

The impact of deinstitutionalisation on the staff of the the Kimberley Centre

The impact of deinstitutionalisation on the staff of the Kimberley Centre







Copyright © 2008 Donald Beasley Institute Incorporated

Donald Beasley Institute Inc. Mathews House 44 Dundas Street PO Box 6189 Dunedin New Zealand

Published 2008

Copyright note: No part of this book may be reproduced without written permission except in the case of brief quotations embodied in critical articles and reviews.

Authors

This report was written by Sue Gates, a Senior Researcher at the Donald Beasley Institute.

Research Team

Sue Gates, Paul Milner, Dr Claire Stewart, Dr Trevor McDonald, Sarah Sharp, Dr Brigit Mirfin-Veitch, Associate Professor Anne Bray

Cultural Advisor

Turoa Haronga

Staff interview and Focus Group interview content

Associate Professor Anne Bray, Dr Brigit Mirfin-Veitch

Staff Interviews Team

Sue Gates, Paul Milner, Dr Claire Stewart, Sarah Sharp and Dr Trevor McDonald

Staff Focus Groups

Sue Gates, Paul Milner and Dr Claire Stewart

Interviews and Focus Group transcribing

Roz McKenchnie, Roz Cavanagh, Colleen Dixon

Analysis of staff interviews and Focus Group interviews

Sue Gates

Questionnaire content

Associate Professor Anne Bray, Sue Gates, Paul Milner and Dr Brigit Mirfin-Veitch

Questionnaire Analysis

Sue Gates, Dr Daniel Schumayer

Formatting of report

Dr Daniel Schumayer

Acknowledgements

The research team would like to thank the management of the Kimberley Centre for their unstinting assistance and encouragement while we were completing Phase I of the study at the Kimberley Centre.

We are also grateful of the many Kimberley Centre staff who talked and debated with us and who graciously consented to interviews and Focus Group during Phase I of the study.

We are also indebted to Te Timatanga Whanau group at the Kimberley Centre for opening their whare to us, so we had a place to rest and reflect in between our observations and interviews.

Many thanks to the community-based service support staff who were most generous with their time and also consented to interviews during Phase II of the study.

Contents

\mathbf{C}	onter	nts	viii
1	1.1	The New Zealand Context for deinstitutionalisation	1 3
2	1.2 Me t	The Kimberley Centre	3 5
_	2.1 2.2 2.3 2.4 2.5	Research method and design	5 8 9 10 12
3	The	e questionnaires	15
4	Ma.	jor themes and key findings	23
	4.1		23
	4.2	The Culture of the Kimberley Centre: What was it like to work there?	25
	4.3	The management of the closure for the staff	29
	4.4	Staff relationships with the residents of the Kimberley Centre	32
	4.5	Abusive relationship	35
	4.6	Family Perceptions of staff at the Kimberley Centre	36
	4.7	Community Perceptions of the Kimberley staff	40
	4.8	Staffs' views on community-based services	43
	4.9	Honouring the Contribution of the Kimberley Centre Staff	46
B	iblios	vranhv	47

Introduction

People with intellectual disabilities, variously described throughout the centuries as mentally deficient, mentally retarded, mentally handicapped, fools, simpletons, feeble-minded, defectives, incurable, idiots, morons and moral imbeciles have been regarded with contempt, ridicule and often treated very cruelly. From early times such people were abandoned or abused, cursed and feared because they were different.¹ Throughout the centuries there was never any professionalised human services for anyone, least of all people who were seen as defective. It is only in the last 200 or so years that people with intellectual disabilities were deemed to be worthy of consideration and support. Up until then it was the responsibility of families to provide that oversight and care.

The origins of institutional care in the early 1800's in the USA were in the form of temporary residences for 'incurables' or children who were mentally deficient. These dwellings were intended as short-term boarding schools where children who mastered skills were then sent back to their families.¹ However, they very quickly changed from being places where a mentally retarded person was educated, to become a permanent home for people who had 'failed' the educational programme or were 'difficult to place'. Groups of failed, difficult to place people gradually became a problematic group.

Mansell and Ericsson (1996) also noted in Great Britain that institutions for people with intellectual disabilities began as a humane response to the oppression and misery of the workhouses and the lack of support in increasingly industrialised communities. Nevertheless the original benevolent aim of institutions quickly became unimportant as eugenicist ideas took hold and society demanded to have sites set aside for this population of people who were different. As land was cheaper outside of metropolitan areas and there were fewer neighbours to see what went on, institutions were built in the countryside, on the fringes of a town or city. Increasingly also, the original notion that institutions would be places of rehabilitation for individuals was discarded in favour of a custodial model¹ where people were contained on site away from the outside world to live their entire lives.

Even as early as 1843 people were recording publicly that institutions were places of degradation and neglect. There were reports of patients living in shameful, undignified and abusive environments but the staff who worked in these environments were also seen as victims of that system as much as the inmates.¹

Erickson (1978) said, "Institutions are pervasive phenomena... they prescribe the boundaries for what individuals can do on a day-to-day basis". You could surmise that 'individuals' included the staff of the institution as well.

There is very little in the research literature about the staff who work or have worked in institutions. When they are mentioned they are usually portrayed as a troubled work force with high turnover rates, poor morale and feelings of ineffectiveness and exhaustion. It is not exaggerating to say that staff in institutions have never had good press and have been treated in an oddly dehumanised way, similarly to their charges.

Staff in those early times were ordinary men and women who did not have the skills, knowledge or resources to provide decent and humane care for their 'patients' who were mentally deficient. Even so institutions still had problems attracting and retaining those unskilled personnel.^{1,2} Early institution staff themselves perceived people who were mentally deficient as not quite human and therefore not worthy of sensitive, experienced or highly qualified people to look after them.

Glouberman (1990) described staff in institutions as 'keepers' who exercise control over the lives of others.³ In his account of storiesfrom inside institutions he maintains that staff come to personify our negative feelings about institutions. Like the residents the staff are stigmatised. He states that institutions tend to be poorly functioning organisations, yet have been targets of reform and change right from their inception. But no amount of change and restructuring can change the fact that segregated institutional living is not living in a community and accessing the life of the community. Institutions deprive people of their freedom and they become completely dependent on others for their daily needs.

Deinstitionalisation has been the most important development in the way services for people with an intellectual disability have been organised in the past 50 years. In the late 1960's there was shift from the traditional forms of institutional care of the 1950's and 1960's to models of care based in the community. During the latter part of the 1970's the process of closure of institutions began in the UK, Scandanavia and the United States.⁴ From 1970 to the present day there has been a gradual decline in institutional living for people with intellectual disabilities in Western Europe, North America and Australasia. This trend has not been as prevalent in other parts of the world.

There has been a significant amount of research documenting the closures of institutions and the impact on residents and their families, but little if any official research has been conducted and/or documented on the staff who worked in these environments. Even today research and government documents give little, if any data on staff who have had long careers in institutions.⁵ What research there has been tends to concentrate on the need for staff training, the documenting of the high rate of staff turnover, stress and work performance. There is negligible mention in the literature about the working lives of institutional staff and the impact for them as they go through the deinstitutionalisation process.

Marchetti (1984) noted the increasing societal concern for the treatment of people with intellectual disabilities in institutions. Public exposes and court litigation around unsatisfactory treatment of people with intellectual disabilities by institutional staff became more common. Professional and parent advocacy developed to address these issues.

Abuse and neglect of residents/patients was a concern as far back as the 1960's, but little was done to remedy the situation for patients. Rabb and Rindfleisch (1985) posited in their research that abuse and neglect in institutions continued for so long because there was an absence of operational definitions and guidelines for identifying events as abuse and/or neglect. They suggested that agencies look at the organisational factors that would impede or facilitate the reporting of abuse and neglect. They hoped that their study would prove

useful in the development of law, policies and guidelines to increase the protection of people residing in institutions and all human services.

In the early 1960's it was also acknowledged in the USA at least, that training of personnel to work in institutions with people with intellectual disabilities was essential. As early as 1966 there was a concerted effort to describe the work in institutions in terms of occupations involving diagnosis, care and rehabilitation of people with intellectual disabilities. Boss and Gregg (1996) described twenty seven full time occupations and included the necessary worker traits such as aptitude and temperament and the necessary physical demands of the working environment in the institution.

It was recognised that there needed to be an increase in staff to patient/resident ratios for a variety of medical, educational, therapy and safety reasons. As well as increasing the number of staff in institutions 1970's research revealed the importance of orienting new staff to the institution and the residents, investing in training the staff and providing adequate remuneration.⁶

By the mid 1970's in spite of all this effort to improve the lives of residents in institutions by training staff and developing best practice codes many western governments were committing to the demise of institutions, and this became known as the deinstitutionalisation movement.

1.1 The New Zealand Context for deinstitutionalisation

New Zealand acknowledged the need to close its institutions but instigated the process very gradually over a period of more than twenty years. The closure of the last institution for people with intellectual disabilities, the Kimberley Centre, was effected in October 2006.

This report provides an account of the process of deinstitutionalisation from the perspective of a small number of Kimberley staff who chose to participate in this research. To this end the research reported on here contributes to an acknowledged gap in the deinstitutionalisation literature through its specific focus on the experiences of institutional staff.

1.2 The Kimberley Centre

The Kimberley Centre was located on the edge of the Levin township, an hour north of Wellington, the capital city of New Zealand. The Kimberley Centre was originally an airforce base and in 1945 the then Department of Health adapted the buildings to accommodate a large influx of people who had intellectual disabilities.

The Kimberley Centre was a significant employer in the region, notably health professionals, direct-care workers, administrators and trades people. The Centre had been in existence in the Levin community for over 60 years and had influenced the working careers of many people in the area.

Since it first opened in 1945 the Kimberley Centre systematically and inexorably made its way to closure. It never stood still. It continually examined its rationale for being, embraced the current philosophies of the time, introduced and maintained training schools for its staff and was in the 1960's internationally recognised for its unique programmes for people with intellectual disabilities. It provided along with other similar institutions in New Zealand, an important residential and educational service for people with intellectual disabilities when there was no such thing as community support or community-based services.

By the mid 1970's the western world was slowly but surely questioning the practice of segregating large groups of people with intellectual disabilities on one site, and on the fringes of towns and cities. In New Zealand the preparation started slowly for the comprehensive movement of people into their local communities. Although it took a very long time occur, the deinstitutionalisation of the Kimberley Centre was the logical last step for this institution.

Many of the staff who were integral to the operation of the institution for a significant number of years were still working at the Kimberley Centre as the research project started. Some had worked at Kimberley in excess of 25 years. Not only were they now on the verge of being part of an important change in the lives of the residents they had supported for many years, but they also were going to experience a major change in their working lives.

Method

2.1 Research method and design

The research findings presented in the current report comprise one component of a large, longitudinal study to comprehensively explore the deinstitutionalisation of the Kimberley Centre. Findings on residents and family experiences are provided elsewhere.

One of the 5 aims of this research project – **Examination of the outcomes of the resettlement of residents from the Kimberley Centre** – was to "identify the outcome and impact of resettlement for Kimberley staff and their families." With the data gathered from staff participants we proposed to,

- * build an impression of the culture of support that was offered to residents and staff at Kimberley and how this changed over time;
- * discover how staff saw their role and what they valued about their work;
- * identify the strengths and weaknesses of institutional care; and
- * determine the impact of the closure on staff's own quality of life and the quality of life experienced by the Kimberley Centre residents they cared for.

Consultation with management, families, staff representatives, including the Te Timatanga Whanau Group, (a Maori staff group) and staff unions began in November 2002 at the Kimberley Centre. Consultation continued through December and the early part of 2003. The consultation meetings informed these diverse audiences about the research project being planned, the research procedures that would be used, and the required ethical processes to be followed. Although the Ministry of Health had agreed to fund this research at the request of the Hon. Ruth Dyson, Minister for Disability Issues, all stakeholders were assured that this research project was independent of the Ministry of Health. Feedback from the groups about the proposed research and suggested methods was encouraged by the research team, then considered and incorporated into the overall research project design. Consultation about the nature of the research continued with management, staff and families through to March 2003.

Between March and June 2003 the research proposal was refined and an ethics application was completed. Because of the sensitivity, complexity and considerable length of our ethics

application we requested a face-to-face meeting with the Manawatu/Whanganui Ethics Committee. On June 16, 2003 the research team, including the Kimberley Centre Kaumatua, Turoa Haronga, attended the Ethics Committee meeting and with a few minor alterations the Committee gave final permission in July 2003 to proceed with the research project.

The research project began with the Kimberley Centre management agreeing to send information packs about the Kimberley Resettlement Project to all staff on site. At the beginning of August 2003, this pack was attached to all staff payslips. It contained a letter from the Manager of the Kimberley Centre (see Appendix 1 Letter from Kimberley Centre Manager to Staff) explaining that a research team from the Donald Beasley Institute would be in Kimberley documenting the closure process, and also included information about the research project specifically for staff (see Appendix 2 Study Information for Staff). The information detailed the aims of the research project, information about how staff might like to participate in the project, and ethical information about confidentiality and that participation was strictly voluntary.

In September 2003, Kimberley management attached a further letter from the research team to all staff payslips, (see Appendix 3 Dear Staff Member). This letter reiterated that staff were a key part of the research project and the research team would welcome their participation. They were given an opportunity to complete a "before the centre closes" Questionnaire (see Appendix 4 Questionnaire for Kimberley Staff) and return the completed Questionnaire to the research team in an attached stamped addressed envelope.

The questionnaire comprised three parts. The first part focused on demographic information, including employment status, current position at the institution, training, formal qualifications, length of service, income and number of dependents. Part two concentrated on staff's experience of the deinstitutionalisation process, comprising questions about when the closure was announced, staffs' perception of how the closure process had been handled, what staff were offered from the management and who staff identified as being supportive of them during the deinstitutionalisation process. The final section of the questionnaire sought information about the future for the staff and their families, including their expectations for future employment.

In December 2003, the process of observations and gathering information about the 50 Kimberley residents started. This aspect of the study that focused on residents' experiences is comprehensively detailed in a separate report titled "The impact of deinstitutionalisation on the residents of the Kimberley Centre". However, in order for the research team to gather data about each resident's daily life and skills it was crucial for the research team to talk to the residents' key staff people. Permission for key staff to discuss a particular resident with the research team had been obtained from families in the first series of family interviews that took place in September through to December 2003.

