An examination of the outcome of the resettlement of residents from the Kimberley Centre
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Authors

This report was written by Paul Milner, Sue Gates, Dr Brigit Mirfin-Veitch and Dr Claire Stewart. The authors are employed by the Donald Beasley Institute.

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1 Introduction

1.1 Background

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 an intellectual disability in New Zealand. The Kimberley Centre Resettlement Research Project was undertaken by the Donald Beasley Institute to evaluate the impact of resettlement on the residents, their families and staff of the Kimberly Centre. This report presents key findings related to the study and comprises six sections. Section One provides background to the project and includes an overview of institutional care for people with an intellectual disability, and discussion of deinstitutionalisation and deinstitutionalisation policy in New Zealand. A description is given of the Kimberley Centre and events leading up to the announcement that the institution was to close. Section Two provides details relating to the development of the Kimberley Centre Research Project, the objectives, and the research methods utilised. Section Three presents findings related to the impact of deinstitutionalisation on former residents. Section Four discusses the impact of deinstitutionalisation from the perspective of families, and Section Five presents findings related to outcomes for the Kimberley Centre staff. The final section, Section Six of this report provides a discussion of linkages between study findings, the extent to which the original objectives of the study were met, the limitations of this study and plans for further analysis.

It is important to note that 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 most widely used in New Zealand at the current time and is adopted in this report. 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 Ngawhatu in Nelson allowed Braemar (the old Nelson Lunatic Asylum) to cater for a younger group of people with an intellectual disability. New Zealand’s two other specialist institutions for people with an intellectual disability were established in 1945 with the Levin Farm Mental Deficiency Colony (Kimberley Centre), 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.

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. 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 described 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 communities. In New Zealand the Intellectually Handicapped Children Parents’ Association (IHCPA) founded in 1949, 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 the time, their challenge to some of these prevailing assumptions about institutional care helped pave the way for the development of community living alternatives for people with an intellectual disability.

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.

The impetus for the closure of institutions has largely been attributed to three main factors. The first of these was a response to revelations about living conditions experienced in institutions such as seen in the work Christmas in purgatory; A photographic essay on mental retardation. A further 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”. 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 should have life experiences like those of others in the culture and society within which they live.\textsuperscript{29,43} Normalisation has been a key concept underpinning deinstitutionalisation and community care\textsuperscript{1,7} 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.\textsuperscript{23} 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.\textsuperscript{37} IHC services (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 an intellectual disability 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”.\textsuperscript{30} 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, Tokamui and Kingsseat 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 Effect of deinstitutionalisation on people with an intellectual disability

Investigations into the effects of deinstitutionalisation on people with an intellectual disability have largely shown improvements in adaptive behaviour, material standards, personal development, participation in activities of daily living, family contact and involvement in activities in the community.\textsuperscript{35} In a New Zealand study\textsuperscript{31} people with an intellectual disability 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 the 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.\textsuperscript{6,20,33}

Bigby and Fyffe have argued\textsuperscript{3} that deinstitutionalisation entails more than the 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 considered important to the life quality of people who depend on disability services for support. Community-based services have often failed to deliver expected outcomes in terms of social relationships and community inclusion\textsuperscript{2,44} personal choice\textsuperscript{15} and valued social roles.\textsuperscript{31}
The National Health Committee’s review (*To have an ‘ordinary’ life. Community membership for adults with an intellectual disability, 2003*) of the lives of people with an intellectual disability in New Zealand 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.\(^{26,40}\) 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 an intellectual disability it is not for their family member and concerns about untrained community staff.\(^{10,16,22,26}\)

Conroy and Bradley (1985) conducted the earliest deinstitutionalisation study\(^9\) 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.\(^{5,16,27}\) Increased quality of life and general happiness of their family member after resettlement have been identified as factors in changes in family attitudes.\(^{5,9,22}\)

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.\(^{22,27,40}\) Having well trained and experienced staff is also an issue that remains at the forefront of families’ contributions to deinstitutionalisation research.

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.

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.\(^{34}\) It is acknowledged in the
literature that across all types of institutions (including prisons and long stay hospitals) staff can unwittingly come to personify the strong negative feelings about institutions broadly held within the community. 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. Within the small body of research focussed on the experiences of institutional staff, it is reported 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. 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 an intellectual disability. On the other hand, some institutional staff dislike having their established ways of working challenged by community staff.

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. The first female residents were admitted in 1947, and had 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. 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 750 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. In 1974, the Government imposed a moratorium on the building of further psychiatric and psychopaedic hospitals. The move signalled a policy shift towards community living and from that time more able Kimberley residents began to leave for community-based services in greater numbers than were being admitted to the Kimberley Centre. 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. Legislation had previously 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 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. 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 to extend activities beyond custodial care into education, work, recreation and social activities. 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 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 an intellectual disability.

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. 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 a significant role in the 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 organization 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) and the 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 Ministry of Health, 2001):

* Consultation was undertaken in 1994 by MidCentral Health, the Ministry of Health, and the Kimberley Parents and Friends Association with parents and family members of people living at the 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 remain across the region; or all services be widely spread across the region.

* A deinstitutionalisation plan for the residents of The Kimberley Centre (July 1998 and May 1999) was prepared for the Minister of Health by the HFA. The Minister of Health at that time refused to accept the report as he considered that it did not take enough cognisance of families’ views.

* In August 1999 KPFA sent out a questionnaire to the families of every Kimberley resident and 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 assessment for all residents to determine specific supports needs; the Project Working Group (PWG) to consider three options for the 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 an intellectual disability living at the Kimberley Centre.
Project design

2.1 Research method and design

In March 2003, the Donald Beasley Institute† received funding from the Ministry of Health to commence work on research on the deinstitutionalisation of the Kimberley Centre and resettlement of residents into community-based services. The project was developed by the Donald Beasley Institute and was focused 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 project.

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/Whanganui 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 The Kimberley Centre, Public Service Association, NZ Nurses Association, Kimberley Parents and Friends Association (KPFA), and Life Unlimited (Needs Assessment Service Coordination agency [NASC] contracted to coordinate the resettlement process). 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 (entitled “Examination of the outcomes of resettlement of residents from the Kimberley Centre”) was to explore the outcomes associated

†The Donald Beasley Institute is an independent, non-profit research organization that aims to advance the health and wellbeing of people with disabilities and their families in New Zealand through research and education, with a primary focus on intellectual disability.
with the closure of the Kimberley Centre for three separate, but inter-related groups of people: residents, their families and the Kimberley Centre staff. The specific aims of the project were:

* To compare the life in the Kimberley Centre and in community services for residents of the Kimberley Centre;
* To identify any changes in adaptive behaviours and daily functional skills among residents which occurred 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 family member;
* 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.

2.2 An institution in decline

The deinstitutionalisation of the Kimberley Centre was the last major institutional closure in New Zealand. As such, the closure of the Kimberley Centre represented a last opportunity to document a moment of major social change for people with an intellectual disability.

For a number of decades, the Kimberley Centre was at the centre of defining best practice in the care of people with an intellectual disability in New Zealand. In 1959, an on-site school of nursing was established and five years later, New Zealand’s first Psychopaedic Nurses graduated from the Kimberley Centre. The National School for Training Officers was established in 1967 and, consistent with an understanding of institutions as self-sustaining communities, the residents contributed to the up-keep of the Kimberley Centre before being supplanted by training and day support programmes.

At it’s peak, the Kimberley Centre was the largest specialist institution in the Southern Hemisphere. The Kimberley Centre was home to 759 men, women and children in 1979 and in the 1980s\(^1\), it was estimated that 15% of all New Zealanders identified as having an intellectually disability resided there.\(^1\)

After the Department of Health Review in 1974, 200 of the Kimberley Centre residents were identified as suitable for community living and were subsequently resettled to community-based support services. This reversal of the historical flow of residents towards the Kimberley Centre continued until the gates finally closed in 2006. Residents and staff left, workshops closed and services were constantly retrenched.

When the Kimberley Centre Research Project began, 349 residents remained at the Kimberley Centre and the Centre was actively engaged in the process of managing its own closure. Like most deinstitutionalisation research, this assessment of the impact of closing the Kimberley Centre occurred, therefore, at an atypical moment in the life cycle of two different types of services. The research team saw an institution in terminal decline and a set of community-based services set up to meet the demand created by the resettlement of a large group of the Kimberley Centre residents.

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\(^1\)Estimates of the highest resident population at the Kimberley Centre vary, some sources suggesting in excess of 1000 may have lived there at one time. Hunt (2000) is cited here as a reliable secondary source.
The broad aim of the Kimberley Centre Research Project was to accurately and honestly document the impact of closure during this process of change. Because valid conclusions could only be drawn from direct observation or primary sources, an effort has been made to restrict the generality of research findings to the five years in which the research was conducted, except where the reflections of residents, families and staff could provide historical, retrospective information that could usefully inform the project.

2.3 The Kimberley Centre Research Project research methods

A number of principles guided the selection of the final research design and measures chosen to inform an assessment of the impact of closing the Kimberley Centre.

A prospective, longitudinal research method was employed. A prospective research method is a forward looking research design that identifies a population of interest prior to an environmental change and assesses its impact by measuring and comparing the performance of study participants before and after the moment of change.

The advantages of using a prospective research design are that it helps to control for retrospective bias (judging events differently after they have occurred) and minimises the effects due to individual differences in population characteristics. The Kimberley Centre Research Project is one of only two known studies that have been able to employ a prospective design to explore the impact of deinstitutionalisation in a New Zealand context.

It was also important that the study, incorporate a multi-method approach to the assessment. A wide range of sampling measures were chosen to compare the outcomes of deinstitutionalisation for residents, families and the Kimberley Centre staff. Using a wide range of measures increased the scope of the assessment and allowed the research team to explore any differences from a number of different perspectives.

Finally, analysis of the impact of the Kimberley Centre’s closure was drawn from within the Quality Of Life (QOL) construct. The QOL construct is a relatively new way of thinking about and measuring how well services are supporting people with an intellectual disability to live full and personally meaningful lives. The QOL construct has a number of important principles. One of the most important principles is that basic building blocks to life quality (core domains) are common to all people. To assess the impact of closing the Kimberley Centre on the life quality of all the three groups included as participants in the project, the research team needed to include all of the QOL core domains that are acknowledged as generically contributing to life quality.

