss of the independent service coordinator role.

Towards the completion of Phase Three interviews for this study the presence of independent service coordination was withdrawn as a new national system of service coordination and needs assessment was implemented. For some families this was a disappointing development in the deinstitutionalization process. Although most families had high quality relationships with their relatives' service providers, it was common for families to continue to value the ongoing relationship that they had with their service coordinator. Even in cases where families reported that they only engaged their service coordinator to address issues in situations of last resort, many continued to value the opportunity to talk and discuss their relative with their coordinator. A significant number of families were

unpleasantly surprised to learn that service coordination (in the form they were familiar with) would not continue in the long term.

The loss of service coordination was more distressing for families who relied on their service coordinators to take a more active role in the communication that occurred between themselves and their relative's service provider. These families had to develop their own strategies for communicating with service staff and managers and for having issues addressed.

Overall, the role of independent service coordination was assessed by families to be a valuable one in the process of deinstitutionalization that occurred at Templeton Centre. We believe that one of the critical aspects of this role was that it afforded families the opportunity to have one-to-one contact with an individual who got to know them and their relative with an intellectual disability. This created a situation whereby families could have **their** questions answered in a way that was relevant and appropriate. Before the introduction of service coordination families had often struggled to gain information that was relevant to their individual family circumstances and relevant to the specific needs of their relative. Future deinstitutionalization processes need to consider the inclusion of a similar role in order to ensure that families' personal needs and aspirations are met.

Chapter Three
Sibling's views

> "Quite amazing really. It's opened my eyes quite considerably. It's been good for all of us because we didn't really have a brother and now we have. It's fascinating- and each time you go now you sort of wonder, well what else has he been doing and what else is he up to and what else is he going to do!"

A strong focus of this research was the inclusion of "other' family members, not just parents. In almost all cases, other family members who took part in this research were the now adult brothers and sisters of people with intellectual disabilities. While in the earlier reports we did not specifically discuss the contributions we received from siblings, we felt it was appropriate in this report to provide greater detail about the role of siblings in the deinstitutionalization of Templeton Centre. We feel that our commitment to including the views and perspectives of siblings and other family members was extremely important to gaining a more complete understanding of the way in which families make decisions relating to their relatives with intellectual disabilities. Because other research on deinstitutionalization largely has focussed on the role of parents, the important role that other family members (usually siblings) can play in this process has frequently been overlooked.

Before describing the role that siblings and other family members can play in the process of deinstitutionalization it is important to provide some information about siblings' views of the institutionalization of

their brothers and sisters with intellectual disabilities. This research identified that it was extremely common for parents (and more particularly mothers) to make decisions about institutionalization based on their concerns for the wellbeing of their non-disabled children. Specifically, parents worried about: not spending enough quality time with their non-disabled children; their non-disabled children having to assume a level of responsibility for the care of their brother or sister that was not typical in other families; family life being limited by the sibling with an intellectual disability; and non-disabled children feeling unable to have friends home because of the presence of the child with an intellectual disability.

The interesting thing about this research was that while the (now) adult siblings usually understood and supported their parents in the earlier decisions that they had made regarding institutionalization, very few, if any of the siblings viewed themselves as the reason that their brother or sister left the family home in the first place. When asked, most siblings attributed the institutionalization of their disabled sister or brother to the fact that their parent(s) could no longer cope with the stress and pressure associated with caring for the person at home, and the fact that there were no community based service alternatives at the time placement was sought. Some of the siblings recounted stories told to them by their parents regarding incidents that occurred involving them and their brother or sister that highlighted the fact that they had experienced difficulties and frustrations. Very few siblings recounted similar incidents from their own perspectives.

What appeared to be stronger and longer lasting memories for siblings were family visits to Templeton Centre when their brother or

sister was a child living there. Many siblings remembered such visits to be quite sad, or disturbing for them. Central to siblings' feelings on this issue was the feeling of guilt that their brother or sister was experiencing a completely different life to their own. That guilt sometimes stayed with siblings into adulthood. Siblings' discomfort with visiting their brother or sister in the institutional environment sometimes meant that they visited less and less over the years and often did not have a well-developed relationship with their family member, or a real understanding of their daily life.

The movement of people with intellectual disabilities from the institutional setting into a range of community based alternatives has, for many families, been the catalyst for a rekindling or reconnecting of family relationships. The caption used to head this chapter indicates very clearly that the process of deinstitutionalization can result in an increased understanding and awareness of men and women with intellectual disabilities by their families. This is because the deinstitutionalization process provides opportunity for change and development in the lives of people with intellectual disabilities. While change and development may have occurred within the institutional environment, it was not usually as evident to families, nor were they an integral part of a process as they were in the case of deinstitutionalization.

As we said earlier, although siblings may have had their own private thoughts and views relating to the institutionalization of their brothers and sisters, no siblings blamed their parents for the difficult and painful decisions they had previously made. The adult siblings who took part in this research were incredibly supportive and understanding of their parents and the decisions that they had made

regarding the institutionalization of their brother or sister. They were also very worried about the impact of the planned deinstitutionalization process on their parents and wanted to protect and support them through it. A significant number of siblings felt that their parents had not received appropriate support or information in the early stages of the process of deinstitutionalization and continued to feel angry about level of stress and anxiety that their parents had been required to work through.

