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

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Introduction to the Kimberley Centre research project report

On the 26 October 2006 the gates at Kimberley Centre shut for the last time. The departure of last few remaining residents brought to a close the era of large scale institutional care of people with an intellectual disability in New Zealand.

In 1985 the New Zealand Government announced that, in keeping with international trends, it was adopting a policy of community living for people in long-stay institutional care.[1] The deinstitutionalisation of Kimberley Centre would be the last in a string of institutional closures throughout New Zealand. Despite the many years of uncertainty, planning and delays that characterized the closure process, the 26 October 2006 represented the realisation of this Government policy objective.

The policy of community living had, however, been signposted two decades before. In 1974, following a review of people residing in institutional care conducted by the Department of Health, the Government imposed a moratorium on the expansion of psychiatric and psychopaedic hospitals. This moment marked a radical and swift departure in the disposition of the State towards the welfare of people with intellectual disabilities and their families.[2] For over a century, different forms of institutional care had been advanced as the most appropriate State response to the support of people with intellectual disabilities.

Deinstitutionalisation is generally understood to refer to the movement of people out of institutions and into community-based services.[3] The implementation of deinstitutionalisation, both as policy and practice, has led to dramatic changes in the sizes and types of places where people with intellectual disabilities live.[4] It has also dominated the development of services for people with intellectual disabilities in Western countries.[5,6]

The outcomes of deinstitutionalisation, however, are expressed in the everyday lives of those who are changed by the process of institutional closure. Despite our long history of institutional care, the stories of the men, women and children for whom the institution was understood to be a home have only just begun to be told. Similarly, the experiences of families who faced difficult and often traumatic placement decisions and staff who devoted their professional lives caring for people in institutional settings, find only scant expression in the New Zealand research literature. One of the consequences of this silence has been that key stakeholders have had to make important decisions in the absence of research grounded in the New Zealand context.[7] Furthermore, the need for an investigation into the outcomes of institutional closures like Kimberley Centre has assumed greater importance given growing unease that the process of depopulating institutions may have frustrated the broader aims of deinstitutionalisation.[5]

Johnson and Traustadottir (2005) argue that a lack of clarity exists about what is meant by deinstitutionalisation and, rather than heralding a fundamental shift in the way people with intellectual disabilities are understood and supported, all we may have accomplished in the move to community-based support is a change in the address of service delivery.[8]

Similar sentiments were echoed by the New Zealand National Health Advisory Committee[9] (NHC). After consulting with people who used adult disability services, the NHC concluded that deinstitutionalisation in New Zealand had been characterized by a "*translocation*" of the "*life defining*" social practices of institutions with "*custodial and constrictive*" service provision tending to follow people with an intellectual disability into community-based settings (NHC, 2003; p.8).

Exposure in the media to incidents of poor and sometimes abusive support practice, combined with the modest progress being made by towards social inclusion and meaningful self-determination seems to have diluted calls to never return to the bricks and mortar of institutional care. Despite evidence that larger scale support settings are associated with poorer quality of life outcomes,[6] Bigby (2004) notes that the most recent institutional closure programmes in Australia and New Zealand have moved towards accommodating larger scale replications of congregate in the form of clustered settings.[7]

As last in a long string of institutional closures, Kimberley Centre represented a final opportunity to document a moment of major social change for people with an intellectual disability. It was also our last opportunity to ground an evaluation of the impact of deinstitutionalisation within the real lives of New Zealanders either making the journey or affected by the process of closure.

This report summarises the main, resident related findings, of a five-year research project that aimed to provide a comprehensive analysis of the outcomes associated with the closure of Kimberley Centre.