Quality of Life research has also demonstrated that objective and subjective assessments of life quality are only weakly related. A comprehensive assessment needed, therefore, to incorporate both as measures of what contributes to the experience of living a good life. Objective QOL properties can be directly observed and measured by attributes such as frequency (the number of times something happens) or quantity (the amount of something someone has). Subjective QOL properties are harder to determine because they exist in the private consciousness of individuals and can only be accessed and verified through repeated conversation. Such attributes would include what makes us proud or what aspects of living somewhere have personal meaning and value.
2.4 Building the design around the Kimberley Centre residents

Although the Kimberley Centre residents, their families and support staff were considered to be distinct study populations, their lives and life quality intersected through common concern for the well-being of the Kimberley Centre residents.

The Kimberley Centre residents were at the centre of the Kimberley Centre Research project. Most of the people who participated in the project were drawn from within each resident participant’s support network (Figure 2.1).

In August 2003 information packs outlining the project aims and intended methods were sent to all families of residents who were living at the Kimberley Centre at that time. All families that expressed an interest in participating were accepted as study participants and those who chose to continue, gave proxy consent for their family member to be included in the study.

Figure 2.1 — The Kimberley Centre Project design structure

2.5 Building a picture of life quality before and after resettlement

The Kimberley Centre Research Project had a simple research sampling design. The project was conceived of as having two phases. In Phase I, data were collected to enable a comprehensive picture of participants’ lives to be built up while people lived at the Kimberley Centre. By repeating the same data collection measures, the picture was reassembled at prescribed intervals (phases IIa and IIb) after residents moved from the Kimberley Centre. Differences in life quality were detected by comparing Phase One and Phase Two data.
The multi-method, prospective research design employed yielded three important axes of comparison.

By sampling stakeholders at two, and for residents, three moments in time, the research team was able to capture changes that occurred in objective and subjective indicators of life quality following each resident’s move from an institutional to a community-based support setting. The research team was also able to determine if any changes occurred within community-based services between residents first moving to their new homes and their first year after leaving the Kimberley Centre.

In the context of a wider debate about the success of the dispersed community-group home as a model for the support of people with an intellectual disability, recent research had argued that cluster houses might be associated with poorer Quality of Life outcomes. By comparing the size and direction of changes in Quality of Life that occurred for residents resettled either to cluster or community-group home support models, the Kimberley Centre Research Project was also in a good position to contribute to this important debate.

And finally, there has been a tendency in deinstitutionalisation research to assume that people who live in institutions like the Kimberley Centre are a relatively homogeneous population. Given the very different support needs of the Kimberley Centre residents, the research team was interested in knowing whether the impact of closing the Kimberley Centre was experienced differently by people who had previously lived in different Kimberley Centre villas.

2.6 Research measures - Residents

To explore the impact of deinstitutionalisation for the Kimberley Centre residents, the array of Quality of Life measures described in 2.1 were employed while they lived at the Kimberley Centre and 3-6 and 12 months after resettlement to a community-based service.

The objective measures of life quality included:

**Adaptive Behaviour** Adaptive functioning for individual participants was estimated using the AAMR Adaptive Behaviour Scale, ABS-RC:2. Staff identified as knowing a resident well (key staff) completed the examination booklet, guided by a researcher at each phase of the project. The ABS-RC:2 is the standard assessment tool for adaptive behaviour with proven validity and reliability.

**Participant observation** Six 30 minute participant observations were conducted at randomly assigned times for individual participants at each phase of the project. Running record narratives were post coded by researchers into a coding schedule that recorded the location of activity, type of activity, and key elements of the nature and duration of social and communicative interaction. Inter-rater reliability and consistency was determined on a randomly selected sample of 10% of the coded summaries.

**ComQol-ID (Objective Scale)** The ComQol-ID scale has seven discrete domains that in combination, include all of the major quality of life components, including material well-being, physical well-being, productivity, intimacy, safety, place in society and emotional well-being. On the objective axis, each domain comprises three items scored on a five-point scale. The objective scale yields good internal consistency and test-retest
reliability. It has established utility as a quality of life measure and the scale has proven to be valid, reliable and sensitive to change. Key-staff completed the scale, assisted by a trained researcher during each phase of the project.

**Choice Questionnaire** Personal freedom and the ability to exercise control over decisions that affect one’s life are cherished rights and widely recognised as an essential component of quality of life. Most conceptualisations of the quality of life construct include it as a key element. The Choice Questionnaire is a 26 item scale used to assess the degree of choice available to people with an intellectual disability across various areas of their life, including: domestic matters, staff, money and spending, health, social activities, community access, personal relationships, work or day activities and general choice making. The measure has demonstrated sound reliability and construct validity and satisfactory test–retest reliability, internal consistency, inter-scorer agreement and content validity. Key staff completed the questionnaire assisted by a trained researcher to avoid problems of non-equivalence between self and proxy reporting.

**File Information** Detailed information was transposed from each resident participant’s individual file in phase one and at the close of the project. Data collection was organised around the domain themes of the ComQOL-ID and included: diagnostic information, medical and medication history, outpatients records, support plans, programmes and interventions, Special Incident reporting, material well-being, and levels of engagement within the community.

The subjective measures of life quality included:

**An individual interview** Residents judged able to consent by key staff and a member of the research team, were given an opportunity to contribute a guided interview. In the taped interview, residents were invited to reflect on how they experienced each setting with themes drawn from within the quality of life construct informing the interview schedule. Participants were also invited to discuss their hopes and fears for the future, especially those related to the move from the Kimberley Centre into community settings. Key staff were identified for residents wanting support to read through their transcript. Final copies were sent to all participants. Interviews were designed to take an hour at a place of the participants’ choosing.

**Key Staff Interview** Key staff, (identified by The Kimberley Centre management in the first phase of the project, and the residential service provider in the second phase), were interviewed in a semi-structured format about each participant at each phase of the project. The focus of the taped interview was to get complementary qualitative information to gain greater insight into residents, their support needs and how they were addressed in both support settings. Themes for the interview were drawn from within the key domains of the quality of life construct. Additional insight into how residents were “understood,” by key staff in each support setting and how they perceived deinstitutionalisation affecting each resident were prompted for during the interviews. Copies of the transcripts were posted to key-staff and analysed in the same way as resident interviews.

The Kimberley Centre Research Project would ultimately be informed by 667 participant observations, yielding in excess of 20,100 discrete minutes of coded data, 113 adaptive behaviour scales, 114 ComQOL-ID scales, 116 Choice Questionnaires, and 116 key staff interviews, with return rates ranging between 79 - 97% during all phases.
2.7 Research methods - Families

A primary aim of the Project was to ascertain how the lives of families who had a relative living at the Kimberley Centre were affected by deinstitutionalisation. Listening to families describe how they perceived the process of institutional closure to have affected the life quality of the wider family had the potential to enable a better understanding of ways to support, consult and potentially engage with families as important people within the support that surrounds some people with an intellectual disability.

Capturing family reflections about the process of closing the Kimberley Centre therefore represented one of the most important ways of advancing the other project aims of improving the quality of life outcomes for people with an intellectual disability and assisting the design of better support services.

The Kimberley Centre Research Project began with the family members of the Kimberley Centre residents participating in an interview. Families were subsequently re-interviewed as close to 6 months after their relative moved to a community-based service as was possible.

Interviews were semi-structured and conversational in tone, allowing families the chance to guide the content and level of detail given. The interview sessions took between 40 minutes to two hours and were transcribed (written out) and sent back to participants so they could edit their own interviews.

2.8 Research methods - Staff

Staff volunteered to be participants in any or all of the following:

Pre Closure Questionnaire This questionnaire was sent to all staff at the Kimberley Centre at the start of the project. There were three parts to this questionnaire. The first part focused on demographic information. Part two concentrated on the staff members’ experiences of the deinstitutionalisation process while continuing to work in the Kimberley Centre, while the final section sought information about the future for the staff and their families, including their expectations for future employment.

Key Staff Interviews Themes related to changes in the culture of Kimberley Centre, the relationship Kimberley Centre staff had with residents and staffs’ reflections about the process of deinstitutionalisation that emerged from within the Key Staff Interviews were also analysed to meet the study aims related to the impact of Kimberley Centre closing for staff. Forty-five Kimberley Centre staff volunteered Key Staff Interviews in Phase One of the project

Staff Personal Interviews during the closure process Staff were given an opportunity to have a personal interview discussing with a researcher their own personal views about the closure and the impact it was having on them and their families.

Focus groups Focus groups were offered as an alternative strategy that gave staff the opportunity to talk about their working lives at the Kimberley Centre and discuss the approaching closure in a group setting with their colleagues.

Post Closure Questionnaire Similarly to the Pre Closure Questionnaire the Post Closure Questionnaire focused on demographic information. The second section concentrated on staffs’ perceptions of the experience and effects of the deinstitutionalisation process,
their present quality of life and their personal assessment of the impact of the closure on the residents of the Kimberley Centre they had previously cared for.

**Staff Personal Interviews following closure of the Kimberley Centre** Interviews were offered to former Kimberley Centre staff to discuss their working and personal lives following the closure. These interviews allowed staff to reflect on their time at the Kimberley Centre, the good and bad aspects of working there, the impact of leaving former residents and staff, their “brickbats and bouquets” about community-based services and former residents’ responses to living in the community.

### 2.9 Recruiting participants - Families and residents

In August 2003, 349 study information packs were sent to the families of each resident who remained at the Kimberley Centre. Families who were interested in participating in the project could express their interest by returning a Participant Interest Form to the Donald Beasley Institute. Every family who expressed an interest in informing the project was contacted by a member of the research team to clarify any questions and ultimately, to begin to work through the process of obtaining informed consent. Family members who were also the welfare guardian of a Kimberley Centre resident gave proxy consent for their relative to be included in the study.

The process was slightly different for potential participants who self-identified as Maori. Initial contact made with residents’ whanau was made by telephone or letter by a Kimberley Centre Maori staff member identified as knowing the resident and their whanau well. This initial contact was to seek permission for a ‘kanohi ki te kanohi’ (face to face) visit by a member of the Te Timatanga Whanau 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 according to their wishes. Five Kimberley Centre families self identified as Maori participants.