The siblings that took part in this research displayed a variety of roles in relation to their level of involvement with the decision making that occurred for their brother or sister with an intellectual disability. A small number of siblings followed the lead of their parents with regard to decision making. Some were already fulfilling a decision making role in partnership with their parent(s). Others had a lead role in the decision making that occurred in relation to their brother or sister but still considered the wishes of their parent(s). A few siblings were in the position of being the only family decision maker.

This research has shown quite clearly that the adult siblings of people with disabilities often play an integral part in facilitating the movement of their brothers and sisters with intellectual disabilities from institutional environments into disability services based in the community setting. Most of the siblings who took part in this study felt that they needed to help their parents negotiate the (often) anxiety provoking process of considering a change in model of service delivery. This point was particularly pertinent within families where parents were quite elderly. Some siblings reported that they felt that the methods used to communicate and disseminate information were

not accessible by their parents. Usually their concerns relating to accessibility related to the language and terms used in correspondence, and the use of large public meetings that made it impossible for families to have individual concerns addressed.

In situations where parents shared a decision making partnership with their adult children, decisions were made about resettlement more quickly and more positively. It was very evident that siblings played a significant role in helping their parent(s) to understand more about the process of deinstitutionalization in general and community based services in particular. If siblings had a positive view of what the future could hold – parents were more likely to follow their lead and embrace the notion of resettlement as well. A significant number of families whose family members were amongst the first to move from Templeton Centre were families in which siblings played an active decision making role. Their support of the proposed changes in service delivery made it easier for parents to take the initial step toward resettlement.

Many siblings were surprised and delighted to observe the changes in their brother or sister with an intellectual disability that occurred after they had been resettled from Templeton Centre. Siblings appeared to embrace very quickly the notion that life in the new model of service delivery could offer their brother or sister a great deal more opportunities. A significant number of siblings became actively involved in suggesting and creating new opportunities for their brother or sister.

Not all siblings reported that they saw a change in the skills or abilities of their brother or sister but almost all siblings said that they

felt the new situation was better for the family as a whole. As it was identified in Chapter Two, siblings, like parents, believed that they had a greater level of understanding of, and involvement in the life of their brother or sister. They also felt that they had a more comprehensive level of communication with management and direct staff working in the new services. One thing that siblings particularly seemed to appreciate was that they were informed of new and positive developments in the life of their brother or sister rather than just learning about problematic or negative issues as had been more common in the past.

An interesting point to end this chapter on was the finding that siblings were very conscious of the need for them to step in to a more active role with their brother or sister in the future. They were aware that as their parents became older that they would be required to take on a greater level of responsibility for their brother or sister. Some siblings had already begun to formalize this legally by becoming welfare guardians while others chose to become involved in governance roles in the new community based services. It is important to conclude by saying that the siblings who took part in this study showed enormous sensitivity toward their parents, the decisions that they had made in the past, and the decisions that they were being forced to grapple with in regard to the future. Siblings did play an important role in the process of deinstitutionalization that occurred at Templeton Centre.

Chapter Four

Reflections on the process of deinstitutionalization

> *"Well all I can say is that it has been a long and painful process. Probably it would have been painful however it was done. But the outcome I feel is for the betterment of the resident's lives."*

One of the aims of this research was to learn more about families' experiences of deinstitutionalization in order to draw some conclusions about how to best support "other" families through similar processes. One might assume that because a significant number of families reported concerns and problems prior to the resettlement of their relative they would have clear thoughts about how the process could have been implemented differently to ensure that their needs and the needs of their family member were met. In reality, despite families having been through this lengthy process, it was difficult for families to be very clear about what would have improved their own experience of deinstitutionalization. As families moved through the second and third phases of the research (i.e. after their relative had been resettled) they seemed to acknowledge some of the difficulties in implementing a process to suit everyone, and some of the inconsistencies in their own feelings and responses as the deinstitutionalization process progressed. What we hope to achieve in this chapter is to highlight some of the areas of the deinstitutionalization process that posed particular difficulties for families, as well as some ways of addressing such difficult areas.

"We didn't trust them, I suppose it was them and us."

Many families felt that a consistent message about the aims and intended outcomes of deinstitutionalization had been missing from this process. As we talked with families, (particularly in the early stages of the research), it was clear that many families did not understand that deinstitutionalization was intended to result in positive outcomes for the people most closely involved in the process – that is people with intellectual disabilities themselves. Most families saw deinstitutionalization as being solely a cost cutting exercise. This made them suspicious of the motives of those involved in planning and implementing the process and a "them and us" situation was created and became very hard to shift. Linked to this was the resentment felt by families that the closure of Templeton was a "fait accompli" and therefore the submission process was a farce.

Despite the fact that families resented what they saw as a situation that had been decided without their involvement and one which was not open for debate, they were critical of what they saw as a lack of a transparent and accessible plan. Families believed that they would have felt more comfortable with the notion of deinstitutionalization and the subsequent resettlement of their relative if a clear plan had been presented to them. This shows that families did not perceive themselves as being able to have any significant input into the development of the new community based service system. It is possible that if families had genuinely felt involved in the planning process they would have felt more positive about deinstitutionalization.

