

2008



**The impact of
deinstitutionalisation
on the families of the
Kimberley Centre residents**

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Published 2008

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Acknowledgements

The research team would like to formally acknowledge the involvement of those families who generously allowed us into their lives during the Kimberley Centre deinstitutionalisation process. The information you provided has been invaluable to the research. We also sincerely thank you for your hospitality and your patience.

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Background and context

1.1 Introduction

The last residents of the Kimberley Centre moved to their new community homes in October, 2006 and brought an end to an era of large scale residential institutions for people with intellectual disability in New Zealand. The closure of the Kimberley Centre had been the subject of many years of uncertainty, planning and delays. The Kimberley Research Project was undertaken by the Donald Beasley Institute to evaluate the impact of resettlement on the residents, their families and staff of Kimberley Centre. The focus of this report is on family/whanau experiences of the deinstitutionalisation process for their family member who had lived at the Kimberley Centre and for themselves and other family members.

In this chapter the background to the project is presented beginning with an overview of institutional care for people with intellectual disabilities, followed by a discussion of deinstitutionalisation and its policy in New Zealand. A description of Kimberley Centre is provided along with the sequence of events that led up to the announcement that the institution was to close. Next the development of the Kimberley Research Project and the aims of the project are presented. The chapter concludes with an outline each of the chapters making up this report on families' experiences of the resettlement process.

Over the last century a number of different terms have been used to refer to people who have an intellectual impairment. People with an intellectual disability is the terminology currently used in New Zealand and is adopted in this report. In this chapter, however, on occasions where reference is made to historical material the terminology of the time is used.

1.2 Institutional care

Moves to separate the “mentally ill” from the “mentally deficient” saw the emergence of institutions exclusively for people with an intellectual disability. In New Zealand the Mental Defectives Amendment Bill in 1928 allowed certain institutions to be set aside for the care and training of “mentally deficient” children. Templeton Farm School, which was located outside of Christchurch, opened in 1929 and became the first such institution to be established under the legislation. The construction of Ngāwhatu in Nelson allowed Braemar (the old Nelson

Lunatic Asylum) to in time cater for a younger group of people with an intellectual disability.¹ New Zealand's two other specialist institutions for people with an intellectual disability were established in 1945 with Levin Farm Mental Deficiency Colony (Kimberley), located outside of Levin, and in 1966 with Mangere Hospital, in South Auckland. Psychopaedic, a term unique to New Zealand, was coined in the early 1960s by Dr Blake-Palmer, the Director of Mental Health, in an attempt to further distinguish those who were mentally ill from people with an intellectual disability. Even with the existence of specialist hospitals in New Zealand nearly half of the institutional population of people with an intellectual disability in 1981 lived in "intellectual handicap" wards within psychiatric hospitals.¹

In New Zealand, as with other similar countries, the period through the 1940s to the 1970s saw a rise in the numbers of people with an intellectual disability living in institutions.² While there were changes in terminology and institution names, and some changes in practice, for example the development of medications for use in treatment and advent of behaviour modification, the focus of institutions remained largely custodial. Thomson described³ the purposes of institutions as being to "meet the basic demands of life, shelter people with an intellectual disability from the demands of society and relieve society, particularly families, from the burden of dealing with people with an intellectual disability" (p.85).

1.3 Community care

Community based services had their origins in the creation of parent advocacy groups. These parent groups were critical of the conditions offered in institutions and called for alternatives in local communities⁴ In New Zealand the Intellectually Handicapped Children Parents' Association (IHCPA) was founded in 1949. The IHCPA began as a group of parents who protested against the public sector's emphasis on institutional care for children with an intellectual disability. They also acted as a support group for parents. While parents in these groups were influenced by the dominant views of custodialism of the time, their challenge of some of the prevailing assumptions about institutional care helped pave the way for the development of community living alternatives for people with an intellectual disability.⁴

Deinstitutionalisation refers to the movement of people from institutions to community based care. As a policy, deinstitutionalisation gathered momentum in a number of countries including New Zealand in the 1980s. The implementation of deinstitutionalisation has led to dramatic changes in the sizes and types of places where people with an intellectual disability now live.⁵

The impetus for the closure of institutions has largely been attributed to three main factors.⁶ The first of these was as a response to revelations about living conditions experienced in institutions⁷ such as seen in the work *Christmas in purgatory; A photographic essay on mental retardation*.⁸ Another significant event in the history of deinstitutionalisation was an American district court ruling in 1977 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".⁹ The judge concluded that all people either living at Pennhurst, or who may potentially use Pennhurst's services in the future should be provided with service options in the community environment.

The second factor was the emergence of the concept of normalisation. Normalisation had its beginnings in Scandinavia in the late 1950s and early 1960s as an alternative to institutional care. The principles of normalisation proposed that disabled people have life experiences like those of others in the culture and society within which they live.^{10,11} Normalisation has

been a key concept underpinning deinstitutionalisation and community care^{2,12} and has had a major influence on policy and practice for people with an intellectual disability.

The third factor in the move to deinstitutionalise was the development of community based service systems.¹³ While the first voluntary community day services were started by the Wellington After-Care Association in the late 1920s, the first community services with paid staff in New Zealand were begun by the IHC in 1953.¹⁴ IHC support services (renamed IDEA in 2005) expanded from these small beginnings into being a large provider of community residential and vocational services. Over the years other community-based services providers have established residential and vocational services for people with intellectual disabilities ranging in size from small one to two house trusts, to large organisations.

In line with international trends “the New Zealand government announced in 1985 that it was adopting a policy of community living for people living in long stay institutional care”.¹⁶ This applied to both psychiatric and psychopaedic hospitals and saw the closure of “intellectual handicap” long stay wards as well as those for the chronically mentally ill in all psychiatric hospitals around the country. Among “intellectual handicap” wards to close in psychiatric hospitals were those at Cherry Farm, Seacliff, Sunnyside, Porirua, Tokanui and Kingseat Hospitals. In 1994 Mangere was the first psychopaedic institution for people with an intellectual disability to close followed by Templeton Centre in 1999 and Braemar in 2004. The Kimberley Centre was to be the last institution of its kind in New Zealand to close.

1.4 Impact of deinstitutionalisation on people with intellectual disabilities

Investigations into the effects of deinstitutionalisation on people with intellectual disabilities have largely reported improvements in adaptive behaviour, material standards, personal development, participation in activities of daily living, family contact and involvement in activities in the community.¹⁷ In a New Zealand study¹⁸ people with intellectual disabilities who had moved from an institution and/or those close to them identified a number of positive outcomes from resettlement. These included: feeling a sense of identification with their home; greater personal autonomy; pride in the acquisition of daily living skills; being cared about as individuals; a more varied life; and a greater sense of personal safety. Social and environmental factors identified as being associated with improved quality of life have included increased choice, better material standard of living, increased acceptance in community, increased opportunities for recreational and leisure activities and for using community facilities, greater engagement in ongoing personal and domestic activities and support from care staff.^{19,20}

Bigby and Fyffe have argued²¹ that deinstitutionalisation entails more than closure of large scale institutions and redevelopment of smaller scale houses. While overall improvements have been reported there has been considerable variation in some areas. Community based services have often failed to deliver expected outcomes in terms of social relationships and community inclusion,^{22,23} personal choice²⁴ and valued social roles.¹⁸ In the New Zealand context the National Health Committee’s review²⁵ of the lives of people with an intellectual disability found that services were often prescriptive, life defining and restrictive in ways that denied people opportunities to achieve “ordinary” life goals.

1.5 Impact of deinstitutionalisation on families

Despite the evidence supporting the benefits of deinstitutionalisation many families involved in such processes are often fearful of planned changes and actively oppose any change becoming some of the most vehement opponents of the closure of institutions.^{26,27} Often families report that they have been satisfied with the care their family member has received in the institution and that they want the status quo to be maintained.^{9,26} Issues identified in contributing to families' opposition to deinstitutionalisation have included anxiety about the proposed changes, lack of information in the initial stages of planning, uncertainty about the permanency of proposed new options, suspicion that it is a cost-cutting exercise, a belief that while community living is suitable for some people with intellectual disabilities it is not for their family member and concerns about untrained community staff.^{26,28-30}

Conroy and Bradley conducted⁹ the earliest deinstitutionalisation study to investigate families' opinions before and after resettlement had occurred for their family member. While participating families were satisfied with the care provided in the institution and opposed to closure they reported that they were as satisfied with the community living arrangements following the institution's closure. A similar shift from negative to positive attitudes from pre to post resettlement has been replicated in a number of studies.^{15,29,31} Increased quality of life and general happiness of their family member after resettlement have been identified as factors in changes in family attitudes.^{9,30,31}

Some enduring concerns, however, remain for families after deinstitutionalisation. A major issue is that of the long term security of funding for their family member. Families often report that they do not believe that the funding will be on going and long term.^{15,27,30} Having well trained and experienced staff also remains an issue.

1.6 Impact of deinstitutionalisation on staff

Many research studies suggest that people with intellectual disability feel positive about their move from institutional to community based living, but little research has been undertaken to gauge how staff of those institutions react to these changes. In fact deinstitutionalisation research has largely ignored the impact on staff whose lives are often profoundly changed by the closure of an institution. Where staff have been involved, it has been as informants for the people with intellectual disability whom they have been supporting in the institutional environment. Rarely have the same staff members been asked about their own experiences and perspectives on deinstitutionalisation.

There are, however, there are a number of studies that tell us what it is like to work in institutions. Staff in institutions have high turnover rates, poor morale and difficulty maintaining standards, and often suffer from feelings of exhaustion and ineffectiveness.³² It is acknowledged in the literature that across all types of institutions (including prisons and long stay hospitals) the staff unwittingly come to personify our strong negative feelings about institutions. Staff of institutions are often poorly recognised for their work and there has been little if any acknowledgment that the institution has a significant effect on their lives just as it does for the residents.³² What little documentation there is about staff in institutions does indicate that staff experience anxiety, negative feelings, grief and struggle to cope with the continual restructuring and transitioning as the institution gradually closes down. Yet management appear to do little to acknowledge these difficulties for staff. The distinction in institutions between staff (the workers) and management during the closing down process becomes more apparent and many times the staff blame the management for their predicament.

ment.³³ Moving from the institution to community-based services is also a painful process for staff. Many face prejudice from community-based staff, who believe institutional staff have out-dated skills and have nothing to offer modern services to people with intellectual disabilities.³³ On the other hand some institutional staff dislike having their established ways of working challenged by community staff. The impact of deinstitutionalisation is the specific focus of a separate report titled: “The impact of deinstitutionalisation on the staff of the Kimberley Centre.” (This report can be accessed through the Donald Beasley Institute.)

1.7 The Kimberley Centre

The Kimberley Centre is sited at an ex air force base on large grounds on the outskirts of Levin and opened in July 1945 as The Levin Farm Mental Deficiency Colony. The institution started with 42 young men who had transferred from Templeton as its first residents.³⁴ The first female residents were admitted in 1947 and also moved north from Templeton. The Kimberley Centre was to become a “home for life” for many who had been admitted as children and stayed there through their adult years.³⁴ The institution underwent a number of name changes over its sixty years that reflected shifts in philosophy and service delivery to people with an intellectual disability. The first change was to Levin Hospital and Training School in 1957, then to Kimberley Hospital in 1977 and finally to the Kimberley Centre in 1989.

In its heyday there were productive farms on site, a laundry that did the washing for the entire population at the Kimberley Centre, kitchens, shoe and clothing repairs and maintenance workshops for 900 plus residents. A special school was opened on the site in 1959. Services were held at the chapel on the Kimberley grounds and from 1966 the institution had a resident chaplain. Life at the Kimberley Centre changed over the years with vegetable production ceasing in 1966, farmland being leased out, changes in the operation of the laundry and other areas of the institution and the introduction of industrial and woodwork sections, craft and recreational programmes. A result of the shift in policy to community living during the 1980s there began a significant decline in number of people with an intellectual disability living at the Kimberley Centre with fewer admissions and more discharges. It was noted by the medical superintendent in 1982 that the Kimberley Centre had almost fifty percent more residents who were “severely handicapped” than the reported Department of Health national average for other similar institutions.³⁴

Legislation had required the Kimberley Centre to be headed by a superintendent who was medically qualified. This changed in 1989 with the State Sector Act and in 1990 the first non medical general manager was appointed. Medical care was provided by on site medical officers although by the time of the closure this service was contracted out to local general practitioners who visited the Kimberley Centre.

Nursing staff comprised of registered nurses, enrolled nurses and psychopaedic assistants, who were the biggest staff group at the institution. Separate registration of psychopaedic nurses was introduced in 1960.³⁴ A shift in training to tertiary education institutions led to the closure of hospital based training schools across all registrations. The Kimberley Centre’s school of nursing was the last to close in 1990 with the last graduation in April 1991.

The first training officer in New Zealand was appointed to Kimberley in 1955 with the aim of extending activities beyond custodial care into education, work, recreation and social activities.³⁴ In 1967 the National Training School for training officers was established at Kimberley and a three year course of study was set up in 1973. Changing policy led to the closure of the National Training School in 1989.

Over the years many other staff groups worked at the Kimberley Centre in the domestic, maintenance and administration areas. Occupational therapists were the first allied health professionals to be employed at the Kimberley Centre. Physiotherapists, psychologists, social workers, recreation officers, welfare officers and pharmacists were among the staff at various times in the institution's history. Based on 1982 Department of Health figures, however, the Kimberley Centre had a lower ratio of "paramedical" staff to residents than other institutions in New Zealand catering for people with intellectual disabilities.³⁴

After the establishment of the Templeton Parents Group in 1976 it was suggested that a similar group be set up for the Kimberley Centre. This was done in 1978 with the formation of the Kimberley Parents and Friends Association.³⁴ The objectives of the group were to work with the hospital for the welfare of the patients, put parents in contact with each other and to be involved in planning. The association was to play significant role in consultation processes about the future of the Kimberley Centre.

1.8 The Kimberley Centre Closure

The first official indication that the Kimberley Centre might close came in 1985 with the government adoption of a policy of community living for people with an intellectual disability. What was to follow was a lengthy period of uncertainty and false starts. The processes leading up to the closure occurred against a backdrop of major changes in the structure and organisation of health and disability services in New Zealand. When the prospect of deinstitutionalisation was first raised the Kimberley Centre was part of the Palmerston North Hospital Board which then became the Manawatu Area Health Board. The changes enacted in the Health and Disability Services Act (1993) brought the Kimberley Centre under the Central Regional Health Authority as funder and as part of the MidCentral Health (MCH) Crown Health Enterprise (CHE) as provider. The four regional purchasing authorities were collapsed into a single purchaser Health Funding Authority (HFA) in 1997. This was followed by the disestablishment of the HFA and CHEs in 2001 when the replacement district health boards came into existence. The Kimberley Centre then became part of the MidCentral District Health Board (MCDHB) and it was under that umbrella that the institution was to finish its days.