Fifty-one family members responded, and expressed an interest in participating in the project. Four families 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 45 family and 46 resident participants when data collection began in October 2003. Data collection continued for up to a year after each resident moved to his or her new community-based service. During the four years the project ran, nine participants died. Three Kimberley Centre resident participants died at the Kimberley Centre and three residents died within the first six months of moving to their new community-based service. One other resident died before contributing to the project in the last phase of the project and two more added their story but passed away before November 2007. All information collected from participants informed the project.

### 2.10 Recruiting participants - Kimberley Centre staff

Staff were recruited by requesting administration staff at the Kimberley Centre to attach information about the research and the Pre Closure Questionnaires to staff payslips. The
Pre Closure Questionnaire included a stamped addressed envelope for staff to return the completed questionnaire to the research team.

All staff were given an opportunity to have a personal interview discussing with a researcher their personal views about the closure and the impact it was having on them and their families.

Flyers about focus groups with attached interest forms were sent to all team leaders of all the residential services at the Kimberley Centre, to distribute to each ward, unit, villa and management team. The content of the flyers was discussed at ward/villa staff meetings and staff who were keen to be a focus group participant completed the interest form and returned it to the research team. The focus groups facilitated by a researcher gave another opportunity for staff to reflect and talk about their working lives and discuss the closure in a group setting with their colleagues.

As the research team completed 3 month and 12 month visits to community-based services they met up with former Kimberley Centre staff. Additional personal interviews were offered to these staff to discuss their working and personal lives following the closure.

After the closure of the Kimberley Centre in October 2006 the Post Closure Questionnaire was sent to staff who had completed the Pre Closure Questionnaire.

2.11 The profile of resident participants

Indicative of the more general gender skewing of institutional populations, more males (29) than female (17) residents informed the Kimberley Centre Research Project. The age of resident participants ranged between 31 – 62 years. There was little difference in the mean age of male and female residents with males (mean: 44.50) being only marginally younger than female (mean: 44.94) participants at the beginning of the project.

The women who participated in the project tended to have been admitted at an earlier age and had spent longer living at the Kimberley Centre. Most participants had been admitted to an institution as children. Males had, on average, spent 80% of their lives and females 89% of their lives living on site at the Kimberley Centre.

Resident participants were drawn from all of the 12 villas that remained open at the Kimberley Centre when the project began in October 2003. Residents were assigned to different villas at the Kimberley Centre according to what was perceived to be their primary support need. Residents and staff shared a common understanding of the distinction between villa types. Eleven residents were living in villas designated as supporting people with challenging behaviours, 16 from multiple disability villas and 19 from lifestyle villas.

2.12 The profile of family participants

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. The first interviews with families took place between October 2003 and March 2004, 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. Four families that self-identified as Maori participated in phase one interviews.

Phase Two family interviews took place from October 2004 - November 2007. Thirty-six families whose relatives had resettled completed both interview phases. 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 included 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 was the case with phase one interviews, parents comprised the majority of interviewees.

2.13 The profile of staff participants

Thirty-one staff completed and returned the Pre Closure Questionnaire. Twenty three were female staff and 8 were male staff. Seven of the 31 replies were from staff that self-identified as Maori. The majority of the completed questionnaires were from Psychopaedic Assistants (direct-care staff) and day support staff with fewer replies from management and registered nursing staff. Most staff who completed the Pre Closure Questionnaire had worked at the Kimberley Centre between nine and 34 years. Six of the twelve Psychopaedic Assistants had length of service of over nine years and one had been working at the Kimberley Centre for 21 years. One Registered Psychopaedic Nurse had worked there for 34 years.

Eight staff took part in three focus groups. The participants were all female senior management and senior nursing staff. The focus groups did not attract the direct-care villa staff, with the exception of one Senior Psychopaedic Assistant who had a leadership role in providing direct care to residents. All staff who participated in these groups had worked at The Kimberley Centre in excess of 25 years - three had worked at the Kimberley Centre for over 30 years. All had started at the Kimberley Centre as young people without any experience or qualifications in the field. Two of the eight focus group participants had also completed both pre and post questionnaires.

Seven Kimberley Centre staff agreed to be interviewed about their personal experiences of working at the Kimberley Centre and discuss how the closure would impact on their lives and the lives of the residents. They included two day-support staff, two Psychopaedic Assistants, a team leader, a retired medical officer and a chaplain.

Four former Kimberley Centre staff agreed to be interviewed about their personal experiences following the closure. They included three former Psychopaedic Assistants and one Charge Nurse.

Two of these 11 staff had also completed the Pre and Post Closure Questionnaires and participated in the Focus groups.
The Post Closure Questionnaire was sent to the 31 staff who had completed the Pre Closure Questionnaire. Twelve questionnaires were returned. Of those twelve former Kimberley Centre staff, nine were female and three were male. Three were unemployed, one was a student, one was semi retired, two were in part-time work and five were employed full-time. Of the seven participants in work, four were working in services for people with an intellectual disability, one was in mental health services, one in general nursing and one was working in a rest home.

### 2.14 Data analysis (Quantitative)

Three modes of analysis were used to explore the direction and significance of differences that emerged between groups of residents or between resident performance on key, objective, Quality of Life outcome measures.

Descriptive statistics were used to explore whether general trends were detectable in, for example, the pattern of competencies expressed by residents or the frequency with which they were observed in particular locations or engaged in specific types of activity. Finer levels of discrimination were often made, with villa type (used as a form of shorthand for determining whether having a particular disability-related support need influenced outcomes) being a variable of particular interest.

For all of the Quality of Life indicator measures chosen as informative of the impact of deinstitutionalisation, two-tailed paired t-tests were used to determine the statistical significance of differences in each resident’s global, domain or event frequency score recorded at different phases of the Kimberley Centre Research Project.

And finally, multiple linear (continuous data) and logistical (dichotomous data) models were employed to explore the strength of association between a range of potential explanatory variables (independent variables) and changes in Quality of Life outcomes of interest (dependent variable). Important independent variables included:

- the length of time a resident had lived at the Kimberley Centre;
- whether a resident’s welfare guardian was a parent, sibling or other relationship;
- the distance a resident was from their welfare guardian;
- which type of villa residents lived in at the Kimberley Centre (multiple disability, challenging behaviour or lifestyle villa);
- what model of support they were resettled to (cluster or community group home);
- the age of a resident;
- the sex of a resident.

In each analysis, a number of different models were employed, using both forwards and backwards step-wise regression techniques to arrive at the model with the greatest explanatory power. Bonferroni’s correction was used in post-hoc analysis to minimise the potential for a statistically significant finding to emerge simply by chance because of the multiple comparisons that were being made.
2.15 Data analysis (Qualitative)

A general inductive approach\textsuperscript{38} was used to analyse data collected from both families and staff participants.

“The primary purpose of the inductive approach is to allow research findings to emerge from the frequent, dominant or significant themes inherent in raw data, without restraints imposed by structured methodologies” (p. 238).

Given the specific objectives of this research the general inductive approach was considered to be an appropriate analysis strategy to residents’, families’ and staff’s experiences of deinstitutionalisation.

Transcribed interviews were analysed using a qualitative research software programme (HyperRESEARCH) that broke interview narratives into key research themes identified as emerging from within the data.
The impact of deinstitutionalisation on the residents of the Kimberley Centre

3.1 Relocating the Kimberley Centre residents.

In 1992, the Manawhatu-Whanganui Area Health Board made an application to the Family Court to place the Kimberley Centre residents under Personal and Welfare Guardianship orders. ‘Blanket orders’ were made authorising continuing care including a requirement that residents reside at the Kimberley Centre. Where relationships were known, a member of each resident’s family was appointed as their welfare guardian. One of the effects of these orders was that families became responsible for the decision making related to the future placement of their relative when the Kimberley Centre came to close.

The official announcement that all residents would be resettled to community-based services finally came on 5 September 2001. Families were expected to make decisions about where their family member would move. The decisions that families made in their capacity as welfare guardians ultimately shaped the geography of resettlement, with the model of support and location of families preferred provider emerging as the most significant determinants of where the Kimberley Centre residents finally came to live.

3.2 What model of community-based support were the Kimberley Centre residents resettled to?

As the sequence of major institutional closures in New Zealand and Australia gathered momentum, later closure programmes were characterised by intense lobbying with the purpose of achieving sheltered village/cluster housing service models. The families of the Kimberley Centre residents were able to choose between the dispersed community group home and cluster housing models of residential support as placement options for their family member.

In spite of the reservations many families originally held about the appropriateness of a dispersed community group home as the model of support for their relative, 64% of study participants ultimately moved from the Kimberley Centre to dispersed community group
homes. The number of Kimberley Centre residents resettled to this model of support stood in contrast to the weight of submissions from families that had argued for the retention of the Kimberley Centre or the replication of institutional support in cluster houses. This opposition towards the closure was expressed in both the 1996 consultation and the 2000 Needs Assessment processes.

Residents who resettled to the two different models of support were similar in age and gender distribution. They had lived at the Kimberley Centre for a similar number of years and were evenly drawn from across the Kimberley Centre villa types. This finding confounded any expectation that the perceived vulnerability of residents, or the time families had been separated may have influenced the placement decisions of their families.

One measure of displacement did appear to affect families’ choice of service model. Families who chose cluster housing lived, on average, much closer to the Kimberley Centre (mean: 77km) than families who chose community group homes (mean: 254km). Unlike families separated by greater physical distance, families that lived close to the Kimberley Centre did not have to choose between the pull of proximity and the model of support they preferred. Families at greater distance had no alternative to the community group home if they wanted their relative to live near by, and these families expressed their love by prioritising physical proximity over any fears they held about their relative living in a community group home. Families generally wanted their relative closer to them and the residents who had a sibling as their welfare guardian were found to have travelled the greatest distance to realise some families strong desire to have their relative resettled close to them.

3.3 Closing physical distance

Unlike the more regionally circumscribed resettlements associated with other New Zealand institutional closures, the Kimberley Centre dispersion had a wide geographic reach.

One of the most important consequences of deinstitutionalisation was the shrinkage of physical distance between the Kimberley Centre residents and their families. The greater access they had to their family was found to have the most significant impact on the life quality of the Kimberley Centre residents. All but one resident moved closer to their family after resettlement and the average distance between the Kimberley Centre residents and their families fell from 186km to 82km. Similarly, before the Kimberley Centre closed, less that 10% of residents lived less than 40km from their families. After resettlement, more than 50% of residents lived within this circumference.