The ability that families had to ask appropriate questions of appropriate people was compromised by the fact that those involved in the planning and implementation of the deinstitutionalization of Templeton Centre had confusing and complicated roles. The frequency with which key staff and key roles changed made it difficult for families to identify with a consistent person as having responsibility for specific aspects of the process. This in turn heightened families' feelings of mistrust as they saw themselves as having been forced to commit to a process when key staff involved in planning and implementation did not display the same level of commitment to "see it through" to completion.

There was almost unanimous agreement that large public meetings were not useful for conveying important messages relating to deinstitutionalization. While there was recognition that such meetings were an obligatory step in the process of communicating plans for deinstitutionalization, they were not perceived as fulfilling a useful role in developing effective communication between families and officials. Because such meetings commonly are dominated by the contributions of a few very vocal people, the perception that all families were opposed to deinstitutionalization became entrenched. The level of animosity between families and officials is also heightened. A significant number of families resented their inability to gain appropriate answers to important questions in these forums, at a time when these forums seemed to be the only place where they could ask questions.

A positive difference for families could have occurred through the inclusion in the process of a contact person. This person would ideally have been an independent person who could answer families'

questions relating to the individual circumstances of their family, and the individual needs of their family member with an intellectual disability. Families were without such a person throughout what we believe to be a critical time in the process of deinstitutionalization – the early phase of the planning process. Independent service coordinators fulfilled an important role later in the process but because they were introduced later, families had already suffered an extreme level of anxiety and concern. We believe that a significant number of families could have gone through the process of deinstitutionalization more quickly and with a lot less pain if they had received more individual attention in the early stages of the process.

"No, I think that I probably was the doubting Thomas who had to see it actually happen before I believed it could happen."

A number of families described feeling horrified at the suggestion that their family member could live in a different environment to that provided by Templeton Centre. Many of these families said on reflection that this feeling of horror was caused by fact that families had little or no knowledge of an alternative – they did not and could not conceive of what the future might hold. Some families said that seeing the alternatives made a difference for them, however most families admitted that seeing other people living in community based settings did not change their views. They simply saw these examples as people and places not representative of the changes that their family member was being subjected to. They also did not believe that the men and women they saw in community based services had comparable levels of disability to their own family member. What might have helped these parents is the opportunity to meet on an

individual basis other families who had experienced similar transitions and to fully discuss their concerns and anxieties.

The process of deinstitutionalization is by very nature a difficult one. Any major change in model of service delivery is difficult for families to contemplate and accept. In a situation where the change has not been initiated by families, anxieties and worries are heightened significantly. For this reason it is not easy to say, with absolute conviction, what would have made things better for families. Families themselves acknowledged that this was a process that had to be worked through, and in many cases be experienced before they could relax and begin to enjoy the many positive outcomes for their family member with an intellectual disability. We do believe, however, that this research on families who have experienced the process of deinstitutionalization has provided policy makers, planners and service providers with a great deal of useful information which can be used to achieve more positive family involvement in major changes in service delivery, and in the day-to-day running of services more generally. The contention that we held when we began this research remains - positive family involvement results in more positive outcomes for people with intellectual disabilities themselves. Learning new and better ways of including families in the lives of people with intellectual disabilities should continue to be an important goal of research.

We think that it is appropriate to leave the final word to one family member who summed up what her advice would be to other families who were facing the prospect of deinstitutionalization and the resettlement of their relatives into alternative intellectual disability services in the community.

> *"I would say go ahead and do it, it's wonderful"*

Appendix 7:

Published research article.

Mirfin-Veitch, B., Bray, A. & Ross, N. (2003). "It was the hardest and most painful decision of my life": seeking permanent out-of-home placement for sons and daughters with intellectual disabilities. *Journal of Intellectual and Developmental Disability*, 28(2), 99-111.

"It was the hardest and most painful decision of my life!": seeking permanent out-of-home placement for sons and daughters with intellectual disabilities*

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The issue of out-of-home placement for children with intellectual disabilities continues to receive significant research attention. This focus reflects the fact that some families continue to seek out-of-home placement for their children with intellectual disabilities despite anti-placement philosophy and policy which currently inform disability support services. The present paper explores families' past experiences of seeking out-of-home placement for their relatives in an institutional facility. Data for the study were generated within the context of a longitudinal study on the deinstitutionalisation of a large institutional facility for people with intellectual disabilities. Families were interviewed at regular intervals throughout the resettlement process and were encouraged to talk about their views towards, and experiences of, deinstitutionalisation, and their fears and aspirations regarding the new model of service to be delivered to their relatives. Families' past decision-making regarding out-of-home placement was also explored. One significant finding of this study was a shared story reported by families in terms of their past decisions to seek permanent out-of-home placement in an institutional facility. Critical elements of such decision-making are identified and presented in the context of current research on out-of-home placement.