This report is extensive in its scope, containing ten chapters related to specific project objectives. In Chapter , the closure of Kimberley Centre is placed within the wider historical context of the New Zealand government's response to the welfare needs of people with intellectual disabilities and their families. Chapter 2 provides a general overview of the research methods and measures used this study. Chapter 3 presents findings related to the individual relocation of Kimberley Centre residents into community-based services. Specifically Chapter 3 provides information about the geography of resettlement and the type of service Kimberley Centre residents moved to. The impact of institutional closure on resident adaptive behaviour is the focus of both Chapters 4 and 5. Chapter 4 describes the adaptive behaviour of Kimberley Centre residents while they lived at Kimberley Centre and Chapter 5 presents equivalent findings three – six and twelve months after residents moved to their new community-based service sites. Chapter 6 describes the daily pattern of life for residents while they were still living at Kimberley Centre, followed by Chapter 7 which provides the same information in the context of their new life in community-based services. Chapter 8 provides an analysis of the type and level of activity that characterised resident's lives both within, and beyond Kimberley Centre. Chapter 9 explores whether the outcomes of re-settlement were different for residents moved to Cluster Houses or Community Group Homes. The report concludes with Chapter 10 which has the purpose of drawing the findings together and includes a number of recommendations related to the development of positive community involvement for people with intellectual disabilities.

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Locating the Kimberley Centre within the history of support for people with an intellectual disability

1.1 The institutional care of people with intellectual disabilities in New Zealand.

Because people with intellectual disabilities are understood within the wider sweep of those traditions, values and social structures that define a society, notions of impairment and bodily difference are neither fixed nor absolute.[10] In New Zealand's relatively short post-colonial history, definitions of intellectual impairment and the direction of the disability related social policy have changed in step with the wider course of New Zealand's dynamic social and political history.

In the frontier settlements of New Zealand, disabled people were embedded within the social fabric of their communities in the absence of any other alternative. The Colonial Government's rejection of the British Poor Law system and the absence of an upper-class which limited poor relief through public charity meant families had to be self reliant. Children with intellectual impairments took their place alongside siblings, adding value to their families where they were able.[11]

In contrast to Pakeha settlers Māori were able to draw upon the collective support provided by whānau and īwi.[11] Maori also differed in their understanding of disabled whanau, emphasising whanaungatanga (family relationships) as the cornerstone of identity.[12] The emphasis upon shared familial connection and an understanding of wellbeing that included elements of tīkanga (custom and obligation), manaaki (respect, support and hospitality) and the ability to contribute to īwi and whānau[13] located disabled Maori in a different social position within their own community.

The first legislation indicative of the State's disposition towards the welfare of people with disabilities came with the passing of the Destitute Persons Ordinance 1846. Consistent with

the laissez-faire political climate, the ordinance affirmed in legislation the principle that it was the role of the family, and not the State, to provide for the material welfare of those who required support.[11,14] Before the year was out, however, the Government also passed the Lunatics Ordinance 1848. The effect of the legislation was to make provision for the apprehension and safe keeping of dangerous "lunatics" and "idiots" separate from the gaol house or hospital. Although few would subsequently be confined by the ordinance,[11] the legislation did mark the beginnings of a view that control and containment was an appropriate State response to the "problems" created by mental and intellectual impairment. This view would find similar expression in New Zealand social policy for the next 100 years.

With the establishment of Provincial Governments in 1853, the colonial administration discharged responsibility for the establishment of hospitals and asylums for the care of "lunatics". The first, of what would later be described as New Zealand's first generation asylums, was built in Wellington in 1854 to be quickly followed by others throughout a country struggling to cope with the social costs of a long depression. Thomson (1995) cites Williams, who concluded that the primary function of the first generation asylums was the confinement of a disruptive population.[11] Conditions within the Auckland Asylum were, for example, described in an 1877 report to the Colonial Secretary as "deplorable" and "neither curative nor palliative" with patients "simply prisoners" with "neither occupation nor amusement" (AJHR 1977:H-8-1; cited in Thomson[11]).

Although the 1882 Lunatics Act attempted to arrest the flood of admissions by tightening the definition of insanity, the population confined within New Zealand's asylums continued to grow,[11] and an attitudinal shift towards seeing asylums as totemic of incurability and moral failing became further entrenched by the "save the sane" campaign. The incendiary mix of Social Darwinism (the belief that pauperism, degeneracy and moral failing were inheritable characteristics) and the broadcasting of sensationalised stories of violence and horror within asylums saw humanitarian motives displaced by popular demands for tighter security.[11] The demand was met by New Zealand's second generation asylums built with higher walls in rural areas and away from major population centres.