3.4 Adaptive behaviour at the Kimberley Centre

Adaptive behaviour is generally understood as relating to the ability an individual has to cope with the natural and social demands of their environment. Debate about the most effective way to improve the adaptive behaviour of people with an intellectual disability has been used to fill and then to empty institutions.

To assess what impact the closure of the Kimberley Centre had on the adaptive skills of the Kimberley Centre residents, a picture of their general competence needed to be established while they still lived at the Kimberley Centre.
The Kimberley Centre residents, on average, scored below what would ordinarily be expected of other men and women with an intellectual disability on all domains sampled for by the Adaptive Behaviour Scale-Residential and Community (ABS-RC;2), except for the domain of Physical Development. Physical development, however, is not an adaptive behaviour. It measures sensory and motor skills and is, therefore, considered indicative of a person’s capacity to acquire life skills. The poor performance of the Kimberley Centre residents, despite an equivalent physical capacity to learn, might be explained by residents having an atypically poor predisposition to learning. An alternative explanation is that the day-to-day reality of living in an institution may also suppresses ongoing learning. Anecdotal evidence suggests that the resident population at the Kimberley Centre may have been skewed towards a greater representation of people with profound intellectual disabilities relative to the general population of people with an intellectual disability. However cultural aspects of living in an institution coupled with the improvement in adaptive behaviour that occurred in community settings strongly suggests the poor performance across all adaptive domains was also reflective of the impact of lives lived almost exclusively in an institutional setting.

Almost all of residents’ day-to-day lives unfolded in villa settings. Within the villa, an unbending institutional routine, the prioritising of residents’ medical needs and staff ratios set at levels that left little time for anything other than the delivery of programmed cares, denied staff a wider vision of their support role. Residents typically fulfilled dependent roles with limited opportunities to engage in purposeful activity or to acquire roles or responsibilities that nurtured personal development. The Kimberley Centre residents were similarly distant from community contexts where learning could be reinforced through repeated activity. By the start of the project, Day Support Services had shrunk to the point where people who lived in multiple disability or challenging behaviour villas were seldom observed engaged in day programme activity.

Staff at the Kimberley Centre, reported levels of adaptive behaviour in the domains of Independent Functioning, Economic Activity, Numbers and Time, Domestic Activity, Vocational Activity, Self Direction, Responsibility and Socialisation that on average, would ordinarily be exceeded by 84% of other men and women with an intellectual disability. Relative to their peers, the Kimberley Centre residents performed especially poorly in the domain of Language Development. In this domain 93% of people with an intellectual disability would be expected to achieve a higher score than was, on average, recorded for residents while they lived at the Kimberley Centre.

3.5 The loss of self-expression through language

At the Kimberley Centre 63% of observed communication events lasted less than one minute. Interaction was typically fleeting, tending either to be instructional or reflective of ongoing interaction as busy support staff acknowledged residents in passing. General acceptance of the reality that many residents had entered the Kimberley Centre speaking but would leave silent, represented a quiet, but distressing everyday denial of personhood associated with living in an institution, as it implied that many Kimberley Centre residents could find little self-expression through language.
3.6 Adaptive behaviour in community based settings

When the standardised adaptive behaviour scores were added together to give an overall measure of adaptive behaviour 3-6 and 12 months after resettlement, the average adaptive behaviour scores reported for residents rose at each phase of the Kimberley Centre Research Project. No significant differences were found between consecutive study phases, but the accumulated improvement in adaptive behaviour over the entire year meant that a statistically significant improvement in overall adaptive behaviour did occur one year after residents moved from the Kimberley Centre.

Community living was advantageous to learning in five of the ten adaptive behaviour domains. The most dramatic improvement in living skills occurred within the Domestic Activity domain. This domain measures resident ability to take care of their living environment and perform ordinary domestic activities. Improvement following institutional closure in this domain is now a robust research finding. At the Kimberley Centre, domestic roles were inaccessible to most residents as domestic activity occurred beyond the places residents spent most of their lives. In the more homelike community settings, residents were able to become involved in the ordinary routines of daily living. They also had a greater opportunity to demonstrate previously unrecognised competence by participating in day-to-day domestic activity.

Because community-based staff lived, ate, shared daily chores, shopped and recreated alongside residents they were more likely to notice and build upon emerging competence. Living alongside residents also appeared to support greater interaction between staff and the people they supported. The proportion of time residents engaged in moments of shared communication doubled in community-based settings.

Statistically significant improvements in the domains of Language Development and Responsibility also followed the move to community-based settings as staff worked hard to uncover buried language. Furthermore, living in the community was found to have particular benefit for residents from lifestyle villas who experienced greater freedom to express competency in the domains of Responsibility and Self-Direction.

3.7 The plateauing of adaptive behaviour gain

While overall adaptive behaviour continued to increase, the general pattern to emerge from the data collected was that adaptive behaviour tended to flourish but then stall by the end of residents’ first year beyond the Kimberley Centre. Adaptive behaviour gain slowed dramatically with scores in some domains retreating in the last half of the year. The plateauing (levelling off) of adaptive behaviour is now well reported in the international research literature. This finding is commonly attributed to an initial burgeoning of competence because people have greater scope to demonstrate previously unrecognised adaptive skills in community based settings, but which tend not to be accompanied by support practices that would lead to sustained personal development.

With regard to the Kimberley Centre project it is suggested that the plateauing of adaptive behaviour gain may also be linked to a wider change in the culture of support in community settings that occurred during the year. This notion is described in greater detail in section 3.13.
3.8 What factors were linked to an improvement in adaptive behaviour?

The research was concerned with identifying any factors that appeared to make the acquisition of new competencies more likely. The research literature emphasises a range of potential explanatory variables that encompass: resident characteristics, (including age, gender, level and type of impairment and time spent living in an institutional setting); aspects of service design, (including the size of a dwelling) and whether residents had been resettled to cluster or community group homes. In the current study, however, being close to a family member, and especially a parent, were the only factors to emerge as being statistically significant in improving overall adaptive behaviour. This finding is challenging to the disability sector for a number of reasons.

Aspects of service delivery and design have monopolised the discourse related to improving service and life quality for people with an intellectual disability. The quality of peoples’ family relationships have been to the periphery of professional attention and yet for the residents who moved from the Kimberley Centre, it was the qualitative attributes of being close to family that were found to support ongoing learning and development.

These findings contribute to a small body of research that argues that support services have much to learn from family care. In general terms, the most marked improvements in life quality occurred for individual Kimberley Centre residents who found their way to support relationships that were not solely focused on the formal tasks but which also included a family-like commitment to advocacy and relationship quality.

3.9 Sustaining the sense of viability as developing people

People with an intellectual disability have described good support as communicating a commitment to their continuing viability as developing people. More effective personal planning and more creative day support emerged as potential ways to sustain the rapid learning and personal growth that characterised the experience of former Kimberley Centre residents during the first months of resettlement.

Services were found to have been slow to start, and slow to invite staff to think critically about the process of Individualised Lifestyle Planning. It also appeared that a failure to invest in training and the pre-eminence of procedural lifestyle goals meant that the process was understood by residents and their support staff as a service tool rather than a chance for people to shape their own support. Residents were often excluded, having no sense of ownership either of the process or the outcomes it generated. The potential to build community by collaborating with informal supports to help people achieve lifestyle goals also tended to be missed.

Furthermore, whilst many residents enjoyed the stimulation, colour, sense of momentum and structure attending a day-base added to their lives, the programmatic and collective character of vocational activity made it a difficult to achieve ongoing learning. Not only did the range of activities tend to reflect therapeutic and not aspirational goals, people were separated from more natural contexts. Residents baked in large groups at their day-base, but rarely cooked for their flatmates at home. They went shopping in groups, denying
them the chance to develop a relationship with the local store-owner or practice handling money with an empathetic support person. And they were read to in groups, seldom alone testing the limits of their comprehension. Delivering vocational support in ways that can accommodate individualised support need may be another way of helping former Kimberley Centre residents to continue to develop and maintain the adaptive behaviour gains they demonstrated immediately following resettlement.

3.10 Daily life in the Kimberley Centre

When study participants were observed living at the Kimberley Centre they were found to inhabit a few specific areas. Residents were least likely to be observed outside of the Kimberley Centre. On average, residents were observed in community settings for 1.1% of the total observed time. The few moments where residents had the opportunity to experience some deviation from their extremely circumscribed lives were highly valued. Visits to the community, however, tended to be to participate in a narrow range of ritualised, group activity. Except for the occasional specialist appointment or family visit it was clear from the data that few opportunities existed for people to be in ordinary community spaces in ordinary ways.

Whilst the (previously) immaculate and expansive grounds contributed to the illusion of spaciousness and activity, the reality for residents was that most of their lives were spent in a few, well-populated spaces. The villa was the pre-eminent location. On average, residents were observed to spend almost 96% of their lives within their villa environment. Residents who lived in challenging behaviour villas lived the most geographically restricted lives, spending over 97% of their time locked into their villa. Staff did remind the research team that this had not always been the case and that residents in challenging behaviour villas had been especially compromised by the closure of workshops and shrinkage in Day Support that had occurred as part of the closure programme.

Within the villa, the dayroom and dormitory were the key spaces. On average, between 65 – 75% of residents lives occurred in these settings. Residents exercised a degree of territoriality by sitting in their particular chairs that were placed around the dayroom wall. Predominantly sedentary lives were interrupted by moments of personal care, including the timetabled routines of intimate and personal care, the drinks trolley, coffee club and exodus to and from the dining room for meals.

3.11 Daily life as part of the community

The longer residents were in community-based settings, the more likely they were to be observed beyond the residential setting. The proportion of time residents were, on average, observed in vocational settings more than doubled (4.8% of observed time) and residents were five times more likely to be observed in a community space (10.4% of observed time) a year after moving from the Kimberley Centre. Although the residential service setting continued to be the main space within which residents spent their time (85% of observed time), it needs to be noted that the experience of being in this setting was qualitatively different to residents’ villa lives.
Most community residential settings were large, airy, well-appointed and tastefully decorated homes, permitting both ease of movement and a vicarious involvement in daily domestic activities.

Residents generally found different ways to express pride in their new homes. The more homelike physical setting also made it easier for families, who had historically found the experience of visiting their relative distressing in an institutional setting, to communicate with residents and their support staff more positively.