The process of deinstitutionalisation has been the focus of a substantial body of research over the past 20 years (e.g., Conroy & Bradley, 1985; Cummins, Polzin & Theobold, 1990; Lord & Hearn, 1987; Mansell & Ericsson, 1996). Impetus for the deinstitutionalisation

movement is largely credited to the principles of normalisation (Nirje, 1985) and the subsequent development of a community-based service system (Mansell & Ericsson, 1996). Most deinstitutionalisation research has concentrated on determining the changes in quality of life and the adaptive behaviour of the individuals with intellectual disabilities involved in the transition processes (Dunt & Cummins, 1990; Emerson & Hatton, 1996). There is little doubt that such research has found that deinstitutionalisation represents an improvement in the lives of most previously institutionalised people (Kim, Larson & Lakin, 2001; O'Brien, Thesing, Tuck & Capie, 2001; Young, Ashman & Sigafoos, 2001). Despite this, many families who have relatives involved in such a process are often fearful of the planned changes (Mirfin-Veitch, Ross & Bray, 1998; Tuvesson & Ericsson, 1996) and in some cases actively oppose any change to the model of service delivery currently offered to their relative (Mirfin-Veitch et al., 1998; Tossebro, 1996). While families have been included as participants in a significant number of deinstitutionalisation studies, few studies have involved an in-depth exploration of the impact of this process on families or the decision-making processes employed by families in this situation.

This paper is based on a longitudinal research project which explored the deinstitutionalisation of a large residential facility situated near Christchurch, a city on the South Island of New Zealand. The institution had a 70 year history and at the time this project commenced, 480 individuals with intellectual disabilities were using the service. Despite the fact that the community-based service system for people with intellectual disabilities in New Zealand is well developed, the process of closing large hospital-based residential facilities has moved slowly with strong opposition to proposed changes. The deinstitutionalisation of the Templeton Centre was no exception to this pattern. The process implemented at the Templeton Centre was a protracted one which involved high levels of conflict and emotion. This paper is the first in a series of papers based on research conducted with families prior to, during and following the deinstitutionalisation of the Templeton Centre and the resettlement of their relative(s) into alternative services. This paper focuses on families' past experiences of seeking out-of-home placement for their relatives in an institutional facility. Critical elements of such decision-making are explored and presented in the context of current out-of-home placement research.

Method

This paper is based on research conducted with families to ascertain their views and experiences prior to, during, and following the resettlement of their relatives with intellectual disabilities into alternative models of residential services. The research occurred over a period of 4 years. The general aim of the research was to provide families with an opportunity to articulate their views, experiences and understanding of the process of deinstitutionalisation and to document and explore those views.

All parents/families and/or next-of-kin of Templeton Centre residents were invited to participate in this study. The research team prepared an information pack containing material detailing plans for the study which was then distributed by Templeton Centre administrative staff. This package was accompanied by a letter from the (then) Templeton Centre manager who assured families that the research team had not had access to the families' personal information and that the distribution of study information had been handled entirely by Templeton Centre staff.

The families were asked to complete a consent form and a next-of-kin questionnaire if they wished to participate in the study. The next-of-kin questionnaire was developed as a way of ascertaining basic demographic information from families about their relative currently living at the Templeton Centre. The demographic information sought included: age, gender, date of admission, length of stay, level of disability (as perceived by the study respondent), and the relationship of the respondent to the person with an intellectual disability (e.g., sibling, parent, cousin, grandparent). This information provided the research team with the earliest data from families and also facilitated a process of maximum variation sampling.

Maximum variation sampling refers to the process of purposefully selecting a wide range of variation on the dimension of interest (Patton, 1990). Implementing maximum range of variation on the dimension of interest (Patton, 1990). Implementing maximum variation sampling was necessary to reflect the diversity of Templeton Centre residents and their families. As mentioned previously, information relating to Templeton Centre residents and to their families was sought through the next-of-kin questionnaires. This process enabled us to choose a wide range of family respondents who could report on a diverse range of Templeton Centre residents. Analysis of the next-of-kin questionnaires to achieve maximum variation sampling focused on the following factors: the (current) age of the Templeton Centre resident; their age at admission to the Templeton Centre; the length of time they had resided at the Templeton Centre; their level of disability (as assessed by the family respondent); and whether they were male or female. This information was considered alongside the relationship that the family respondent had with the Templeton Centre resident (e.g., parent, sibling, grandparent, cousin, etc); and whether more than one family member wished to participate in the study.

Selection criteria were also essential in this study because the research team did not have the resources to include all of the families who wished to participate in this study. (Families who were unable to be included in the study continue to be kept informed of the progress of the study and receive research reports on the study findings.) Thirty-five families took part in the research from a total number of 65 families who wished to participate in the study.