The social climate of the time proved fertile ground for the spread of the pseudo-science of Eugenics. Central to Eugenic argument was a belief that the 'feeble-minded' were responsible a range of social ills, including criminality, pauperism and drunkenness.[15] Eugenic theory, and in particular the belief that society could be improved by limiting the fertility of the "unfit," strongly influenced the development of New Zealand social policy during the first decades of the twentieth century.[11] Campaigns for legislation and the expansion of institutional populations here,[11] in the UK[15] and in the US[16] were all built on fear, including the need to protect the moral character of society from the menace of feeble-mindedness.

Protectiveness towards people with intellectual disabilities also found expression in political campaigns for the segregated care of people with intellectual disabilities. Campaigners argued institutions were also required to shelter the feebleminded from the moral dangers of society.[15] At the turn of the century, therefore, institutions were presented as liberating people from inappropriate work-houses, asylums and goals and delivering them into safer care of the emergency medical practices of surveillance, classification and treatment.[17]

In 1911, the New Zealand Government passed the Mental Defectives Act. The Act distinguished between people who were "mentally defective" and "mentally ill" but also extended the reach of classification and committal to include the "socially defective." Walmsley argues that the inclusion of categories like the "socially" or "morally" defective, leaves little room

to doubt that protecting the community by limiting the fertility of women and preventing criminality was the pre-eminent 'protective' impulse.[15] Under the Mental Defectives Act, it became illegal to care for a person with an intellectual disability within a family. Institutions were also required to separate women from men, for whom carnal knowledge became an indictable offence.[11]

The rise of the first major specialist institutions similarly heralded the ascent of a more medically orientated understanding of people with intellectual disabilities. Under the 1911 Mental Defectives Act, medical diagnosis determined the State's response to the needs of disabled men and women[11] and from the 1920s, pre-existing institutions were transformed into hospitals. Nurses replaced attendants, inmates became patients and 'disability' became an individual pathology that required specialist medical treatment.[11, 18]

When the Mental Defectives Act 1911 was amended in 1928, provision was made for the creation of separate institutions for the care and training of mentally deficient children. Templeton Farm School, on the outskirts of Christchurch opened the following year. Thomson described occupation with tasks primarily related to the maintenance of the institution as the primary focus of the school.[11] Boys were pressed into gardening, farm work, carpentry boot-making painting and canvas work and the girls helped in the laundry, kitchen and with domestic tasks. Templeton, like all of the specialist institutions that followed, strove to become a self-sufficient community. They would become a 'home for life,' for a generation of New Zealand men and women with intellectual disabilities.[19]

One of the consequences of the 1928 amendment was that families were required to register their "mentally defective" children with the Eugenics Board. The Eugenics Board was charged with establishing institutional facilities for the care and training of mentally deficient children.[11] Because the institution represented the State's only response to the welfare of people with an intellectual disability, parents permitted or otherwise determined to maintain the integrity of their family had to meet the support needs of their disabled sons and daughters without assistance for decades thereafter.

Those families who were asked about their decision to place their children into care showed an initial and prolonged determination to keep their children at home.[9, 20, 21] Women were ordinarily required to shoulder responsibility for meeting the day-to-day support needs of their disabled children[21, 22] and parental concern about the impact a disabled family member was having on siblings, combined with the physical and emotional demands of care, meant the moment of seeking permanent placement often turned on resilience of mothers.[21] Families also had to resist medical opinion that tended to see lack of developmental potential and the breakdown of families as inevitable and immutable consequences of intellectual impairment. Many families also reported facing social isolation and bodily exclusion within communities that were pre-occupied with creating a more perfect society after the trauma of the second-world war.[11, 16, 19, 23, 24]

The difficulties families faced is, perhaps no more eloquently captured, than by self-advocate Robert Martin (2006). After reflecting on the way living in an institution had separated Robert from his family, he describes struggling to reach a wider personal understanding of the consequences of his impairment, including what it had meant for his family.[23]

> *When I was able to look back on what happened, I started to understand how my disability had affected everyone in my family. They did not have the support of family and friends. No one was there to help them understand my disability. Their friends withdrew. Even their family stopped visiting. They became a "disability family." It has taken me a long time to understand that.*

In the absence of any other support, North Island parents began to lobby for an institution like Templeton. Lack of funds during the depression and the onset of world-war two delayed Government plans, but in 1944 the Department of Health acquired a vacated Air Force base on the outskirts of Levin and on the 27 July, 1945, a bus with 42 men and 3 male escorts drove through the gates of Levin Farm Mental Deficiency Colony*. The men had been transferred from Templeton and two years later, 38 women would make the same journey.[11, 19]

1.2   The flourishing of Kimberley Centre

Four specialist hospitals for the care of people with intellectual disabilities were eventually established. Templeton Farm School (Christchurch), Braemar (Nelson), Kimberley Centre and Mangere Hospital (South Auckland).