The change in life quality experienced by residents having their own bedroom was prominent in all narratives. Families and staff in particular highlighted the bedroom as a place of sanctuary. Residents’ bedrooms were also a space that they could declare their individuality. Family portraits and possessions that belonged only to them lined bedroom walls, communicating a sense of ownership and permanence that was largely absent in the institutional setting.

Two issues were found to have the potential to impact on the way some former Kimberley residents were able to participate in their homes and their community. A number of residents’ homes were constructed for able-bodied people, making ordinary domestic activity difficult for residents with physical disabilities. Sinks and oven tops, cupboards and sometimes phones were all beyond the easy reach of residents using wheelchairs. Even though residents could look over into kitchens, many had doors or gates that prevented them from gaining access. It is possible that this contributed to a more passive role for some residents by unwittingly excluding them from everyday domestic activity and the sense of propriety that comes with looking after ones’ own home.

Furthermore many houses tended to be located in commuting neighbourhoods, at a distance from local amenities. Some were located in cul de sacs where people seldom passed and a few were on the very margins of their town. Being beyond easy walking distance to the shops prevented some residents from developing a continuity of presence likely to lead to their becoming part of the townscape or achieving the valued social roles of neighbour and member of a particular community.

A year after moving into community-based services, residents continued to spend most of their time in segregated service settings and it appeared that few had developed reciprocally valued interpersonal relationships beyond staff, family or other service users.

### 3.12 The pattern of resident activity 3–6 months after moving from the Kimberley Centre

When the pattern of activity that residents were engaged in 3–6 months after moving was compared to their previous lifestyle at the Kimberley Centre, a statistically significant decline in sedentary activity was evident. In the first months of resettlement, disengaged resident activity had become replaced by more active lifestyles.

Residents were out more, participating in trips for pleasure or going to organised events. A statistically significant increase in the Social Activity category 3–6 months after resettlement reflected a greater probability that residents would be “out there” without necessarily becoming “in there” as members of their community.
Increased time was also spent attending to personal cares and, over the course of the year, a statistically significant increase in domestic mobility occurred which appeared to be reflective of both a subtle change in residents’ ability to self-determine their activity and the routine of going to and from their vocational placement.

The most dramatic change occurred within the Indoor Active activity category. Included in this category was the time residents spent engaged in socially orientated conversation. Beyond the Kimberley Centre, the frequency and duration of communication events doubled as community-based staff had greater opportunity to spend time developing relationships of trust with the people they supported.

3.13 The situation for former Kimberley Centre residents 12 months following resettlement

When the research team returned at the end of the year, the initial trend for sedentary lifestyles to be replaced by a more engaged and self-determined activity pattern had reversed. Such was the magnitude of the shift that the gains that were evident at 6 months post resettlement were extinguished as residents returned to an activity pattern similar to that first observed at the Kimberley Centre.

One explanation for this reversal could be that during the first phase of resettlement, residents and staff typically met as strangers. In most homes, residents were met by an ‘ethic of discovery,’ where exposing unrecognised competence, learning new things about an individual’s personality, preferences and aspirations was powerfully reinforcing to staff. As noted previously, this ethic was coincident with significant gains in adaptive behaviour and the inclusion of families, who were eager to work collaboratively with community-based services.

Twelve months following resettlement it appeared that an almost opposing ‘ethic of knowing’ had begun to emerge, whereby knowing, anticipating and managing resident behaviour seemed to have become markers of professional insight. In many services, the shift in service culture was coincident with the loss of original staff who took with them an enthusiasm for making a difference and a delight in discovery. Replacement staff tended to be orientated to the procedural elements of disability support, displacing the original focus on the person. Between 3–6 and 12 months, the changing culture of community-based support was also coincident with the plateauing of adaptive behaviour and a sense, amongst a small number of participating families, that they had been re-marginalised from their relatives’ support.

3.14 Cluster vs. Community Group Home outcomes

As noted previously, during the consultations that preceded the decision to close the Kimberley Centre, families expressed an overwhelming preference for either preserving the status quo or replicating the institutional care they had come to trust in sheltered or cluster home settings. Exploring whether any differences emerged between the quality of life outcomes experienced between people resettled to cluster and community group homes was a secondary objective of this study.
When the potential confounders of age, sex and primary support need were held constant, the type of service model people were resettled to was found to play no decisive role in influencing changes that were observed in adaptive behaviour, Quality of Life domains, the ability to make life choices, or the range of places and types of activity residents engaged in after resettlement.

An improvement in language-related competence for residents resettled to community group homes was evident, but failed to achieve statistical significance ($\alpha = 0.05$) and a larger improvement in the adaptive behaviour domain of self direction for residents resettled to cluster houses was similarly evident but also fell below the level of statistical significance. At first glance these findings confound an expectation that a closer approximation of ordinary life circumstance will necessarily elicit a more normal range of adaptive competencies. It also contradicts more recent research that suggests cluster houses tend to be associated with poorer Quality of Life outcomes.

Caution needs to be exercised about the generality of these findings. The relatively small number of people being compared (only 14 resident participants were resettled to cluster houses) meant that the results were more susceptible to skewing from atypical scores and the possibility of missing real differences between the two support settings was therefore greater.

An alternative explanation for the similarity in quality of life outcomes between cluster and community group homes was that they differed little in service design or support practice. In reality, it was difficult to distinguish one site from another. Both models shared Housing New Zealand as a common landlord with their choice of housing stock and geographic location varying little. Residents shared their home with a similar number of flatmates, the houses were staffed at similar ratios and no deviation in support practice or service values were detectable in either setting, except in services that embraced tikanga Maori as an important element to service delivery. The chosen service provider of cluster housing was a major provider of other forms of residential support, including community group homes, and appeared to have transferred pre-existing support policy and practice to the new cluster sites.

Families that chose cluster housing as their preferred service type spoke of the importance of their relative’s relationships with the people and places that had been built up over the years. They also hoped that keeping a large number of people with similar support needs together would preserve the concentration of expertise and specialist services promoted as a key benefit of institutional care.

Neither was to prove the case, especially in Levin, where the resettlement of the Kimberley Centre residents stretched the support infrastructure. Residential services in Levin struggled to recruit and retain sufficient support staff and also experienced difficulty accessing primary health services, including doctors and dentists. Contrary to the aspirations of families, residents had little contact with their neighbours, regardless of whether they lived in cluster or community group homes.
The impact of deinstitutionalisation on the families of the Kimberley Centre residents

4.1 Introduction

Consistent with previous deinstitutionalisation research, a focus on family was considered important to the current study. Families are recognised as representing the most enduring relationship in the lives of many people with an intellectual disability. Furthermore, deinstitutionalisation creates a situation whereby families are also expected to adjust to a new model of service delivery regardless of their personal feelings about such change. This project incorporated two specific objectives relating to family.

4.2 Family experiences of the Kimberley Centre

Families contributed a great deal of information about their experiences of the care their family member had received during the years they lived at the Kimberley Centre. During the first interview all families were questioned about: 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 family member living at the Kimberley Centre. The Kimberley Centre was not a static place and the changes in the ways in which support and services were delivered were reflected in families' experiences of the institution over time. There were commonalities in many aspects of families' stories but there were also differences.

The original decision to place a family member at the Kimberley Centre was a vivid and life-defining event for all families who participated in this study. Similarly to previous research many families described their battle to keep the family member at home for as long as possible. A number of factors occurring at once usually influenced the eventual decision to seek out-of-home placement with the most influential of these factors being an increasing difficulty in managing physical or behavioural needs, stress on the mother, and/or concern about the impact of the intensive support needs required by their family member with an intellectual disability on their non-disabled siblings.
Research questions about families’ experiences of and views about the Kimberley Centre were asked after the official announcement that the Kimberley Centre was to close had been made. Families’ level of engagement with the deinstitutionalisation process presumably shaped their views about the Kimberley Centre and what they considered to be acceptable support for their family member. An exploration of families’ views of the care their family member had received at the Kimberley Centre showed variation. An overwhelming majority of participating families (71%), however, 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 the Kimberley Centre staff with Kimberley staff being 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 high quality support, as well as times when the Kimberley 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. As a result, most family participants felt that their family members were being poorly supported at the time the announcement for closure was made. The families who participated in this research reported a range of visiting patterns and habits and while most families attempted to keep up regular contact with their family member, reasons of age, ill-health and geographical distance sometimes made this difficult.

4.3 Initial reaction to the announcement of closure

Most participating families reported having been aware of the possibility of the closure of the Kimberley Centre for some time prior to the actual announcement. A number dated this awareness 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 diminish the strong emotional reactions that many families experienced when the announcement was made and the closure of the institution was timetabled. The most commonly reported initial reactions to the news from participating families were feelings of anxiety, upset, worry, fear and even panic.

The majority of families (69%) 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. What families appeared to fear most was that their family member was too old to make a positive adjustment to community living, that they would experience a decline in their health and quality of life and/or the community at large would not be accepting of people with an intellectual disability.

It is important to note however, that just over a quarter of the family participants (26%) 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. A small number of families who participated in this study did not state a position on closure. 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 valued the safety, security, and caring, dedicated staff that they perceived to be available to their family member at the Kimberley Centre and the idea of redevelopment was linked to a desire to see these elements of support being replicated on the original Kimberley Centre site but delivered from new, purpose built facilities.

Conversely some families, including a number who were opposed to closure, identified a number of concerns about the support and services that were provided by the Kimberley Centre. These concerns included the frequent loss of their family member’s personal possessions and clothing; the way money was handled; the frequency of movement from villa to villa; noisy crowded villas; lack of personal space; locked doors; the number of psycho-active medications their relative was prescribed; and unexplained injuries. Furthermore, while most families highly valued the work of the Kimberley Centre staff, a small group of participating families perceived some staff as unsuitable for the role they were in and were, in some cases, viewed as being uncaring.

Families frequently reported that the actions 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, opinions were divided 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 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. Generally, families tended to gain information about the resettlement process from the Kimberley Parents and Friends Association, Life Unlimited, Ministry of Health, MidCentral Health and Kimberley staff. Some families felt that specific questions that related to their family member’s individual situation were responded to in a way that demonstrated little relevance to that person’s actual situation or needs.