In summary, the resettlement experiences of 36 people (23 men and 13 women) who had intellectual disabilities were discussed by family respondents. Five people had been admitted to the Templeton Centre when they were aged between 0 and 4 years; 16 people were admitted between the ages of 5 and 9 years; six people were admitted between the ages of 10 and 14 years; seven people were admitted between the ages of 15 and 19 years; and two people were admitted when they were 20 years of age or older. Thirty-two people were admitted to the centre on a permanent, full-time basis. Four were admitted during the period 1950–1959, nine during the period 1960–1969, nine during the period 1970–1979, and 10 during the period 1980–1989. No full-time admissions were made during the 1990s. (The institution was prevented from accepting full-time admissions during this period. However, respite care or shared care admissions did occur.) A small group of people (four) whose resettlement experiences were reported by family respondents utilised the Templeton Centre on a shared care basis. Shared care (in this study) refers to the situation whereby the care of a person with an intellectual disability was shared between their family and the Templeton Centre. Individual families had their own specific arrangements in terms of shared care. One shared care arrangement commenced during the 1970s, one during the 1980s and two such arrangements began during the 1990s.

Most of the family respondents were parents. In total, parents were involved in interviews relating to 28 (of the 35) Templeton Centre residents. Parents only were

involved in interviews regarding 18 Templeton Centre residents. Parents and siblings were involved in interviews relating to 10 individuals, while siblings only participated in four instances. Other interview combinations included mother–aunt (one), grandmother (one) and sibling–niece (one).

The data used to develop this paper are from interviews conducted with research participants prior to their relative with an intellectual disability making the transition from the Templeton Centre into an alternative model of residential service. This interview was the first in a series of interviews and communications with participating families. The research interviews were unstructured but were assisted by the use of an *aide-memoire* to ensure that similar topic areas were raised with each participating individual or family group. The interviews ranged between 1 and 3 hours in length. Integral to this first interview was a discussion of the families' past decisions to seek out-of-home placement for relatives with intellectual disabilities. The interviews were audio-taped (with the consent of each participant) and transcribed. The interviews were checked by the interviewer and then returned to the study participants who were invited to check their transcript, to add any information that they wished to, or to remove any sections of the transcript that the participant did not wish to be used as data. It was most common for participants to correct their own grammar or to add information that clarified their oral contribution. A significant number of participants did not choose to change any aspect of their interview transcript. All participants (when they were satisfied all necessary revisions had been made) kept a copy of their interview transcript for their own information. This process was repeated at each phase of the research.

Data generated through all phases of this research were analysed for thematic content. The first author was responsible for conducting a preliminary analysis of data which was then discussed and revised with members of the research team. These preliminary analysis procedures informed the development of a coding schedule which was used in conjunction with the qualitative data management software package NUD.IST (Richards & Richards, 1994). The qualitative interview transcripts were entered into NUD.IST and coded according to the previously developed coding schedule. NUD.IST facilitates a process by which information relating to specific codes (topics) is collated from all transcripts. Such a process enables efficient management of large quantities of data (as existed in the present study). As mentioned earlier, this paper has been developed from interviews that were carried out during the first phase of this longitudinal study. In particular, the analysis presented here relates to the issue of families' past decisions to seek institutional care for their relatives.

It is important to explain our use of the term "families" in this research. Unlike most deinstitutionalisation research, we actively sought the participation of a broad range of family members rather than focusing solely on the views and experiences of parents. We realised when we commenced the study that some Templeton Centre residents may no longer have parents who were alive or that other family members may have taken over the responsibility of being involved in decision-making relating to the provision of care. Equally as important to the research team was the notion that not only parents but entire families are affected by major changes in service delivery. An important aspect of this research was the exploration of such impacts from the perspectives of different family members.

Results

The families taking part in this study were all different. The great diversity in families is reflected in their differing views towards their family members with disabilities, towards the plans for deinstitutionalisation and towards the process they experienced as change and transition began to occur. While the diversity among the families taking part in the study was clearly apparent, what they shared was a consistent story of their experiences that led to the decision to seek permanent out-of-home care in the past. During our first interview with the families we explored the decision-making that the families had engaged in when they had sought hospital-based services for their relative in the past. In doing so we were able to identify and interpret this shared experience, which we labelled "a typical family's story". The typical family's story presented as part of this paper is based largely on the experiences, recollections and reflections of *parents*. For this reason the term parents is used more frequently than the term families throughout this story.

A typical family's story

The decision to use the Templeton Centre was never a "spur-of-the-moment" decision for parents, nor was it something that they planned to occur at a specific point in the life of their son or daughter with an intellectual disability. A number of factors were common to families who chose to use institutional residential services on a permanent basis for their children.

A commitment to maintaining the family unit

> We did realise that sooner or later he would have to go, though we put it off as long as possible because you know, he's part of the family.

Parents had a strong desire to have their children live within the family and to be cared for by the family for as long as possible. The Templeton Centre was a service option that many parents refused to consider when their children were young or were first identified as having a disability. Furthermore, when challenges to families' abilities to cope occurred, the Templeton Centre continued to be actively resisted by many parents for a very long time. All parents talked about the importance of keeping their family together and caring for their relative with an intellectual disability at home for as long as possible.

The search for community-based services

> Yeah the strain was certainly beginning to tell on me. Definitely. Because at that time there really wasn't any support at that time from anybody. Anywhere. There wasn't any relief or respite care or anything like that . No. So I guess the strain was definitely beginning to tell on me, which is why she went there in the first place.