New Zealand mirrored the trend of institutional expansion during the period through the 1940s to the 1970s, with an accumulative rise in the number of people living in institutional settings. Despite the existence of the four specialist hospitals, by 1981, nearly half of New Zealand's institutionalised population of people with an intellectual disability remained in 'intellectual handicap' wards within psychiatric hospitals.

Kimberley Centre became the largest of the special hospitals and was at the epicentre of defining best practice in the care and support of people with an intellectual disability for over two decades. Charlie Guy, the first head attendant had proactively sought community involvement, instituting trial work placements for boys at the Farm and the participation of local community groups in sport and recreational activities at the Centre.[19] By 1953, the waiting list for Kimberley Centre had grown to 400[21] and cabinet approved a major expansion plan that incorporated 11 purpose-built villas. At that time, Kimberley Centre had productive farms, a resident labour pool and the infrastructure required to feed, clothe and maintain an expanding institution.

In 1959, an on-site School of Nursing was built at Kimberley Centre, and following the introduction of a new psychopaedic† curriculum, the first psychopaedic nurses in New Zealand graduated from the Centre in 1964.[21] The change in status of the centre was cemented by the first of a number of name changes when in 1959 it became the Levin Hospital and Training School. The first training officer in New Zealand was appointed to Kimberley Centre in 1955 with the aim of extending activities beyond maintenance and custodial care into education, work, recreation and social activities.[19] A special school was opened in 1959 and industrial, woodwork, craft and recreational programmes were introduced. In 1967 the National Training School for training officers was established at Kimberley Centre and a three year course of study was set up in 1973.

When the name of the Centre changed again in 1977 to the Kimberley Hospital and Training School, Kimberley Centre was the largest intellectual disability hospital in the southern hemisphere, with a population, in excess of 700, estimated to be approximately 15 percent of the people identified intellectually disabled in New Zealand.[21]

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*Levin Farm Mental Deficiency Colony had repeated name changes that reflect historical shifts in the philosophy of service delivery for people with an intellectual disability. In 1957 it became Levin Hospital and Training School, 1977 Kimberley Hospital and finally Kimberley Centre in 1989[19]

†Psychopaedic (a composite of "mind" and "child") is a uniquely New Zealand term, coined in the early 60's by Dr Blake Palmer, Director of Mental Health, to distinguish those who were mentally ill from people with an intellectual disability

By 1977 however, the process of closing major institutions and replacing them with dispersed community-based services had already began to gather momentum in Europe and North America.

1.3   Closing New Zealand's institutions

The impetus for institutional closure has been attributed to the confluence of a number of coincident forces for change, including; a response to growing concern about the dehumanising conditions experienced in institutions;[25,26] the principle of normalisation,[27] the subsequent development of community-based service systems;[28] legislative reform[29] and the rise of the disability rights and self-advocacy movements.

In many respects the dismantling of institutions began from the inside, as the intrinsically dehumanising and depersonalising potential of institutions began to be articulated. Goffman challenged the understanding of congregate care as curative, arguing that for the people who lived in them, the defining characteristics of institutional culture were the loss of a progressive sense of personal identity, restrained liberties and the unerring regulation of daily life through the maintenance of social distance between an institution's staff and residents.[30] Five years later, Blatt and Kaplan would provide the illustrations, in their disturbing photographic essay of the "darker corridors" of East-Coast American institutions.[31]

Occurring alongside growing concern about the way people with an intellectual disability were required to live inside of institutions was the development and implementation of the principle of normalisation.[32] The core concepts of normalisation were first articulated by Bank-Mikkelsen in the 1950s. Bank-Mikkelsen advocated that people with intellectual disabilities ought to have the opportunity to experience a lifestyle as close a possible to normal.[27] His ideas were elaborated upon by Nirje who described the normalisation principle as:

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

Although criticised later for being assimilative[33] and for de-emphasising (bodily) difference,[34] the normalisation principle drove the process of deinstitutionalisation. As it became more widely embraced, the philosophy of normalisation insisted best practice required people with intellectual disabilities to be reintegrated within the normal spaces and rhythms of the wider community.[27] Normalisation became both the goal and guiding principle of community-based service practice.[11]

In much the same way as the lobbying of families had contributed to the construction and expansion of institutional care facilities, family activism and their support of alternative community-based services also contributed to their demise.[11,28,32] Much of the early impetus for residential reform came from families who, with the help of like-minded professions, questioned the relative benefits of institutional care over family and community support for their children. The central figures in New Zealand's early activism were Margaret and Harold Anyon.[11,32] Frustrated by a fruitless search for alternatives to institutional placement for their son, the Anyons embarked on a campaign for an occupational centre for people with an intellectual disability in Wellington. The campaign would in short time lead to the

formation of the Intellectually Handicapped Children's Parent's Association* (IHCAP), the establishment of the first non-voluntary community day service in 1953[†] and articulation of a goal to replace large state institutions with "cottage" homes.[32]

The catalyst that transformed IHCPA from a lobby group to community service provider was the galvanising effect of opposition to what became colloquially known as the Aitkin Report. After their first annual conference in 1950, IHCPA petitioned the government to set up a committee to inquire into the needs of 'intellectually handicapped' people and their families.[11] The terms of reference for a Consultative Committee of Inquiry, chaired by Dr Aitkin, were eventually set in 1952. Following submissions and a tour of New Zealand institutions the Committee concluded that

> *the only satisfactory (government) policy is the provision of good residential insti-*
> *tutions, well equipped and well staffed. . . and parents to place their children therein*
> *at about the age of five.*
> (Department of Education, 1953; cited in Thomson, 1995; p131).

The consultative Committee's finding endorsed the then Department of Health's pre-existing view that the long-term residential provision for the 'mentally deficient' was best done by a colony type institution, propelling IHCPA towards introducing the community services they had hoped the Government would introduce.[11]

Despite permitting private organisations and trusts to establish permanent community homes under the Mental Health Amendment Act 1957, the State would hold firm to the public policy of institutional care up until the start of the 1970s. The intransigence of the State through this period was by then occurring against the backdrop of a shift in the attitude of medical opinion towards institutional care.

Bowlby and Baritone's 1950s research into the debilitating effects of maternal deprivation and institutional living, the World Health Organisation's (WHO) recommendation of home care for people with intellectual disabilities, and the British Medical Association's criticism of the Aitkin Report all contributed to a Royal Commission of Inquiry's call for a comprehensive review of the number of people with intellectual disabilities residing in institutional care. The review was conducted by the New Zealand Department of Health and argued that while over half of the 897 children in institutional care should remain in hospital, in excess of a third were able to live in supervised community homes.[11] Thomson believes this survey represented a turning point in the Department of Health's attitude towards institutional care. The Government responded by imposing a moratorium on the building of further psychiatric and psychopaedic hospitals from 1974 with the Deputy Director of Health instructing Hospital Boards to provide for community housing. The "Community Care Programme" was implemented with the aim of identifying and transferring institutional residents from New Zealand's psychopaedic and psychiatric hospitals. Two hundred Kimberley Centre residents were identified as suitable for community placements and resettled to community-based services, reversing the historical flow of people with intellectual disabilities towards Kimberley Centre

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*Renamed IHC (and in 2005 IDEA) services would expand from these small beginnings to become a major provider of residential and vocational services in New Zealand.

†The first voluntary day services for "uneducable" children were offered by the Wellington After-Care Association in 1926.

1.4 The process of closing Kimberley Centre

The first official indication that Kimberley Centre may close came in 1985, when the government announced that, in line with international trends, it was adopting a policy of community living for all people in long-stay institutional care.[1] What was to follow was a lengthy period of uncertainty, planning and delays.