Prior to starting the observations and data gathering, key staff people for each resident were sent a further letter by the Management inviting them to take part in this particular part of the research on behalf of the resident (see Appendix 5 Letter to Staff Familiar with Resident). The letter informed them that they would need to spend approximately 2 hours with a researcher in a taped interview, discussing their particular resident's current functioning, general well-being and quality of life and completing three paper and pencil measures of their resident's functioning and activities. Staff were also informed that Management had agreed they could participate in this part of the research project in 'work time'.

Key staff went through the formal consent process (see Appendix 6 Participant's (staff supporting a particular resident) Consent Form) before they agreed to be interviewed (see Appendix 7 Interview Schedule – Key Staff Person for resident at Kimberley Centre) and

complete the functioning and activities measures. The taped interview with key staff included discussion on their resident's personal history, physical well being, emotional well being, interpersonal relationships, community integration, functional skills and behaviour, personal preferences, self determination and the impact of deinstitutionalisation. The taped interview was then transcribed and sent back to each key staff person with the request that they read through the interview transcript, make any alterations necessary, omit material they did not feel comfortable with and then return their amendments to the research team.

The measures completed by the key staff in collaboration with the researcher included the AAMR Adaptive Behaviour Scale (ABSRC: 2), ComQol-ID Objective Scale and The Choice Questionnaire (A scale to assess choices exercised by adults with an intellectual disability). As mentioned previously, findings related to residents are reported elsewhere.

Staff were also given an opportunity to have a personal interview discussing with the researcher their own personal views about the closure and the impact it was having on them and their families. In particular, key staff people were offered a personal interview when they had completed the interview about their resident. Formal consent procedures were adhered to before the start of each interview. As with interviews about residents, personal staff interviews were transcribed and sent to staff for them to check and alter if necessary before returning them to the research team to be analysed as data.

A further opportunity to be part of the research process was offered to all Kimberley staff by way of participating in Focus Groups. This provided an alternative research 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.

The Focus Group method of gathering data was selected to enable participants to reflect on questions asked by an interviewer, hear other peoples' responses, consider their own views in the context of the views of others and make additional comments beyond their own original responses. It is important to note that Focus Groups are not a problem solving or decision-making group and it is not necessary for the group to reach any consensus.⁷ The Focus Group format was deemed to be the least threatening and most productive method of encouraging staff to speak of their experiences.

Flyers about the Focus Groups with attached interest forms were sent to the Team Leaders of all the residential services at the Kimberley Centre, to distribute to each ward, unit, villa and management team (see Appendix 8 Attention – To staff who know the rich history of the Kimberley Centre and wish to discuss what the closure of Kimberley has meant for them). We asked that the content of the flyers be discussed at ward/villa staff meetings. Those staff who were interested in being part of a group were invited to complete the interest form and return it to the research team to enable the organization of Focus Groups at Kimberley Centre.

Focus Group participants read the consent information and signed the formal consent forms at the beginning of each Focus Group session (see Appendix 9 Interview Schedule for Staff Focus Group Interview about Impact on Staff). All Focus Group proceedings were recorded and then transcribed at a later date. Each Focus Group participant was sent a copy of the written transcript and given the opportunity to amend or add their own contributions in the transcript and return to the research team.

After the closure of Kimberley in October 2006 a further questionnaire (Post Kimberley Closure) was sent out to those staff who had completed the first questionnaire (see Appendix 10 Post Questionnaire for Former Kimberley Staff).

Similarly to the pre-closure questionnaire, this post-closure questionnaire contained an initial focus on demographic information, including current employment status, income, qualifications, and further training or education. The second section concentrated on staff's perception of the experience and effects of the deinstitutionalisation process, their current quality of life and their personal assessment of the impact of the closure on the residents of Kimberley who they had previously cared for.

Additional personal interviews were also offered to former Kimberley staff to discuss their working and personal lives following the closure. Former staff working in community services were approached by the researchers while making 3 and 6 month follow up visits to former Kimberley residents. Staffs' participation was voluntary and consent procedures were followed. These interviews allowed staff a further research opportunity to reflect on their time at Kimberley; the good and bad aspects of working in the Kimberley Centre; the impact of leaving Kimberley on their family; the impact of leaving the former residents and staff; their concerns about community living; the commendable features of community living and former residents' responses to living in the community (see Appendix 11 Interview Schedule for Staff Interview – personal (After the closure of the Kimberley Centre)). Similarly to other interviews staff were given the opportunity to read a transcript of their interview and to make changes, and then return to the research team.

During the final phases of collecting data in the community it came to the notice of the research team that some families and former Kimberley Centre staff were keen to give us information about how they perceived resettlement was progressing within the context of the overarching aims of the research project. This had been prompted by media revelations about the quality of community services and the calibre of staff working in those services. However sharing this kind of information with the research team was beyond the ethically approved process for data collection.

In August 2007 the research team informed the Central Regional Ethics Committee of this ethical quandary and sought approval to gather this sensitive information as long as those volunteers had the opportunity to read and ask questions related to the "Study Information for parents and staff who volunteer information in Phase II" – see Appendix 12 – and consent to the information being recorded and used to inform the project. The Central Regional Ethics Committee gave approval in September 2007 for the research team to gather this further information.

2.2 Background to the staff participants

At the start of the consultation process for this research project there were 349 staff on site at the Kimberley Centre, working in 11 separate villas/wards on the 50-hectare Kimberley Centre campus. One ward, Awatea, was located at Horowhenua Hospital in Levin township. There were three clusters of residents at the Kimberley Centre. They included the Lifestyle cluster, the Medically Frail cluster and the Challenging Behaviour cluster. The staff at the Kimberley Centre included management and administration staff, registered nurse educators, registered Nurses, enrolled nurses, 'psychopaedic'* nurses, psychopaedic assistants, and a range of maintenance staff. Of the 349 staff, 61% were male and 39% were female. Approximately

^{*&#}x27;Psychopaedic' is a peculiarly New Zealand term coined in the 1960's to describe hospitals/institutions for people with intellectual disabilities. This was to avoid confusion with people who had mental illnesses who also resided in hospitals. The word comes from the Greek 'paidea', which meant the development of the character of a child and 'psych' meaning mind. The prevailing thinking at that time perceived people with intellectual disabilities as having minds of children.

200 of the staff were Maori. Many of the staff were long-term employees and it was not uncommon for three to four generations of families to have worked at the Kimberley Centre. The consultation revealed that a large number of staff were untrained and unqualified[†]. It was also noted that few staff had individual contracts, with most being part of a collective contract (notes from 16/12/02 meeting held with senior management at the Kimberley Centre).

During the consultation phase frequent meetings were held with Maori staff (Te Timatanga Whanau Group) and the Kimberley Centre Kaumatua to discuss the research protocols and to receive advice on how the research team might approach Maori families and Maori staff. At this time the possibility of employing Maori researchers to accompany the research team as they visited Maori families was also considered.

The research team meet with the Public Service Association (PSA) and the New Zealand Nurses Association (NZNA) to inform them of the proposed research and highlight the importance of staff participation in the research. Throughout Phase I of the research the unions were sent copies of all our correspondence and information sent to staff. They were encouraged to contact any of the research team if they had any concerns about the research and its impact on the staff.

2.3 Overall response to the research project from the Kimberley Centre staff

With exception of 50 key staff who agreed to be interviewed about the resident they had primary responsibility for, the majority of staff of the Kimberley Centre were reluctant to engage in the research project. When the research team officially started the research on site they were regarded with suspicion and a few staff were resistant and initially made it difficult for the team to access some parts of the Kimberley campus. This was in spite of the fact that they had been made aware that a large independent research project was going to take place to follow residents, families and staff from Kimberley Centre into the community.

All team leaders, charge nurses, clinical leaders and senior management were briefed about the research project and the voluntary nature of the participation in early 2003. As mentioned previously all staff also received individual information about the research. The information made it clear that Kimberley was the last of the large institutions to close in New Zealand and this was an opportunity for the staff to tell of their experiences and stories. Added emphasis was on the fact that little or no research either nationally or internationally had ever taken the views of staff who worked in institutions into account, let alone considered them important stakeholders in the whole deinstitutionalisation process.

Research on institutions has largely ignored the effects of deinstitutionalisation on institutional staff and the possibility that the closure process could profoundly change their lives. The tendency has been for researchers to use staff as informants to provide information about residents' lives and to complete various quality of life, adaptive behaviour and challenging behaviour measures on behalf of the residents.^{8,9} This project sought to deal to this oversight in the research literature.

[†]This was not always the case. Through the years the Kimberley Centre had extensive training programmes for staff. There was an on-site School of Nursing where Psychopaedic Nurses were trained. This programme started in the early 1960's and was disestablished in 1991. The Kimberley Centre also had a National Training School that ran courses for Training Officers who worked cooperatively with nursing staff to develop the full potential of the residents. The National Training School was disestablished in 1989. The title of Training Officer was eventually dropped in favour of Psychopaedic Assistant.

Once the research started on site at the Kimberley Centre in December 2003 the research team spent one week per month for over a year in various villas and wards observing those 50 residents who were part of the research cohort. This time spent in villas and wards also gave the author of this report opportunities to talk with direct-care staff (psychopaedic assistants) about the research and to reiterate that staff were welcome to be part of the project. Many hours were spent unofficially "chatting" to staff on all working shifts in order for them to feel comfortable about the research. A lot of staff were happy to talk to the author in an informal manner, but were averse to engaging personally in the research in a more official way.

2.4 Suggestions as to why staff may have been reluctant to engage in the research

These suggestions have emanated from a distillation of field notes, interviews both personal and resident focused and informal "chats" with Kimberley Centre staff and will be expanded on in the themes and findings sections of this report.

- * At the commencement of the research process staff were often confused about what the research team was doing there and what our role was, in spite of the considerable information that had been circulated. The researchers working on the Kimberley Project were granted honorary staff status and wore Mid Central Health identification badges that made it clear we were researchers and had permission to be on site. However there was a surfeit of other visiting agencies and professionals on the campus at the same time. They included Ministry of Health officials, Mid Central Health officials, Needs Assessment Service Coordination (NASC) agency personnel, various service provider personnel and behaviour support personnel who all had different agendas and a need for information of one sort or another. Many staff felt besieged by the influx of more and more people. A staff person even asked one of the researchers, "Are you another one of the window shoppers?" It took some time to convince staff that we were not a surveillance team there to monitor them.
- * Many of the direct-care staff felt undervalued by the Kimberley management. They felt that the management did not value their skills, their experience and their years of dedication to the Kimberley Centre. They believed management left them out of the information loop, and out of the decision making process around residents' resettlement plans. Staff also thought they knew a great deal more about a resident than the management did and were puzzled as to why they were not consulted more. In addition the management promoted the research and made it clear to all staff that the research team was to have access to all villas and wards and all information about the residents. It was clear to the author that many of the direct-care staff were not trusting or positive about management during the deinstitutionalisation process and the research team was seen as being 'in' with management. While this perception was in many ways detrimental to the "buy-in" the research team were able to achieve from staff, there was no alternative approach that could have provided an ethically sound way in which to engage with staff.
- * Even though the closing of the Kimberley Centre had been mooted for some years many staff at the commencement of the research process in December 2003 believed it would not happen, because they had not heard or seen a great deal of progress

towards the closure*. They were fiercely protective of their work and did not see that deinstitutionalisation could possibly succeed. Subsequently the research team's endeavours to encourage staff to discuss the closure and its effects was not seen as pertinent to them.

It is significant to note that senior staff and management did not deny the reality of the official announcement of the closure to the extent that direct-care staff did. It could have been because they had more information, had marketable qualifications and skills, were more likely to get further employment and thus were more confident about the future.

- * It was clear to this author that many staff felt stressed and apprehensive about the plans for the Kimberley Centre closure, anxious about what was going to happen to the residents and concerned about what their future working careers would be. Some staff hinted they had nothing to offer the research. "I've said this all before and no-one has listened." In fact some did not think that what they had to say was important or had any relevance to the research.
- * As the research progressed and the deinstitutionalisation process became a reality staff were forced to think about future employment options. Working in the community was not an option that many considered at first because some community-based service providers had indicated that they would not see Kimberley Centre staff as having the right philosophy and skills to work in community services. Once again staff believed their skills and experience were being undermined and that they were being judged unfairly. This further compounded the perception held by many staff that they were unable to contribute any information that was valuable to this research.

Through this experience, it became clear to the research team that many of the direct-care staff – the psychopaedic assistants and senior psychopaedic assistants were a demoralised group. The majority of them had worked at the Kimberley Centre for decades and so had their extended families. They were being forced to go through a major change in their working lives that in turn would have significant effects on their whole lives – that is, where they might have to live, finding further employment and missing those residents they had supported for many years and in some cases, not seeing them again. Clearly consenting to be part of a research project that probed these issues was not a priority and was probably seen as intrusive at a time of stress and uncertainty.

As a consequence of this reluctance we had low numbers of staff participants. However the richness of the data gathered from those participants (whose opinions traversed a very wide range of philosophies, attitudes and experiences) has enabled us to generate a picture of a unique work force that has at times been misunderstood and unfairly criticised over the decades. 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 during its heyday and as it gradually closed.

^{*}The pre-closure questionnaire revealed that staff were uncertain about when they first heard the Kimberley Centre was closing. Dates ranged from 1980 to 2000. They were equally uncertain about when they heard about the announcement of definite closure. Dates ranged from 1998 to 2003.

2.5 The staff who took part in the research

Key staff interviews

Approximately 50 staff in various villas and wards agreed to be interviewed about the residents they were primarily responsible for. They tended to be direct-care staff who had known the residents over a number of years and were able to share detailed information about the residents' daily lives in the Kimberley Centre. On occasions one staff person would be the designated key staff for several of the residents who were part of our research cohort.

Questionnaires

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 Maori staff. 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 questionnaire had worked at the Kimberley Centre between nine and thirty four years. Six of the twelve Psychopaedic Assistants had lengths 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.

The post questionnaire was sent to the 31 staff who had completed the pre-closure questionnaire. Twelve questionnaires were returned. Of those twelve former Kimberley 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 intellectual disabilities, one was in mental health services, one in general nursing and one was working in a rest home.

Focus Groups

A total of 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 staff who worked in wards or villas, 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 Kimberley 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.

Personal Interviews

Seven 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 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 questionnaires and participated in the Focus Groups.

Analysis

A general inductive approach¹⁰ was used to analyse data collected from 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." (Thomas, p.238). Given the specific objectives of this research the general inductive approach was considered to be an appropriate analysis strategy and facilitated the emergence of major themes and findings relating to staff experiences of deinstitutionalisation.