Some key events in the process leading up to the decision to close the Kimberley Centre were (as outlined by the MoH^{35,36} in 2001):

- * Consultation was undertaken in 1994 by MidCentral Health, the Ministry of Health Kimberley Parents and Friends Association with parents and relatives of people living at Kimberley Centre. The purpose was to explain the need to change services, propose an approach to the process of service change and to establish how the parties would work together. As a result of the meetings held a protocol was drafted to formalise the principles and processes.
- * In 1996 further consultation took place following the release of the report titled Options for the Future which had been prepared by a working group comprising Central RHA, MCH, KPFA and iwi representatives. The report presented three main options: all services remain on the Kimberley Centre site; some specialist services on a single site with others spread across the region; or all services be widely spread across the region.
- * A deinstitutionalisation plan for the residents of Kimberley Centre (July 1998 and May 1999) was prepared for the Minister of Health by the HFA. The Minister of Health refused to accept the report as he considered that it did not take enough cognizance of families' views.

- * In August 1999 KPFA sent at a questionnaire to families/nominated contact person for every Kimberley resident that asked about preferences regarding the future of the institution. The 1994, 1996 and 1998/99 background documents were analysed in comparison with the KPFA questionnaire results. The resulting report became a reference document for the Project Working Group. In November 1999 an agreement was reached with the Minister of Health that further planning processes be undertaken.
- * Following a change of government in February 2000 the Minister of Disability Issues asked the HFA to proceed with further planning processes that were to be the basis for making a decision on the future of the Kimberley Centre. The Minister directed the planning process to have three key parts: a comprehensive needs assessments for all residents to determine specific supports needs; the Project Working Group (PWG) to consider three options for future and to make recommendations so coordinated planning and decision-making for the future of the Kimberley Centre could commence; and consultation with family members/welfare guardians on future placement and service options to be completed from PWG feedback.
- * The report *Preferred Future Service Provision for the Residents of Kimberley Centre August 2001* was prepared for the Minister of Health and Minister of Disability Issues by the Ministry of Health with the assistance of the MCDHB. The three options considered were: status quo with refurbishment of the Kimberley Centre; partial deinstitutionalisation; or complete deinstitutionalisation. The recommendation of the report was for the last option and that the Kimberley Deinstitutionalisation Plan be approved and the Kimberley Centre be closed.

In September 2001 the Minister of Disability Issues announced that all residents at the Kimberley Centre in Levin would be resettled in the community over the next four years and the centre would close. At the time of the announcement there were 375 people with intellectual disabilities living at the Kimberley Centre.

1.9 Donald Beasley Institute Kimberley Project

In March 2003, the Donald Beasley Institute received funding from the Ministry of Health to commence work on research on the deinstitutionalisation of Kimberley Centre and resettlement of residents into community based services. The project was developed by the Institute and had a strong focus on identifying the outcomes of the planned deinstitutionalisation process for residents, families and staff. The Ministry of Health was supportive of the research and subsequently provided funding to enable the conduct of Phase One of the study.

In October 2005 an application was made under the Health Research Council of New Zealand Partnership Programme to complete Phase Two of the project. Phase Two of the study was designed to focus on data collection and analysis in the community based setting and its inclusion was vital to achieve the overall outcomes of the study. The project was completed under this Partnership Programme. Ethical approval for Part I of the study was received from the Manawatu Regional Ethics Committee. Approval for Part II of the study continued under the Central Regional Ethics Committee. The research team kept in regular contact with both ethics committees throughout the duration of the study.

The final research proposal was developed in consultation with the Minister for Disability Issues, Ministry of Health, Mid Central Health, Kimberley Centre senior management, team leaders and clinical teams, Te Timatanga Whanau Group, kaumatua for Kimberley Centre, Public Service Association, NZ Nurses Association, Kimberley Parents and Friends Association (KPFA), and Life Unlimited (NASC agency). All these groups provided the research

team with information and advice that facilitated the appropriate processes and protocols to be implemented throughout the study.

The broad aim of the Kimberley research project was to explore the outcomes associated with the closure of Kimberley Centre for three separate, but inter-related groups of people: residents, their families and Kimberley staff. The specific aims of the project were:

- * To compare the life in the Kimberley Centre and in community services for residents of Kimberley Centre;
- * To identify any changes in adaptive behaviours and daily functional skills among residents which occur during the resettlement phase;
- * To describe the experiences of their families/whanau of the resettlement process, and their perceptions of what it has meant for their relative;
- * To identify the outcomes and impact of the resettlement for the Kimberley Centre staff and their families;
- * To identify any issues of service quality and service gaps within the resulting community services for the Kimberley Centre residents.

1.10 Families Report

This report relates and analyses the experiences of participating families/whanau of the resettlement process for their family member who lived at the Kimberley Centre and their perceptions of what it has meant for their relative and their family. Chapter Two describes the process of the research, methods used and the participating families in the study. In Chapter Three families' initial reasons to place their family member at the Kimberley Centre are considered and their experiences of the institution are reviewed. Chapter Four outlines families' responses to the announcement that the Kimberley Centre was to close. Chapter Five investigates family reports of the processes around decision making for the resettlement of their family member. Family/whanau experiences of family member's community living following their resettlement are discussed in Chapter Six. In Chapter Seven family reflections on the resettlement process and looking to the future are presented. The report ends with conclusions from the research project in Chapter Eight.

2

Research processes, phases and participants

This chapter outlines the research processes utilised in the Kimberley Research Project relevant to the focus of this report on families' experiences of institutional closure and resettlement for their family member with an intellectual disability. The aims of this report within the wider project were to:

- * Describe the experiences of their families/whanau of the resettlement process, and their perceptions of what it has meant for their relative;
- * Identify the outcomes and impact of the resettlement for families;

The two phases of interviews with families are outlined and participating families at Phase One and Two are described. Background is given about the wider context of the project within which the research with families took place and other sources of information that were drawn upon are also identified. The chapter concludes with an overview of the analysis undertaken on the information gathered in the study.

2.1 Participants in the Kimberley Centre research project

As discussed in Chapter One considerable consultation was undertaken with stakeholder groups prior to the commencement of the study to develop the research protocols and processes. Negotiating entry into the field for the research team took place over many months.

Invitations to participate

In August 2003, 349 Kimberley Research Project-Study Information Packs were sent to the welfare guardians of residents who remained at the Kimberley Centre. Families who were interested in participating in the project indicated their interest by returning a participant interest form. Every family that expressed an interest in informing the project was contacted by a member of the research team to clarify any questions and where families wished to proceed, work through the process of obtaining informed consent. Family members who were also the welfare guardian of Kimberley Centre residents gave proxy consent for their relative to be included in the study.

Table 2.1 — The number of residents that contributed data at each phase of the Kimberley Research Project.

	Expressed Interest	Phase 1	Phase 2	Phase 3
Chose not to participate	4	—	—	—
Withdrew	1	—	—	—
Resettled without baseline data	1	—	—	—
Died during phase	—	3	3	3
Number of residents who contributed data during the phase	—	46	43	39
Number of resident participants at the end of the project phase	46	43	39	37

Table 2.2 — Participating resident age at start of the Kimberley Centre project (2003)

Age	Number of residents	Percentage of residents
31 – 40 years	14	30.4
41 – 50 years	20	43.5
51 – 65 years	11	23.9
65+ years	1	2.2
Group total	46	100

The process was slightly different for potential participants who self-identified as Maori. Initial contact with resident’s whanau was made by telephone or letter by a Kimberley Centre Maori staff member identified as knowing the resident and their whanau. This initial contact was to seek permission for a “kanohi ki te kanohi” (face to face) visit by a member of the Te Tīmatanga Whānau Group who gave the whanau information about the project. If permission was granted, the meeting took place and consent forms were either completed on the day or left with the whanau.

Kimberley Centre resident participants in the research project

Fifty-one family members responded to express an interest in participating in the project. Four welfare guardians subsequently chose not to begin as study participants and one resident was resettled to their community-based service before data collection began. Forty-seven participants started the project, however one family withdrew after the first family interview, yielding 46 Kimberley resident participants when data collection began in October 2003 (Table 2.1). Data collection continued for up to a year after each resident moved to their new community-based service (CBS). During the four years the project ran, nine participants died. Three Kimberley resident participants died at Kimberley Centre and three residents died within the first six months of moving to their home. One other resident died before contributing to the project in the last phase and two more added their story but passed away before November 2007.

Similar to institutional populations of people with an intellectual disability 29 (63%) resident participants were male and 17 (37%) were female. Five of the resident group were Maori. The age for participants ranged from 31-62 with a mean age of 44.67 years (SD=8.51). The mean age for male and female participants was similar. Nearly 93 percent of participants for whom this information was able to be collected had been admitted to the Kimberley Centre when they were under twenty-one years of age (Table 2.3). This was evenly split between

Table 2.3 — Participating resident age when first admitted to the Kimberley Centre.

Age	Number of residents	Percentage of residents
0-6 years old	19	46.3
7 - 21 years old	19	46.3
21 or older	3	7.3
Group total	41	100

Table 2.4 — Years lived at Kimberley Centre by participating residents.

Number of years	Number of residents	Percentage of residents
0 - 20 years	3	7.5
21 - 30 years	7	17.5
31 - 40 years	15	37.5
41 - 50 years	8	20.0
51 - 60 years	7	17.5
Group total	40	100

those who were admitted between birth and six years of age and those aged between seven and twenty years of age. Of the 40 residents where their file indicated date of first admission, 75 percent of participants had lived at the Kimberley Centre for 31 years or longer (Table 2.3).

Participating families in the research project

While there were three phases of data collection with resident participants, interviews with families took place in two phases: Phase One occurred before the closure of the Kimberley Centre and Phase Two occurred after their family member's resettlement. Initial invitations to participate were sent to the identified welfare guardian, however by the time interviews were conducted, it was not uncommon for other people to have become involved. More than one family member took part in many of the interviews. All of these voices were heard in the interviews and are referred to generically in this report as "family."

Participating families were widely spread throughout the North Island with nearly three quarters of families living in the lower half of the North Island. Interviewers travelled to families' homes to conduct the interviews. Interviews with non Maori families were undertaken by researchers from the Donald Beasley Institute. A Maori interviewer was contracted to complete the interviews with Maori families.

Forty-five families who had consented for themselves and their family member resident at the Kimberley Centre to participate in the research project took part in Phase One interviews. One family consented to their family member being included in the three phases of resident data collection but was not able to be contacted to arrange for either of the two family interviews. Interviews were undertaken with 34 families at Phase Two, following their family member's resettlement to community based services. At the request of two families, a second interview was undertaken despite the fact that their family member had died before resettling from the Kimberley Centre. Descriptions of participating families are given in following sections on Phase One and Phase Two.

Table 2.5 — Phase One family interview participants and relationship to family member resident at Kimberley Centre.

Relationship	Number of interviews
Both parents	10
Mother	14
Father	4
Parent(s) plus sister (s)	2
Sister*	10
Brother [△]	2
Sister & brother	1
Other	2
Total interviews	45

* Two interviews included brother-in law

△ Interview included sister-in-law

2.2 Phase 1: Before the closure of the Kimberley Centre

The first interviews with families took place between October 2003 and March 2005, with most interviews being completed between October and December 2003. A total of 65 people took part in the 45 Phase One interviews with families. The majority of interviewees were parents, followed by siblings, most of whom were sisters. Interviewee groupings in the 45 family interviews are identified in Table 2.5. Four Maori families participated in Phase One interviews. Five interviewers completed the interviews with non Maori families and all were researchers employed by the Donald Beasley Institute. Phase One interviews with four Maori families were undertaken by a Maori interviewer contracted to the project.

A semi-structured interview schedule was used to guide interviews with families. Areas covered included families' initial decisions to place their family member at the Kimberley Centre, their experiences of care at the Kimberley Centre, their initial reaction to the closure announcement, views about the closure and proposed resettlement, their family member's support needs and their hopes and concerns about resettlement. Interviews were recorded and took between forty minutes to two hours to complete. The interviews were then transcribed and a copy sent back to the families to read to make any changes they wished to send back to the research team.

2.3 Phase 2: After resettlement

Phase Two family interviews took place from October 2004 to November 2007. Second interviews with families had originally been planned to have been conducted six months after their relative had moved from the Kimberley Centre and resettled in the community. As the study unfolded, however, it was not possible to complete all Phase Two interviews with all families within that timeframe. Late notification from Kimberley Centre of some participating resident's resettlement, family ill health, difficulty contacting some families and in arranging suitable interviewer travel times contributed to delays in undertaking Phase Two interviews. Furthermore the research team was by this stage completing follow-up visits with former residents at the same time as completing Phase Two family interviews. The length of time between family member resettlement until completion of the Phase Two family interviews ranged from five to seventeen months with a median of just over eight months.

Table 2.6 — Phase Two family interview participants and relationship to family member resettled from Kimberley Centre.

Relationship	Number of interviews
Both parents	6
Mother	15
Father	4
Parent(s) plus sister (s)	2
Sister*	7
Brother	1
Other	1
Total interviews [†]	36

* one interview included brother-in-law

† total includes two interviews where family member died before resettlement

Six participating residents died either before or very soon after their resettlement from the Kimberley Centre. Phase Two interviews did not take place with those families although at the request of family a second interview was undertaken with family for two of the deceased participants about their views of the resettlement processes and options. Thirty-six families whose relatives had resettled completed both interview phases. One family could not be contacted to undertake a second interview about their family member's move. At the time of writing this report the Maori interviewer contracted to do the interviews with Maori families had not been able to arrange the second interviews with the four original Maori whanau.

Every interview had at least one of the family interviewees from the first interview. Where there were changes this was often as a result of the death of a parent or unavailability due to ill health. In some instances a family member not present at the first interview had become involved and took part in the second interview. A total of 47 people took part in the 36 Phase Two interviews. As with Phase One parents were the majority of interviewees (Table 2.6). Three researchers from the Donald Beasley Institute completed the Phase Two family interviews. In all but one instance these were conducted in family member's homes with one interview being done by phone. For 22 of the interviews the researcher who conducted the interview with the family in Phase Two had also been the interviewer in Phase One. For all but one family the researcher had also visited the family member after resettlement in their new community based service. The exception was one family who participated in both interviews but whose family member had resettled before resident data was able to be collected.

A semi-structured schedule was used to guide Phase Two interviews with families. Areas covered included how families decided on a community based service provider, family involvement in decisions, family member adjustment to resettlement, experiences of new community service provider, relationships with staff, family contact, views on resettlement, and future hopes and concerns for their family member with an intellectual disability. Families were also asked about outcomes in relation to preferences expressed in the Phase One interview for service model option and location and their earlier hopes and concerns for resettlement.