Throughout the country a number of parent or family support groups had anticipated residential reform and formed associations for peer support. Following the example of the Templeton Centre Parents Association, families with relatives at Kimberley Centre formed the Kimberley Centre Parents and Friends Association (KPFA) in 1978 with the stated aims of working with the hospital for the welfare of patients, peer support and to be involved in any subsequent service planning.[19]

The KPFA was to play a significant role in a sequence of consultations that began in 1994. MidCentral Health (MCH), the Ministry of Health (MoH) and a representative from the KPFA met with Kimberley Centre families/whanau in 21 consultation meetings throughout the North Island. The purpose of the meetings was for the Ministry to explain the need for and to propose an approach to the process of service change. At the conclusion of the meetings, a protocol was established to formalise the principles that would guide the deinstitutionalisation process. The Protocol was adopted by the MCH and Central Regional Health Authority (RHA) and included as important elements that;
* The *Standards for Needs Assessment* would guide assessments of individual support need
* Any change in service provision must be in that person's best interest and enhance life quality including a full range of occupational and recreational activities
* Residents able to express their own preferences be engaged in decisions about their future service needs
* Independent advocacy would be available to residents and with families in the event of conflict regarding placement
* Parents/relatives would not be required to provide direct care, have their relative home or pay for care
* The quality of service provision will be maintained at Kimberley Centre during any change
* A skilled and competent workforce will be available to meet future service needs
* Public awareness programmes will be developed to promote community inclusiveness.
(Ministry of Health, 2001, p83)

A further consultation round took place in 1996, following the release of *Options for the Future*, a report which had been prepared by a working party comprising MCH, Central RHA, KPFA and iwi representatives. The report presented three main options;
* All services to remain on the current (Kimberley Centre) site
* Some specialist services on a single site with others spread across the region
* All services widely spread across the region.

Independent analysis of family submissions made during the consultation reported a great deal of anxiety. Over 70 percent of families expressed a preference for the retention of Kimberley Centre or a transferring of institutional type care into a clustered housing development.[35]

Three years later the Health Funding Authority (HFA) prepared an updated deinstitutionalisation plan for the residents of Kimberley Centre for the Minister of Health. The Minister, however, advised the HFA that he was not prepared to approve the plan as he considered it did not take sufficient cognisance of the preferences of families. Embodied in the plan were six principles, four which had had formed part of the 1996 consultation document *Options for*

the Future and two that had been added in response to the 1996 consultations with relatives that followed. The first four principles were:

1) The principle of normalisation.
2) The least restrictive alternative (expressed as the right to live as independent of support as an individual is able).
3) The right to live in the community.
4) Inclusion (expressed as the right to service delivery that promotes social connection and relationship with friends, family and the local community).

And the two principles incorporated after consultation with families were;

1) The right to choose (expressed as the right for residents [or proxies] to choose the accommodation and services they felt best meet resident needs).
2) The need for support and security (expressed as balancing all other principles against the need for support and security, including well-trained and supported staff).

The difference between the two sets of principles is revealing of the contrasting positions from which the key stakeholders framed the potential impact of Kimberley Centre's closing on the life quality of residents.

In advocating for a more well-rounded consideration of the support people with an intellectual disability require, John O'Brien warns of the danger of holding only one end of the agency/dependency continuum in view. O'Brien argued that a complete conversation about the support needs of people with intellectual disability required acknowledging a person's vulnerability and dependency in addition to their need for agency and self-discovery.[36] To O'Brien, a single focus on either pole of the continuum omitted half of the understanding required to design and deliver quality human support.

The rights and principles advanced by the state and by families as they approached the issue of institutional closure clustered towards opposite poles of the continuum. Families tended to emphasise the importance of providing supports that acknowledged the vulnerability of their relatives and the State articulated the importance of agency and inclusion as key indicators of service quality (Figure 1.1). It is probable that the resident population of Kimberley Centre may have been skewed towards being more severely disabled in the wake of the moratorium on admissions and exodus of residents that occurred during the Community Care Programme. It was noted by the medical superintendent in 1982, for example, that Kimberley Centre had almost 50 percent more residents who were "severely handicapped" than the Department of Health national average for other similar institutions.[19] However, conclusions about the vulnerability of Kimberley Centre residents need to be tempered. Mirfin-Veitch[32] (2005) found that families experiencing the closure of Templeton Centre typically perceived their relative as having significant or very high support needs. Mirfin-Veitch observed that this social construction tended to lead families to refute policies that emphasised the positive aspects of community living as they appeared "unreal" in the context of their understanding of their relative.