Summary

Despite rigorous design and ethical procedures the staff component of the Kimberley research achieved a low rate of participation from the Kimberley Centre staff. As outlined in this chapter, there are a range of reasons for this low participation rate. In the context of an earlier New Zealand deinstitutionalisation process attempts were made to engage institutional staff in research. These attempts were unsuccessful despite the fact that a high degree of interest and participation was achieved from families who had family members involved in the same deinstitutionalisation process. However, this research was successful in obtaining important information about the working lives, and futures of a small but diverse group of Kimberley Centre staff. Their contributions have enabled important themes to emerge.

The questionnaires

There were two questionnaires offered to all Kimberley Centre staff. The first questionnaire was sent out to staff during the closure process. The second questionnaire was sent out after the Kimberley Centre had closed.

Thirty-one staff completed the first questionnaire during the closure of the Kimberley Centre. Of the 31, 22 were full time employees, seven were part-time employees, one was a temporary employee and one was a part-time casual staff. Seven replies were from Maori staff. Nine replies were from male staff and 22 were from female staff

The majority of the staff who completed the questionnaire tended to be the direct-care staff, i.e. Psychopaedic Assistants, and day activity staff. Smaller numbers of replies were from management staff, ie administrative staff, team leaders and registered nurses. Their ages ranged from 19 years to 62 years. Ten staff were in their forties, nine were in their thirties, eight were in their fifties and there was one 19 year old and one 62 year old. Two staff did not indicate their ages. Of the 31 completed questionnaires eight staff were the only income earner in their family, whereas 21 staff were one of several earners in their household. Three staff did not answer this question.

Staffs' income at the time of completing the questionnaire ranged from less than \$10,000 to more than \$50,000. The majority of staff earned in the \$30,001 - \$40,000 bracket. Those staff who were in the lower brackets of less than \$10,000 and \$10,000 - \$30,000 were part time and casual staff. Three staff did not indicate their income on the questionnaire.

The length of service for the staff who answered the questionnaire ranged from four to 34 years. The greater number of staff had worked at the Centre between 4 and 14 years. Six Psychopaedic Assistants had lengths of service over seven years. Twelve staff had worked between 15 and 34 years. One Psychopaedic Assistant had worked at the Kimberley Centre for 21 years. The staff person who had worked for 34 years had risen through the ranks from nurse assistant to charge nurse on a villa. One staff person did not note their length of service.

As part of the investigation into how staff would cope after the closure we asked staff how many dependents they had at the time of answering the questionnaire. Twelve staff had no dependents, ten staff had two dependents, six staff had one dependent, two staff had five dependents and one staff person had four dependents.

The research team was interested to know if staff had worked continuously in one villa or ward during their working life at the Kimberley Centre. The majority of staff who replied had worked in most of the villas and wards on the Kimberley campus. The exception was those staff who worked in the frail health wards, especially Awatea Ward based at Horowhenua Hospital who tended to have worked continuously on that one ward.

Staff were asked if they had any formal qualifications. Fourteen staff did not have any formal qualifications. Six noted school certificate as a formal qualification, two had a NZIM Diploma in Management, four were registered Psychopaedic Nurses, one was a Registered General Nurse, one had an Advanced Diploma in Nursing and the remaining three had Diplomas in Teaching People with Disabilities, Recreation and Adult Teaching.

The research team were aware that generations of families had worked at the Kimberley Centre through the years, so staff were asked to list the members of their families who had worked there. Sixty-five percent of the staff who completed the questionnaire had had family members working there. Four staff talked about their extended family working at the Kimberley Centre. They included mothers, fathers, aunties, uncles, cousins, sons and daughters. Seven staff specifically noted their mothers and sisters, six staff noted their brothers and four noted their husbands. Other family members mentioned were grandmothers, wife, mother-in-law and partners.

The second part of the questionnaire focused on staffs' experiences of the closure and how they were managing with the changes.

Staff were asked how they heard about the pending closure of the Kimberley Centre. They were allowed to indicate as many of the options they believed applied to them. Just over half of the staff specified that they had heard about the closure from the Kimberley Management. Ten staff indicated they had heard about the closure from other staff at the Kimberley Centre. Ten staff commented they had heard about the closure through the Media, through gossip and rumours and "at my interview in 1989." The Ministry of Health was the third most common way of hearing about the closure, followed by the Unions, Mid Central Health, senior staff and parents of residents. No one indicated that Te Timatanga Whanau Group had told them about the closure.

When staff heard about the definite closure was surprisingly variable. Forty percent heard the official announcement in 2001 followed by 23% in 2002, 10% in 2000, 7% in 2003 (the year of the questionnaire) and 10% variously in 1988, 1998 and 1999. Ten percent did not answer the question.

The staff were asked about how well the process of deinstitutionalisation had been handled for them. The majority of staff indicated that the deinstitutionalisation process for them was all right in some parts, but not so good in other parts. Seventeen percent of the staff answering the questionnaire indicated that the process went really well for them while 25% said it went reasonably well. Only 8% said the process went poorly for them.

Staff who completed the questionnaire were then asked how the process could have been better managed. Fifty-eight percent of the staff thought that the communication from the Ministry of Health was not good. Forty-nine percent of staff indicated that provision of information from the management of the Kimberley Centre could have been improved. Thirty-six percent felt that consultation with staff could have been much improved followed by careers advice, training assistance, union involvement and provision of personal help. No one indicated that the process was handled well. One staff person said that the Ministry of Health should have been the one to officially tell staff of the closure. Another staff person said that "...not knowing the actual 'real' closure date was frustrating and unsettling."

Staff were then asked what the Kimberley Centre had offered them by way of support and professional development through the closure process. Staff could indicate as many options as were applicable to their experience. They clearly agreed that the Kimberley Centre Profile was the major offer from the management followed by information meetings, in house training, regular progress updates, personal counselling, job counselling and finally external agency training.

Staff then indicated what they **actually** took up from the Kimberley management. The actual offers taken up by staff reflected what they had been offered by management. One staff person commented she did not take up any offers from the Kimberley Management, because she worked part time hours for the evening shift and by then all information meetings etc had been held. In fact she felt completely left out of the communication loop.

Staff were asked if they were considering taking redundancy. Seventy-percent of the staff answering the questionnaire said they would take redundancy while 30% indicated they would not.

Those staff who indicated they would take redundancy were then asked what effect taking redundancy would have for them. Undoubtedly the most common effects redundancy was going to have for staff was to reduce debt, followed by an opportunity to start up their own business. Having a holiday and finishing paying off the house were the next most common effects. The same number of staff indicated that redundancy would have no effect at all. Assisting your children and buying a new car were the least common answers. Five staff did not answer this question.

The questionnaire also sought information about who staff considered to be supportive of them throughout the deinstitutionalisation process and participating staff were invited to mark as many options as they wished. While the deinstitutionalisation process was going on staffs' families were the most supportive of staff, followed by other staff. The third most supportive group was the residents' families, closely followed by the Kimberley management. The remaining groups, Te Timatanga Whanau Group, unions, the Kimberley Parents and Friends Association and the community in general were indicated by two to four staff, with the Kimberley residents being the least supportive.

Part three of the questionnaire focused on the staffs' families' futures and their expectations for further employment. This information was considered by the research team as important to collect given that uncertainty for the future was undoubtedly an integral part of daily life for many staff at the time the research was occurring.

Staff were asked what steps they had taken for future employment. Eleven staff stated they had not taken any steps to find future employment. Eleven staff indicated they were investigating various training courses, ranging from computer courses, university courses to training in Maori Mental Health and completing university degrees. One registered nurse was currently negotiating with a District Health Board to introduce specialist nurses and resource nurse advisers. Another staff person said she was already working part time with another residential service provider. Two staff said they were leaving New Zealand and seeking work overseas. Another two staff said they were looking at setting up their own businesses and one staff person was looking at setting up as an activities provider. "At 54 years I'm being realistic", was the reply from another staff person and finally one staff person said, "I can't plan, not sure if I'm loosing my job. I don't see the need to look for a job when I already have one!"

Nineteen staff wanted to continue working with people with intellectual disabilities, while seven staff did not. Six staff indicated they were unsure at the time of the questionnaire whether they wanted to work with people with intellectual disabilities. Five staff did not answer this question.

They were further asked if they wanted to work in community-based services. Eighteen staff were keen to work in community services, whereas 8 staff were not. Five staff did not answer this question

Staff were asked how they perceived the closure of Kimberley would affect their families. Fourteen participants stated that they believed there would be both good and bad effects. Four said there would be some negative effects for their family, and four said the closure of the Kimberley Centre would probably be the best for their family. Three participants said the closure would have very significant negative effects for their family, while two others said their family would be much better off overall.

Staff were asked about the things that worried them about their futures. Evidently the lowered standard of living was the major worry. Loss of work, missing the residents and other staff were equally important. Having to move from Levin was seen as a possibility and thus worrying. Interestingly, finances, boredom and no training or work experience were less worrying, although one staff person said, "I fear unemployment, I mightn't get a job."

A significant area of the questionnaire sought to understand staffs' perceptions and views about the impact of deinstitutionalisation on Kimberley residents. Notably, the question about how they saw the future for the residents of the Kimberley Centre was problematic for some staff. Five indicated that the residents' quality of life would be much improved in the future. Seven staff thought that the residents' lives would improve, while one staff person thought there would be no difference in the residents' lives in the future. Six indicated the residents would have a poor quality of life once they moved out and three thought they would have a much poorer quality of life. Four staff did not answer this question. This question raised a number of issues for five staff. Two staff marked both improved quality of life (for some) and much poorer quality of life (for some) and one added that smaller numbers would be a plus, but quality of staff, accountability to clients, staff isolation and frustration could impact on the quality of life that residents would be able to achieve in community-based services. Another staff person did not indicate what she thought the future would be for residents, but wrote the following statement,

"Until there is a process in place that can check regularly without warning providers, the safety, care and protection of clients cannot be satisfied. There is no outside checks in place on those who do placements – are they moving clients from one institution into a smaller institution – [will they be] regularly checked?"

At the end of the questionnaire staff were given the opportunity to write about any positive changes they were looking forward to in the future? Only 13 out of the 31 staff made comments.

"Extending my personal and professional development"

"The deinstitutionalisation process has been too slow - I hope the community homes are OK".

"Being in control of my future without the uncertainty of not knowing."

"To manage groups of people with intellectual disabilities in community settings"

"Finishing my education – using my Kimberley experience to benefit others in the community"

"To continue my work in this field"

"Residents being able to move beyond the stigma of the institution."

"To be listened to, to make decisions, use my leadership skills"

"I'm kind of excited about a new job."

"More training and becoming registered"

"There are no positive changes when a place like Kimberley closes."

"I want to work in community services but how many jobs will there be for ex Kimberley staff?"

"Hoping to transfer my skills and experience to the community"

"Maybe leave town."

The second questionnaire was offered to those 31 former staff who had completed the first questionnaire, after the Kimberley Centre had closed in October 2006.

Only 12 former staff replied.

In the first section, which sought demographic data, staff were asked if they had gained any additional qualifications since leaving the Kimberley Centre. Most staff had not gained any further qualifications.

Staff were asked what their present employment status was now after leaving the Kimberley Centre. Out of the 12 staff who replied only 5 were employed full time, three were unemployed, two were in part time work, one was now a student and one was retired but performed voluntary work.

Three were nursing, four were support workers for people with intellectual disabilities, one was a carer in elderly care, one was studying, three were unemployed with one doing voluntary work.

Nine staff were in households where there was more than one income earner. Three staff were the sole income earner in their household.

On the question of personal income 4 staff were earning less than \$10,000 per year. Two staff were in the \$10,000 to \$20,000 bracket, and two staff were in the \$20,000 to \$30,000. A further two staff earned between \$30,000 and \$40,000 and the last two were in the \$40,000 to \$50,000 bracket.

Staff were asked about how many dependents they supported. Six staff were without dependents, five had one dependent and one staff person had two dependents.

The staff who completed this questionnaire had all finished work at the Kimberley Centre in 2006, ranging from February to October 2006.

Most staff cited redundancy as their main reason for leaving. However two staff said their reason was they "had had enough", while three stated they took another job. One staff person said they were "headhunted," and one said, "because the place closed!" Of the twelve replies, 11 indicated they did get redundancy and one did not. They were then asked what they did with their redundancy and eight stated they used it to reduce debt. One person had a holiday and one bought a new car. Others invested their redundancy, had surgery or put it towards retirement savings.

Similarly to the first questionnaire, staff were asked how well the deinstitutionalisation process had been handled for them. Six staff said some parts of it were ok and other parts not as good. Three stated, "reasonably OK", two stated "very well" and one said it had been handled "very poorly."

When questioned about how the process could have been improved for them the answers were variable. Staff were permitted to indicate as many options as they thought appropriate to

their personal circumstances. Two staff said they thought the deinstitutionalisation process for them had been handled well. Six staff indicated that the communication from the Ministry of Health and the Kimberley Centre management could have been improved. Four said they would have preferred more assistance with further training and two staff stated they would have liked career advice. Three staff indicated the unions could have been more helpful and two staff said consultation with staff could have been vastly improved. One staff person stated they did not know how the process could have been better managed for them.

Staff were then asked what offers they finally took up from the Kimberley management. Regular progress updates and information meetings were the most common offers taken up by staff, followed by the Kimberley Centre Profile and external agency training. The least chosen options were in house training and job counselling.

Similarly to the first questionnaire staff were asked who had been supportive of them through the deinstitutionalisation process. As for the first questionnaire, family and former Kimberley staff had been the most supportive.

Part three of the post-closure questionnaire focused on staffs' expectations for the future. They were asked if they had continued working in the field of intellectual disability.

The majority said they were no longer working in the intellectual disability field while a third said they were. Additional comments from the staff about why they were no longer working in the field included.

"I decided before leaving that I didn't want to work with intellectually handicapped again."

"I may have continued if a suitable job was available."

"I have been told I'm too old."

"Had had enough"

Further comments about why they continued to work in the field included,

"They offered me a job and I needed the money/job to support my family."

"It was easy to get a job, [in the field of intellectual disability] due to not having any other qualifications."

"I only have a few more years until retirement – happy to continue with the same kind of work until then."

"I had the experience."

A question on the positive aspects of community-based services drew the following answers:

"Service users are getting more individual care and support."

"Smaller quieter environments – more input into decision-making."

"Food's better - better support from the managers."

"The clients have more community opportunities, more personal space and a 'quieter' home to live in."

Comments on the negative aspects of community based services tended to focus on staff quality and included,

"Providers appear to employ 'anyone' (almost in desperation)... I was appalled at some that were employed and extremely disappointed that ex Kimberley staff (a minority) with previous history of aggression, intimidation, and verbal abuse were employed."