2.4 Other sources of information

While Phase One and Two interviews with families were the main sources of information, other sources also contributed to informing the report. Field notes from visits and contact

from families to the research team outside of the two interview times were drawn upon. Material from the analysis of submissions from families, whanau or welfare guardians,^{35,36} newsletters sent to families (e.g. KPFA, Life Unlimited) and media coverage of the closure and resettlement was also referred to.

2.5 Analysis

A general inductive approach³⁷ was used to analyse the data. Family interview transcripts were read to identify the themes, patterns and categories that were relevant to building a picture of families' experiences of institutional closure and resettlement for their family member with an intellectual disability. These themes, patterns and categories formed the basis of the coding schedule for the data. The development of the coding schedule was also guided by the topic areas covered in family interviews. Each interview from the two phases, before the closure and after resettlement, was then coded using the coding schedule.

Two levels of analysis were undertaken. The first was as at the group level for all participating families at Phase One, before the closure and at Phase Two, after the resettlement of family members with an intellectual disability. Data were analysed for commonalities among families and also for diversity in order to represent the range of experiences reported by participants. Consideration was given to different views expressed by participants with differing relationships to the participating resident family member. Comparison was made at the sample group level between views at two points in time as voiced at phase one and then Phase Two interviews. Of particular interest were participating families' views of resettlement and satisfaction with their family members' care before the closure and after the move to community-based services.

The second level of analysis was undertaken horizontally within individual participating families to investigate and compare their experiences and views across the time of the study between Phase One and Two interviews. Specifically data was analysed to see if there were any changes within individual families between Phase One and Two interviews regarding their view of resettlement. Outcomes as experienced after resettlement were compared with hopes and concerns for their family member reported by the family at the first interview. Any differences of opinion within a family were noted.

3

Family experiences of the Kimberley Centre

This chapter reports on families' conversations about their experiences of the care their family member received over the years they lived at the Kimberley Centre. During the interview process families discussed: their decision to seek an out of home placement; satisfaction with the care at the Kimberley Centre; views on staffing; relationships with the Kimberley Centre staff and family contact with their relative resident at living at the Kimberley Centre. The Kimberley Centre was not a static place and changes were reflected in families' experiences of the institution over, what was for most, a lengthy period of time. There were commonalities in many aspects of families' stories but there were also differences.

3.1 Decision to place a family member at Kimberley Centre

With over seventy-five percent of participating residents (for whom an admission date could be established) having lived at the Kimberley Centre for thirty one years or longer and a mean of about thirty-seven years living in the institution, families' were talking about decision and moves made a considerable time ago. Most parents who took part, however, were still able to vividly recount the events leading up to them seeking an out of home placement for their family member. A small number of siblings had recollections of the time when the decision was made, while others relied on what their parents had told them. Two sisters had been unaware that they had a sibling living at the Kimberley Centre until they were in their twenties.

For nine participating families the Kimberley Centre was not the first out-of-home placement their family member had experienced, having previously lived in other residential homes or institutions. For one family, their son had never lived at home staying in hospital after his birth as he had not been expected to live and then moving to another institution. The Kimberley Centre was the first out-of-home placement for the remaining thirty-six families. Where the age of admission was established for participating residents, admission to the Kimberley Centre was when 46% were aged under six years of age with a further 46% being admitted before they were twenty-one years of age. Only three participating residents were admitted to the Kimberley Centre as adults over twenty-one years of age, and one of this number came from another institution.

Regardless of the age of admission the decision to seek an out of home placement was described as a difficult one by most families. This was particularly the case when parents had gone to great efforts to keep their son or daughter living at home typically with little or no community support. Many parents reported resisting earlier advice from medical personal (paediatrician who made the diagnosis, family GP, district nurse) that an institutional placement would be best for their son or daughter. A number and combination of reasons were cited by participating families for deciding to look for an out of home placement for their family member. The most frequently reported reasons were:

- * increasing difficulty in managing the physical or behavioural demands posed by their family member;
- * the stress placed on the family, particularly mothers, in caring for the disabled family member's needs;
- * concerns about the impact of the family member with an intellectual disability on their siblings.

In most instances among participating families the decision to seek an institutional placement was described as being agreed to by both parents. For a small number, siblings related differences of opinion between their parents. One sister interviewed reported that her mother remained upset until her death about her daughter's placement at the Kimberley Centre.

For some, once the decision was made to seek institutional care their family member moved quite quickly to the Kimberley Centre. Others had names placed on the waiting list and moved when a place became available, sometimes after experiences of short stays before a permanent move. A small number of families, however, talked of extensive searches for residential services and having to battle either to get their family member accepted into the Kimberley Centre, or to get a placement in a timely manner.

When the shift to the Kimberley Centre eventually came this was another difficult time for families. The standard advice of the time that was given to parents recommended that they should not visit their family member at the Kimberley Centre for the first few months to allow them to settle in. One father described the time after his son's admission to the Kimberley Centre in the following way

I think we didn't go back for six months and I think the first year I think they said come every three months. And that you know, so that was eighteen months I think we saw him four times. Pretty hard on a mother...

A mother recalled

Then we packed him up and he went and it took us a long time to get over it really. We were so used to having him.

3.2 Experiences of care at the Kimberley Centre

Many families talked about a range of experiences of the Kimberley Centre resulting from changing practices at different times over the many years their family member lived there. At the time of the first interview, however, 32 of the participating 45 families described being satisfied (Table 3.1) with the care their family member received at the Kimberley Centre. Many of this group rated themselves as being very happy or very satisfied with the Kimberley Centre. The Kimberley Centre was their family member's "home" and indeed it was seen by a number of participants as a "home for life." Two families described the Kimberley Centre as having been a "haven."

Table 3.1 — Ratings of family satisfaction with care at the Kimberley Centre for relative from Phase One interview.

Satisfaction	Number of families	Percent
Satisfied	32	71
Not as satisfied	5	11
Mixed	3	7
Not satisfied	1	2
Not stated	4	9
Total	45	100

Those who expressed satisfaction with the Kimberley Centre typically reported that their family member was happy there and that they got good care in a safe environment. This common opinion can be seen through the following quotes:

He is happy, he has said it...well, if he wasn't happy we would be trying to take him out.

Excellent, marvellous (care at Kimberley).

We have no complaints with the treatment that [Son] has had there (at Kimberley), it has been brilliant, over the years I will just pop in, I won't ring and say I am coming down tomorrow and I will pop in and catch them au naturelle and you can't catch them out, it is wonderful

Well, (daughter) is happy there... It's her home basically.

The five families who described themselves as “not as satisfied” were still reasonably happy with the care their family member received but were not as satisfied with the institution as they had been in the past. They felt that standards had deteriorated over recent years. During interviews other families also expressed that the Kimberley Centre had been allowed to deteriorate and was not the place that it had been. This theme is explored further in later in this section on families’ experiences of the Kimberley Centre over the years.

The three families who gave a “mixed” rating to their satisfaction with the Kimberley Centre did so because they thought there were both “good and bad things” about the institution. Either their family member seemed happy but the family was not happy with the care or the opposite was the case with their family member not being happy at the Kimberley Centre but the family were satisfied with their care. In the one instance where the family interviewee was “not satisfied” with the Kimberley Centre for her relative this was due to a number of factors that resulted in the Kimberley Centre now not being a “nice place to be”. Among the opinions that were expressed there were no differences between relationships between interviewee and the family member resident at the Kimberley Centre and the likelihood of them being “satisfied”, “not as satisfied” or “mixed.”

Most families noted changes in the Kimberley Centre over the years that their family member had lived there. The most typically reported pattern was for families to speak of improving circumstances with shift to more personalised care, a greater number of activities and more communication with families from staff. Fourteen participating families reported that either they or their family member were not happy in the early days at the Kimberley Centre but that things had improved.

He was very unhappy to start with because to start with they weren't very good at Kimberley way back then... and where he was it was pretty basic. And they they slowly started to improve and the staff they've got now are just fantastic. They really care about each resident.

A number of other families had not been unhappy with the care provided for their family member in the earlier years of them living there but thought that things had improved over time.

We would have to say that it's (care at Kimberley) probably improved continuously over the years hasn't it, not that we had any fault with it at the beginning. . . It has certainly changed for the better. . . she does more things I think.

Nearly a third of families talked about the “boom times” at the Kimberley Centre when they considered that they saw the Kimberley Centre at its peak. They described the Kimberley Centre as a vibrant place with lots of activity going on, trips out for residents on the bus and work available for those who could in places such as the laundry.

Oh it's really been marvellous, you know actually I've see Kimberley which was possibly, that was acclaimed to be the best in the world at one stage, and we used to go there and it was lovely to go in there and see these, everybody there, there'd be hundreds, playing cricket and football and all those sort of things you know, and everybody was going out walking and things and the beautiful grounds and the buildings at that particular stage were top class.

There was a strong sense from many families that over the preceding few years the Kimberley Centre had been wound down and it was not the place that it had been. Their family member no longer had access to the range of activities that they had previously and the buildings had not been maintained. This state of affairs was attributed to the impending closure of the Kimberley Centre which had been mooted for some years before the formal closure announcement was made in 2002.

I have to say over recent years because of Kimberley being downgraded or whatever you want to say, some of the things he used to do like physiotherapy, swimming, horse-riding those sorts of things have gradually been diminished so that now he's only really getting you know general personal care. I feel disillusioned when I go there, previously I had been happy to take friends and I wouldn't take anybody there now, I wouldn't like people to go in and see my son living in that environment now because it has been neglected and run down. . . Just to walk around, there is nothing there, the laundry has closed down, there is nothing happening in the gym, it's sad.

Consistent with the high levels of satisfaction reported by families most had mainly positive experiences of care at the Kimberley Centre for their family member which was variously described as “wonderful”, “brilliant” and “marvellous” by some. Most families felt that the Kimberley Centre provided a safe environment for their relative with everything available on site to meet their needs. A number of participants also considered that very good care was provided by staff who knew and understood their family member well.

The Kimberley Centre grounds and the security provided by the institution were the two most frequently reported features that families liked about the Kimberley Centre and often these two aspects were spoken of together. Participating families considered that the large grounds provided a safe environment for their family member to walk around in attractive surroundings. This was something that many families felt their family member very much enjoyed and would miss about the Kimberley Centre. The next most mentioned like about Kimberly was the caring and dedicated staff who worked with their relative.

I think probably the big thing will be the grounds. He loves wandering around and he's not traffic savvy right? She has also got lots of space and the staff were caring. . . in Kimberley they have got all the space in the world and they go for walks around the grounds.

In Kimberley there is security.

Families reported negative experiences with the care at the Kimberley Centre at a far lower rate than positive experiences. Indeed when asked if there were any things that they disliked about the Kimberley Centre a number of families replied that there was “not a thing they didn’t like” with one family adding that they were “just so grateful to have someone to look after him (family member living at the Kimberley Centre)”. The most frequently mentioned dislike was the way the Kimberley Centre had been run down as was discussed earlier.

A few families noted their dislike of the loss of their family member’s personal possessions and clothing at the Kimberley Centre. They related experiences of visiting and not being able to find clothing and other items, including furniture, that had been given to the family member.

No, he did have a lot of possessions but he loses the whole lot. . . I couldn’t tell you how many watches he had and how many razors he has had, he never got a thing, in fact it’s a shame because he never wants to take anything back, he says no thank you I will leave it here and he looks quite worried, and it is oh no I will leave it here and I will say are you sure, he never wants to take anything back.

Another area of dislike for a few families concerned the handling of their family member’s money. Some felt that the money was not well accounted for and that money was spent on clothing or other items that the family felt was not suitable. Three families reported not liking the number of villa moves that their relative had experienced at the Kimberley Centre. They felt these moves occurred often for administrative reasons rather than for the benefit of their family member. These families felt that the villa moves had set their family member back each time they happened and it took quite a while for him or her to settle in the new villa. Those negative experiences with moving were the basis for some of their concerns about how their family member would adjust to moving from the Kimberley Centre as it was for a number of other participating families.

Every time (son) is moved, even at Kimberley, from villa to villa, it sets him back. He hasn’t liked it as he loses touch with his friends. The only thing that we didn’t like about every now and again there, that they change villas, because of things there. And she takes a little while to settle down, sometimes quite a long time, we’ve gone there and she wouldn’t even be, talk to us, she’d just run away you know, and of course she’s out of her environment you know.

Other dislikes mentioned included the institutional nature of noisy and crowded villas, lack of personal space, locked doors, the lack of activities, the number of drugs that their relative was taking and some of the staff on one particular ward. One family member reported disliking visiting her brother at the Kimberley Centre and never felt comfortable with the environment. A small number of families spoke of past incidents at the Kimberley Centre which resulted in an unhappiness with the care provided. These involved poor treatment of the resident family member by staff, unexplained injuries and not being notified of or consent gained for a medical procedure.

Adequacy of staff

The majority of families were very positive about staff at the Kimberley Centre describing them using words such as “wonderful”, “caring” and “fantastic”. They most frequently talked about the direct care nursing staff as this was the staff group they had the most contact with. Generally families viewed staff as dedicated people who knew their family member’s needs

well. There was acknowledgement from two parents that staff did a difficult job, one that they would not be able to do.

*We can't praise them (staff) enough
I think she has got security down there, I think she has very very very much got security because they know exactly what her needs are.
A lot of those staff – most of them – are dedicated because they wouldn't be there if they weren't dedicated because it's a heck of a job. It really is a heck of a job coping with those residents.*

A number of families mentioned staff by name who they felt gave very good care to their family member or who had taken particular interest that had extended to taking their family member on trips, to the staff's home, or arranging a birthday outing in the staff's own time. One family spoke of the real love and caring that staff showed towards their relative.

A smaller group of participating families were mixed in their views about the adequacy of the staffing. One family considered that although generally the care was quite good there were some nurse aides “who shouldn't be there.” Another felt that compared with past years the present staff “don't care as much” and in a similar vein one interviewee thought that the staff had been “better in early days, some of better staff have left”. Some families noted that with the impending closure staff were “doing a difficult job under difficult circumstances”.

Family and family member relationship with the Kimberley Centre staff

Families spoke of varying experiences in their relationships with staff at different times of their family member's life at the Kimberley Centre. The distance that the family lived from Levin also impacted upon the type of relationship with staff that was possible. About a third of families who commented considered that they had a good relationship with Kimberley Centre staff. They felt welcomed by and able to talk with staff. One father even said he classed “staff as family”. Five families noted that they found staff in recent years to be more open to families than they had been previously, that there was better communication and that their opinion was sought more. One of this group speculated that this situation may have arisen for her because of a past complaint that she had made about her relative's treatment. One family, however, felt that staff did not communicate with the family as well as they used to. Another commented that staff in the villa changed so much it was difficult to have a relationship with any of them.