Parents were serious in their efforts to locate alternative disability support services in the community for their sons and daughters. As parents struggled to keep their sons and daughters at home they often tried a number of options. However, these options were perceived as failing to meet the needs of the person with a disability, and the family's needs as a whole. Parents often talked about the difficulties they experienced in "matching" their sons and daughters with the available services. This difficulty hastened

parents' moves towards using the Templeton Centre's services. It was most common for this use to take the form of respite, at first sporadically and then more frequently as the families' needs became greater. A smaller number of parents did not experience the Templeton Centre as a respite provider and told of making a decision about permanent out-of-home placement when their children were very young. In this situation the child's break from the family was usually swift, complete, and sustained over a long period.

Challenges to caring

> It was a matter of balancing things. There was no such thing as family life. It was a full-time job, frustrating, and the most important thing was [son with intellectual disability].

Parents (particularly mothers) faced intense and sustained pressure as issues associated with caring for their sons and daughters increased over time. A number of factors contributed to families' feelings of being unable to cope. Meeting the physical needs of their family member became an issue as children grew bigger and parents became older. Both parents and other family members (such as siblings) identified the provision of personal care as becoming increasingly difficult over time. Despite these problems, parents tended to cope with issues related to providing physical care for their sons and daughters more easily than those related to behaviour. Parents often felt powerless to deal with difficult behaviour and felt that such behaviour had a detrimental effect on the entire family. Parents were particularly concerned about their other children whom they felt were prevented from inviting friends to the family home. Parents themselves reported feeling increasingly isolated from their own social support networks.

Throughout this period in the families' lives there remained a resistance to seeking permanent out-of-home placement for their relatives with intellectual disabilities. It was during this time that many parents initiated an association with the Templeton Centre as a respite care provider. Many mothers had never had a break from caring for their child until they began to use the Templeton Centre for short-term respite. Furthermore, as services in the community failed to meet families' needs, the Templeton Centre became more critical to families as their only respite option. Parents who found it increasingly difficult to cope viewed the institutional service as critical to their ability to continue to care for their children. The increased use of the Templeton Centre as a provider of respite care facilitated a gradual acceptance of permanent out-of-home placement in the institution.

A sense of inevitability present in many families' stories became evident at this stage. Families struggled to delay the use of the Templeton Centre for as long as possible, but at the same time they described having a sense that they were delaying the inevitable. The families felt that they would not be able to care for their child in the long term, primarily because they perceived that the community-based service system could not meet their needs. During this period of delaying the inevitable, the families "got used to the idea" of having their relative live away from the family environment on a permanent basis.

The influence of professionals

> I mean when [paediatrician] said to us—when he told us about [son] and what life would be like, he said when you want care outside of the home you

go and get it. He said, don't hesitate. I said oh yeah sure, not believing that we would ever do it or need to but [mother] was sort of a bit more realistic perhaps and decided that, you know, the time had come.

Contrary to an enduring perception that health professionals (such as general practitioners, paediatricians and/or psychologists) made decisions for parents regarding out-of-home placement, the role of health professionals reported by the families taking part in this study may be more accurately described as "facilitators". Parents who were resistant to the idea of permanent out-of-home placement were often given "permission" to begin to think about the Templeton Centre as a service option by health professionals who knew both their child and their family circumstances. Professionals were occasionally very assertive in their views to parents, but it appeared that it was more likely for such individuals to give validity to what families (particularly mothers) were feeling. Parents were reassured that their feelings of stress and inability to cope were to be expected and that they should not feel guilty about seeking additional help. Mothers' poor mental health and its impact on the rest of the family was often observed and raised by health professionals.

The catalyst for permanent out-of-home placement

> You just cracked up one Saturday didn't you?

Individuals with intellectual disabilities usually remained at home until an event occurred within the family that altered the balance of family life. For many families, the birth of additional children signalled a change in the ability of mothers to cope. The ill-health of another child or an elderly family member was a frequent catalyst for change, and in some families the health problems of mothers compromised the ability for a person with an intellectual disability to be cared for within the family environment. A significant number of parents attributed their decisions relating to the care of their child with an intellectual disability to their perception that their other children in the family were "suffering" as a result of parents' (mothers') efforts to provide care within the family environment.

The mental health status of mothers determined to a large extent the timing of a transition into permanent out-of-home care at the Templeton Centre. Mothers who had struggled for many years to enable their children to remain within the family usually chose to utilise the Templeton Centre's services when they felt they were no longer able to cope emotionally with the demands of caring for their son or daughter with an intellectual disability as well as the usual demands of family life. In some cases, other family members, friends, or professionals articulated what parents had difficulty admitting to themselves.

Every parent who took part in this research described the decision to choose permanent out-of-home placement for their son or daughter with an intellectual disability as the hardest and most painful decision of their lives.

Parents talked about a great sense of sadness, and in some cases an enduring feeling of guilt and failure when they felt they could no longer care for their children. These long-held and very personal feelings intensified when parents were confronted with the announcement of plans to deinstitutionalise the Templeton Centre.