4.4 Family decision making about resettlement

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. Most particularly, families were focused on achieving a high level of service quality, and an environment where well-trained staff continued to be available to support their family member. Unsurprisingly, families reported that their family member’s ongoing happiness was their greatest aspiration for the future. Other stated aspirations for resettlement and community living included that their
family member would: make gains in independence and adaptive behaviour; experience new
opportunities; enjoy compatible relationships with their “house-mates”; have staff who loved
them; and experience a reduction in the distance from their family. Most families expressed
a desire to have their family member living closer to them, and as previously stated, many
families had a strong view about the model of service they preferred (cluster versus dispersed
group home).

Families shared a number of concerns with regard to the planned resettlement of their family
member. Such concerns were centred on issues of safety and security, staffing quality, and
loss of the companionship with other Kimberley Centre residents and staff. 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 service provider their
family member would utilise, some families reported feeling unsupported and ill-prepared to
make an informed choice. In particular, 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 family member diminished 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 the colours and the
furnishings used in their family member’s new home. Furthermore, families expressed more
positive views about the actual transition process in situations where their family member
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 in this study who, along
with their family, tended to experience their new home for the first time on the day they
moved into it.

4.5 Family experiences of community-based services

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 the former Kimberley Centre residents into new homes in the
community. The majority of 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 home. 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 family member’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 happy or happier in their new
home. These families reported feeling very happy with the care their family member was
receiving and that the support that their family member was receiving was “better than they
had thought possible”. This finding represents a complete reversal of attitudes expressed in the initial interview whereby the majority of families stated that they were opposed to the resettlement of their family member.

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. The features of community-based support and services commonly identified by families as contributing to their overall positive assessments included: homely, lovely environments; comfortable surroundings with more freedom; spacious and well-designed; opportunity to have own room, own space and personal belongings; that their family member was doing more, saying more and contributing more; greater choice; individualised care; and that the homes were closer and more welcoming to visit.

A small number of families expressed mixed feelings about their family member’s new home. These mixed opinions were centred on families feeling their expectations had not been met with regard to the degree to which their family member experienced opportunity for personal development.

The families who were dissatisfied with their family member’s community placement shared a common mistrust of the standard of care being delivered by the community-based service and a perception that health-care needs were not well recognised. The specific issues raised by families who were not completely happy with community-based services included: a lack of access to swimming and other activities; services not being completely finished or set up when their family member arrived; a lack of involvement in the community; medical support being inadequate; no registered nurse in charge of a home (when the family had understood there would be a registered nurse in charge) and an inadequate level of staff training.

While most families valued and appreciated the efforts of community-based service staff, they frequently expressed concerns about the level of experience and training that staff possessed. Coupled with this concern was the difficulty that families saw community-based services as experiencing with regard to recruiting and retaining staff. Overwhelmingly, however, families reported having good quality relationships with staff working in their family members’ new homes and that they saw themselves as being able to be more involved in the home and with their family members’ daily life than was the case when they were living at the Kimberley Centre. Families were found to develop a very strong focus on the personal characteristics of staff as they made the adjustment to their family members’ new model of support in the community.

4.6 Reflections on resettlement

Families’ reflections on their family members’ lives 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.” This study sought specifically, to contrast families’ views prior to resettlement with their perceptions following the resettlement of their family member into community-based services. A number of families made comparisons
between their family members’ 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 their family member experienced a better quality of life and better lifestyle in community-based services, as well as more personalised care and one-to-one contact. Also frequently mentioned by families was the fact that their family member had their own bedroom and greater privacy as a result. Families also noted that their family members seemed more alert and happier, were more communicative, and were involved in a greater degree of choice-making. Families also valued the easier access to staff in the community-based services and the fact that they found it easier and more comfortable to visit than when their family member was living at the Kimberley Centre.

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. Similarly to previous New Zealand deinstitutionalisation research, the discontent with resettlement that was expressed by a small number of families seemed to be based on a failure of their family members’ transition to live up to the high expectations held about the potential opportunities that deinstitutionalisation could offer. These families did not question the quality of care that their family member received but rather a lack of opportunity for personal development and greater independence. Many families identified the positive aspects of their family members’ 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. 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.

Overall, families who participated in this study aspired to a happy future for their family members with the continued stability of their chosen support service being particularly important. Regardless of their stance on deinstitutionalisation, families frequently reported feeling concerned about the ability of the community-based service system to recruit and retain staff with appropriate values and skills.
The impact of deinstitutionalisation on the staff of the Kimberley Centre

5.1 Background

This section of the report provides an account of the deinstitutionalisation process from the perspective of a small number of Kimberley staff who chose to participate in this research. The views and experiences of the majority of the Kimberley Centre staff are missing because they declined to be part of the research project. In reading this report it must be noted that the findings are only reflective of the staff who volunteered. It is possible that the majority views and experiences would have mirrored the data we were able to collect. On the other hand it is also likely that we could have been presented with an even more diverse picture of working life in an institution in its heyday and as it gradually closed. Notwithstanding the small numbers of staff participants the research reported here contributes to an acknowledged gap in the deinstitutionalisation literature through its specific focus on the experiences of institutional staff.

5.2 The Kimberley Centre Staff

Staff at the Kimberley Centre included management and administration staff, registered nurses, registered nurse educators, enrolled nurses, ‘psychopaedic’ nurses, ‘psychopaedic’ assistants and a range of maintenance staff. Male staff made up 61% of the total staff population with female staff registering 39%. Few staff had individual contracts, with most being part of a collective contract.

Many of the staff who were essential to the operation of the institution for a significant number of years were still working at the Kimberley Centre as the research project started. Indeed some staff had worked at the Kimberley Centre in excess of 25 years.
5.3 Staff Demographics

In December 2003 when the research process officially started with staff, the Kimberley Centre was a major employer in the Levin-Horowhenna area. Approximately 350 staff were employed at the Kimberley Centre at this time working in 12 separate villas/wards on the Kimberley Centre campus. Of the 350 staff, 200 were estimated to be Maori. Many of the staff who volunteered to participate in the research were long-term employees of the Kimberley Centre. Length of employment ranged from 4 years to 34 years. It was not uncommon for three to four generations of families to have worked at the Kimberley Centre.

5.4 Why were staff reluctant to be part of the research project?

The majority of Kimberley staff were reluctant to participate in the research, despite a rigorous research design, ethical procedures and a lot of unofficial time spent with staff getting to know them. Suggestions as to why they may have been reluctant to engage were gleaned from field notes, interviews, both personal and resident focused, focus group data and informal “chats” with the Kimberley Centre staff. At the time the research started the Kimberley Centre staff were confused about why the research team was there despite having received copious amounts of information about the project. At the start of the project many staff did not believe that the Kimberley Centre would close and saw little value in participating in a project about a process that might not happen. Staff felt besieged by the influx of more and more visiting agencies and professionals on the campus at the same time as the project started. Many staff felt undervalued by the management of the Kimberley Centre and therefore wanted nothing to do with the research team who were seen to be “in” with management. There was overall low morale amongst all staff and many believed they had nothing to offer the research. There was also a strong feeling that the research process was too intrusive and too hard at a time of upheaval and stress for them.

However those staff who did engage with the research tended to participate in more than one of the research opportunities.

5.5 The closure of the Kimberley Centre: How did staff feel about the pending closure?

In 2003 management and senior staff were inclined to accept the idea of the closure in a positive way, whereas direct-care staff were much more opposed. As deinstitutionalisation proceeded many direct-care staff accepted that the institution was closing, but they still opposed it. It is probable that senior staff and management had more employment options, more qualifications and a more assured future than many direct-care staff. It was obvious to the research team that senior staff and management had more precise information about the closure process and were more involved in major decisions about residents, whereas direct-care staff were many times only informed about those decisions when it was time for a resident to leave.
Various staff (along with a number of families) felt the Kimberley Centre should remain open, albeit in a different form. Both these staff and a significant number of families promoted the cluster-housing model on site of the Kimberley Centre campus. Staff believed that a revamped Kimberley Centre would allow residents to be more independent than a house in the community. Residents would be able to maintain their relationships with other residents and staff. All services would be on site and they would not have to worry about the unpredictable nature of community-based living.

There was discussion about the planning for Maori residents to leave the Kimberley Centre and the marked difference in that planning for Pakeha residents. These differences extended to how Maori and Pakeha residents were being transitioned to the community and how they were being received by community-based services. The closure was an emotional time for staff. Many found the departure of residents personally painful.

5.6 The Culture of the Kimberley Centre

It has to be noted that the Kimberley Centre was in the final stages of closing when the project started. Staff were having to deal with a closure that many did not accept, with management being seen as masterminding the deinstitutionalisation process. There was a lot of enthusiastic and nostalgic discussion around the culture of the Kimberley Centre in days gone by with fewer references to the present day culture, other than to mention incidents of abuse as illustrative of the cultural practices of some who staff perceived to be negative, careless and unprofessional.

There were many references to the present management, administration and villa/ward senior staff as having all the control and decision-making authority and direct-care staff, although essential to the running of the institution seeing themselves as having a very disempowered position. Some staff did talk about the frequent changes in how care and support was provided to the residents – “swinging between custodial and empowerment models”. Staff were generally of the opinion that for residents living in an institution it was unavoidable that they would lose some of their individual identity and become subsumed into the group labelled intellectually disabled. This was the very nature and culture of institutions and it was no less for the Kimberley Centre. Associated with this fact was the large number of residents and their support staff who were required to get their “work” done quickly and efficiently, leaving little time for relaxed interactions between staff and residents.

Even though there was a culture of caring for and supporting residents, staff mentioned the need to be vigilant about their attitudes and behaviour towards the residents and the need to be aware of becoming desensitised to the human rights of the residents and the value of their lives. Those staff who were interviewed were also alert to the danger of becoming immune to bad practices in the Kimberley Centre.

Staff talked about the positive features of the Kimberley Centre including the safety of living in a predictable environment relative to perceived unpredictability of community living. The centralised aspect of all the health services on site at the Kimberley Centre was considered to be an advantage for the residents. There was always easy access to doctors and nurses and other professionals and staff did not have to negotiate and then wait for medical appointments that they perceived was a prominent feature of community-based health services.
5.7 The management of the closure for staff

When institutions close the major focus has always been on the safe, speedy departure and transfer of the institutions’ residents into community-based services. There has also been the expectation that the institution staff will embrace and assist in the closure process and ensure that the residents leave the institution well prepared and ready for life in the community. The Kimberley Centre staff acknowledged that this focus was essential, but felt that there was little acknowledgement that they too were moving out and going through a difficult period in their lives as well. Many staff felt keenly about the lack of respect shown by management for their feelings about the closure, their concerns for the residents and their worries for their own futures.