Several families expressed their concerns for staff. This related both to working in the institution as things wound down for the closure and for what they would do in the future. Many hoped that the Kimberley Centre staff would work in the new community homes.

I try to say good things to the staff when they go there, and let them know that I do appreciate it but some of them are just hanging on there until they retire. The staff themselves... I just feel for the whole community because they have worked there, they have worked there by choice, they like working there. And I just feel sorry for the staff.

A number of other families reported not having much interaction at all with the Kimberley Centre staff. Those who lived a distance from the Kimberley Centre and were unable to visit were restricted to their relationship with the Kimberley Centre staff largely being by phone or letter. There were also a number of families in this group who had in the past visited the Kimberley Centre regularly and established relationships with staff but because of ill health or not driving any longer this relationship had lessened considerably.

Family contact with family member living at the Kimberley Centre

There were changes over time for many families in having their family member resident at the Kimberley Centre home to visit and in the visits that they were able to make to the Kimberley Centre. This occurred as parents aged and were not as able to have contact as in earlier years. A number of participating siblings had taken on some of the contact with their family member that their parents had previously had but the demands of their own family or shifts had reduced what was possible in many instances. For those who lived at greater distances from Levin visits to the Kimberley Centre were more difficult to organise.

About a third of participating families reported a pattern of reasonably frequent visits to the Kimberley Centre. For those who lived closer, it was possible for resident family members to visit their family at home. Regular contact had been kept up over a period of many years. For many in this group, however, ill health, no longer driving, or finding the resident family member harder to handle had contributed to a significant decline in the frequency of contact.

Eleven families said that they did not visit often. This group included some who did not drive, did not have access to transport or who could not afford the cost of making the trip to visit. One mother who lived a considerable distance from Levin, and could not afford the transport costs, had never visited her son in the Kimberley Centre. Other family who had lived closer had however been to visit her son at the Kimberley Centre.

Some families told of just popping in to see their family member at the Kimberley Centre while others would phone first to organise. A number of families outlined a routine whereby they would take their family member out for a drive when they visited although for some this had lessened over recent times as they found it more difficult to manage their family member's behaviour. Time was spent on the ward also. Five participating families commented that they found that they could not do much with their family member in that environment. Reasons for this included their relative being focused on staff when they were in the ward, the ward environment being stressful, and getting bored due to the fact there was nothing to do.

3.3 Summary

The official announcement that the Kimberley Centre was to close came in the context of families' experiences of care for their family member resident there. This shaped families' views on the closure and what they considered to be acceptable for their family member. An exploration of families' views of the care their family member had received at the Kimberley Centre showed variation. However, an overwhelming majority of participating families reported feeling satisfied with the level of care provided in this setting. Particularly important to families was the belief that the Kimberley Centre had provided a happy and safe home for their family member, often over a prolonged period of time, and that there was nothing to be gained by changing this arrangement. Most families acknowledged the work of Kimberley Centre staff who were judged by families to be dedicated, caring and knowledgeable. Families' reflections on the Kimberley Centre highlighted the changing face of the institution with families identifying periods of great positivity, as well as times when the Centre, in their view, provided less satisfactory support to their family member. It is significant to note that most families commented on their displeasure at the way the institution had been left to deteriorate during the lead-in to deinstitutionalisation. The families who participated in this research reported a range of visiting patterns and habits and while most families endeavoured to keep up regular contact with their family member, reasons of age, ill-health and geographical distance sometimes made this difficult.

4

Family responses to the Kimberley Centre closure announcement

Chapter Four outlines participating families' responses to the official announcement made in September 2001 that the Kimberley Centre was to close and that all residents would be resettled in the community. Families' initial reactions to that announcement, along with their position on the closure and views on resettlement are presented. The main sources of information used by families are identified and families also discussed how adequate they had found the information provided. Actions undertaken by families in response to the closure announcement are outlined along with families' perceptions of the understanding of their family member resident at the Kimberley Centre of the process.

Phase One interviews with families are the main source of information for this chapter. Most of these interviews took place between October and December of 2003. For a few participating families this first interview took place later and therefore a longer time had elapsed from the closure announcement. Where this time delay might have impacted on interviewee responses it is noted.

4.1 Initial reaction to announcement

Most participating families reported having been aware of the possibility of the closure of Kimberley Centre for some time prior to the actual announcement. A number dated this as far back as the mid 1980s when deinstitutionalisation was embarked upon as a policy in New Zealand while other families mentioned the consultation and reporting processes undertaken between 1994 and 1999. This background of awareness, however, did not mitigate against strong emotional reactions from many families when the announcement was made and a timetable given for the closure of the institution. The most commonly reported initial reactions to the news from participating families were feelings of anxiety, upset, worry, fear and even panic.

*Well we didn't like it at all... it was upsetting to us.
For the first time in years of course I felt uncertain.
In a panic, in a panic.*

Table 4.1 — Participating families’ positions on the Kimberley Centre at time of Phase One interviews.

Position on closure	Number of families	Percent
Opposed	31	69
Mixed	6	13.3
Positive	6	13.3
Not stated	2	4.4
Total	45	100

Some families expressed “anger” at the closure announcement, saying they were “appalled” and “horrified.” A few families thought that government “cost cutting” was behind the decision. Families spoke of their sadness that their resident family member was to lose their home. Even though there had been signs for sometime with other institutional closures and the Kimberley Centre buildings being run down a few families reported shock and disbelief that the decision to close the institution had been made.

Many families talked about immediate concerns that were raised for them once the closure announcement was made as to “where their family member would go?” They had viewed the Kimberley Centre as their family member’s home for life and could not envisage anywhere else where their relative could be settled and happy. A number of parents commented that it was particularly difficult at their stage of life to have to be considering again where their son or daughter would live. Fears were expressed by some families that their relative would be placed with an existing community service provider with whom the family had had previous bad experiences or may even be returned home to the family. Even among some of those who were who were positive about the closure the official statement still bought with it concerns about where and when their resident family member would shift.

Four families reported that at the time of the announcement they thought that the closure would not happen. By the time of the Phase One interviews, two of these families were resigned to the fact that the Kimberley Centre would indeed close. The other two families, however, still considered that a closure of the institution would not happen. Three participating families stated that they had decided to put their worries on hold until they were approached directly about their relative’s resettlement.

Five participating families spoke of not having any particular reaction at all when the official announcement was made as they had been expecting the announcement, although not necessarily supporting the decision. These participants either had links with or were on the KPFA committee so had what they described as some insider knowledge. One sibling who disliked the place the Kimberley Centre had become talked of feeling a sense of “relief” that finally a decision had been made and a timetable put in place for resettlement.

4.2 Families’ positions on the closure of the Kimberley Centre

Not surprisingly given the high levels of satisfaction with the Kimberley Centre reported in chapter three, the majority of participating families were opposed to the closure of the institution (Table 4.1). At the time of the Phase One interviews 69% of the sample group rated themselves as opposed to the closure with many voicing a strong and vehement opposition.

A bloody big mistake (to close Kimberley).

Completely screwed up (decision to close). I don't think it's fair. And I think that's the saddest most stupid thing our government have ever decided.

Among the 31 families who were opposed to the closure, 22 stated their preference for the the Kimberley Centre site to continue to be used with an upgrading and redevelopment of the facilities there. Some families used the term “sheltered village” while others spoke of “clustered housing” on the Kimberley Centre grounds. Most wanted new purpose built residential facilities.

I was suggesting that they had the facilities there, they had the staff there, instead of spending all that money on new locations and new staff, it would be a far better idea if they turned around and upgraded what they had already got. That's been my thoughts since this started off. Why can't they subdivide and sell off what's not required and establishing on what they retain – I think it's an ideal spot myself.

A few in the opposed group of families told interviewers that they were resigned to the closure and did not think that they would get their desired redevelopment of the Kimberley Centre site. Most, however, remained adamant in their opposition to the closure and in their belief that the best option was the redevelopment of the Kimberley Centre.

Six participating families were positive about the closure. One brother described the Kimberley Centre as “outdated” and another sister was glad that institutions “were a thing of the past”. Families who were positive about resettlement could see possible benefits for their resident family member in living in a smaller home with greater opportunities for more individualised care and activities. Some also were looking forward to having their family member move to live closer to the family.

I am quite happy that it is closing but I would just like to know where [Family member] is going. I think that is probably a good thing that the place is closing down, it is dated, it is, I mean it was probably some of the blocks that they are in now, are probably past their use by date.

At the time of the Phase One interviews most families had not embarked on the process of looking at and deciding on community based services for their family member. One mother who had, however, had only become positive after seeing the house that was proposed her daughter.

I never wanted her to go into the community. When it was first (announced) – no way. There was no way I wanted her to go because I thought this was a bad thing for her... but then when we really thought about it and talked it all out and for (daughter)... its probably ideal for her. Because, I've seen the house... So I have come around to that way of thinking that this is best for (daughter).

The remaining six participating families were mixed in their position on the closure of Kimberley Centre. For most in this group there was a sense that resettlement for their family member could be “good in some ways” offering possible benefits but they still had concerns about the difficulties in shifting for their family member as they had “lived at Kimberley for so long” and it was their “home”.

Among the participating families there was no pattern of different views on the closure dependant on the relationship between the interviewee and their family member. A small number of interviewees, however, did report that there were some differing opinions within their family about the closure. Two siblings reported that their mothers were more anxious about the closure than they were.

4.3 Families' views on resettlement in the community

Many but not all participating families had negative views about their family member living in the community. The Kimberley Centre was regarded as their family member's home and had been so for many years. A commonly expressed opinion was that their relative was too old and had lived at the Kimberley Centre for too long to be resettled successfully. A number held the view that their relative would not be able to cope with the change. For these families there was nothing to be gained by their family member resettling and they predicted that their family member could even suffer a decline in health and quality of life if they were to move from the institution.

She is going on 60, she can't be deinstitutionalised. She can't be helped, the time to help her was way back 25, 30 years ago. It's too late now to do it, she's an old lady, she is tired, she has chronic heart failure, high blood pressure... let her stay at Kimberley.

When he went to Kimberley I didn't like that to start off with but at least I thought well the break has been made and this has been his home for life now and in fact that hasn't happened and I think he is settled there and now he is going to be uprooted and put somewhere else.

But I don't think she'll actually gain anything... it'll upset her for a start because of the change.

I don't think he has anything to gain if it was just to move in to a house in a street which is the sort of thing [one disability provider] has been pushing for and they want them to live a normal life and I think that's pushing it too far because they are not normal, they can't live a normal life. They have got to have special needs and special things and I don't think just living in an ordinary house in a street, he probably couldn't cope with it.

Another theme expressed by families was that while community living was suitable for some people with an intellectual disability it was certainly not for their family member. These families were of the view that those who were able to cope had already left the institution and that their relative definitely did not belong to that group. Institutional care was viewed as the best and most appropriate option for their family member. Some even saw institutional care as the only option. A few families believed that their relative's behaviour problems would not be able to be managed in a community setting.

I don't think that as far as (daughter) and people like her are concerned that there doing any good, I think that they should be in an institution, when I say institution I mean something like Kimberley... because we didn't think (daughter) could handle outside

I think they are down to about 360 but that's still a lot of beds to find, so the ones that are going to cope in the community have already gone

Eight expressed the view that deinstitutionalisation was not successful policy. It was described as an idea that had been imported from overseas and pushed by people who did not understand the needs of people with an intellectual disability like their family member. A couple of families voiced the view that deinstitutionalisation had "failed" and a number of others related examples from the media as evidence of the folly of pursuing such a policy.

I really think that someone makes that decision who doesn't know enough about intellectually handicapped people. Because you see on TV sometimes these poor souls who can't really look after themselves, they're plonked in a flat or something and they might be able to get out and buy a bit of food, but you'll see them just

deteriorate, deteriorate, deteriorate. And they're just open home to anybody that wants to rob them or anything like that don't they? Because they're trusting.

Several families believed that the community was not accepting of people with an intellectual disability. This was even the case for one mother who was positive about the closure for her daughter. These families were concerned that their family member would be isolated living in a house in the community and that they would be vulnerable to abuse.

To go out and live in the community like that, you know and they're not wanted, it's not a nice thing to be there, if they go out into the community they've got to be wanted.

But this wonderful thing called the community, will come to the party and provide a lovely living environment for these people and everyone will live happily ever after, and I'm sorry I just don't buy it. . . I know a lot of IHC people in those houses are really isolated from the community, it's very difficult for them to interact with the rest of the community and be accepted, I see them walking the streets quite lonely.

It was not uncommon for families to speak of the Kimberley Centre as a community where their relative had friends and that had all the facilities that their family member needed. Unlike other communities Levin was seen as being accepting of people who lived at the Kimberley Centre because they were used to them.

I believe Kimberley is part of the community of Levin, it's always had good interactions with people in Levin and other places in Levin, so I don't regard it as some isolated concrete type thing called an institution.

Twelve participating families thought there could be gains for their family member in living in a smaller home that was more personalised, afforded greater opportunities to do more things, and was closer to family. Nine from this group had positive or mixed feelings about the closure while three were opposed the closure.

I personally think that (brother) could really do well in a smaller house. . . I think having a smaller number of people – and I imagine in a house there would probably be more one on one contact with the staff – I don't know, but I would think that would be good for (brother). . . my understanding is that people from institutions go back to the community and live in more sort of normal environments more like a family or independent – well not independent living, but. . . less of a being looked after, less of a patronising kind of. . .

One sister who was very hopeful about possible positive benefits of resettlement for her brother expressed regret that this had not happened sooner for her brother as there may have been greater benefits from an earlier move.

It will just be the making of him, because it will actually really bring him out of this, I'm like this and I don't have to bother stuff. . . So I think it will be really good from his perspective – I guess the only sadness is that it's actually in his later years and it's a pity that the turn around or the benefit that he gets from it will be fabulous, but perhaps not as potentially as good as it could have been if we'd done it so much earlier.

Among participating families there was a slight tendency for siblings to be more favourably disposed to resettlement in the community for their family member. However, this was by no means the pattern for all participants. There were siblings who had negative views of community living and parents who were positive.

4.4 Main sources of information about the closure identified by participating families

The use of the term information in this section refers to information about the closure process and resettlement options in a general sense rather than to more specific detail relating to individual resident family members.

KPFA was by far and away the most frequently cited source of information by families with 58 percent (26) participating families citing them as either their main source or among their sources of information about the closure. Meetings organised by the KPFA and their newsletter were frequently mentioned by families. A small number of participants were active in the KPFA and often were privy to information before it was more widely available. Some families mentioned receiving information via the Kimberley Centre or directly asking the Kimberley Centre staff. A smaller number identified Life Unlimited (NASC agency contracted to undertake service coordination for residents resettling from the Kimberley Centre), the Ministry of Health and MidCentral Health as sources of information. It is likely that a number of the unidentified newsletters and meetings mentioned by families came from the previously mentioned sources but in the mass of information that a number of families reported receiving there was some confusion as to what information came from where.