The announcement implied, to some parents, that they may have "done the wrong thing" in the past and that their sons or daughters would have enjoyed a better life had it

not been for their past decisions. This was particularly distressing for some parents who felt that the process of deinstitutionalisation occurred with little or no acknowledgement of their emotional experiences or needs. Some parents resented the (perceived) implication that they had "done the wrong thing" and responded by rejecting the notion that the deinstitutionalisation of the Templeton Centre was planned to occur for anything other than financial reasons. These parents based their opposition to deinstitutionalisation on the premise that the transition into alternative services in the community would be disadvantageous to people with intellectual disabilities themselves.

The typical family's story presented here reflects the experiences, views and perceptions of parents who chose to take part in this study. All the families taking part in this research willingly and openly talked about the decision-making process that occurred in considering and, at a later date, actively seeking out-of-home placement for their sons and daughters with intellectual disabilities. Throughout this story, two themes were significant and deserving of individual presentation at this point.

Mothers' roles

..oh he took my time up fully.

A central and powerful theme relates to the role of the mother in families that included sons and daughters with intellectual disabilities, and who took part in this study. Regardless of the time period in which a person with a disability began to use institutional services on a permanent basis, mothers had provided the care necessary for their sons and daughters with intellectual disabilities to remain in the family home. Mothers fulfilled the emotional and physical needs of their children and were without exception committed to the well-being of their children and to doing whatever possible to ensure that their child could remain at home for as long as possible. Mothers described the enormous physical and emotional stress associated with caring for sons and daughters with intellectual disabilities. As the children grew older, behaviours that were manageable when the children were small often became increasingly difficult for the whole family to cope with. A number of mothers and/or now adult siblings reported that fathers began working long hours leaving mothers to cope with the tasks associated with caring for their child with a disability and the usual demands of family life. This finding is consistent with the findings of previous New Zealand research on fathers of children with disabilities (Bray, Shelton, Ballard & Clarkson, 1995). The stress and pressure that mothers had to deal with was enormous. A number of mothers reported that their husbands had a negative response to their child with an intellectual disability and that some fathers went so far as to completely reject their son or daughter with an intellectual disability.

As mothers were the major care providers it was also evident that mothers took responsibility for making the final decision about when to seek permanent out-of-home placement or shared care on a formal basis at the Templeton Centre. While fathers often took a central role in describing events and challenges to family functioning that had occurred while their son or daughter was being cared for at home, it was clear that mothers were attributed with the task of making the final decision to seek out-of-home placement. It was common for mothers to express feelings of guilt and remorse about this decision and, in the context of the announcement to deinstitutionalise the Templeton Centre, to question whether they had made the "right" decision in the past. This discomfort with their decision was made worse for some mothers when their husbands or

their other children reacted negatively to their need to seek out-of-home placement for the child with a disability. It is important to note, however, that there was a small number of exceptions to these findings relating to the role of mothers. In the situation where fathers were parenting alone they reported very similar experiences and feelings to those expressed by mothers relating to the decision to seek permanent out-of-home placement for their son or daughter.

Consideration of siblings

In the early years? I think it affected my other children quite badly. I think they missed out on an awful lot. In particular I think I spent too much time in the early years looking after and being with [son]—because he needed that special time—that there was never enough time for them...

As mentioned previously in this section, parents frequently identified concern for other children in the family as a significant component in their eventual decision to seek permanent out-of-home placement for their child with a disability. A great deal of this concern related to the fact that they felt that their other children were embarrassed by their sibling with a disability and were isolated from their friends as a result of that sibling being cared for at home. More frequently expressed were parents' feelings of guilt and worry about the lack of time and attention they believed they were able to give to their children without disabilities. Parents (particularly mothers) reported feelings of inner tension and conflict as they struggled to balance their need and desire to spend a great deal of time with their child with a disability, and to also provide an adequate level of time, care and support to other children in the family. At the time of being interviewed for this study (often many years following the institutionalisation of their child with a disability), parents continued to express concern regarding the possible impact of their attempts to care for their child with a disability within the home on other children in the family.

As a number of families told their story, however, an interesting contradiction became evident. While many parents identified their concern for other children as a catalyst for out-of-home placement, it was clear that siblings in a significant number of families did not react positively to the institutionalisation of their brother or sister with a disability. Parents reported that in some instances other children in the family had been openly opposed to their decision regarding out-of-home placement. Other children sometimes displayed behaviour changes that parents attributed to the transition of their sibling from the family home and into institutional care.

The findings presented above have related to parents' perceptions and experiences, although this study was not confined to the views of parents alone. Other family members were also included in this study in order to be able to explore the impacts of institutionalisation and deinstitutionalisation on the family unit as a whole. All of the siblings who took part had stories and views of their own relating to the decision to seek out-of-home placement for their brothers and sisters with intellectual disabilities. The siblings who took part in the research often held the view that their mother was the parent who took the greatest responsibility for providing the care for their brother or sister with an intellectual disability. While the adult siblings who took part in this study were supportive and understanding of their parents' decisions to seek out-of-home placement in the past, some continued to struggle with the notion of institutionalisation and with the fact that their brothers and sisters had lived such vastly different lives to their own.