This mismatch in the way Kimberley Centre residents were understood persisted throughout the closure process. Even as resettlement approached, parents continued to report failing to recognise their relatives in the rhetoric of the successes of community living.[37]

Following a change in government in 1999, the new Minister of Disability Issues asked the HFA to proceed with further planning processes that were to be the basis for making a decision on the future of Kimberley Centre. The Minister directed the planning process to have three key parts;

∗ a comprehensive needs assessment for all residents to determine their specific supports needs,

Figure 1.1 — Kimberley Centre deinstitutionalisation principles after the 1996 consultation round.

Agency

Vulnerability

Possibility

* The least restrictive alternative
* The right to live in the community
* The principle of normalisation
* Inclusion

* The need for support and security
* The right to chose

Dependency
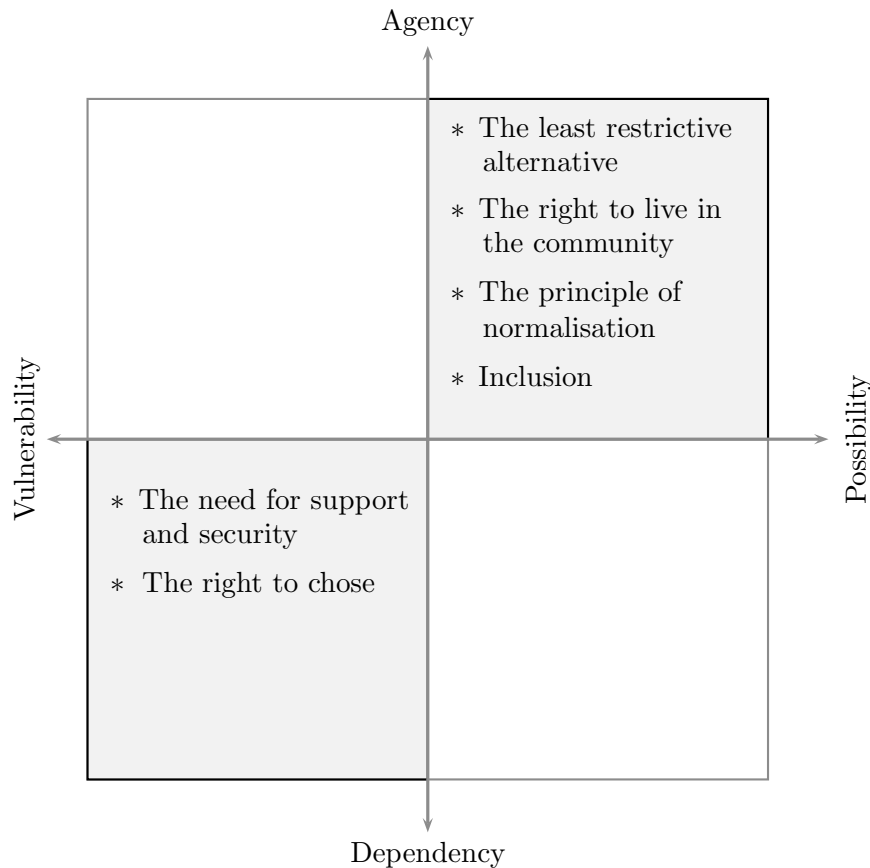
* the formation of a Project Working Group (PWG) to consider the three options presented in the Options for the Future document and to make recommendations to the General Manager DSS that would guide future planning and
* a process of consultation that engaged families in discussions about future placements and service options once the PWG recommendations had been made.

The needs assessment process began in April 2000. Placement recommendations were made by needs assessors based on their assessment of the views of the individual, family, staff, specialised assessors and others important in the individual's life.[35] The residential preferences of families were also recorded, allowing a comparison to made between the preferred service option of families and the indicative recommendations of the needs assessors (Figure 1.2).