Two families who lived quite a distance from Levin and were unable to get to any of the regional meetings had other family who attended the Kimberley Centre meetings on their behalf and passed information back to them. A number of other families living further away spoke of being reliant on mailed information that they received. For some this was difficult to understand and they would have liked to have had more face to face contact. The whanau group and media mentioned by one family were each a source of information about the closure process.

4.5 Activities undertaken

As with the preceding section the activities described as being undertaken by families relate more generally to responses to the closure than to specifically finding out about and deciding on community based options for their individual family member. There were some families who were further along the path of resettlement for their relative and three participating families had chosen a new community service provider by the time of the Phase One interview. Some mention is made of these activities for those families in this section but detailed discussion concerning decision-making for all participating families follows in Chapter Five.

Throughout the interviews there was a strong sense from families that the driving force for activities that they individually undertook in response to the closure announcement was to get the best possible outcomes for their resident family member. This occurred whether they were gathering as much information as possible in order to make an informed choice, seeking out potential community service providers or lobbying for cluster housing. Many families spoke of having to be advocates and fight for their family member as their relative was not able to speak for themselves.

I mean he is your son and he can't speak for himself.

She's got no control over anything, she has got nothing that she can say I want this, I don't want that, she has got no say in anything, no voice, she is voiceless.

As identified in the previous section many families attended meetings about the closure and resettlement processes, including some meetings where community based service providers

talked about their proposed services. This was a forum for getting information and, for some, a venue at which to express their opposition to the Kimberley Centre's closure. This was less of an option for families who lived some distance from Levin. Even though some regional meetings were organised not all families in those areas were able to attend. Some families networked with other families who had a relative living at the Kimberley Centre. Where this occurred, both in the Levin area and other areas, it was often facilitated through KPFA links.

A number of participating families were actively involved in lobbying for cluster housing to be an option available to residents resettled from the Kimberley Centre. At the time the Phase One interviews were conducted many families did not know whether cluster housing would indeed be an option funded by the Ministry of Health. Several families spoke of indicating this as a preference on the survey sent to families by the KPFA and/or at their family member's needs assessment. Typically these earlier preferences had been for housing on a redeveloped Kimberley Centre site.

At time of Phase One interviews nine families had either visited or intended to visit Auckland to view housing options developed for resettled institutional residents. The trip was funded by the Ministry of Health. Those who had been before they took part in the first interview reported having been impressed with the quality of the housing and services they saw and said they would be happy if their relative resettled from the Kimberley Centre lived in houses of a similar standard. Other activities undertaken by one family were to write to their Member of Parliament, the Ministry of Health and to use the free phone line about the closure.

Seven families had made direct inquiries with local providers about what services they may have to offer. Some families visited housing options in their area to see for themselves. One mother approached a local rest home to see if they were be interested in having a unit for people with intellectual disabilities from Kimberly including her son. This group of families included a number who although opposed to the closure were at the time of the Phase One interview resigned to it happening and decided to be proactive in finding somewhere, so their family member could "move before they were pushed out." Three participating families had gone further than making inquiries and had chosen the community based service where they wanted their family member to resettle. The resident family member from one of these families had also visited the new home with his sister.

4.6 Family perceptions of their relative's understanding of the Kimberley Centre closure and resettlement

Only a few participating families had either talked with their family member resident at the Kimberley Centre about the upcoming changes or knew that staff at the Kimberley Centre had done so. The majority of families felt that their family member would not understand what was going to happen. Some also had concerns that it would be too confusing for their relative as they would not comprehend the long timeframes and might become upset.

We wouldn't be able to (tell son about plans for closure)... We wouldn't want to upset him. Possibly he wouldn't understand what we were trying to tell him and if he did it would upset him and we don't want to do that... We are trying to do everything we can for his benefit

Well not a lot (involved in process) because she doesn't understand it, for (daughter) you don't tell her what you are going to do until the night before of that morning. She wouldn't understand that she was going to live in a different place.

4.7 Families views on the “official” presentation of information

The category of “official” information covered both written information sent to families and verbal material presented at meetings and included that from the Ministry of Health, MidCentral Health, Kimberley Centre and Life Unlimited. These groups had a difficult task presenting information in the face of the known considerable resistance from families to deinstitutionalisation. Participating families expressed a range of views about how they found the “official” presentation of information and its adequacy.

Those who were unhappy with the “official” information and responses given felt that families had not been heard nor their expertise about their relative valued. Some described the information presented as “PR spin” using “flannel words.”

I have still got this feeling that I have been bulldozed somewhere. The closing of Kimberley was not what we wanted. We have been made to look as though we have chosen it, the way they have put it.

It was horrible, it was a terrible feeling in that meeting and she didn't listen. We asked a few questions and they were just ignored.

Others considered that the Kimberley Centre had been misrepresented with images of run down buildings that no one had lived in for years. A number of families also felt that the option of cluster housing had not been presented fairly. When first interviews were conducted with some families the option of cluster housing had not been finalised. A number of families spoke of their confusion in trying to work out who was doing what in the closure and resettlement process.

Well we don't know, it is the uncertainty, it sounds OK, they are promising all sorts of things and we are wondering what the future holds, it is confusion, OK everyone who works at Kimberley, changes in positions and different titles and all this sort of thing, saying you can have this or you can have that or this option, just got very confusing.

(Sister) gets written stuff which is often written so that it is difficult to understand and you think well what does that mean and who is that and project manager for who? . . . we think well hey, how many people are involved in this. The Parents and Friends newsletter has been quite helpful and there is some good stuff and apart from that, no, there is quite a lot of confusion.

A similar number of families considered that the information they received was adequate and reasonable, although one family said they did not know whether intentions were honourable. These families were referring to the general information that was given rather than the specifics for their individual resident family member. A couple of interviewees added that they did not think the officials knew that level of detail. Three commented that the way information was conveyed had improved considerably since the initial letter they had received informing them of the closure.

4.8 Summary

The majority of families who participated in this study reported being opposed to the planned closure of the Kimberley Centre. Whilst a range of opinions did emerge from the data, most families considered the Kimberley Centre to be the best support option available to their family member. It is important to note however, that just over a quarter of the family participants held either positive or mixed views about the planned closure

with some participants in this category expressing excitement about the opportunities that deinstitutionalisation could provide for their family member. The progressive deterioration of the Kimberley Centre over time was a disappointment to many families with nearly half at the time of first interview reporting that they wanted the Kimberley Centre to be redeveloped and upgraded but to remain on the original site.

Families frequently expressed that the activities they had undertaken at the time of the closure announcement were motivated by a desire to achieve the best possible outcome for their family member. Families sought out information about possible options, community-based providers, and joined the lobby for cluster housing. Of those who expressed an opinion about the effectiveness of information sharing strategies, there was fairly divided opinion between those who were happy with the level of official information they had received and those who were not. A number of families felt they were not listened to, and that information was disseminated in a generic sense and sometimes did not demonstrate any relevance to the specific situation of needs of their family member. Finally, there was a significant level of confusion for some families who struggled to establish “who was doing what.” It was difficult for some families to understand the specific role of the organisations and individuals involved in the deinstitutionalisation process.

5

Decision making about resettlement

In this chapter consideration is given to families' decision making about resettlement for their family member at the Kimberley Centre. In the Phase One interviews families identified their relative's support needs and their hopes and concerns for resettlement. Families also stated their preferred service options and locations. In Phase Two interviews, which were conducted after their family member's resettlement, families related their experiences in choosing community based service providers. Family involvement in the process of moving, and the actual move by their relative to their new homes are described.

Phase Two interviews were undertaken with 34 families whose family member had resettled from the Kimberley Centre. Participating residents shifted to their new homes at different times during the Kimberley Research Project as services became available. Some participating families had relatives who shifted early in the process while others did not move until the final few weeks before the institution closed.

5.1 Support needs for family member

In identifying their family member's support needs families were motivated by having their "family member's best interests at heart." As reported in the previous chapter, even though many participating families were positive about the institutional care that their family member had received they had been dismayed by the deteriorating state of the Kimberley Centre in the years leading up to its closure. As one father summed up

Our kids deserve the best and it is time they had the best

Most used the Kimberley Centre as a benchmark against which they judged how their family member's needs should be met, with care provided in community based services that "was as good as" and delivered in a similar way to that at the Kimberley Centre. A few expressed some support needs that they felt had not been well met in the Kimberley Centre. The majority of families identified very particular and individual needs for their family member. A small number commented that as their family member had lived at the Kimberley Centre for so long it was the Kimberley Centre staff who knew their relative's support needs best.

Nearly all participating families identified the need for what was either described as "full care", "full supervision" or "24 hour care" for their family member. This included the need

for a “safe and secure environment”. A number of families spoke of their relative’s high support needs in the area of health care and/or managing behaviour. For many, health needs were increasing as their family member aged. Staff in who families could “trust” were viewed as critical in ensuring that their relative’s support needs were adequately met. Important attributes identified included staff who were:

- * Caring and understanding of family member’s needs;
- * Well trained and qualified to do the job; and
- * Able to pick up the early and often subtle signs of problems.

Other support needs for their relative mentioned by families were:

- * enjoyable and stimulating activities;
- * access to medical care and specialists; and
- * having their own personal space.

5.2 Family hopes for relative’s resettlement

Families’ hopes for their relatives’ resettlement paralleled the support needs identified and the often cited “same or better care than Kimberley’ position. Some also added features that were not current such as having their family member live closer or to have their own bedroom among their hopes. Dominating participating family hopes, however, were that their relative would be happy in their new home and be well cared for.

(Hope he) enjoys his life and that he is happy and that he is safe.

I want her to go in there (new home) and be happy, be happy with her surroundings.

I want the best of care for (son)...I want to know that I can go along and see (son) is happy and contented; that he is loved by the staff and other residents and that he loves them back.

Some families hoped that their family member would be able to make gains living in an environment with smaller numbers of residents and more staff one to one time. They wanted to see their family member offered more opportunities and activities.

(That) she will have a little bit more freedom to experiment with new things.

A number expressed their hope that suitable staff would be employed in new community based services who “genuinely cared” for their relative. This was also seen as necessary in order to create an environment for their family member to have new opportunities. Having staff and residents who were compatible with their relative was also mentioned as an aspiration for resettlement.

Several families expressed the hope that their relative would resettle in a location close to their family home. This would not only make visiting easier but also would enable family to be more involved in their family member’s life than had been possible when they lived in Levin.

5.3 Family concerns for resettlement

Participating families expressed a number of concerns about resettlement for their family member, although a small number responded that they had “no concerns.” The most frequently raised concerns were about their relative’s adjustment to resettlement and staffing in community based services.

Many families were worried that their family member would not settle in their new home, that they would be too old to shift and they would not cope with the change. A few even expressed fears that their relative may suffer a major decline in their health and well being. Some raised concerns about what would happen if their relative did not settle into their new home or was not compatible with the other residents. They wondered what would happen if that situation eventuated and they did not want to have to go through the process of another shift.

For some families there were concerns that the environment would not be safe and their relative would not be well cared for. A number spoke of their resident family member having no road sense and not having experienced regular traffic conditions due to them having lived at the Kimberley Centre for so long.

Many families mentioned staffing in community based services as an area of concern. Some were concerned that staff would become isolated working in smaller homes and they would not have the same back up as had been available at the Kimberley Centre. This particular concern was a major reason for some families opting for cluster housing as they felt there was more security in a service with a number of houses on one site. Staff turnover was also a concern expressed by some.

But the worry that I have is always can they keep the staff up in an isolated place. If you have got a cluster of houses, and you have all your staff there, someone can come from the next house... That is my biggest worry is the staff turnover.

Several families also spoke of their concerns as to where community services providers would get their staff from and whether or not they would be able to attract staff who were sufficiently well trained and qualified to care for their relative.

That's my major concern about people coming out from Kimberley, who is going to look after them. What qualifications are they going to have?

Another concern raised by some families was that their relative would lose the companionship of staff and residents that they had experienced at the Kimberley Centre. Others feared that there would not be enough funding or resources to do the job properly and that adequate support systems might not be in place.

5.4 Making the decision

Participating families had different experiences in deciding on a community service provider that were impacted upon by where the family lived, the preferred service model and location for their family member and when resettlement occurred. Families contact with the Needs Assessment and Service Coordination Agency Life Unlimited varied with some having a lot of contact throughout the process while others had very little dealing directly with the new community based service provider early in the process. Some relied on guidance from Life Unlimited in seeking out service providers while others took the initiative themselves. A few families who had chosen a service provider at the stage of the Phase One interviews disappointingly had their plans fall through and they had to revisit the process of finding a community service provider.

A common theme that emerged for many families in the early stages was that of the difficulty in being asked to choose a service provider when they did not have direct knowledge of available options for their family member. One father summed this situation up in the following way:

We had a number of meetings and we were given pamphlets on this provider. . . they said well here they are, you make your choice. Well you couldn't actually go, you don't buy a house unless you go and have a look at it do you, or a car, or anything else and it was very, very difficult. In my opinion we were placed in a difficult position of having to choose providers without even – I mean I had never heard of New Zealand Care. I had never heard of MASH, where do I go to find out about them, nobody knew. . . So how can you possibly make appropriate choices for your family member when you don't know what you are trying to choose or can't see what you are trying to choose.

The process of deciding was compounded for some when there was confusion about who was responsible for what aspects of resettlement and when there were changes in the personnel who were dealing with the process.

By the time we got there you had different people wearing different hats and then you think you have got it sorted out and they have moved on and you have got another job and you think oh my gosh, back to the drawing board again.

For most, however, a pattern emerged of families feeling much more comfortable with processes and making decisions when they had met potential service providers and learnt more about their plans and intended practices. This was even further improved when families were able to visit other houses run by the provider or actually view the intended house for their family member.

When I went to see the houses in (in selected location). . . I was just – because I had never seen it before, I had never seen it before and I had no idea what these houses were like. I didn't know but as soon as I walked in, I thought cripes this is what we need, exactly.

I had confidence in what they were telling me and it gave me the opportunity to find out things for myself. It gave me the opportunity to go and see the house, see what I thought. This was all before it was altered. . . but. . . yes, the quality of the house.

Most families reported that they were happy with the decision making processes that they experienced and that they felt their wishes were heard and respected. For some families this continued after the new service provider had been selected to being involved in helping select sites for housing and choosing furnishings and colours for their family member's new home. A few families took part on selection panels interviewing for community staff for their family member's home. Where these involvements occurred families were very appreciative of being included.

One family reported having to “stick to their dibs” to get their desired location for their family member, but did get what they wanted. A few families felt that they had not been consulted adequately or in a couple of instances not at all when decisions were made about where and with which provider their family member would resettle with.