Even though there appeared to be a lot of information about the closure circulating around the Kimberley Centre, direct-care staff in particular thought they did not receive enough information. Most staff reported that provision of information about the closure process was unreliable and late and that many times the Media were privy to information before they were.

However staff did admit that the management of the Kimberley Centre had done their best with the resources available to them and had offered them a number of practical arrangements such as information meetings, regular progress updates, in house training, personal counselling, job counselling, external agency training and a Kimberley Centre Personal Profile. Unfortunately only a few staff indicated what offers they took up from management, but it was clear to the research team that management were considering all staff and were prepared to assist them if they wished.

Staff felt their own families, other staff and the residents’ families were far more supportive of them than the Kimberley Centre management during the closure process. As staff went through the closure process, including the leaving of friends, the abandonment of a long-term workplace and the seeking of new employment, it was only natural for staff to want to blame someone for these unwanted challenges. The management who were implementing the closure were the logical “fall guys.” Nevertheless staff did acknowledge at times that management had an unenviable task and were possibly as disenchanted by the process as they were.

5.8 Staff relationships with the residents of the Kimberley Centre

Researchers have argued that direct-carers are the most important people in the lives of people who depend on human services.\(^{13, 17, 42}\) Direct-care staff are at the forefront of delivering good quality care and support to people and they have an indisputable impact on the day-to-day lives of service users.\(^{18}\)

At the Kimberley Centre, Psychopaedic Assistants were those direct-care workers. Not only were they influential in the residents’ lives but they also had the majority of contact with the residents’ families. Staff had an awareness of how important they were in the lives of the residents, particularly for those residents who had little or no contact with their families.

Some staff talked about their fondness for particular residents, while acknowledging that loving the residents was not a requirement of the job. Many said they found it difficult to
avoid making emotional attachments and maintain a strict working relationship with the Kimberley residents.

While staff were continually demonstrating their attachment and concern for the residents, many of the residents were reciprocating by initiating interactions and responding to staff in a way that illustrated their care and attachment for their staff.

All staff talked about how they were going to miss the residents. With the pending closure, staff grieved and talked unashamedly about their feelings for the residents. There did not appear to be a system in place that would have allowed staff to keep in touch with residents as they resettled in communities all around the North Island. The authors believe this was an oversight not only for staff but also for residents who had equally strong attachments to their staff. Many relationships of many years standing were cut short with no acknowledgment of how important they had been and could have continued to be and offered no preparation for either party to deal with their feelings of loss, grief and abandonment. These relationships were further damaged by the lack of feedback about how residents were managing in their new homes.

Both the Kimberley Centre management and some community-based service providers discouraged staff from visiting the former residents as they settled into their new homes. This decision to dissuade the Kimberley Centre staff from visiting has a strong parallel to what parents were told when they first put their family member in the Kimberley Centre all those many years ago. Reminiscent of parents’ experiences, the staff also had an emotional connection with the residents that they were being told to break.

While most interactions between staff and residents were respectful and loving the research team were aware of staff who took advantage of some residents’ vulnerability and were abusive towards them. Those staff interviewed talked about staff who treated some residents with contempt and who were inadequate in terms of regard for authority and experience, best practice and their interactions with the residents.

5.9 Family perceptions of staff at the Kimberley Centre

Families were supportive of the Kimberley Centre staff. They were grateful for the support and love the staff had shown to their family member through the years. They were mostly keen for the Kimberley Centre staff to continue being part of their family members’ lives in community-based services. Families acknowledged how well staff knew their family member and commented on how staff loved the residents as if they were their own family member.

Families also commented about their relationships with staff and that in recent times communication between families and the Kimberley Centre had improved. When they visited the Kimberley Centre they were always made to feel welcome and staff willingly spent time with families when requested or required. Families generally stated they felt comfortable speaking openly to staff about their concerns.

The positive comments about the Kimberley Centre staff were directed in the main to the ward/villa staff and tended to concentrate on the Psychopaedic Assistants. They were not so positive about management staff. Management were seen as implementing the closure and any problems with the process either with the resettling of residents or the redeploying of staff tended to be seen as a failure of the Kimberley Centre management.
5.10 Community perceptions of the Kimberley Centre staff

Staff who work in institutions rarely get good publicity in the community. As institutions have closed there is a new open-mindedness towards people with an intellectual disability and a recognition that they belong within local communities, not on the fringe of rural towns. However the same welcome has rarely been directed at the staff who have worked in institutions, as they too have come back into local communities. They tend to be regarded as having lesser value by virtue of having worked in institutions and continue to personify society’s negative feelings about institutions.

The Kimberley Centre workforce was sensitive to how they were being portrayed in the community at large. They felt they had been much maligned by people who knew little about their skills, their experience and their extensive working careers with people with an intellectual disability.

The Kimberley Centre staff were initially concerned that community-based service providers were not appreciative of their skills. The abuse incidents in community-based services were difficult for many former staff to deal with and they were justifiably concerned that they were being judged on the behaviour of a few former “rogue” staff.

5.11 Staffs’ views on community-based services

A range of views were expressed by the Kimberley Centre staff on community-based services. While the institution was in the process of closing staff felt undervalued and hurt by community service providers’ comments and this more than likely coloured their opinions of community-based services at that time. Nevertheless there were staff who were supportive of the community living philosophy and practice while still working at the Kimberley Centre and expressed their views openly.

However the overwhelming feeling that came from the Kimberley Centre staff was the need to have their working lives acknowledged by the community at large and more specifically by community-based service providers. They felt they were being doubly condemned by the community. Not only were they in the unusual position of having their work-place closed because it was no longer considered an appropriate environment to accommodate and support people with an intellectual disability. But the work they had done through the years supporting people with an intellectual disability was now considered of inferior quality. In fact they felt their skills and experience were being denigrated and dismissed without any recognition that they had spent many years of their lives believing they were doing a good job.

Even though staff felt they were under appreciated by the community at the beginning of the closure process, as time moved on many were eventually employed by community-based services. Those that were employed in community-based settings perceived a growing acknowledgement of their skills and experience.

Despite personal difficulties and disappointments, those former institutional staff who were interviewed were able to identify and celebrate the positive aspects of community living for those men and women with intellectual disability who had formerly lived at the Kimberley Centre.
Conclusion

This report has detailed findings related to an in-depth exploration of the deinstitutionalisation of the Kimberley Centre. Specifically, the research sought to capture the experiences of Kimberley Centre residents, their family and staff as three groups most significantly impacted by the closure of an institution. The research was underpinned by a set of five objectives and in this final section of the report key findings related to each of these objectives are presented and discussed. Later in this section the limitations of the study are acknowledged and plans for further analysis of specific data are detailed.

6.1 Objective 1: To compare life in the Kimberley Centre with life in community-based services for residents of the Kimberley Centre

In one of the first summaries of the research findings related to the impact of institutional closure on people resettled to community setting deinstitutionalisation researchers Emerson and Hatton\textsuperscript{15} stated that in the United Kingdom:

"better outcomes are generally, but not inevitably associated with less institutional, community-based settings (p.33)"

Their conclusion provides a relevant and succinct summary of the findings associated with the current project. No two journeys out of New Zealand’s last institution were the same. After being resettled from the Kimberley Centre a small number of participants found it hard to adjust to community-based settings and some experienced difficulty reproducing aspects of living at Kimberley Centre that had sustained their sense of positive wellbeing. For the majority of Kimberley Centre residents, however, their stories reflected well on the aims and outcomes of deinstitutionalisation. All but one resident in this study had been relocated closer to their family illustrating that families’ early aspirations to have their family member nearer to them had been met. More importantly, the greater access they had to family was found to have the most significant impact on the life quality of former Kimberley Centre residents. Many residents were able to rekindle strong relationships with their family and some were also able to develop relationships with staff that were based on mutual trust and respect. Former Kimberley Centre residents typically moved to houses they were proud of, experienced an improved material well-being and, in some cases, a wider re-humanising
amongst their primary support relationships. That is, they were recognised for their own skills, characteristics and individualism. Significantly, staff working in community-based settings spoke to former Kimberley Centre residents twice as often and for longer (than communication exchanges recorded in the institutional setting) and were found to spend more time in the pursuit of creating more trusting relationships. Residents were also able to exercise a greater degree of autonomy over the decisions that affected their daily lives. They spent less time in service settings and were much more present in the ordinary spaces of their local community than they were able to achieve while they lived at the Kimberley Centre.

6.2 Objective 2: To identify any changes in adaptive behaviour and daily functional skills among residents which occur during the resettlement phase.

Whilst still living at the Kimberley Centre, Kimberley residents scored below what would ordinarily be expected of other men and women with an intellectual disability on all domains except for the domain of Physical Development. During the first year after leaving the Kimberley Centre, residents who participated in this study experienced a statistically significant improvement in overall adaptive behaviour. Community living was found to be advantageous in five of the ten adaptive behaviour domains with the most dramatic improvement occurring within the Domestic Activity domain. Statistically significant improvements in Language Development and Responsibility also occurred during the first year of community based living. Despite these improvements however, analysis of data identified a plateauing of adaptive behaviour gain toward the end of residents’ first year in the community.

With regard to daily life, former Kimberley Centre residents were more likely to be observed outside of their residential setting, usually in vocational or other community spaces than they had been whilst living in the institutional environment. Furthermore, while residents continued to spend the majority of their time at home, the experience of being home was qualitatively different in the community context with individuals enjoying homely surroundings, and their own space and personal belongings.

It is important to note however, that most houses tended to be situated on the outskirts of town possibly precluding some residents from fully exercising the opportunity to become “part of” a community.

6.3 Objective 3: To describe the experiences of family/whanau involved in the resettlement process, and their perceptions of what it has meant for their relative

Similarly to recent New Zealand research on family involvement in deinstitutionalisation, families who participated in this project 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. At the time they made the decision to institutionalise their child the families who took part
in this study did not perceive that community-based disability services or family support services were available to meet their needs. This is not to say that such services were not available at the time but rather that families had found these services to be unsuccessful in meeting their needs.