"Lack of expertise in ID within the providers' management. The emphasis in the community is mostly on aesthetics not actually the service provided...lack of access to support services...

"Lower pay... [negative] comments made about staff who used to work out at Kimberley."

"Lack of resources"

Staff were asked how the closing of the Kimberley Centre affected them personally. The loss of good pay and conditions was a major personal effect. Loss of employment was the next most common effect, followed closely by loss of friends, staff and residents, and loss of job satisfaction. On the more positive side an opportunity to start a new life was indicated by four staff, and the opportunity to stay in Levin was chosen by three staff. A chance to move elsewhere was seen as a positive effect for three staff while one staff person indicated that good pay and conditions at a new job was personally positive for them.

When staff were asked to comment on how the closure affected their families five staff stated there was minimal or nil effects on their families. Four commented about lower pay and a change in employment conditions having a major affect on their families.

"Change in work conditions and loss of wages affected family resources"

"A drastic change in finances and lifestyle"

Two staff discussed the emotional toll on their families.

"Wife had to put up with me, more so."

"A partner had to have lots of patience as I didn't work for almost a year."

A question on how satisfied staff were in their new jobs revealed that 40% of them felt that job satisfaction was significantly worse, while 20% indicated it was worse. Thirty percent indicated that job satisfaction was about the same, while 10% said it was better.

Since leaving the Kimberley Centre 11 staff had undergone some training of one sort or another. Training specifically associated with their work in community based services included support worker modules, core skills, first aid, health and safety and a PEG placement course. Training outside the field included completing a Bachelor of Nursing, computer studies, and National Certificate in Adult Teaching and Diploma in Psychiatric Nursing.

As with the first questionnaire staff were asked about their concerns for the future. In line with concerns about lower wages in community-based services staff indicated their biggest worry was a lowered standard of living, followed by loss of work and missing other staff and residents. Less frequently indicated were no training or work experience, boredom, having to move from Levin and finances. Loss of opportunity for their children was only a worry for one staff person.

Staff indicated they had kept in touch with former residents and former staff of the Kimberley Centre. All twelve staff indicated they kept in touch with former Kimberley staff, while only half kept in touch with former Kimberly residents.

Staff were asked to indicate their impressions of the impact of deinstitutionalisation on the former Kimberley residents quality of life. Even though staff were asked to mark only one option, many marked several options making for a somewhat confused picture. Four staff indicated that the former residents had an improved quality of life, while two staff thought they had a much-improved quality of life. Two staff said there was no difference in the quality of life for the former residents, while three said they had a poorer quality of life and two indicated a much poorer quality of life. One did not answer this question.

Additional comments to this question on quality of life for former Kimberley residents included.

"Surprised at the number of avoidable deaths which could have been prevented with quicker treatment or more experienced staff."

"The Kimberley clients are seldom seen in the community – several have died through reduced medical interventions – several assaults have occurred that would not have happened at Kimberley."

"There have been documented cases of abuse, assaults and high staff turnover."

"I don't think they are that well looked after. They were better looked after at the Kimberley Centre."

"Improvement in living conditions, meals, choices, but poor access to professional services."

"It has been better for some, more than others, it has affected each individual differently."

Staff were invited to write their final comments about their experiences of the closure process. They mainly focused on how the community-based services were functioning and the calibre of the staff in those services. One staff person commented.

"They need an independent monitoring system to check up on the standards in house to prevent abuse, neglect and fitness/appropriateness of staff."

Another staff person made the following observation.

"I was disgusted that Levin WINZ office was told to get inexperienced unemployed people off the benefits and into employment in the intellectual disability field in Levin."

Two staff still felt strongly about how the closure process was handled by the Kimberley Centre management and wrote,

"Bitter angry staff, uncaring managers. The MoH did not care at all when they made the decision of closure. I needed to help staff through the grieving process, because management was not interested."

"I was disappointed and sometimes angered by the attitudes of some management/team leaders. Their attitude to us was a show of power over us...it was like they were given powers and they over activated [towards] the staff, because management were 'flexing their power' as they had not much more to do at the time. This has left me bitter towards these people...they have forgotten that people don't forget being treated badly."

However there was one positive comment,

"I believe the clients have gained a well earned sense of home, independence and community involvement – 99% of the staff [in community-based services] are excellent."

Major themes and key findings

As outlined in Chapter Two: Method, data gathered from the staff participants were analysed using a general inductive approach and resulted in the emergence of seven major themes. Chapter Four has the purpose of presenting findings related to these seven themes which include:

- 1. How the staff viewed the closure of the Kimberley Centre was it a commendable idea or a flawed notion?
- 2. The culture of the Kimberley Centre the good and bad features of the institution.
- 3. Management of the Deinstitutionalisation process how well informed were the staff, how included were they in the decision-making surrounding the deinstitutionalisation process? Was the management aware of how staff may be feeling and coping with the closure?
- 4. Relationships with the residents of the Kimberley Centre what was the nature of the relationships over many decades?
- 5. Family perceptions of staff through the years
- 6. Community perceptions of the Kimberley Centre staff community-based service providers' interactions with Kimberley staff did the community-based services acknowledge the skills, experience and extensive knowledge of the Kimberley staff?
- 7. Staff views of community-based services their concerns about community services gaps in those services as understood by former Kimberley staff commendable features of community services.

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

A striking feature about how the closure of the Kimberley Centre was received by staff was the division of opinion between management and senior staff, including Senior Psychopaedic Assistants and the direct-care workers known as Psychopaedic Assistants. Management and senior staff tended to accept the idea of the closure in a more philosophical and positive way. Psychopaedic Assistants were inclined to be more opposed to the closure.

In fact, at the beginning of the research project many staff continued to deny that Kimberley Centre was going to close. It appeared that the staff heard about the definite closure at different times. Most staff indicated they had heard of the closure officially in 2001. Some said they heard in 2000 and 2002 and even 1999. This variability would possibly account for the denial of closure by many staff. However when it became obvious that the institution was indeed closing many Psychopaedic Assistants became more vocal expressing their reservations about the wisdom of the closure.

"No I think some residents would be better off staying here, I really do...you look at those—they are hospitalised and they know the people here and they need 24 hour care and medication and that and they are happy here so I mean why upset them...I can't see that it would advantage a lot of them...but a lot are not going to register they are in the community or wherever."

One staff person indicated that most staff were not behind the closure at all and would have preferred for the institution to remain open.

"That's what a lot of staff want out here."

While another person was fatalistic about the closure.

"Well what is the point in whining, it is happening and we have accepted it, yes well I have accepted it."

"Honestly I thought years ago it [the Kimberley Centre] was closing...it doesn't affect me, I don't feel bad about deinstitutionalisation really, except I just hope the residents are going to get it better out there...I'm actually here much longer than I anticipated."

"When I started here they always said, we have only got about five years because there is this thing hanging over that Kimberley will be closing and so it has always been there, that it is not going to be very long, but as it is I have ended up being here for nine and a half years."

"I am sorry to see the place close, but you can't do much about it."

Some staff (along with a number of families) believed the Kimberley Centre should stay open even if in a different form.

"I think it's a jolly shame that they did not make a village as a complex here. Do away with those big buildings, make smaller houses and have a really nice set up using this campus because we have got a hall...heated swimming pool, nice admin. block...but the units are crap and should have been bowled over years ago."

A number of staff suggested that a collection of smaller houses could be built on the Kimberley site along with appropriate ancillary services and residents would be free to walk around wherever they chose, unescorted and in safety.

"That's what a lot of staff want out here community housing on the property on site. Bowl all these big dormitories down, put up modern cluster housing out here. The land is there so use it. And it is a safe environment as far as they are watched 24 hours a day."

These staff seemed to believe that a revamped Kimberley Centre would allow the residents to be more independent than in a house in the community. They could maintain their friendships with residents and staff, all services would be on site and they would not have to worry about the unpredictable nature of living in the community.

Conversely, other staff mentioned the dilapidated state of the Kimberley Centre and the winding down of programmes and services and said, "This place can't stay open."

Once staff adjusted to the reality that the Kimberley Centre was definitely closing they then focused on the preparation of residents for their final departure. A number of staff talked about how the departures of residents were affecting them personally. But they were also concerned about how residents were leaving and how the community-based service providers were receiving them. They distinguished between Maori residents who were formally farewelled and formally received by their new service, had a handover that was carefully planned with and by staff who knew the residents well and were closely involved to oversee the process of leaving. This was not the case for non-Maori residents whose departure from Kimberley Centre and arrival at their new service were not as structured or planned.

At the beginning of the research project direct-care staff talked about how the closure had been mooted for many years and that the process for closure had been slow to the point of being non-existent. Therefore the staff were very cynical about the closure and preferred to talk up the need to keep the institution open. This cynicism waned as the closure process became a reality. These staff then concentrated on preparing residents for departure. They were not impressed with the way many residents were being transferred from the Kimberley Centre to homes in the community and believed that they could have played a greater role in settling residents into their new environments.

Staff talked about the lack of a proper transition process to the community for the residents. They recounted stories of going with residents to their new homes and leaving them there all in the space of a day. For many residents the first time they saw their new home was the day they moved into it.

"The odd staff has gone with them [resident] and stayed a day and then come back. I heard of one lately who flew up with them and flew back the same day...drop them off, drop the luggage off, throw them in the door, see you later I am gone."

One staff person commented about how a resident might be feeling at this unceremonious 'dumping'.

"That to me would be really horrifying, I would hate it. One minute you are here, the next minute you are there, no explanation."

Staff discussed how it would have been better if a resident's key staff person had gone with them to their new home and stayed with them for a number of days helping them to settle in, adjust to new routines, and meet new staff and their new house mates. Staff knew this would be a difficult time for the residents and they believed if the resident had a familiar staff person with them for a period of time then the settling in process would not be so overwhelming. This would have also been a way for staff to see where the person they had been involved in supporting had moved to, and may have allowed for a less traumatic farewell for both staff and resident.

4.2 The Culture of the Kimberley Centre: What was it like to work there?

What were the beliefs, practices, customs and social behaviour of the Kimberley Centre staff? Even though the staff were a specific, unique and possibly "the last of a breed" of institutional workers in New Zealand it is questionable whether they all shared the same beliefs and agreed and adhered to the same practices.

Suffice to say it would be incorrect to infer there was only a single culture amongst staff at the Kimberley Centre. The divide between management, senior staff and the direct-care staff was continually revealed as these quite distinct groups worked, many times not so collegially, to provide support to the residents.

Management and senior nursing senior staff, including senior psychopaedic staff, were seen by Psychopaedic Assistants to be powerful and somewhat dismissive of them.

Psychopaedic Assistants saw themselves as bearing the heaviest burden, as being essential to the running of the institution, and of undertaking the really hard, hands-on work of feeding, dressing, and toileting of people who would never perform these tasks independently. They felt they were rarely recognised for the hard work that they did and certainly not supported or praised for their efforts. However it must also be appreciated that at the time the data was collected the institution was in the final stages of closing down and a number of staff were coping with closure processes they had difficulty accepting.

Staff appeared much happier to discuss what they saw as the culture of the place in years gone by and described Kimberley Centre as a thriving, self-supporting community of residents and staff. There were discussions about a staff hierarchy that existed with nurses at the top and the training officers much lower down the ladder. In those days when the residents numbered over 800 staff discipline was strict and unyielding. The management had high expectations of staff and the Centre was run in a military like manner.

"They had expectations and by God you stuck to them. Like I remember not being able to leave the day room. We had 15 in the day room... and you couldn't leave without the charge nurse inspecting whether you had polished all the shoes for school the next morning... but it was good. I mean you knew what you had to do and you did it. And you worked hard."

Staff talked about the halcyon days of sports days, big drama productions that were staged with both staff and residents participating and about how the Levin community would come out to the Kimberley Centre to join in the fun.

"Talking about the old days – I mean we had 900 odd people here living at Kimberley when I first started. There were a lot of good people with very good skills... They had lots of singing groups at Kimberley and plays put on by the residents. There were lots of fun things to do. I think of those sports days. One really sticks in my mind is that instead of the residents going back to the units for lunch, we all had sandwiches and cream buns and all sorts of things to eat – those cream buns stick in my mind – it was beautiful sitting under the big trees and having lunch – we had a lot more community integration back then – sports teams from Levin would come and play on our sports fields – well everyone would come out here. In the old days we kept more to ourselves out here, everyone would come here, it was all very insular."

The Kimberley Centre was known for its education and training programmes for the residents. Staff talked about these in a very positive way and expressed concern about how those highly effective programmes were allowed to lapse.

"Kimberley was very good at training the residents – I don't mean training them like monkeys, I mean toilet training, teaching them how to use cutlery and feed themselves. We were very good at that, very good and internationally recognised as well and it was second nature that when you were working with people you looked at that sort of thing and you automatically tried to enhance what skills they had whereas nowadays it is probably more of a custodial approach."

Several staff people thought that even though the Kimberley Centre had a custodial culture in those early days it was a safe, nurturing and caring place. One staff person inferred that the caring, protective and nurturing philosophy was not what was appropriate for people with

intellectual disabilities now and that a more empowering and respectful approach needed to be encouraged.

"But now there is more respect for the resident I think and more treating them like people. Yeah and real regard, real genuine relationships which is really good."

A further cultural dimension of the Kimberley Centre that was prevalent in discussions was the significance of food. As with most institutional living food and eating was a focus in the daily lives of the residents. Staff regretted that food was no longer cooked on site and the residents never participated in food preparation or smelt food cooking. A particular cook was mentioned by name by several staff.

"He was the best cook and it didn't matter which unit you were in you could smell the lunch, the creamy mashed potatoes and the puddings. You could smell it all morning and I tell you what it certainly made you hungry. It would be ten years plus since they've cooked out here and I think that's the suckiest thing that has ever happened here."

This comment illustrates that due to the long lead-in to deinstitutionalisation some of the positive aspects of living in Kimberley Centre were lost to residents and to staff. Further to this point, in the past the Kimberley Centre had been almost self-sufficient and staff talked about how staff and residents worked together to keep the Centre functioning.

"Back in those days the residents used to run the laundry. They would go down at 7 o'clock in the morning and start the laundry off and come back and have breakfast and go back and finish."

Contrary to this description, at the time the research team was spending time at Kimberley Centre very few Kimberley residents had any sort of meaningful daily routine or occupation.

The staff who had worked at the Kimberley Centre for many years talked about loyalty to the Centre, and to their colleagues.

"The one good thing about those days was the loyalty amongst the staff...it doesn't happen now of course. During that time it was very happy times and people volunteered to come in and do things for nothing and that happened a lot for our pantomimes and what have you."