Many families who took part in this research reported feeling unfairly judged by today's parents and professionals involved in the disability field who respond negatively to out-of-home placement. More particularly, families were affected personally by the assumption that they did not love or care for their children but rather abandoned them to an institution. The opportunity to talk about their earlier decisions to seek permanent out-of-home placement was a unique experience for some families and an important process in their participation in this longitudinal study.

Discussion

The families participating in this study shared a common story in terms of their experiences of caring for a family member with an intellectual disability and, subsequently, their decision to seek permanent out-of-home placement for that person. This supports the findings of a study by Blacher (1990) which identified that the decision to seek out-of-home placement is a process rather than a discrete act. The purpose of presenting a "typical family's story" in this paper is to identify the elements of such a process from the perspective of families themselves.

Integral to the "typical family's story" was a desire by families to have their relative live at home for as long as possible and an initial reluctance to consider alternative care arrangements outside of the family home. Such reluctance has been identified in other out-of-home placement studies (Bromley & Blacher, 1989) and refutes the notion that out-of-home placement studies who eventually do seek out-of-home care do not care for their family members with intellectual disabilities. The families who took part in this study did not perceive that community-based disability or family support services were available to meet *their* needs. This is not to say that such services were not available at the time that they were caring for their family member at home, but rather that formal services were not successful in meeting the needs of *some* families. The question of why community-based services failed to meet the needs of the families who chose to participate in this study is the subject of a further paper planned by the current authors. Bromley and Blacher (1991) reported that the availability of appropriate support services was only moderately influential on the decision to seek out-of-home placement. Further to this point, researchers have emphasised the importance of creating a range of family support options to ensure that *all* families feel able to access a formal support system that meets their specific support needs (Herman & Thompson, 1995; Llewellyn, Dunne, Fante, Turnbull & Grace, 1999).

The issue of family well-being was highlighted in this study through the finding that the families experienced increasing pressure on family life over an extended period of time. In a recent review, Cummins (2001) explored the quality of life of people caring for a relative with a severe disability within their family. This review of qualitative and quantitative research concluded that data indicate that primary caregivers are at considerable risk of high stress, clinical depression and a low quality of life. These issues were identified and described by the families participating in this study as factors contributing to their eventual decision to seek out-of-home placement. Other studies have confirmed that parents' perceived daily stress is a strong influence on placement decision (Beckman, 1991; Bromley & Blacher, 1991; Kobe, Rojahn & Schroeder, 1991).

Additional factors that received specific emphasis in the results section of this paper were the role of the mother and the consideration of siblings in decision-making related to out-of-home placement. Mothers were the major care providers and therefore the

major decision-makers in terms of seeking out-of-home placement. This meant that the mothers often carried the emotional responsibility for making such a decision, including significant and long-held feelings of guilt. Furthermore, many parents identified that their concerns for their other children without a disability influenced the process towards out-of-home placement. Concern for family relationships in general, and the well-being of siblings in particular have been identified as critical to out-of-home placement decisions in a number of studies (Bromley & Blacher, 1991; Hanneman & Blacher, 1998; Llewellyn et al., 1999). However, little research attention has been paid to understanding how siblings perceive(d) the impact of removing a child from the family home to be cared for in another environment. This issue will be explored in a future paper planned by the present authors.

The fact that this study was based on families' retrospective accounts of their experiences and decision-making could be seen as a limitation of the study. A number of researchers have questioned the validity and relevance of data collected retrospectively. In particular, researchers have raised concerns about the accuracy of memory in parental report (Bromley & Blacher, 1991) and the possibility that parents may try to justify their prior decision-making processes (Cole & Meyer, 1989). Blacher (1990) also contended that retrospective studies are more likely to result in out-of-home placement being seen as a discrete act rather than a gradual process. The families involved in this study made decisions regarding out-of-home placement during a period spanning 40 years. Interestingly, the factors contributing to, and influencing, family decision-making were found to be remarkably consistent across all participating families, despite the retrospective data reported here. Furthermore, the findings are consistent with the findings of current studies aimed at determining the factors influencing out-of-home placement (Blacher, 1990; Blacher & Hanneman, 1993; Llewellyn et al., 1999).

This area of research continues to have relevance despite the fact that current policy and services are based on philosophy which supports family-based and/or community models of care. In a recent Australian study, Llewellyn et al. (1999) found that 25% of the families participating had already sought or were considering placement for their children with high support needs. This very significant finding highlights that some families continue to feel unable to cope with supporting a family member with a disability at home despite current policy and practice which encourages such caring practice. It is clear that some families will seek out-of-home placement at some point.

The findings presented in the current paper are intended to contribute to the research literature on out-of-home placement through providing a greater understanding of families' experiences of caring for, and subsequently seeking out-of-home placement for, family members with intellectual disabilities. The experiences and needs of family carers have recently been explored in a document commissioned by the British Department of Health (Ward, 2001). Under a section entitled "Emotional support", the following point was made:

> So often the psychological demands of caring are underestimated in comparison with the tasks of physical care. The emotional needs of all members of the family need to be recognised and supported (p. 21).

The findings presented here also identify the need for the emotional or psychological demands of caring to be recognised and reflected in the planning and implementation of family support services.

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