In the current project families were found to hold a range of views about deinstitutionalisation, and the resettlement of their family members into community-based services. However, the significant majority of families reported that they opposed institution closure during phase one interviews. When discussing their opposition to plans for deinstitutionalisation many families failed to see how it was possible for their family member to make a successful transition from institution to the community due to that person’s age, behaviour, or simply the length of time they had lived at the Kimberley Centre. Families’ fears and concerns typically related to their relatives’ 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 the Kimberley Centre.

The current research identified only a very small number of families who reported feeling negative about the impact of deinstitutionalisation after they had experienced the resettlement of their relative. It was common for families who held favourable views with regard to the impact of deinstitutionalisation, to describe their relative as having made gains in the areas of 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 the family could now begin to reassert itself as having an important position within that person’s life.

This research pointed very strongly to the important role of family in the lives of men and women with an intellectual disability and suggests that attention should continue to be paid to the ways in which families can be positively included in the planning and delivery of current and future disability support services.

6.4 Objective 4: To identify the outcomes and impact of the resettlement for the Kimberley Centre staff and their families

The Kimberley Centre employed a very large workforce. It must be acknowledged that the Kimberley Centre employed a great number of staff who were loyal and dedicated to their work, who did all they could to professionally and personally enhance the lives of the residents. However, within that workforce there were staff who were less than satisfactory, in fact there were staff who were uncaring and disrespectful and even openly abusive towards residents.

As the Kimberley Centre closed many staff felt stigmatised by their association with the institution. They also felt unappreciated, unfairly targeted and somewhat culpable for having
worked in a service that was now no longer valued within the disability sector, nor within the wider community.

It must be remembered that many of the Kimberley staff had started their working lives there when consigning people with an intellectual disability to institutions was considered best practice. Similarly to people with an intellectual disability themselves and families, former Kimberley Centre staff entered a time of change and transition and were greatly affected by the deinstitutionalisation process. Also similarly to residents and families, the ultimate impact of this process was specific to each individual and included both positive and negative experiences with regard to life after the Kimberley Centre.

6.5 Objective 5: To identify any issues of service quality and service gaps within the resulting community services for the Kimberley Centre residents

Within the broad reach of the Kimberley Centre resettlement, the 4-6 person group home was the only model of support available to families. Because families and services had little control over which former Kimberley Centre residents ended up living together, the resettlement process incorporated an element of chance. Issues of incompatibility (and in some cases peer-abuse) were, therefore, inevitable.

This study also found that a number of community-based staff were poorly trained in positive behaviour support and specialised services were perceived (by staff) to be divorced from the day-to-day reality of supporting households to respond to challenging behaviour. The specialised services tended to be invited in as the option of last recourse. Additionally, the large size and centralisation of community-based services appeared to prevent direct care staff making quick responses to things that went wrong as they were required to wait for Special Incident Reports to pass up and then back down the lines of accountability. A lack of capacity for alternative support arrangements other than the community group home model existed because respite was not well accessed in times of crisis and the absence of direct funding options precluded the implementation of alternative, more individualised support arrangements.

Finally, findings generated through this research suggest that some former Kimberley Centre residents were more vulnerable to incidents of abuse as a consequence of the lack of effective advocacy. Health and Disability Advocacy is not responsive to the reality of intellectual disability for a cohort of people unlikely to complain and for whom decades of institutionalisation has separated them from natural sources of advocacy. Furthermore, families were not always well informed about the action they could take to address concerns that they had with regard to the support that their family member was receiving.

Improving the responsiveness of the sector to incidents of abuse and issues of service quality, including the need to incorporate informed and proactive community members as partners in a web of support that include people who rely on disability services to live quality lives were identified as important areas for service development.
6.6 Limitations of this research

As noted previously (Section 2.2) data collection for the Kimberley Research Project occurred at two atypical moments in the life-cycle of an institution and community-based service settings. In this respect the research findings are directly comparable to existing deinstitutionalisation research, drawing as the study does, from a similar time-frame.

However, because direct observation and measurement were central to assessment of the impact the Kimberley Centre’s closure had on residents in particular, the generality of the research findings are confined to the five years during which the research was conducted. The narratives of Kimberley residents, their families and support staff provided important additional insight into the way all three groups interpreted the changing character of the Kimberley Centre and the impact the institution made to their life quality over that time.

Given the context within which this research was conducted it is not possible to assert that any particular outcomes will necessarily be indicative of the life quality former Kimberley Centre residents can anticipate in the future due to the fact that the wider socio-political context in which disability support occurs changes over time. Indeed evidence of the transience of quality of life outcomes was reported in the study as adaptive behaviour gain and the pattern of resident activity both changed during the course of residents first year beyond the Kimberley Centre. To determine how entrenched observed support practice and related quality of life outcomes prove, the current project needs to be replicated beyond the transition phase of deinstitutionalisation.

This project was informed by 46 Kimberley Centre residents and members of their family. This sample represented slightly more than 13% of the 349 residents that remained at the Kimberley Centre in October 2003. Determining how representative participants were of the wider Kimberley Centre population was problematic given the lack of comparable, publicly available data. Comparing the mean adjusted age profiles and support need classification reported in the Ministry of Health (2001) document Preferred Future Service Provision for the Residents of Kimberley Centre revealed an almost perfect ‘fit’ to the respective profiles of the residents who participated in this study.

The blending of quantitative and qualitative research methods required that the number of participants needed to be large enough to detect possible differences in objective outcome measures but small enough not to overwhelm the qualitative analysis. Because the study was relatively underpowered, some otherwise detectable differences may have been missed. Given the small sample size, however, we can be confident in the robustness of the statistically significant differences that were reported. Similarly, given the wealth of participant narrative available for analysis, the themes reported as emerging from within the qualitative data tended to be well represented across participant responses.

The same confidence could not be expressed in the representativeness of the staff that chose to participate in the study. In spite of the array of different data gathering techniques employed, the Kimberley Centre staff remained reluctant to volunteer their experiences. The small number of staff that returned a Post Closure Questionnaire precluded anything other than descriptive analysis and an obvious skewing towards longer serving managerial staff in the project focus groups meant that the perspectives of newer direct-care staff were not captured. The reverse was true for personal interviews conducted beyond the closure of Kimberley. Only
those staff that continued to work in human services were accessible to the research team and as a consequence the voices of those who retired or chose alternative careers were absent. Those staff who did participate were most comfortable recounting their personal experiences of Kimberley and reflecting upon the impact of the closure on the residents they supported. They were less well disposed to speak about the impact the process of deinstitutionalisation was having on their wider family, meaning this dimension of the research tended to be under-reported and a fertile area for further research.

And finally, the small number of families who self identified themselves and their family member as Maori and the difficulty experienced in arranging follow-up interviews with this cohort meant that it was unwise to contrast the quality of life outcomes or experiences of Maori residents and their families with the Kimberley Centre residents of other ethnicities. If the research team is able to capture the missing narratives of Maori families future research will focus on the similarities and differences that exist in cultural understandings of a good quality of life.

6.7 Plans for further analysis

The Kimberley Research Project was a large study, blending different research methods and data streams. Some of the data collected is yet to be analysed comprehensively. The project also broke new methodological ground and many of the reported findings have much to contribute to the body of published disability research.

During the course of the project, information was transposed from residents’ support files at the Kimberley Centre and in their community-based setting. The file information has been collated but is yet to be comparatively analysed. The research team is particularly interested in using this information to explore a number of key issues alongside the narratives of staff, residents and their families.

In the National Health Committee’s 2003 report, *To Have an ‘Ordinary’ Life: Kia Whai Oranga Noa*, the prescribing of multiple psycho-active drugs for people with an intellectual disability, often in the absence of a formal diagnosis of mental illness, was described as “disturbing” (p. 9). Data from the Kimberley project will be used to explore whether patterns of prescribing are detectable and in particular, whether changes in prescribing occur following resettlement and if coincident cultural shifts in support practice are evident.

File information will also be used to explore issues of resident safety, including a more fine-grained analysis of Special Incident Reports. Of particular interest are training related issues, including errors in the dispensing of medication, the frequency of accident and non-accident related injury, and the prevalence and response of staff to incidents of peer abuse and intimidation. Staff narrative, including their interpretation of abusive events and the impact on service users will support this analysis.

The ability to make life choices is integral to individualised service delivery. Although an analysis of overall choice-making did inform the final report, the research team plans to conduct a more in-depth analysis of resident self-determination, including the scope and variables that influence residents’ ability to make decisions in particular life domains. Changes in type of individualised goal setting and staff and resident reflection will also be used to support this analysis.
Aggregating resident data is essential to gain insight into the size and variability of any differences that exist between different groups of people or the same people at different moments in time. What is lost, however are the nuances and diversity of individual experience. For this reason the research team is interested in using individual case studies as a form of dissemination. Case studies provide a useful way of combining all of the data in one story as well as the chance to include the perspectives of non-researchers.

Case studies also allow the ordinary process of analysis to be inverted and the research team is interested in identifying individuals that experienced the most dramatic positive and negative changes in life quality, to better understand what accounts for the variability present in the outcome measure used in this study.

Another area planned for future analysis is that of learning more about the factors that contribute to the high levels of staff turnover. Staff focus group and personal interviews will be combined with a more detailed analysis of key staff reflections about the factors that most influence the quality of support they are able to provide residents to gain greater insight into the stresses of direct-care support work.

In the course of conducting this research, the Kimberley Research Project introduced new ways of gathering information and generated conclusions that add to the body of published disability research. Further analysis of the data collected during this study will necessarily accompany the dissemination of study findings in published papers, conference presentations and seminars.

A number of writing themes have already crystallised. During the study a new method for summarising and analysing observational data was developed and we are interested in exploring its utility for improving disability support service delivery. The research team was also in the unique position of being able to explore coincident changes in the life quality of the Kimberley Centre residents with different support needs. Mapping the ways the experience of deinstitutionalisation was both similar and dissimilar for people with different types of support needs and will be the focus of ongoing research. The findings related to the impact of shifts in the cultural values of support services, especially as related to the plateauing in adaptive behaviour and active lifestyles has not been reported elsewhere. The potential role that families can play for a relative supported by a residential support provider has also received scant attention in the research literature and yet this research found that being close to a family member was amongst the most important determinants of improved life quality.

It is the intention of the research team to seek to publish on both of these research themes. The planned work and dissemination outlined above will occur over the next two years.
Bibliography