Staff then reflected on the culture of more recent times where it seemed to them that the administration of the institution had become more important than the residents.

"I would say it is a culture of almost where you are constantly having to check yourself to make sure everything is in the appropriate boxes and that the right paper work is signed because failure to do that can get you into trouble. And there are a lot of mad things that happen out here."

Staff were asked to comment on what they perceived to be the positive aspects of the Kimberley Centre and influences these had on the Centre's culture as a home, and as a workplace.

"I think it is the safety aspect in terms of being protected from the community – you know vehicles and stuff like that... and the sort of centralised thing, the access to good health care, the doctors and nurses, all those things [are] readily available and they are here in a phone call, there is no sort of having to ring the doctor and go and sit in the waiting room... that could be quite traumatic for them [the residents]."

"I think it is the whole family concept and the sharing of ideas and skills...like when you are having difficulties in a particular situation you have got lots of other people you can sit down with and nut it out... the interdisciplinary meetings all here on site."

"I think the size of the grounds and the fact that people who maybe haven't worked through some antisocial behaviours yet can sort of – they can still walk around and nobody is mocking them or demeaning them and they are not at risk that's the good thing about it [the institution]."

"I think the grounds, the facilities that are here and the safeness of it."

Staff mentioned assisting the residents to become more independent as an important aspect of their work highlighting that the concept of empowerment for people with an intellectual disability was not forgotten or seen as unimportant in the institutional environment.

"You were able to help them and get people to be a bit more independent. I think that was the big thing, it was sort of trying to train as many as you could to do things for themselves."

Whilst participating in the range of data collection strategies utilised as part of this research, staff were asked to comment on what they saw as the negative aspects of institutional life and work.

"The desensitisation around a lot of values, and that sort of stuff, I don't like that, that's a horrible part of an institution. And the fact that people can bring their own personal values into a big place like this and it is not as noticeable as in a small place."

"... people can work here for a long time, get set in their ways and basically just run amok with how things are done."

Some staff also recognised the institution as a place where individuals lost their identities and became subsumed into the group of people labelled intellectually disabled.

"I think that in terms of care for the residents, the bad thing about it is that they become a number and the whole sort of – it gets swallowed up by the actual institution... one of the bad things about an institution... is the lack of individuality where people become just sort of almost clones and there's no celebration of difference or individuality."

In particular staff talked about a culture of incompetent and negative workers. One staff person defined incompetent staff as those who did not care for the residents and who worked for an easy life. The hardest part of the job for many staff working at the Kimberley Centre was co-existing with pessimistic colleagues who were unsupportive, and unmotivated in their work.

"The hardest part about working at Kimberley is working with negative colleagues. You don't feel as though you get the support you deserve. A lot of negativity out there, that's because the place is closing and people are just hanging out there until it closes sort of thing and basically holding on for their redundancies."

It appeared from the comments of staff participants that they perceived that some of their colleagues were working to the barest minimum to get by.

"Getting the job done in a really short period of time, getting things out of the way. Sitting back with their feet up and the residents behaving themselves."

Worryingly, but perhaps unsurprisingly in light of previous research on institutional living, a number of participants talked about the culture of staff covering up abuse.

"There were some cases of abuse – I mean over the years a lot of them, abuse cases were swept under the carpet or else you couldn't prove anything because their mates wouldn't back you up. You might have seen something but no one else had, everyone turned blind ..."

"There is a lot of staff out there that shouldn't be there basically. They don't let them go. What this guy has done, so many things that he shouldn't have...he should have been fired

and they just moved him and it is wrong. He has been moved about four times at least, it's disqusting."

One former senior staff person also expressed concern about how some abusive staff were being considered for employment in community services. At that time she was also working in community services and had some influence over who was hired.

"Some of them [former Kimberley staff] are bad and that's why when I went there I was lucky to be on interview panels and stop some bad people coming in. But people who were rough, aggressive, verbally and physically I didn't want them to be part of those people [the former Kimberley residents]. I didn't want them to go into the future with some horrible person continuing the intimidation, the bad language and certain behaviour."

The culture of the Kimberley Centre was changeable through the years depending on the philosophy and practice that was in vogue at any one time. Through the years custodial and more laissez-faire models of working with people with intellectual disabilities went in and out of fashion. These models influenced what was considered good or bad practice in the institution. The one constant in the culture of the institution was the presence of a small number of unsatisfactory staff.

4.3 The management of the closure for the 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 in local communities. Furthermore the process of institutional closure has frequently been accompanied by an expectation that the 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.

No less was expected of the Kimberley Centre staff. However the staff felt that the closure's emphasis on the residents, although essential and obviously necessary, did little to acknowledge that they too were moving out and going through a most difficult period in their lives as well.

Menzies in O'Driscoll (2006) writing about organisational change found that many staff in human services had difficulty with change because they had established ways of working and thinking about changing the way they worked engendered anxiety and resistance.¹² Menzies (2006) suggests that staff who are anxious and resistant tend to repress what may be happening and then blame the management for their uncomfortable feelings. They create a distinction between them (the management that makes them feel bad) and us (the workers). This is very common in times of stress.

The Kimberley Centre staff reported feeling all of the above. The difficulties they experienced were not so much a change in the way they provided support to people, but that the type of support they were providing was no longer required or deemed appropriate. Many direct-care staff felt that senior staff and management were making major decisions without consulting or informing them. But most importantly they felt the management did not recognize they were dealing with major loss and change and they were allowed little time to become accustomed to and reflect on the rapid changes that were taking place.

O'Driscoll (2006) stated that there needs to be more attention given to staff in human services, when dealing with major change. In reference to this point, those staff who were interviewed as part of the Kimberley study were asked if the deinstitutionalisation process had been respectful to them and kept them informed about what was planned to occur at each stage. One staff person who had only been at Kimberley for four years said,

"Yes I would have to say it would have to be, like it's not an issue for me. I have my sort of opinions about it but yeah it has gone really well."

Even though there appeared to be a lot of information about the closure circulating around the Kimberley Centre campus, direct-care staff in particular thought they did not receive enough information.

"The ones who were actually working on the wards never got much information."

"There was a lot of paper work and a lot of it was seen to be pretentious because some of the team leaders were so full of their own self importance."

When asked about what had been problematic about the process of deinstitutionalisation for them some staff said the provision of information had been very unreliable. In fact they said they had become irritated by the media who seemed to be privy to information they could not access.

"I don't know where they [the media] get their information from but they seem to be in the know."

However staff did admit that management 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 Personal Profile. Unfortunately only a few staff indicated what offers they took up from the management, but it was clear that management were considering the staff and were prepared to assist the staff if they wished.

A senior management staff person did recognise the closure was stressful for staff and commented that many staff were not coping well, but clearly she felt powerless to do anything.

"I am not enjoying the last six months, because watching the process and how it turned out and the way some staff behave in a very stressful environment, you still expect a certain behaviour, human behaviour from people"

This same senior staff person made observations about how staff behaved during the final stages of the closure process and then suggested why they were cross at management.

"Well I think that people can see the place is closing now, it is real and I suppose it's the vying for jobs that has made people... the greed... people wanting their redundancy early has made people nasty. I think it's the grieving process now and people are not coping with it. Personally I think they are not recognising what they are feeling."

"They are like not turning up for work, or using up their sick leave and not treating each other with respect, not treating the management group with respect, because we are seen as the ones implementing all these awful changes in their lives – their jobs are being disestablished and I think the anger towards who they perceive are the ones that are making all the changes is us at our level, so it is quite difficult at our level."

This particular senior staff person was also eager to convey how the Kimberley management were also feeling about the closure.

"[They are] acting out. Yes and the managers we are trying to manage that [the other staffs'] behaviour but we are going through it as well, probably on a – I would say higher level really, without disrespecting what they [the staff] are going through. We are having to deal with theirs [grief] and support them but we have got ours [grief] too. So it's pretty difficult at times."

However many direct-care staff felt keenly about the lack of respect shown for their feelings about the closure, their concerns for the residents and their worries for their own futures.

In particular they were disappointed that they rarely heard how the former residents were adapting to their new homes.

"Well once they started going out, to start off with, we were quite brassed off because people were disappearing and we didn't know exactly where they were going... The ones that were actually working with discharge and transfers [the 'Deinst team'] they knew where they had gone. We never got any feed back from the providers as to how they were going or whether they were settling in". The only feedback we got was bad feedback. You know if someone died or there had been something gone wrong. We got that feedback, but we never got positive feedback...it was really quite nerve wracking to start with and we thought where are they, what is happening and I think it was the same for the residents."

Many staff admitted they were grieving for the residents, the loss of friends, and the loss of a work place. One staff person likened the feeling she was having now to the time a resident died that she was very close to.

"I was privileged to be a pall bearer for that particular man I was very close to and I can remember thinking, 'What am I going to do now?' because he was a big part of my life. I used to spend time with him. But yes that is how it is feeling now. Sort of like, what is going to happen? I will never see these people again, you know."

There were poignant discussions about preparing to say goodbye to residents as they left and coping with personal feelings and responses as the institution closed villa by villa.

"... you think this will be the last time or this will be the last week or this will be the last day."

"And particularly painful this week when Kaniere closed, that's the first villa I started in and there are a lot of memories there. And it was more overwhelming than I though it would be and I actually went back again and walked around by myself in that place and it was a very strange feeling, just remembering all those staff and all those people who had lived there and the things we used to do and the fun we used to have – so Kaniere was quite difficult."

As discussed in the questionnaire chapter staff commented about the management of the many aspects of the deinstitutionalisation process. When staff first heard about the official date of the closure was highly variable ranging from 1998 to 2003. How staff heard about it and from whom was also variable. The three most common ways of hearing about the pending closure was through the Kimberley management, other staff or the media. When asked about what the Kimberley Centre management offered by way of acknowledging their needs for future employment the most common answers were information meetings, in house training and the Kimberley Centre Personal Profile. Unsurprisingly, these were the items they actually did take up from the management. This was in contrast to the views of some staff expressed through personal interviews whereby management were seen as not forthcoming with information

Staff felt their own families other staff and the residents' families were far more supportive of them than the Kimberley management during the closure process. Nevertheless the management were indicated as more supportive than the unions, Te Timatanga Whanau Group and the Kimberley Parents and Friends Association. Most certainly the management were indicated as more supportive than the community in general.

According to the research on organisational change the Kimberley Centre staff were not unusual in their feelings towards management. As they went through this difficult and compulsory process of closure including the leaving of friends, the abandonment of a long-term work place 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'. However staff did acknowledge at times that management had an unenviable task and were possibly as disenchanted by the process as they were.

4.4 Staff relationships with the residents of the Kimberley Centre

"I am yet to meet a person with an intellectual disability that really wants a professional in their life. They want someone they can trust, have a good relationship with and they work hard to dissolve every single boundary that stands in the way of it."

(Psychopaedic Assistant, 2005.)

It is recognised that the relationships between staff and residents at the Kimberley Centre determined to a very large extent the quality of life residents living in the institution were able to achieve. While staff continually demonstrated their attachment and concern for the residents, many of the residents reciprocated by initiating interactions and responding to the staff in a way that illustrated their care and attachment for their staff.

Research tells us that direct-carers, those workers in an organization who do all the hands on care, are the most important people in the lives of any resident or client using the services of that organization.^{5,13,14} Direct-care staff are at the forefront of delivering good quality care and support to people and they have an indisputable impact on their daily lives.¹⁵

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. Yet in disability organizations, whether they are institutional or community services, direct-care workers are usually the most poorly paid are rarely consulted, and typically not included when major decisions are being made about the service.

Despite this obvious anomaly, the bulk of the Kimberley staff went about their work with an enthusiasm and determination to give the residents a good quality life within the constraints of an institutional setting.

Staff talked about how coming to work at the Kimberley Centre became an important part of their lives, and broadened their thinking about people with intellectual disabilities.

"I have learned so much out here. I don't think I would have learned it anywhere else – yes I really treasure my time out here."

"Kimberley just grows on you and it becomes your heart and soul and you become passionate about intellectual disability, you wouldn't think of going..."

"Working at Kimberley has certainly affected my politics concerning intellectually disabled people and their treatment... I had no empathy prior to coming to Kimberley, well I had a certain amount but not enough but after coming here and embracing the kaupapa I find I have strong views about them."

"People would patronise me and say oh you, must be a wonderful person to work with people like that and I would say, come on I am lucky to work with people like that, they teach me so much... I don't think they realised how lucky I was."

Some staff had a well-developed 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.

"He's been here since the age of five, he is one of the longest here...he has really little contact with his family and as I say it (the institution) is his whole life. I guess in some respects we are his whanau and that's good."

Some staff talked about their fondness for particular residents, while acknowledging that loving the residents was not a requirement in their job.

"I mean a lot of the other girls didn't like her but she was my baby and I mean I really miss her...they say don't get attached to them, but it is easier said than done."

"I have really enjoyed coming to work...especially the relationships I have had with all the residents here...I just love them, I love working. I love seeing them achieve something. I love seeing them do something good you know."

Cummins (2005) talks about how enduring relationships create a sense of belonging. ¹⁶ The Kimberley chaplain commented about the depth of the relationships between residents and staff and about staffs' love for the residents. She inferred it was difficult to avoid making emotional attachments and maintain a strict working relationship with the Kimberley residents.

"... some staff really love the residents, but they have been told over the years, do not get emotionally involved with people. A lot have had a huge amount of input into residents' lives and just enjoyed them as people and given them a huge amount. [Staff] show grief when [residents] die... but that kind of friendship, family relationship that develops... I don't think you can work here without it happening, emotional attachments... the staff really have friendships with the residents."

Staff noted the rewards of getting responses from residents who were known to be unresponsive. Staff who had worked with residents for many years were able to detect the smallest of changes in behaviour and capitalise on their communicative value.

"... what she does is something she sort of does with her head, she sort of looks at you like that, or a sort of head movement sort of thing and you start talking to her and she will sort of smile."

"And to me it is like we look safe to him, so he will come to the staff and sit by you and stay there."

They talked readily about the communication between themselves and the residents even though many of the residents were unable to express themselves verbally.

"There's an affection in the way he looks at you – when he does that he is happy I think."

Staff were realistic about relationships between residents and staff and acknowledged that they did not always have the best of relationships with some residents. One Psychopaedic Assistant stated,

"Some staff she likes and loves and adores, but some staff she hates and I am one of them... she doesn't have anything to do with anyone other than her family really... she doesn't like sharing attention. Whenever the attention goes off her she goes sour."