*I didn't choose it, we were just told. We were just told that it was (service provider) that was going to provide it. We didn't choose it. There was **no** choice – we got a letter to inform us that a house had been purchased in (location) and there had been no consultation at all with the parents.*

Some families whose relative had shifted early in the resettlement process expressed relief that they had been able to do so. They felt that they had probably had more choice at that stage, their relative avoided being “pushed out” and they avoided the scramble at the end before the closure of the Kimberley Centre.

And we're probably quite lucky in the way that (daughter) was one of the first few that are going because I would be very worried if it was at the end. Where are they going to get the staff then? It's going to be a shambles.

Service option

When asked at Phase One interviews what service option they wanted for their relative a number of families felt that they did not have enough information at that stage to make that choice. Many, however, had very definite ideas either as to what they wanted or what they did not want in a service provider, some of which were based on not wanting their relative placed with existing community services where families had had previous bad experiences.

Among those who had a preference, 21 families nominated cluster housing and about half of this group wanted it to be on the Kimberley site. A further three were seriously considering cluster housing as the option they would eventually choose. Eleven of participating families whose family member resettled did move to cluster housing. Where this initial preference did not result in being the option that their relative moved to it was typically because there was a greater preference for the family member to live closer to the family and cluster housing was not available in that location. Only one service provider was funded to provide cluster housing and this only happened in Levin and Palmerston North.

Among other participating families three had chosen a service provider and one family had been notified that their family member would be moving to a home located close to family. These were all single house community group homes. In two of the instances where the family had selected a service provider the proposed homes did not eventuate and families had to engage with another service provider.

Location

As has been discussed earlier, many families wanted their resident family member to settle nearby to where the family lived. For some this overrode their desire for cluster housing and their relative resettled in a community group home closer to family. For others their preference for cluster housing dictated the location of resettlement which often was not closer to family.

I also wanted him to go in to a cluster housing and the only way he could go in a cluster house he was to stay in Levin.

Two parents expressed concerns that it might be too upsetting for their son or daughter if they shifted too close to their families. Their family member did move closer to them but did not resettle in the same area as the parent's home. For four families the move was not as close as they would have liked. For two, their family member was closer to them than when they lived in Levin but still some distance from where family lived. For the other two families who lived in the Wellington area, their family member resettled in cluster housing in Levin.

Choices available

While some families considered that they did have choices in resettlement options, for many their choices were limited by available providers in their preferred area or dictated by their choice of cluster housing. Families whose relative moved early tended to indicate that they had a greater range of choices.

I think we were given quite a lot of choices actually. I think at the end of the day they realised that (brother) also had rights and so did the families and they wanted the integration to be as smooth as possible and try and fulfill all the needs of all the people and so we were asked what would be the best options that we thought as a family would be best for (brother).

Most cluster housing did not become available until just before the Kimberley Centre closed and those participating families who had a relative who moved to this option were amongst the last families to see their relative resettled. They also had no choice of provider as there was only one.

In the end it was really Hobson's choice.

No, no choice, (service provider), they had the franchise if you want to put it that way.

A small number of families who had not opted for cluster housing also reported that they had no choice and had simply been told who their relative's new community based service provider would be.

When the time came I was told that (service provider) are doing it, so I didn't actually get a choice.

Reasons for choosing

Many of the reasons given by families for choosing the option that they did have already been discussed in preceding sections. Cluster housing was the preferred choice for some as they felt this option offered greater security and more available staff support with a number of houses on the same site. Other families wanted their family member to be closer and so chose options in the same area as the family lived.

Where families had choices and were able to talk with service providers or visit community homes they chose on the basis of what they thought would best suit their family member and themselves. Some liked what service providers said they would offer. They were impressed that services said they would involve and consult families. They were also impressed by the staff they met who would be working in new services. For those who visited homes they felt the atmosphere created was one in which their family member would thrive.

5.5 Family involvement in the moving of family members

As previously discussed some families were able to be involved in decisions around their family member's new home such as deciding on room furnishings and selecting staff. Some families who lived close to where their relative was going to resettle also took their family member to visit their new house before they shifted although usually they were not able to go inside as houses were still be altered. A couple of others thought that the Kimberley Centre staff had shown their family member where their new home was.

Yes, they would go for a visit every now and then. They were very clever the way it was all done. She was taken to visit and then taken back to Kimberley... as it (new home) was being finished so it was just lovely. Very well thought out, marvelous.

During the course of construction I would actually take him there too on a weekend. I will take him, and, he went around like this, yeah you are right (son), that's your house there. So that's the way I handled it and I thought I was more

concerned initially about how [son] would handle it. I wasn't too worried about myself. I thought I can do this but he handled it very very well and I still think he has but I think that little bit of just sort of extra ground work if you like, I think it made all the difference.

When residents had been able to visit their new home prior to resettlement, families considered that this had been beneficial to them in making a successful transition. Most participating residents, however, did not have the opportunity to visit and their first sight of their new home came on the day they shifted from the Kimberley Centre.

A number of families spoke about how hard it was for their family member at the Kimberley Centre as the institution wound down and familiar staff and other residents “disappeared” from their villa.

It was hard but when (son's friend) finally left Kimberley (son) mourned, there is no other word for it. He wouldn't sit down in the day room, he wouldn't watch television, he stood with his face in the corner.

There was also sadness for families as their connection from the Kimberley Centre became more remote.

We have no connection, there was no personification of Kimberley at all. I really wouldn't know who to write to.

When the time came, a few families were able to be with their family member on the day they resettled. They went to the Kimberley Centre and then accompanied them during the move to their new house.

Yes it is quite interesting because I actually involved myself with (brother's) shift. I actually came up here with the van and picked (brother) up and went all the way down to the (new home). It was good and he was as happy as, it went quite well. He didn't seem to mind.

A number of others were able to arrange to be at the new house either when their family member arrived or soon after. There was no such positive experience for one family member, however, who had wanted to be at her relative's new house on the day but was not notified of the shift.

5.6 Summary

Families' decisions relating to the resettlement of their family member were motivated by consideration of that person's best interests. While families were aware of and to some extent involved in collective action and activity with regard to the Kimberley Centre closure, the needs of their own family member took precedence for them. Particularly, families were focused on achieving a high level of service quality and an environment where well-trained staff were available to support their family member. Unsurprisingly, families reported that their relative's ongoing happiness was their greatest aspiration for the future. Families shared a number of concerns with regard to the planned resettlement of their relative. These concerns largely centred on issues of safety and security, staffing quality, and loss of companionship of the Kimberley Centre residents and staff in this study. For these reasons a significant number of participants expressed preference for cluster housing models of service delivery. When the time came to make the decision about which community provider their relative would utilise, some families reported feeling unsupported and ill-prepared to make an informed choice. Particularly, families felt they were required to choose a provider when they did

not have direct or complete knowledge of the options available to them. For most families however, this lack of confidence about their ability to choose the best provider for their relative dissipated after meeting potential providers and learning more about their plans and intended practices. Families who were particularly satisfied with their role in the decision-making process tended to be those who felt their wishes were heard and respected, and those who had had an active involvement in choosing colours and furnishings for their family member's new home. Furthermore, families expressed greater positivity about the actual transition process in situations where their relative had been shown his or her new home prior to resettlement, and when family were also involved in this process. However, this was not the case for most residents who tended to experience their new home for the first time on the day they moved into it.

6

Family experiences of community based services

This chapter reports on Phase Two family interviews which focused on families' experiences of the care their family member had received since resettling in community based services. Families talked about their family member's adjustment to their new home and their satisfaction with the care that their relative had received. Families' views on community staffing, their relationships with community providers, and contact with their relative are discussed in this chapter.

Phase Two family interviews took place from October 2004 to November 2007. The length of time between family member resettlement until completion of the phase two family interviews ranged from five to seventeen months with a median of just over eight months.

Thirty-four families whose relatives had resettled were interviewed. There were commonalities in many aspects of families' stories about resettlement but there were also differences.

6.1 Family member adjustment to move

Most participating families considered that their family member had settled into their new home and that the move had gone well.

No it went incredibly smoothly. . . he just seemed to adapt to a different place. . . it was just like he had lived there all his life. He just kind of slotted in.

This was to the relief of a number who had had been concerned that either their relative would not cope with the shift or that they would take a long time to settle.

He went in at 10.30 the day he went in, and we went down at 2.30 and he was just so different, you couldn't believe it. His eyes were calmer and he was just sitting there, in his chair like he sits in all the time, his comfy chair and he was wonderful. . . the worry that we had was how are these people going to react to the shift. Will we have to take them a couple of hours and back again and a couple of hours later on but (son) had shifted straight in, with no troubles.

Table 6.1 — Ratings of family satisfaction with care after resettlement in community based services.

Satisfaction	Number of families	Percent
Satisfied	27	79
Mixed	5	15
Not satisfied	1	3
Not stated	1	3
Total	34	100

Other families reported that it took a longer time for their relative to settle. families felt that this had now occurred. For two participating residents, health problems soon after they moved delayed their settling in.

She took a while to get used to it. If they couldn't find her she would be out standing by the van waiting to go back to Kimberley. So it took a while and we didn't go and visit her for a little while just to let her settle in but she is very happy.

For a small number of participating residents families reported that there continued to be some ups and downs with their behaviour. However, most in this group felt that overall the new services were managing and that their family member was settled and adjusting to the change. The difficulties for one such person had not been resolved and her family reported at the time of the Phase Two interview that she was about to shift to another home in an attempt to address the problems she was experiencing.

6.2 Experiences of care in community based services

When families talked about their experiences of care this mainly related to residential care as this was the aspect that families were most familiar with. Some families also referred to day support services or other supports that they had familiarity with. At the time that Phase Two interviews were conducted the majority of families rated themselves as being “satisfied” with the care that their family member was receiving in community based services (Table 6.1). Indeed a number in this group expressed that they were “very happy” with the care and it was better than they had thought possible. As had been the case with the Kimberley Centre, an important factor on which families based their satisfaction with care was that of their family member’s happiness. Sixteen of the participating families whose family member had resettled spoke of their family member being “happy” in their new home with a number of families adding that their relative “seemed happier.”

(Brother) seems very happy as well. We do ask him, he does say he is happy. And I think he would say something if he was not.

Some families gave examples that reinforced to them how comfortable their family member seemed and that they liked their new home.

She is certainly very happy there, she loves it. She loves her own room. She taps her bed and turns it down herself, yes, really nice... you always get taken down there and she shows you all the dressers and all the things in the wardrobe, she likes that and then she always has to go to the bathroom and you have to look in there and say oh isn't it lovely. There are lots of things she likes.

I think they have just made her a person. Made her an individual person and I don't think I can really say much more about it you know, they recognised her as a person. . . They haven't dumped her in as a lump, she is an individual person.

Many families commented that they felt that their family member was well looked after and their support needs were being well met. Descriptors included “fantastic care”, “excellent care”, “well catered for” and “its brilliant”.

Wonderful (care), couldn't complain about anything at all.

Well in (daughter's) case they couldn't (do anything better) because it is A1 as far as I am concerned.

Several families expressed their delight in the more individual care that their family member received and the improvement in their relative's well being. For some there was pleasure in seeing their family member learn and do new things.

I never ever dreamt that [son's] new home could be so good – because [house] is lovely, it is teaching him as much as it can teach him, and the staff are very loving and caring.

He seems really happy. He has got this neat chair and he hangs out, he has got a good life, he seems quite relaxed and happy about the changes. . . He has gained a far better life style. He has gained more variety. He has just got a far nicer life style now. I mean the physical atmosphere of the house is nice. He is living in a nicer place and obviously he is going out far more and he's one of only five so he has got a bigger place in there. He is not just another person in the wheel chair third from the left. So yes, he is more of an individual. And he has got more opportunity. He will do more stuff.

His health has improved because he is not sitting in the chair all the time and he is able to walk around for himself instead of having to be wheeled around. . . I think it has been extremely beneficial for my brother. I have seen incredible. . . he is actually able to do things he wasn't able to do at Kimberley probably because of the situation of being in a large group and not enough staff to cater for the independence needs that would be beneficial to them whereas you can do that in a community home that he is in and they actually emphasise that and they allow him to do that.

A number of families were impressed by the standard of the housing that their relative had resettled in. Families also liked the “homely” atmosphere that had been created with one noting that his brother's new home was a much “more user friendly environment” than the Kimberley Centre had been.

And it is, it is just like walking in to my house. They haven't probably got all the little knick knacks that we have got, but you know for the lounge, they have got a beautiful wooden table and the nice bright china, it is just brilliant and the pot plants and everything and to me a lot of home houses haven't even got that.

A few families were “mixed” in their satisfaction with the community based services where their family member had resettled. While there were many aspects that they were happy with, there were others that did not meet their expectations. In the main this group were happy with the care provided and felt that their family member was happy in their new home. A common area of disappointment for these families was that more was not done with their family member in supporting them in activities or learning new skills. In one instance the family felt that their family member was doing fewer activities of daily living.

Sometimes I feel a bit cynical and I think they talk the talk but what actually happens during the week. They do say that they go out every day and they have

these programmes and stuff and I sort of think well how do I know, how do I know that that is really happening? They tell me, but I don't know... When I go there, one thing I find difficult... when I go and visit (brother), they are all kind of mooching around with nothing happening. I don't know what they are doing there and I find that a bit depressing I suppose.

I just don't feel that the support that is there is professional enough if I can say that. I mean most of them that are there are carers and they are wonderful and they just really look after them. They have got a hard job looking after them etc but I just don't feel completely satisfied with it and I don't really know why.

One of the things that (family member) did (at Kimberley), the staff there, took her every day and that and hung the washing out and at the house, when I went to the house and was shown the house, the washing line and everything and where the thing was, now this was supposed to be, now this was in (family member's) plan for going there, was to do those activities. Well they don't have time, that slows them up too much with her and so it has been a bit of a disappointment as far as that is concerned, the actual activities at the house.

For the family who were “not satisfied” with community based services for their family member there were concerns about the standard of care that was provided. The family felt that health care needs were not well recognised by staff. Also reported that they were not happy with the number of activities available and thought the staff did not have access to sufficient resources.

Features of their family member's resettlement that were appreciated and valued by families included:

- * “homely” environment, lovely atmosphere;
- * their relative seemed “at home” and comfortable and could move freely around the house;
- * spacious and well designed houses;
- * family member has their own room, personal space and personal possessions;
- * family member doing more things, a number of families commented that their relative was more communicative, saying more words;
- * family member had choices;
- * more individualised care and like the way staff treat their family member; and
- * closer and easier for families to visit.