All staff talked about how they were going to miss the residents, and they believed the residents would miss them too. Those staff who had been working at the Kimberley Centre for many years talked about how they had known and supported a lot of residents from the time they arrived as little children through the years as they grew to adulthood. These staff knew the residents personally and had formed strong and lasting attachments with them and their families. With the pending closure, staff grieved and talked unashamedly about their feelings for the residents.

"Oh it's really hard we all cry when our residents go especially the last have gone now, oh we miss them... oh man we cry, cry, cry and he is just like a brother to us...it's really hard."

One staff person said he was upset for the residents, who had friendships with staff because when they left they were unlikely to see each other again.

"The things I don't like about deinstitutionalisation was I would have preferred [the residents] to go out and be in the general area [in Levin] because that is their family out there... Their family is the other residents at Kimberley and I have seen residents grow up together and been really good friends and bang... One goes to Auckland and one goes to Wellington and they never see each other again, too far away... and that's cruel."

One staff person lamented that a resident she was very fond of had been resettled and she couldn't visit him.

"I mean this guy who has gone up north, I mean I can't visit him, which is a shame... I actually sent him a birthday present last year, because I thought he would love it, but I didn't hear anything back... I looked after him for so many years and then all of a sudden he's gone and I don't hear anything."

One staff person recounted that she even missed a resident when he was relocated to another villa on site before his final resettlement. She told the staff at the new villa,

"You can send him home if he looks the other way...you don't have to keep him there, we want him back...I have even gone over there to visit one night to look for him and said, when you get sick of him, don't forget, send him back."

Without doubt, staff valued their relationships with the residents and some were obviously grieving for particular residents as they left. There did not appear to be any 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 author believes this was not only an oversight for staff but also for the residents who had equally strong attachments to their staff. These 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 the 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. Some staff reported that the Kimberley Centre management discouraged staff from visiting the former residents in their new homes.

"...I would most likely go and see him, but are we allowed to, that's the thing. This is what I've been told we are not supposed to have anything to do with them because it might upset what they have got in place."

This decision to dissuade the Kimberley staff from visiting former Kimberley residents 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 residents that they were being told to break.

Staff also said that some community service providers had told them they did not want visits from Kimberley staff. It felt to many Kimberley staff that the community staff were not honouring the relationships the residents had with the staff from the institution. When some staff did go to community homes the staff of the community service made them feel most unwelcome.

"...they think we are going to come along, we are going to see that they are not up to the par they said they were, that we're going to criticise them but we are not, we are just there to make sure they are looking after our mates."

As previously mentioned, staff were also worried about the transition procedures from the Kimberley Centre to community services. They believed that there was not enough information going out with the residents, and that the transition happened too quickly – one minute the

residents were there and then the notification of move was given and the very next day they were uplifted and moved with little time for farewells.

"It's terrible, I mean they have been here most of their lives, and then all of a sudden they move away from here and we hear nothing."

"I do worry about them out in the community and I think I hope they are going to be safe, yeah, and just hope they are safe and treated right."

These comments indicate the depth of attachment and concern that the former residents were going to be well cared for. It could also be inferred that the Kimberley staff were dubious of community staffs' experience and ability to care and support the residents as well as they did.

4.5 Abusive relationship

Staff had a powerful position in the lives of the residents. How the staff initiated and maintained interactions with residents and how residents responded to the staff was an indicator of the quality of life residents had in the institution. Many residents did not initiate interactions with staff. However some did and it would be safe to assume that those initiations also contributed to the nature of the overall interactions. Most interactions were respectful and loving, but the research team was made aware of stories of staff who took advantage of some residents' vulnerability.

Those staff interviewed talked about other Kimberley staff who they identified as treating some residents with contempt and who were inadequate in terms of regard for authority and experience, best practice and their interactions with some of the residents.

"I don't like the attitude of some people."

"I think that abuse can raise its ugly head in these places because of the sheltered environment. I think in terms of care for the residents the bad things about it is that they become a number...your first priority should be that you care for the residents but sometimes their first priority is to cover their arse which is ridiculous...I couldn't believe that these people worked in this job and their first concern was to cover their arse and they had no idea of the reality [about abuse] outside the gates"

"There are staff that shouldn't be there...they talk nasty to the residents, they are rude to the residents, they are rude to the staff they work with...and the way they speak to them [residents] it is almost abuse, well it is abuse"

"I have seen residents hit, I have seen residents sworn [at] and treated like shit."

"I don't know, they think it's a way of keeping control. I have seen the worse people in my life and they work here and they are being paid to work here and care for these people and I have come from the outside world four years ago and I have known some pretty violent people in my time but none of them would ever hurt a handicapped person. And then to come here and see someone working as a carer just basically thumping people anytime they like... I just call them scumbags."

A senior staff person when questioned about the presence of abuse in institutions remarked,

"I think the institutional abuse that goes on is the awful thing about an institution but you can only do what you can do. While you know it exists, you can't...deal with it unless you see it or it is reported if you know what I mean... and the fact that you know is making you uncomfortable. Or if people tell you off the record about something but they won't take it any

further and they haven't got enough evidence. Then you feel like you are a party to it and [the reporting staff person] feels good now because they have got it off their chest, but they are not strong enough to deal with it. They turn a blind eye to it."

Some staff talked about how residents reacted to certain staff. One staff person observed residents either getting up and walking out as a certain staff person came into the day room, or of becoming very quiet and still.

"I hate that. I feel like that's not right that you can walk into a room and they feel like they can't do what they were just doing before. And I think that falls back on staff. I don't know whether it is true or not, but I feel like there have been some cruel staff out here at times... and that's why they [the residents] can't be their natural selves. And they have been told off so often that when you walk in it is like I have got to be a good little soldier".

Nevertheless one staff person believed the abusive practices were not as prevalent as they had been.

"Basically these days there's still a little bit of that goes on, not as much as it did, but there is still a bit of that and some wards are worse than others. They say when you go for a job here and you see a resident getting hit or anything like that, don't hesitate, get in touch with management, we will sort it out, no problem, but its not as easy as that."

To summarise, relationships between the staff and residents of the Kimberley Centre were a major indicator of how the institution was functioning. Most staff valued and respected the residents. Many staff were irrevocably attached to the residents they cared for and were upset at the breakdown of those relationships, when the residents left. Alternatively, however, contributions from staff also pointed to some negative aspects of institutional life at the Kimberley Centre whereby residents were subject to abusive practices, and staff were required to struggle with unsupportive and unmotivated colleagues. Ultimately it was clear from the data collected and analysed for this research that Kimberley Centre staff generally were hoping that the people with intellectual disabilities they had cared for lived safe and well supported lives in the community.

4.6 Family Perceptions of staff at the Kimberley Centre

During the first family interviews most family members mentioned the competence of staff at the Kimberley Centre. They also alluded to their relationships with various Kimberley staff through the years. However, due to the fact that the Family Interview Schedule was used as an approximate guide for the family interviews there were instances where discussions about staff did not take place.

Seventy-seven percent of parents discussed the competency of the staff while 70% of parents discussed their relationships with the Kimberley Centre staff. The majority of comments about staff were targeted to the direct-care staff (Psychopaedic Assistants). Parents did not have such an obvious appreciation for management staff. This is more than likely due to the fact that they had more contact with direct-care staff than management staff. It is also possible that during the closure process staff may have revealed their frustrations with management to families, hence the lack of positive comments about the management. But it must be noted that the research team did not specifically ask families about their interactions with management staff per se.

The majority of families were complimentary about the staff at the Kimberley Centre.

"I can't praise the staff enough..."

"... staff are wonderful, really great – their hearts are in the right place."

"Staff are qualified and dedicated and enjoy their job."

"Staff are always there to help...well trained, professional and caring."

Families also acknowledged how well the staff knew their family member. In some instances they believed that the staff knew their family member better than they did.

"Staff knows ...'s needs, know him better than me."

"The nurses know how to handle him...nurses know exactly how to treat him."

When asked who they thought were the most important people in their family members' lives families replied,

"His support workers definitely."

"Probably the staff that know him best that he gets on with."

"Well I would have to say it is the caregivers."

"I think the staff around him."

Some families who did not have a lot of personal contact with their family member did not know whether their family member had any people in their lives who they responded to more favourably than others. However they still acknowledged the work of the staff and admitted how indebted they were to the staff of the Kimberley Centre.

"They are wonderful for doing that job, I couldn't do it."

"I take my hat off to staff, wouldn't catch me doing that job."

Families commented that many of the Kimberley Centre staff had developed close, personal relationships with their family members. They believed that staff cared and loved the residents as if they were their own family members.

"... fantastic, really care about each resident, know each individual..."

"Caregivers have a real love for him."

"... admire the staff for their love and adoration to ..."

"Staff are lovely, all very fond of him."

"... feels very secure with the nurses, she is like a foster mother."

A sibling spoke about her family member having preferences for particular staff.

"But he will pick which ones he wants to be involved with him... women staff."

This sibling added that she was confident that when her family member was sick he would have staff who would genuinely care for him.

"When he is sick, he knows there are certain staff there and he can lean up against them and they make him feel better. I think for him it is an emotional thing."

Further comments were made about how some staff would take their family members home for meals, overnight stays and weekends. They talked appreciatively about how staff would purchase extra things for their family member and give up their spare time to include them in their own family's life.

"...they are brilliant...they take him on trips.. [had his] birthday party at the staff's home."

"There was a staff member who took out in her own time."

Families mentioned particular staff by name who had a key role in caring for their family member. One family talked about how their family member got upset when a preferred staff member left. Another family mentioned a particular staff person who had been involved with their family member's care over a number of years and they considered her part of their family.

"We don't class the staff as staff, we see them as a member of our extended family, they keep us informed...very approachable."

During the family interview discussions families highlighted what the Kimberley Centre offered by way of a safe, supportive and educative environment that catered for the every need of their family member. When families were asked about what a family member might miss about the Kimberley Centre the majority of replies focused on the staff.

"I think she will miss the staff more so than anything else because...a lot of the staff here are very attached to her and display their affection to her."

"She could miss some of the staff I suppose... she would have to because they have been around for a good part of her life."

Families voiced their concern for the staff predicament during the closure process. They understood that many staff would have kept on working at the Kimberley Centre had it remained open. They were sensitive to the fact that staff were now being forced to leave and seek new employment. Families acknowledged that the Kimberley Centre had been a place of work for several decades for many staff and that they were leaving residents for whom they had a strong and abiding affection. Not only were staff and residents leaving but the Kimberley Centre, the last institution of its kind in New Zealand, was no longer seen as an appropriate service for people with an intellectual disability and was being shut down and abandoned. Despite their own sense of upheaval and stress at the pending closure families were able to relate to the staffs' issues. They expressed concern about how staff might be treated through the process.

"staff are doing their job in difficult circumstances with the closure"

They also showed concern for staffs' future welfare and employment. This concern revealed itself when families expressed uneasiness about how their family members would respond to new and different staff in community services, after decades of being cared for by the same staff in Kimberly. As a consequence some families contacted individual staff personally to enquire whether they would continue to be part of their family members' lives in community services. They were keen to continue a continuity of care and ensure the same staff kept on caring and supporting their family member. A staff person reported a conversation she had with a family.

"Families know the staff that are good to the people that lived here. They would say I hope you are going to go and work for [service provider] because we want you to look after our daughter. You know our daughter and we want you there and let's hope you get a job."

Families never mentioned abusive staff at the Kimberley Centre during the interviews. It is possible that families were not informed about abusive behaviour towards residents unless it directly involved their family member. However they did suggest that some staff were better than others.

"The care is quite good, but some nurse aides shouldn't be there."

"The staff now compared to those few years back don't care as much."

As the previous comments illustrate, families were for the most part positive about their relationships with the Kimberley Staff. Their positive comments were directed in the main to the ward/villa staff and tended to concentrate on the Psychopaedic Assistants. They did not comment so positively about management staff. Management, who were responsible to the Palmerston North District Health Board and the Ministry of Health, were implementing the closure and any problems with the process, either with the resettling of residents or the redeploying of staff, tended to be seen by parents as a failure of the Kimberley Centre management. It is unlikely that the Kimberley Centre management was entirely responsible for all of the closure difficulties and decisions but they were an easy target for the frustrations of families and staff.

"Direct-care staff are welcoming, management sucks, they direct us to talk to only certain people"

"I have arguments with management."

"I trust the staff rather than the management."

Most families were grateful for their relationships with the staff. They felt that in recent times communications between the Kimberley Centre and families had improved significantly.

"Communication has improved, for a long time there was no communication."

"We have been talked with more in recent years."

Many families talked in glowing terms about how staff were kind and understanding towards them. Staff kept then regularly informed of their family member's progress. If families did not visit they were phoned and given progress reports.

"Staff ring and keep in touch."

When they visited the Kimberley Centre families reported that they were always made to feel welcome and staff willingly spent time with the family when requested or required. Families stated that they felt comfortable speaking openly to staff about their concerns.

"Staff make us welcome, nurses listen...we find out more from them about what's going on."

"Staff are good, understanding, welcoming and give out lots of information."

"Staff involve our family, seek our opinion, talk with us more than in recent years."

One sibling commented on how caring staff were to his mother.

"They are welcoming and warm to ...'s mother...they have even rung concerned that his mother is not well."

However there were some families, especially those families who lived a long way from the Kimberley Centre, who were not as positive about their contact with the Kimberley Centre staff.

"Because of the distance I really don't have a relationship with the staff."

One parent who did not visit regularly felt that staff were constantly changing because whenever they phoned or she phoned them she seemed to talk to a different staff person each time. One parent said that she had very little interaction with staff and they only seemed to contact her when there was something medically wrong with her family member. In fact she said staff did not keep in contact like they used to.

Another parent stated that her relationships with the staff had changed for the better.

"I am always made welcome now, they keep in touch with me more because of my earlier complaints."

In summary the families who volunteered to participate in this research were predominantly supportive and grateful for the support and love the Kimberley Centre staff had shown to their family members through the years. They were mostly keen for the staff to continue being part of their family members' lives. They also expressed concern for the futures of the staff.

4.7 Community Perceptions of the Kimberley staff

History tells us that people who work in institutions rarely get good publicity in the community. Glouberman (1990) depicts staff in institutions as 'keepers' who exercise control over the lives of others. Institutional staff are portrayed as powerful individuals who use their authority in ways that contain and oppress other people. While society acknowledges the need for containment of certain kinds of people, it is an uncomfortable acceptance. Nowhere is the questioning of containing people on one site more evident than in the deinstitutionalisation of large congregate facilities for people with intellectual disabilities.

As institutions have closed there is a new open-mindedness towards people with intellectual disabilities and a recognition that they belong within local communities, not on the fringes 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. It would appear that former residents of institutions are not nearly as stigmatised as former staff.

This research project revealed that the staff of the Kimberley Centre were no less stigmatised. At the beginning of the project it was clear to the research team that the community at large, various government agencies and community-based service providers had made up their minds as to the calibre and competence of the Kimberley Centre staff. There was talk about staff not being suitable to work in community services. The fact that there was no tangible evidence to suggest that the Kimberley Centre staff did not have the requisite skills to work with people with intellectual disabilities in the community did not make these community and government agencies reconsider their initial beliefs. This view of the Kimberley staff was a feature of the deinstitutionalisation process in the Horowhenua and Manawatu areas where the majority of the 340 plus residents were resettled and almost all former Kimberley staff were living and seeking employment.

The Kimberley staff who participated in this research were aware of the negative way they were viewed by some sectors of the community and were, as a consequence very resentful towards some community services.

"I also believe that IHC has been feeding the Ministry of Health a lot of rubbish [about staff who work in institutions] hiding behind People First. There is a perception formed by those who do not work at Kimberley that the workers are inept and abusive. The comments by Ministry staff in the media reinforces these ideas."

"I tend to think that [working at the Kimberley Centre] is like a cross against you, you have looked after them all these years... We are not going to have you look after them any more, we have got community people out there that can look after them normally and they sort of look upon us as not good enough."

"We are told we are not wanted out there anyway."

A long-standing senior staff member with considerable qualifications and experience in the field was concerned she might not be employed after the closure because of the stigma of having worked in an institution.

"My years working in an institution may not be viewed favourably... I believe this should not disadvantage me."

To be fair, in the initial stages of setting up services in readiness for deinstitutionalisation, community-based service providers did employ senior nursing staff from the Kimberley Centre. However it seemed that providers did not have the same confidence in the remaining Kimberley staff. As deinstitutionalisation proceeded apace and increasing numbers of residents moved out to the community, services providers found that the shortage of skilled and experienced staff became a major problem. Many service providers also struggled in the early days with high staff turnover and to remedy these problems they finally admitted defeat and set about employing former Kimberley staff.

"In the end I think they [service providers] realised they didn't have a choice because I think they realised that the experience is what you need with these people. . . . for instance M. . . came back home to experienced staff."

Unfortunately when one community-based service provider did eventually employ some former Kimberley staff the residents in their care were neglected and abused. The abuse was such that the staff were immediately fired and arrested. (The Court case relating to this issue is currently pending). In this case community-based service providers were shocked and understandably believed their initial views about former institutional staff were correct. When other former Kimberley staff were asked about these incidents they were not surprised because they knew these staff had been abusive in the institution. In fact, they were astounded that these staff had been employed at all. The following quote however, contradicts this knowledge and reverts to the position that no such abusive activity ever took place at Kimberley.

"The only thing I can say about that is...a lot of Kimberley staff when they heard about it [abuse incident] they were actually quite shocked because it seemed totally out of character...a lot of us are bewildered because that certainly didn't go on at Kimberley."

One staff person believed the abuse happened in community-based services because there was not enough close supervision of staff interactions with residents in the houses.

"People are working more on their own and there is not that strict supervision like at Kimberley. I think in a way that was a good thing, because hardly anyone got hurt. Naturally you are going to have in a big outfit like that, someone will get hurt but it was really minimised."

All staff interviewed were concerned that they would now be grouped together with these abusive staff, as dangerous staff simply because they had worked in the institutional environment.

"Oh it's not good... there is a lot of good staff out there doing their best and just for the sake of a few who have let the system down it is a bit unfair that everyone should be judged on that line."

Those few substandard staff aside, the stigmatisation was felt acutely by many of the direct-care staff. They were particularly offended at how the Needs Assessment Service Coordination Agency treated them. They reported they were made to feel they were not worthy of consulting about individual residents. They believed their knowledge, skills and experience with individual residents was not valued and was used far too infrequently.

"Life Unlimited aren't always appreciative of some staff's opinions and treat us like low degenerative people that don't know anything."

"Monowai staff had big problems when they tried to talk to these people that were coming in, they weren't interested in the intimate things, the idiosyncrasies which are really important because this is what makes these guys up. That's basically what they are, and it is little things like that that set them off and they go, no, no, no and they read the notes."

"They probably could have found out a bit more about the residents from the staff that have been looking after them. They could have kept us in the know a bit more and made us feel like we are key players in the whole business as well as instead of something like we will only listen to you because we have to listen to you, but we have better ideas and where they go they are going to be a lot better off."

Many staff reported that a senior government minister had impugned their reputation by telling a meeting of the Kimberley Parents and Friends Association that Kimberley staff would not be appropriate or even qualified to work in community services. This angered parents attending the meeting and they also opposed the Minister's comments.

"Staff felt very bitter and hurt when Ruth Dyson stood up at a KPFA meeting and said she didn't want any Kimberley staff out there as they would bring their institutional ideas with them. How dare she say that when she has no idea of the skills and qualifications staff at Kimberley have."

"We get the Minister saying we don't want Kimberley staff working with these people because they are institutionalised. These people may be, these workers know the residents, and they know their needs, they know all their cares...."

Kimberley staff believed that the Minister's comments had influenced service providers to the extent they initially employed anyone as long as they were not former Kimberley Centre staff.

Parents were loyal supporters of the Kimberley staff and voiced their loyalty to staff to the Minister following her comments. One staff in retelling the above incident said,

"...for a lot of [parents] that's why we have so many [former residents] in Levin, are housed in Levin because the parents didn't want them moving away from the area in case all the nurses stayed around Levin. They wanted the expertise still with their [family members], and that's why there are over 200 of them [former Kimberley residents] around Levin."

There has been a tendency in past research to represent institutional staff as a troubled work force with high turnover rates, poor morale and feelings of ineffectiveness and exhaustion.

However this was not always true of the Kimberley workforce. In times gone by they had been a very well trained and efficient workforce with high morale and low staff turnover. In the last ten to fifteen years while the value of institutional living was being seriously questioned by successive governments in New Zealand, the services provided by institutions to people with intellectual disabilities were being significantly reduced. The Kimberley Centre workforce was affected by this gradual change in focus, and only then did staff turnover start to appear as a problem.

Nevertheless the Kimberley Centre still retained, right up till the final closure, a core of staff who had worked there for two decades or more and had been trained at the Training Officer School and or the Nursing School. In fact for those staff, working at the Kimberley Centre was their chosen career.

With the advent of the closure and the rejection of institutional practices it was only natural that staff would speculate about the work they had done through the years with people with intellectual disabilities and feel somewhat betrayed and unappreciated by a society who had now concluded that institutions were not good places. And it is no surprise that many staff felt ineffective, anxious and exhausted during the closure process.

In summary 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 skills, their experience and their extensive working careers with people with intellectual disabilities. They 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 staff to deal with and they were justifiably concerned that they were being judged on the behaviour of a few former 'rogue' Kimberley staff.

4.8 Staffs' views on community-based services

The Kimberley Centre staffs' views on community-based services were variable. While the institution was in the process of closing the staff felt undervalued and hurt by community-based service providers' comments and this more than likely coloured their opinions of community services at that time. Nevertheless there were staff who were very supportive of the community living philosophy and practice while still working at the Kimberley Centre and they expressed their views openly. Many of those staff who held negative views about community-based services did acknowledge after they had worked in the services that there were many aspects of community services that were superior to institutional living.

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 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 intellectual disabilities. But the work they had done through the years supporting people with intellectual disabilities 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.

"I was very proud, if that doesn't sound too egotistical, very proud of what we did. We had some really great teams [of staff]. There were people there that loved the people that lived at Kimberley with a passion... I was privileged to work in wards like Awatea, Ianthe and Kaniere... I loved caring for them and I loved being able to give them some sort of quality of life and I have learnt so much... and also the unconditional love. Oh it [Kimberley] was an important part of my life."

Some staff also felt that the importance of the residents long and extensive lives in the institution were also similarly unacknowledged by community-based service providers.

During the closure process one staff person, although he agreed that residents' lives would be better in the community, did say he felt uncomfortable about the way service providers came into the institution to "inspect" the residents. He referred to the service providers as the "shadow shifters".

"We have staff from the new providers come in and work or stand next to us and watch what we do when clearly they are not going to do anything like what we do, because they have got their own plans about what is to be done. Yes it is that part I don't like, I didn't want

the shadow shifters working with me... It is a strange thing, I mean it seems crazy to send someone fresh into the institution to learn something they are never going to do."

Staff did comment frequently about service providers coming along and supposedly getting to know a resident in the wards and villas of the Kimberley Centre – in the institutional environment, the very environment they were leaving. As previously mentioned, there was a strong view that staff should have gone with the residents to their new homes and spent a number of days there helping the resident to settle in and get to know the new staff in that new environment.

Some staff who did accompany residents to their new homes were concerned about the lack of experience and skills of the community-based services staff.

"You get out there and it is like the skills that we have here at Kimberley, we are told 'oh that's not how we are going to have them... what gives Kimberley the right to do that?' Well it's not about me personally it's about the residents... and like we are having people who have had three weeks orientation telling us how it's going to be."

Some staff while still working in the Kimberley Centre talked about the quality of staff being employed by community-based service providers in those early days.

"It should be a specialised job...not just grab some Joe Bloggs that has never had anything to do with them [the former Kimberley residents] before, have to have someone that has had experience."

"I saw some of the people they [a service provider] were hiring and I thought come on, you know, what's wrong with some of the staff at Kimberley?"

Some staff who eventually went to work in community-based services were very concerned about the lack of skills and knowledge of the community staff.

"I already knew a lot about the residents, but they didn't give out much information on the ladies...it wasn't really right we never had anyone on the medical side or behaviour support. We didn't have a staff nurse or someone above us on the shifts [this particular service at the time didn't have shift leaders], so you had a lot of people who had never nursed before, and they didn't know too much about their behaviours...I found it difficult because I didn't have someone who was medically wise to look up to on my shift. I found that was a bit scary myself."

One staff person implied it was easier to get medical help on site at the Kimberley Centre. But out in the community-based services it appeared that if clinical help was not available an ambulance was called.

"The only thing I think that wasn't good was on the medical side. It wasn't up to the standard that these ladies have lived in Kimberley... these ladies and men had good lives out at Kimberley, they never wanted for anything, all their cares, their medical side was bang, bang. Where out here, it is hard to get to the doctors, going to the doctors is a big stress on our ladies."

One of the major misgivings about community-based services for former Kimberley staff were the wages and conditions for the staff working in those services. Former Kimberley staff keenly felt keenly the drop in wages and many said the lower wages were proving to be a hardship for them and their families. One staff person made the following comments after she had taken a job at a community-based residential service.

"They [the service provider] are offering me \$4 less an hour. I worked seven years hard work to get what I was earning at Kimberley, \$16 an hour and now I have dropped \$4 an

hour...it's hard. When your redundancy ran out it was hard and where it hits you was your food cupboard. It is a big drop, it is about \$400 a fortnight drop."

Another staff person was considering her options while still working at the Kimberley Centre.

"I would have looked at working in vocational services but the pay is so bad...so I don't know, I will have to rethink what I am going to do."

"The pay, that would be the biggest thing, because I have gone from \$33 an hour to \$22 an hour and I still have to pay the mortgage."

"Our lifestyles will have to change – not that we are extravagant anyway, but we won't have that money to do things we used to be able to afford to do and things like that, so it [having to work in community-based services] will affect us financially."

But staff admitted that community-based services one year after the closure of Kimberley Centre were handling staff and resident issues more capably, and that community service staff were now acknowledging that many former Kimberley staff were invaluable when it came to supporting residents.

"Things are settling down a lot more than they were and people are getting used to working with our guys and seem to accept the fact that they are not going to cure them. I think a lot of them [community service staff] thought they were going to be able move into the house and eradicate a lot of these behaviours and make them in their eyes, well again, but they are not sick."

"The staff are a bit more stable now... they will say to us [former Kimberley staff] what would you do in this situation and we will explain what we would do and we will explain to them what to look for and how to recognise problems... yeah it all seems to be working out now."

The positive outcomes for former Kimberley residents living in community-based services were spoken about enthusiastically. One staff person talked about how community staff had time and energy to spend with the residents. Because the staff ratio to residents was higher there was now time to relax and explain things to the residents. Former staff noted the changes in former Kimberley residents.

"They are just so much more relaxed and much happier – I find a lot of improvement in most of them... their lives are fairly full now which is good."

"I like the thing about community houses. I do, even though I have looked after them [the residents] there is only five or four in a house and you know the staff ratio in any one of these houses you might be having three residents to look after a day, whereas in Kimberley you can have up to five or six which takes a lot more time, so you can't spend as much time [with residents] as you want to."

"It has been good...it is fresh, new ideas, new ways. Some of them [community service staff] are good because they listen to you, because you have got experience."

"They [the former residents] have beautiful things, beautiful clothes, beautiful hygiene things. Lovely, lovely, I can't fault that...things are more relaxed, more choices, more understanding that there are choices in life."

Even though staff felt they were under appreciated by the community at the beginning of the closure process, as time moved on and they were employed by the community-based services they acknowledged that their experience and skills were now more valued. However the reality of community based wages, and their affect on their standard of living remained a major issue for many former Kimberley Centre staff mirroring a more general concern about pay-rates for support work amongst the disability sector. It is also important to reiterate that despite the personal difficulties and disappointments, former institution staff 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.

4.9 Honouring the Contribution of the Kimberley Centre Staff

The Kimberley Centre employed a very large workforce. It goes without saying that within that workforce there were staff who were less than satisfactory, in fact there were some staff who were uncaring, disrespectful and even openly abusive towards the residents. This is not an unusual phenomenon and is not confined only to staff who work in institutions. It was clear from the accounts provided by some staff that while unacceptable staff behaviour was recognized, it was often difficult to have such behaviour addressed in the institutional environment. However it must also be acknowledged that the Kimberley Centre employed a greater number of staff who were loyal and dedicated to their work, who did all they could professionally and personally to enhance the lives of the residents.

The Kimberley Centre workforce was predominantly stable and a considerable number of staff had a long work history of over 20 years. Only in recent years with the advent of the closure had a section of this workforce become changeable.

With the closure of the last large institution in New Zealand came the dissolution of this unique workforce.

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 Centre staff had starting their working lives there when consigning people with intellectual disabilities to institutions was considered to be best practice. Community-based services are now heralded as state of the art in services for people with intellectual disabilities. Nonetheless we must be careful not to denigrate or dismiss the previous work of staff in institutions who should be recognised for their significant contribution to the lives of people with intellectual disabilities and their families in New Zealand, and who, at one time also performed their work within an environment considered to offer 'best practice' standards. Similarly to people with disabilities themselves and families, ex-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 Kimberley Centre.