These elements of community living appreciated by many participants' families are summed up in the following quote:

She loves the idea that... that is her home, it is hers and she can stay there as long as she likes, you know, this sort of thing and possessive of that because she only has the one or two carers or something there with her... I think she likes the freedom, she can wander where she likes. She doesn't have to go and sit in the chair and wait for tea or whatever, she can go in the lounge or she can't watch TV but she is listening to TV or she can wander on where she wants to. The feeling of space as well because the rooms and everything you know, there is so much more space than (villa at Kimberley). I am sure that's what she loves more than anything, is that whereas Kimberley wasn't home, it was never mentioned I am going back home. It was always I am going back to Kimberley)... Here, she says home, now I am going to go home and it has become her home.

A number of families responded that there was nothing that they did not like or had concerns about in community based services. However, there were disappointments these included:

- * not having the same access to some activities their relative had done at the Kimberley Centre (for example swimming, Riding for the Disabled (RDA), disco in town);

- * not doing as much and not having the opportunity to participate and learn as much as family had expected;
- * day service facilities, support and opportunity not delivered to a standard expected by families;
- * not mixing with other houses in the cluster to the degree that the family had hoped for;
- * house record keeping and safety procedures not being performed to a level expected by families; and
- * staffing changes (for example one team leader per house to one team leader for two houses).

The following quote illustrates the disappointment that one family felt with regard to their expectation of service quality not being met.

Well to me, there wasn't any thought put in. (Son) didn't have to think of anything, he would just pick up the brush and go like that and he had done it. Before, he used to be so thrilled when he had actually done those other things. He had done it with his hands and he knew he was making it for me and he was really thrilled about it. . . I feel that he could be doing more than he is actually doing.

While most families said they could not identify any gaps in services or supports a small number of families identified a number of problem areas. These included:

- * a lack of access to swimming and other activities;
- * some services not being set up when family member arrived;
- * a lack of involvement in the community;
- * medical support not as good as it should be;
- * inadequate safety procedures;
- * no registered nurse in charge of the home (after being assured an RN would be in that position); and
- * inadequate level of staff training.

Adequacy of staff

Families had varying experiences of community based services staff. In the main, however, families reported finding community based staff caring, and as having a good understanding of their family member's needs. A number of families expressed their appreciation for the work the staff did and for how they related to their family member.

At (house) they are well staffed there. . . Yes, they are lovely staff and how they entertain her at day support services I would not know because she does nothing and it is very hard to capture her attention.

Well I mean these caregivers, they are just a mum, and they have just taken [daughter] as another child under their wing like all the others that are there as well. Yeah, um, no I think it has worked out wonderful really.

I think there are some staff down there that know him and understand him very well and one particular one seems to be the one I am generally in dialogue with but there is also another guy there that has been there for the phone calls and we have had a chat as well and he seems to know and understand and like him and have a lot of empathy with (brother) so those are all nice traits.

The actual day to day staff and we saw them when they were all brand new wondering what on earth they had taken on so that was a bit interesting but some of them, and the ones who were closest to him, had really warmed to him. It has been quite extraordinary.

A few families expressed concerns that while most staff seemed “caring” they needed to have more support and training so that they could do more with the people they supported. They also perceived some staff as not being professional enough. Families felt that some staff were good at the care but not so good at supporting their family member to access greater opportunities in the community. There was also the perception that service providers had, in some instances, taken the staff they could get and that such staff did not always have the necessary background or experience to do a great job.

They do seem to struggle trying to get staff.

I feel that if they are going to have the carers there it is fine while they are doing the physical things for them, but I do feel they need support and need a bit of training themselves and some of them have? I know it is very very difficult to get staff for things so they have to take what they can get I suppose but I feel that ones that have had no contact with these type of residents should have some training.

While some families experienced stable staff in their family member’s residence, others noted that there had been some turnover of residential staff since their relative’s house opened and they had seen a number of different staff faces in a short period of time. A number spoke of the relatively low pay for residential staff and wondered how this would impact on both staff retention, and on attracting new staff.

Family and family member relationship with community staff and service providers

The vast majority of participating families reported that they considered that they had good relationships with community services staff, at both direct care and management levels. Many commented on how approachable they found community staff, and that staff were friendly and made them feel welcome. Most families felt that there was good communication from the community service and that they were kept well informed about their family member.

A number of families reported some variability in the relationships that they were able to establish with staff – some direct care staff seemed more interested in families than others, and families felt more comfortable with some direct care staff than with others. A few families felt there could be an improvement in the relationship they had with staff and in two instances families commented that they felt relationships with staff were strained as a result of certain events with their family member or issues that the family had expressed concern about. One family felt they had better relationship with direct care staff than with the management of the community-based service their relative utilised.

A number of families commented on the difficulty in establishing relationships when staff always seemed to be changing. A few had had limited contact with staff as they did not live close to the service and therefore had not had a lot to do with family member’s home but in these cases there was contact by letter and phone.

Most families felt that their voices were heard with regard to their family member’s ongoing care and that they were able to have some influence. Many reported being invited to attend, or attending where they were able, meetings about their relatives lifestyle plans and needs assessments. A number reported that they felt if there was an issue for their relative they would be able to talk it through. One family member noted the greater level of involvement that the family was able to have in the community based service than had occurred when their relative was living at the Kimberley Centre.

Yes, and whereas before historically that’s been advocated because we were not allowed to be involved because there was a bit of a shut door policy with Kim-

berley and if complaints were raised the doors would go down and so on and so forth whereas with this one, we certainly have much more access and ability to do something with that

Another added that while she felt listened to, she also respected that the community service provider would make good decisions for her daughter.

Oh I think so (able to influence support) but then at the end of the day they are the professionals at that, not me, and so I respect whatever that they are actually doing but when they raise anything I always voice my opinion on it and it is up to them to take it as they see fit and I think that they do listen... We haven't had any issues really to deal with but I do feel that I am being listened to.

A few felt, however, that they were not able to shape the supports that their family member received as much as they would have liked, and while they were listened to, changes were not based on family concerns or suggestions. One family reported a dilemma in not being happy with some aspects of her family member's care but not wanting to be placed in the position of being seen as a complaining parent. This family felt their family member's care suffered as a result of their fear of acting on their concerns. One family found they were not as able to be as involved with community services as they would have expected, due to the service's attitude and approach toward them. This made the family feel as though they were not welcome and that their suggestions were unimportant.

6.3 Family contact with family member following resettlement

Generally families reported being able to have more contact with their families in their new community homes, and certainly this was the case for those families whose relative had shifted closer to them. In one situation, however, an on-going period of being unsettled experienced by a former Kimberley Centre resident meant that family visits agitated him still further so at time of interview the family had been unable to make desired visits to their relative's new home. While many families had visited the new home soon after their family member had arrived, two parents had kept to the practice advised when their son or daughter had moved to the Kimberley Centre and had not visited for some time so their family member could settle in.

In making visits to family member's new home families were positive about the following factors:

- * that making visits was much easier and, for most, closer to their family home;
- * they could see their family member more often;
- * they were made to feel welcome;
- * they could just pop in anytime;
- * they were invited to birthday parties and other special events; and
- * that a greater number of family members were now able to have more regular contact with relative.

Some had got to know the other residents in their family member's house and had met other families. A number commented that they felt more comfortable when they visited and that there was more to do with their family member than had been the case during visits to the Kimberley Centre. For one family however the reverse was the case due to the location of the house and layout of the property.

As with the Kimberley Centre, family ill health and/or not being able to drive had limited visits and some families had not been able to visit as much as they would have liked. Some

still had a distance to travel between where they lived and their family member's new home. One mother reported her son's reluctance to visit her at home when he would not come past the gate when delivering a Mother's Day present – she speculated that this was because he liked his new home so much and he was scared he may have to return to the Kimberley Centre. Two mothers commented that they were disappointed that the community service had not made the effort to bring their son or daughter to visit them when they had been unwell and unable to get to their relative's home.

6.4 Summary

Families' experiences of community-based services were sought during interviews completed during Phase Two of the study. Most family interviews took place approximately eight months following the resettlement of men and women with intellectual disabilities from Kimberley Centre into new homes in the community. Most families who participated in this phase of the research reported feeling satisfied that their family members had experienced a positive transition and that they had settled well into their new environment. This finding contrasted with families' fears as expressed during Phase One of the project whereby a significant number of families predicted that their family member would not respond well to the transition from the Kimberley Centre. Only a small number of the families who participated in this research reported having experienced difficulties with regard to their relative's transition, or that early difficulties had remained unresolved. The vast majority (79%) of participants stated that they were satisfied with the care that their family member was receiving in the community-based service setting and many spoke of perceiving their family member to be as happy or happier in their new home than they had been at Kimberley Centre. It is important to note that some families commented specifically on the greater degree of personal autonomy, and the way their family member's individualism was celebrated in their new home. A small number of families expressed mixed feelings (15%) about their family member's new home and these mixed opinions seem largely to centre on families' expectations not being met with regard to opportunity for personal development that they wished to be available to their family member.

For the families who were not satisfied (3%) with their relative's community placement there seemed to be a pervasive mistrust of the standard of care being delivered by the community-based service and a perception that healthcare needs were not well recognised.

While most families valued and appreciated the efforts of community-based service staff, families frequently expressed concerns about the level of experience and training that staff possessed. Coupled with this concern was that of the difficulty that families saw community-based services as experiencing with regard to recruiting and retaining staff. Overwhelmingly families reported having good quality relationships with staff working in their relatives new homes and that they saw themselves as being able to be more involved in the home and with their relative's daily life than was the case when they were living at the Kimberley Centre.

7

Reflections on resettlement

In this chapter families' reflections of the deinstitutionalisation implemented at the Kimberley Centre are presented. Specifically, families' views prior to resettlement actually occurring are contrasted with their perceptions following the resettlement of their relative into community-based services. Information relating to families' experiences of community based services, their views of "community" and the impact of the deinstitutionalisation process on their family is also presented. Chapter Seven also incorporates families' responses to a number of serious "incidents" involving ex Kimberley residents now living in the community that were covered in the media during the conduct of this research and concludes with families hopes and concerns for their family member with an intellectual disability.

7.1 Family views on resettlement post closure

As described in Chapter Six, most participating families reported that they were satisfied with the care that their family member received following that person's transition from Kimberley Centre. The level of satisfaction with new services reported by families was similar to those given by families regarding their satisfaction with care at Kimberley Centre before the closure of the institution (see Tables 3.1 and 6.1). Figure 1 illustrates the level of satisfaction families felt with regard to the care their family member received at Kimberley Centre. Figure 2 illustrates the level of satisfaction families felt with community-based services at least six months following their relatives' transitions.

The comparative satisfaction with care at the Kimberley Centre and community-based services for the 34 families whose member resettled from the Kimberley Centre to community-based services (CBS) is shown in Table 7.1. During the conduct of Phase Two interviews families were asked their opinion on resettlement following institution closure and the resettlement of their relative (Table 7.2). Among families whose family member had resettled in the community the majority were positive about the move. This is compared to a majority who were opposed to the closure at Phase One. This is illustrated in Figures 7.1. and 7.2.

Overall, most families reported that the transition from the Kimberley Centre into a new community-based service had been a positive one for their family member. This general and frequently expressed perception is best illustrated by the following quote which identifies positive impacts for both the individual and for his or her family.

Figure 7.1 — Families' satisfaction with care at the Kimberley Centre and community based services.

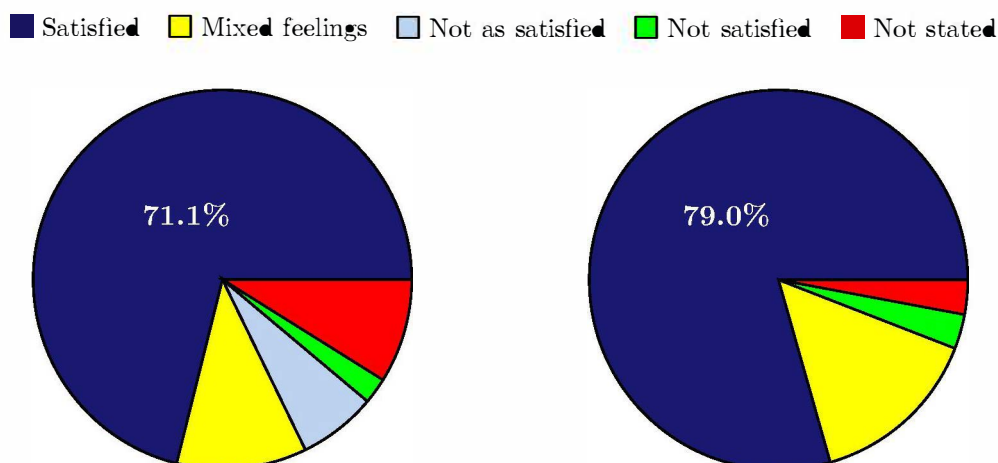


Table 7.1 — Satisfaction with care.

Satisfaction with care	Number of families
Satisfied both Kimberley and CBS	18
Satisfied Kimberley/mixed CBS	5
Satisfied Kimberley/not satisfied CBS	1
Not as satisfied Kimberley/satisfied CBS	2
Mixed Kimberley/satisfied CBS	4
Not satisfied Kimberley/satisfied CBS	1
Satisfied Kimberley/not stated CBS	1
Not stated Kimberley/satisfied CBS	2
Total	34

Table 7.2 — Families' position on resettlement at Phase Two.

Family position on resettlement	Number of families	Percent
Positive	25	73
Positive but	2	6
Mixed	1	3
Negative	1	3
Should have redeveloped Kimberley	4	12
Not stated	1	3
Total	34	100

Oh a brilliant thing (resettlement), brilliant for (family member), for the whole family.

While most had been satisfied with the care at the Kimberley Centre, at the time Phase Two data were collected a number of families reported that they perceived the care to be better in community based services than had been delivered in the institutional setting, and that their family member was happier.

And she is happier, you can see in herself, she is happy just to sit there and you talk to her and she is looking around and doesn't miss a thing, she has got to know what is going on every minute, anybody moves, she knows – and that's good whereas at Kimberly they would sit her in front of the TV and she would stay there or put her in her bed and she would stay there.