Bibliography

- [1] Blatt, B. (1987). The Conquest of Mental Retardation. Austin, Texas: Pro-Ed Inc.
- [2] Zaharia, E. S., & Baumeister, A. A. (1978). Technician turnover and absenteeism in public residential facilities. *American Journal of Mental Deficiency*, 82(6), 580-93.
- [3] Glouberman, S. (1990). Keepers. Inside stories from total institutions. London: King's Fund Publishing.
- [4] Mansell, J., & Ericsson, K. E. (1996). Deinstitutionalization and community living. Intellectual disability services in Britain, Scandinavia and the USA. UK: Chapman & Hall.
- [5] Dempsey, I., & Arthur, M. (2002). Support staff in a sample of Australian community-based services for people with a disability: career intentions, personal characteristics and professional development needs. *Journal of Intellectual & Developmental Disability*, 27(3), 201-214.
- [6] Lakin, C. K. (1982). Turnover of Direct-Care staff in National Sample of Residential Facilities. American Journal of Mental Deficiency, 87(1) 64-72.
- [7] Patton, M. (1990). Qualitative evaluation and research methods. (2nd Ed). Newbury Park: Sage Publications.
- [8] Bigby, C., & Fyffe, C. (2006). Tensions between institutional closure and deinstitutionalisation: what can be learned from Victoria's institutional redevelopment? *Disability & Society*, 21(6), 567-581.
- [9] Conroy, J., Spreat., Yuskauskas, A., & Elks, M. (2003). The Hissom closure outcomes study: A report on six years of movement to supported living. *Mental Retardation*, 41(4), 263-275.
- [10] Thomas, D. (2006). A general inductive approach for analyzing qualitative evaluation data. American Journal of Evaluation, 27, 237-246.
- [11] Mirfin-Veitch, B. (2008). personal communication
- [12] O'Driscoll, D. (2006). Managing organisational change. Community Living, 20(1), 18-19.
- [13] Hall, P. S., & Hall, N. D. (2002). Hiring and retaining direct-care staff: After fifty years of research, what do we know? *Mental Retardation*, 40(3), 201-211.
- [14] Williams, R. J., & Rose, J. L. (2007). The development of a questionnaire to assess the perceptions of care staff towards people with intellectual disabilities who display challenging behaviour. *Journal of Intellectual Disabilities*, 11(2), 197-211.
- [15] Hatton, C., & Emerson, E. (1993). Organisational predictors of perceived staff stress, satisfaction, and intended turnover in a service for people with multiple disabilities. *Mental Retardation*, 31(6), 388-395.
- [16] Cummins, R, A. (2005). Caregivers as managers of subjective wellbeing: A homeostatic perspective. *Journal of Applied Research in Intellectual Disabilities*, 18(4), 335-344.

- [17] Balcazar, F., MacKay-Murphy, M., Keys, C., Henry, D., & Bryant, F. (1998). Assessing perceived agency adherence to the values of community inclusion: Implications for staff satisfaction. *AJMR*, 102(5), 451-463.
- [18] Barr, O. (2007). Editorial. It is not enough to know what to do. *Journal of Intellectual Disabilities*, 11(2), 123-126.
- [19] Allen, D., & Tynan, H. (2000). Responding to aggressive behavior: Impact of training on staff members' knowledge and confidence. *Mental Retardation*, 38(2), 97-104.
- [20] Baum, N. (2005). Quality of life is not only for people served it is also for staff: the Multi-Focal Approach. *Journal of Intellectual Disability Research*, 49(10), 809-811.
- [21] Blumenthal, S., Lavender, T., & Hewson, S. (1998). Role clarity, perception of the organization and burnout amongst support workers in residential homes for people with intellectual disability: a comparison between a National Health Service trust and a charitable company. *Journal of Intellectual Disability Research*, 42(5), 409-417.
- [22] Boyle, G. J., & Comer, P. G. (1990). Personality characteristics of direct-service personnel in community residential units. Australia & New Zealand Journal of Developmental Disabilities, 16(2), 125-131.
- [23] Bramston, P., & Lundin, R. (1987). Residential care: Staying in touch. *Interaction*, 1(4), 9-10.
- [24] Campbell, M. (2007). Staff training and challenging behaviour. *Journal of Intellectual Disabilities*, 11(2), 143-156.
- [25] Cattermole, M., Jahoda, A., & Markova, I. (1990). Quality of life for people with learning difficulties moving to community homes. *Disability, Handicap and Society*, 5(2), 137-152.
- [26] Hastings, R., & Horne, S. (2004). Positive perceptions held by support staff in community mental retardation services. *American Journal on Mental Retardation*, 109(1), 53-62.
- [27] Hatton, C., Emerson, E., Rivers, M., Mason, H., Mason, L. S., R, Kiernan, c., et al. (1999). Factors associated with staff stress and work satisfaction in services for people with intellectual disability. *Journal of Intellectual Disability Research*, 43(4), 253-267.
- [28] Clements, J., Clare, I., & Ezelle, L., A. (1995). Real men, real women, real lives? Gender issues in learning disabilities and challenging behaviour. *Disability & Society*, 10(4), 425-435.
- [29] Conroy, J.W. & Bradley, V.J. (1980). *The Pennhurst Longitudinal Study*. Philadelphia: Temple University Developmental Disabilities Center/UAF.
- [30] Corrigan, P. (1993). Staff Stressors at a Developmental Center and State Hospital. *Mental Retardation*, 31(4), 234-238.
- [31] Davidson, C. & Tolich, M. (1999). Social Science Research in New Zealand. Many Paths to Understanding. Auckland: Longman.
- [32] Edwards, P., & Miltenberger, R. (1991). Burnout among staff members at community residential facilities for persons with mental retardation. *Mental Retardation*, 29(3), 125-128.
- [33] Felce, D. (1998). The determinants of staff and resident activity in residential services for people with severe intellectual disability: Moving beyond size, building design, location and number of staff. *Journal of Intellectual and Developmental Disability*, 23(2), 103-119.
- [34] Furvey, E., & Keharhahn, M. (2000). What supervisors, managers, and executives know about the abuse of people with mental retardation. *Developmental Disabilities Bulletin*, 28(2), 40-59.
- [35] Goble, C. (1999). 'Like the Secret Service isn't it'. People with learning difficulties, perceptions of staff and services: mystification and disempowerment. Disability & Society, 14(4), 449-461.
- [36] Grbich, C. (1999). Qualitative Research in Health: An introduction. Sydney: Allen & Unwin Pty Ltd.

- [37] Green, C. W., & Reid, D. H. (1991). Reinforcing Staff Performance in Residential Facilities: A Survey of Common Managerial Practices. *Mental Retardation*, 29(4), 195-200.
- [38] Shaddock, A., Hill, M., & van Limbeek, C. (1998). Factors associated with burnout in workers in residential facilities for people with an intellectual disability. *Journal of Intellectual & Developmental Disability*, 23(4), 309-318.
- [39] Taggart, L., & McConkey, R. (2001). Working practices employed within and across hospital and community service provision for adults with an intellectual disability and additional needs. *Journal of Learning Disabilities*, 5(2), 175-190.
- [40] Rice, D. M., & Rosen, M. (1991). Direct-Care-Staff: A Neglected Priority. *Mental Retardation*, 29(4).
- [41] Rose, D., & Rose, J. (2005). Staff in services for people with intellectual disabilities: the impact of stress on attributions of challenging behaviour. *Journal of Intellectual Disability Research*, 49(11), 827-838.
- [42] Hastings, R. P. (1997). Measuring staff perceptions of challenging behaviour: the Challenging Behaviour Attributions Scale (CHABA). *Journal of Intellectual Disability Research*, 41(6), 495-501.
- [43] Hatton, C., Rivers, M., Mason, H., Mason, L., Emerson, E., Kiernan, C., et al. (1999). Organizational culture and staff outcomes in services for people with intellectual disabilities. *Journal of Intellectual Disability Research*, 43(3), 206-218.
- [44] Henry, D. B., Dubdevany, I., Keys, C. B., & Balcazar, F. E. (2004). Attitudes of American and Israeli staff toward people with intellectual disabilities. *Mental Retardation*, 42(1), 26-36.
- [45] Holburn, S., Cea, C,D., Coull, Linda., & Goode, David. (2007). What is Working and Not Working: Using Focus Groups to Address Quality of Life of People Living in Group Homes.

 Journal of Developmental & Physical Disabilities, 20(1), 1-9.
- [46] Holman, A. (1999). The lessons of Longcare. Community Living, 12(3), 12-13.
- [47] Hunt, A. (2000). The Lost Years. Christchurch: Published by Anne Hunt.
- [48] Jenkins, R., Rose, J., & Lovell, C. (1997). Psychological well-being of staff working with people who have challenging behaviour. *Journal of Intellectual Disability Research*, 41(6), 502-511.
- [49] Johnson, K. & Traustadottir, R. (Eds) (2005). Deinstitutionalization and People with Intellectual Disabilities. In and out of Institutions. London: Jessica Kingsley Publishers.
- [50] Kelly, S. (2001). Exploring the boundaries of relationships. Community Living, 15(2), 12-13.
- [51] Kerkham, G. (1993). Jurassic Park is alive and well. *Interaction*, 7(2), 26-27.
- [52] King, A. (2000). From institutionalization to community: How far have we come? *Journal of Leisurability*, 27(1).
- [53] Kobe, F., & Hammer, D. (1993). Who is interested in careers in mental retardation and developmental disabilities? *Mental Retardation*, 31(5), 316-319.
- [54] Larson, S., Hewitt, A., & Anderson, L. (1999). Staff recruitment challenges and interventions in agencies supporting people with developmental disabilities. *Mental Retardation*, 37(1), 36-46.
- [55] Lord, J., & Pedlar, A. (1990). Life in the community. Four years after the closure of an institution. Ontario: Centre for Research and Education in Human Services.
- [56] Mansell, J., & Elliott, T. (2001). Staff members' prediction of consequences for their work in residential settings. *American Journal on Mental Retardation*, 106(5), 434-447.
- [57] Mansell, J. (2006). Deinstitutionalisation and community living: Progress, problems and priorities. *Journal of Intellectual & Developmental Disability*, 31(2), 65-76.

- [58] Marquis, R., & Jackson, R. (2000). Quality of life and quality of service relationships: experiences of people with disabilities. *Disability & Society*, 15(3), 411-425.
- [59] Metlen, G., Majure, A., & Stroll-Reisler, C. (1996). A person centered approach to supporting people with severe reputations. *TASH Newsletter*, 22(7), 8-9.
- [60] Milloy, D., & Kreuger, J. (1996). Restrictive practices: Issues in power and control. *Journal of Practical Approaches*, 20(1), 24-28.
- [61] Miltenberger, R., Lennox, D., & Erfanian, N. (1989). Acceptability of alternative treatments for persons with mental retardation: ratings from institutional and community-based staff. *American Journal on Mental Retardation*, 93(4), 388-395.
- [62] Wilson, C., S, & Bartak, L. (1997). Staff understanding of normalisation and social role valorisation: Anstey and Gaskin (1985) revisited. *Journal of Intellectual & Developmental Disability*, 22(3), 213-219.
- [63] Wolfensberger, W. (1975). The Origin and Nature of our Institutional Models. Syracuse, New York: Human Policy Press.
- [64] Mitchell, D., & Braddock, D. (1993). Compensation and Turnover of Direct-Care-Staff in Developmental Disabilities Residential Facilities in the United States. I: Wages and benefits. *Mental Retardation*, 31(6), 429-437.
- [65] Mitchell, D., & Braddock, D. (1994). Compensation and Turnover of Direct-Care-Staff in Developmental Disabilities Residential Facilities in the United States. II: Turnover. *Mental Retardation*, 32(1), 34-42.
- [66] Murray, G., McKenzie, K., & Quigley, A. (2000). An examination of the knowledge and understanding of health and social care staff about the grieving process in individuals with a learning disability. *Journal of Learning Disabilities*, 4(1), 77-90.
- [67] Nota, L., Ferrari, L., & Soresi, S. (2007). Self-efficacy and quality of life of professionals caring for individuals with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 4(2), 129-140.
- [68] Pelletier, D., Coutu, S., & Lamonde, A. (1995). A comparison of work-life quality among direct-care staff in institutional and community agencies for persons with mental retardation and staff in juvenile delinquency agencies. *Developmental Disabilities Bulletin*, 23(2), 16-31.
- [69] Rabb, J. & Rindfleisch, N. (1985). A study to define and assess severity of institutional abuse/neglect. *Child Abuse & Neglect*, 9, 285-294.
- [70] Rapley, M., Ridgway, J., & Beyer, S. (1998). Staff:staff and staff:client reliability of the Schalock and Keith (1993) Quality of Life Questionnaire. *Journal of Intellectual Disability Research*, 42(1), 37-42.
- [71] Razza, N. (1993). Determinants of Direct-Care-Staff Turnover in Group Homes for Individuals with Mental Retardation. *Mental Retardation*, 31(5), 284-291.
- [72] Rose, J. (1999). Stress and residential staff who work with people who have an intellectual disability: a factor analytic study. *Journal of Intellectual Disability Research*, 43(4), 268-278.
- [73] Rosser, K. (1988). Care Givers and The Law Of Negligence. *Interaction*, 2(4), 18-20.
- [74] Schwabenland, C. (2000). Getting the balance of power right. Community Living, 14(1), 6-8.
- [75] Test, D. W., Flowers, C., Hewitt, A., & Solow, J. (2003). Statewide study of the direct support staff workforce. *Mental Retardation*, 41(4), 276-285.
- [76] Thompson, D., Clare, I., & Brown, H. (1997). Not such an 'ordinary' relationship: the role of women support staff in relation to men with learning disabilities who have difficult sexual behaviour. *Disability & Society*, 12(4), 573-592.

- [77] Tsiantis, J., Diareme, S. P., & Kolaitis, G. (2000). The Leros PIKPA Asylum Deinstitutionalization and Rehabilitation Project. A follow-up study on care staff fears and attitudes. *Journal of Learning Disabilities*, 4(4), 281-292.
- [78] Weiss, N. (1998). From the Executive Director. TASH Newsletter, 24(9), 2-3 & 27.
- [79] Williams, P., Symons, K. & McGinnis, B. (2002). Problems are solved by values, commitment and responsibility not by control and inspection. *Community Living*, 15(3), 3-5.

newzealand.govt.nz