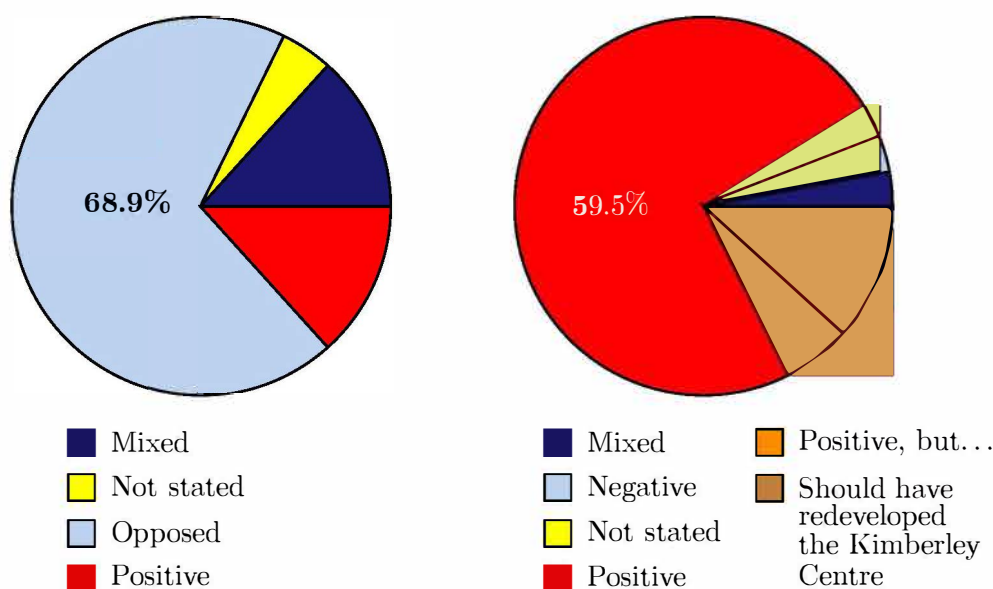
Several families commented that they had not expected their family member's resettlement to work out as well as it had.

I didn't think it (resettlement) would be as good as it is for (son), She has been there (Kimberley) for so many years and she seemed happy there but it was just sort of hospital type but knowing what we know now, I didn't expect it to be this nice, the houses, I didn't think for a minute there would be so much comfort and well looked after. I think it is all for the best now Since he has gone to (community based service), as far as we are concerned personally, that's the best thing that ever happened to him much to our astonishment

Others expressed that they had “changed” their mind about their initial opposition.

In a way, while being totally opposed to start with, I am exactly the opposite now.

Figure 7.2 — Families' positions on the Kimberley Centre closure and resettlement.



One mother expressed how pleased and positive she was about the closure even though she had initially been opposed.

I have seen differences and I am thinking now why was I so (afraid) – and I guess it is because the fear of the unknown. How would it work for him and because he has had so many, well most of his life, in an institution, one which was terribly horrendous, I am glad it is bull dozed and its gone, good job

A number of families wondered whether there may have been greater benefits for their family member if options similar to the community-based services had been available when they made the decision to seek out-of-home placement, or if their relative had been able to move from the institution sooner. While for some this bought sadness thinking of what might have been, there was also acknowledgement that the Kimberley Centre was the best available option at the time.

Table 7.3 — Position on resettlement for the 34 families whose family member resettled before and after the Kimberley Centre closure.

Position before closure/after resettlement	Number of families
Opposed/positive	20
Opposed/positive but	1
Opposed/negative	1
Opposed/should have redeveloped Kimberley	3
Mixed/positive	3
Mixed/mixed	1
Positive/positive	2
Positive/positive but	1
Positive/not stated	1
Not stated/should have redeveloped Kimberley	1
Total	34

Totally, totally, (happy with shift) yes, yes, I mean goodness if only we could put the clock back, I mean what we did when she went in to Kimberley as a nine year old, could we have – she was marginally functioning, she was continent when she went there, she had speech when she went there and everything she lost. But you can't go back. It meant that the rest of our family could function.

Where families held a “positive but” or “mixed” position they were generally accepting of the level of care their relative was receiving and felt that their family member was happy in their new home but their reservations linked to the sense that services “could be doing more”. Such reservation about the community-based services was found to relate particularly to families’ perceptions that their family member had limited opportunity to enjoy a diverse range of activities, or to enjoy greater independence, personal development or personal autonomy.

I am not complaining about the way they are looking after him, I just think a bit more thought could go in to what they give him to try.

The one family who held a “negative” position post-resettlement had experienced problems with the community service provider’s care of her son and felt that it was not a good place for him to be living.

I feel that [the provider] have not provided the service that I was expecting...I don't think that that is the right environment for him (son).

At the time that Phase Two interviews were conducted, four families were still of the view “that the Kimberley Centre should have been redeveloped.” It is interesting to note that two of this group rated themselves as satisfied with the care their relative was getting in community-based services.

Comparing the position held about closure for the 34 families interviews whose relative had resettled there was a shift in position for the majority with 20 families who had initially been “opposed” at Phase One being “positive” at Phase Two. Among the four who had been “mixed” three rated themselves as “positive” after resettlement and one remained mixed.

Among the four who were positive before the closure, two remained positive at Phase Two, one was mostly positive but thought there could be more done for family member and the “not stated” family had not been able to visit their relative as hoped and subsequently felt unable to answer a question regarding their views post-resettlement. A number of families made comparisons between their experiences of their family member’s involvement in community-

based services with their previous experiences of the Kimberley Centre. Most viewed the community more favourably in these comparisons. The most frequently cited advantageous comparisons were that in the community-based service there was:

- * better quality of life for family member, better lifestyle;
- * more personal care, one to one contact;
- * own bedroom, privacy.

Families also noted that:

- * family member more alert, seems happier in themselves;
- * family member was more communicative, learning to do more, can make more choices;
- * easier to access staff, family has more contact with staff;
- * easier to visit family member, more contact with family member, family member seems more comfortable when family visits and family more comfortable visiting family member's home.

Families made far fewer comparisons where the Kimberley Centre was viewed in a more favourable light than their family member's current community-based service. Where such comparisons did occur families commented on:

- * Limited outdoor space for relative at CBS compared with the Kimberley Centre;
- * Relative had access to fewer activities, (eg. no swimming or RDA);
- * Family member more isolated at CBS than at Kimberley Centre;
- * Family member had less independence than they had at Kimberley Centre;
- * Kimberley Centre staff better qualified.

7.2 The "community"

In the context of the current study only a small number of families talked comprehensively about the level of community inclusion or integration they felt that their family member had actually achieved following their transition from the institution into the community. A number of families however made specific mention of the fact that they appreciated that their family member had the opportunity to be "out and about" doing regular things like going to the hairdresser, having coffee at a café and other such everyday activities.

Yes, he really is down town and I think on a larger scale, there is a difference in culture around town and I am possibly going back further than I need to, thinking about how odd it was to see a person who was obviously IHC walking up town and I don't know – I mean I see people around town all the time and nobody seems to bat an eyelid that there is an IHC person walking by. It's not even remarkable and that's so healthy.

One parent reported that she was dissatisfied with the level of community involvement that was being offered to former Kimberley Centre residents and said that she was actively trying to resolve this gap by seeking out, and passing on to the services, information relating to a range of community activities and events.

One family expressed indignation that people with intellectual disabilities are frequently perceived as not having a right to be in and of their community.

All these people say "yes these people should be out of Kimberley, so long as it is not in our street of course". And that's someone here. (near where family member has settled) They have got a right to be on the street just the same as everybody else has.

7.3 Looking back on the process

The starting point for families when they reflected back on the process of resettlement was still the same as expressed in their initial interviews – that they wanted to do the best for their family member.

That's the key to it, trying to figure out what you can and what you can't so that's where the difficulty has been so you talk to as many people as you like but at the end of the day you have to do what you think is right for your family member and we all have different views on that and of course lots of our family members had different needs and different requirements and need to be treated differently.

For one family this also meant recognising the need to compromise:

You have to want the best for your daughter or your son but you also have to do a little bit of compromising. And (family member) has to learn that too.

Families reported varying experiences with regard to how stressful they had found the process of resettlement of their relative for their family. Some spoke of the “toll it had taken on their lives” – a toll that had extended over a long period of time. Others reported that while they were very worried earlier on they found they were “much more relaxed now.”

Well I am a happy person, I am happy that (daughter) is happy. I do not worry about her like I used to. I know she is in good hands, and I will tell you what, that's a great riddance after all those years of not knowing what is going to happen.

A few participating families thought that “perhaps the process could have been better managed.” Rather than finding their family member’s resettlement being stressful they described it as having been “frustrating more than anything” with delays in their relative being able to move and sometimes a lack in coordination between all involved parties.

Some families reported that they had not felt stressed at all by the process and did not consider that it added any extra responsibilities for them. One mother, although initially opposed to the closure found that it had been “exciting being part of it all” and another family member said she had “learnt new things” from being involved.

Several families reported that they had not been prepared for a role that involved property management (under the Protection of Personal and Property Rights Act, (PPPR Act) 1988) and that this had also been a time consuming task for them. These families felt that they could have been better prepared for their property management role and felt disappointed that they had not received relevant information from the Kimberley Centre or any other service or organisation about what was required of them in this role.

7.4 Family responses to “incidents”

It is important to mention that a small number of high profile incidents relating to former Kimberley Centre residents were reported in the media during Phase Two of the research with families. A few families commented on these reports and some did have family members directly involved with some of the incidents. The families who did talk about these incidents to the research team were horrified that these issues had occurred and the major concern for one family was that a representative from the service provider involved had said that they could not guarantee that such an incident would not happen again. Others however saw the incident where a former Kimberley Centre resident was seriously assaulted by staff as a rogue incident and removed unconcerned about their own family member’s ongoing safety. Given

the level of upset and mistrust about the safety and security of community-based services prior to resettlement occurring, it is interesting to note that families had grown to trust their relative's community-based service to such an extent that serious incidents could be rationalised in this way.

7.5 Looking forward to the future

Although many families spoke of feeling more comfortable about the future for their family member now their relative was happily resettled, they reported that they continued to feel it necessary to remain vigilant about their relative's care. One family member expressed those thoughts the following way:

Because these people need, they need care you know and they are vulnerable and if it is all down to money and they are saying they are not getting enough money, or they are just not getting the right assistance from the government, and the government has got to come out and do their bit because this is going to go on and on.

Families' key hopes and aspirations for their relatives' futures were centred on the desire for standards currently seen in the community-based services to be maintained into the future. Their hope was that their relative would continue to make improvements and gains in their level of independence, and most importantly, that they would continue to have a nice life.

A significant number of families said that they now had no future fears or concerns but for those families who did hold concerns, they centred on the following issues: Staffing, particularly staff recruitment and retention issues; the adequacy of funding and resourcing; the impact of service management changes; and the response to the ill-health of their relative.

7.6 Summary

Families' reflections on their relative's life after the Kimberley Centre highlighted very positive perceptions about the impact of resettlement. Families were, for the most part, extremely willing to articulate their changing attitudes towards the major process of social change that characterised the deinstitutionalisation of Kimberley Centre. Specifically, families described the strength of their earlier opposition to deinstitutionalisation, and in many cases expressed their delight about "being proven wrong." Similarly to previous research in this area,⁶ the discontent with resettlement that was expressed by a small number of families seemed to be based on a failure of their relative's transition to live up to the high expectations held about the potential opportunities that deinstitutionalisation could offer. These families did not simply question the quality of care that their relative received but instead identified a lack of opportunity for personal development and greater independence. Many families identified the positive aspects of their relatives' new lives in the community in comparison to that which they had experienced in the Kimberley Centre with far fewer families continuing to see the Kimberley Centre as having provided a better living environment. Overall, families who participated in this study aspired to a happy future for their relatives with the continued stability of their chosen support service being particularly important. Regardless of their stance on deinstitutionalisation, families expressed concern about the ability of the community-based service system to recruit staff with appropriate values and skills, and to retain those staff. This concern is shared by all sectors of the disability community at the present time.

8

Conclusion

This report has outlined families' experiences of the resettlement process that occurred during the deinstitutionalisation of Kimberley Centre. The findings reported here are consistent with national and international research literature relating to deinstitutionalisation and the purpose of Chapter Eight is to discuss the Kimberley Centre findings against the backdrop of this other research.

Similarly to recent New Zealand research on family involvement in deinstitutionalisation,^{6,15} families who participated in this study were found to have resisted institutionalisation as a service option for their relative for as long as possible, but to have eventually succumbed to a range of factors which progressively increased the level of stress their family was under. The decision to seek institutional care for a family member was not instantaneous but was rather a decision made over time. This finding is consistent with the findings of a study³⁸ by Blacher that identified the decision to seek out-of-home placement as a process rather than a discrete act. The purpose of exploring families' experiences of institutionalisation during Phase One of the current study provided a framework from which to approach the issue of deinstitutionalisation in accordance with Lord and Hearn who contended³⁰ that understanding the factors that contributed to families' decisions to seek institutional care is critical to understanding their later processes around deinstitutionalisation.

In the current study families were found to hold a range of views about deinstitutionalisation, and the resettlement of their relatives into community-based services. However, the significant majority of families reported that they opposed institution closure during Phase One interviews. Willer et al. contended that family opposition to deinstitutionalisation is caused by having to revisit their painful, earlier decisions to institutionalise their relative with an intellectual disability. In her study³⁹ Funnell also found that institutionalisation created long held emotional difficulties for parents, siblings and for people with an intellectual disability themselves. While families' themselves may not interpret their negative responses to deinstitutionalisation as being grounded in their earlier decisions to seek institutional care for their family member, it is clear from this research that it is important to consider the emotional responses that families have towards 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. It is also important to note that while many families reported that they felt concerned and anxious about the impact that deinstitutionalisation, some families were positive about the opportunities that

an alternate model of service delivery could offer their family member. When discussing their opposition to plans for deinstitutionalisation families frequently highlighted the deficits they perceived their family member to have. This meant that families could not see how it was possible for their family member to make a successful transition from institution to the community. Families' fears and concerns typically related to their relative's long-term stability and safety, and the perception that community-based service staff were not suitably trained or supported in their roles.

While most of the families expressed fears about the possible impact of deinstitutionalisation, they also expressed hopes and aspirations for their family members' futures, most families simply wanted their relative to be happy. Other families aspired to their family member having far greater opportunity for personal autonomy than they had been able to experience while living at Kimberley Centre

This research sought to understand how families experienced the reality of deinstitutionalisation. 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 considered⁹ 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.^{9,28-31} The present research was consistent with such findings and at the conclusion of the study only a very small number of families reported feeling negative about the impact of deinstitutionalisation. 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.

Integral to some families' positive evaluations of deinstitutionalisation was the sense that as a result of community placement their family member with an intellectual disability had been made more accessible to their family and that the family could begin to reassert itself as having an important position within that person's life. This finding links strongly with Funnell³⁹ who highlighted the centrality of familial love to developing an understanding of how institutionalisation and deinstitutionalisation impacts on families.

Research into the impact of deinstitutionalisation has far greater relevance than simply being an account of what occurred during a particular process at a particular moment in time. This study generated important information extends beyond institutional closure and can be used to assist community-based disability service providers to develop strong, supportive and lasting relationships with family. Research exploring the impact of deinstitutionalisation on former Kimberley Centre residents points very strongly to the important role of family in the lives of men and women with an intellectual disability (The impact of deinstitutionalisation on the residents of the Kimberley Centre, 2008). For this reason attention should continue to be paid to the ways in which families can be positively included in the planning and delivery of disability support services.

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