The disparity between the attributes of service provision key stakeholders prioritised re-emerges in their separate determination of a preferred accommodation model. Consistent with their understanding of the vulnerability of their relative, families emphasised continuity of institutional care by expressing a strong preference for the status quo (40%) and Cluster House (23%) options over community-based services (28%) In sharp contrast, the needs assessment process recommended Community Group Home placement for nearly two thirds of the Kimberley Centre residents (62% of volunteered placement preferences), whilst retaining Kimberley Centre barely figured in their recommendations (2%). The gap, between families preference for the status quo and the recommendation following needs assessment was greatest for residents with multiple or severe impairments*.

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*To maintain consistency throughout the report the Needs Assessment resident categories were collapsed into the villa typology employed at Kimberley Centre. Lifestyle residents included independent functioning,

Figure 1.2 — The residential placement preferences of the Kimberley Centre families and indicative recommendations following the 2000 Needs Assessment.

Family Accommodation preference

Needs Assessment recommendation

- ☐ (yellow) Community home
- ☐ (blue) Cluster housing
- ☐ (light grey) Status quo
- ☐ (dark blue) Specialised
- ☐ (pink) Unspecified

"Unspecified" includes families who were not prepared to sign off the needs assessment without more information about future options and where no agreement existed between contributes about a recommendation.

In 2001, the Ministry of Health, with assistance from the MidCentral Health District District Health Board presented the Preferred Future Service Provision for the Residents of Kimberley Centre report, recommending the full deinstitutionalisation of Kimberley Centre to the Minister of Health and the Minister of Disability Issues.

On 5 September 2001 the Minister of Disability Issues announced that all residents at Kimberley Centre would be resettled in the community, with a projected closure date of March 2005. At the time of the announcement, 375 people were living at Kimberley Centre.

The first Kimberley Centre residents left for community-based services towards the end of 2003. But by March 2006, over half of the original 375 residents were still living at Kimberley Centre. Approximately one third of the original population were eventually resettled three months after the final projected closure date of June 2006. Two factors contributed to the delay. Firstly, an earlier decision by the Manawatu-Whanganui Area Health Board to place Kimberley Centre residents under personal and welfare guardianship orders slowed the process. Because the wording of the order required residents to reside at Kimberley Centre, individual applications had to be made to the Levin Family Court for approval to move to an alternative service provider[†]. Secondly, the Kimberley Centre Resettlement Plan also called for the separation of house ownership from service delivery. Housing New Zealand was contracted as the sole provider of new housing stock and delays throughout the first years of resettlement were also attributed to difficulties in acquiring, adjusting and satisfying consent and code of compliance requirements.[38] As the closure progressed,

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verbal prompting & physical assistance needed SNC levels; Challenging behaviour included high behaviour needs and behavioural and medical needs SNC levels and Multiply disabled included high medical needs SNC level residents

[†]The process was eventually expedited by a decision to process multiple applications

difficulty was experienced accessing primary health providers and recruiting staff, particularly in the Manawhatu-Horowhenua region. In this region the sudden influx of Kimberley Centre resident into relatively small communities threatened to overwhelm their ability to meet the additional demand on material, infrastructural and human resources. In Levin, for example, the Ministry of Health felt it necessary to respond to the problems services were experiencing recruiting suitable staff by asking families to revise Horowhenua as a preferred location and approaching WINZ and the Horowhenua Learning Centre to recruit staff.[38]

As the pace of community placement slowly gathered momentum villas closed and ancillary services were cut back. The longer residents remained at Kimberley Centre the more likely they were to experience the loss of therapeutic and day activities. Some were repeatedly moved as villas sequentially closed. The Kimberley Centre workshops closed in 1988 and Kimberley Centre school was phased out. By 1990, both the National Training School for training officers and the Kimberley Centre's psychopaedic nursing school had been disestablished and over the final closure years Day Support Services were cut back and access to on site facilities became more difficult. Mindful of the 1994 Protocol to maintain the quality of service provision at Kimberley Centre, some parents would later report the progressive withdrawal of specialist services and facilities during deinstitutionalisation profoundly affected the life quality of their family member.[39]

For visiting families, the immaculate grounds and paint peeling from skeletal buildings would evoke contradictory images of Kimberley Centre past and an institution in terminal decline.

2

The Kimberley Centre research project method

2.1 Project Origins

The proposal to investigate the outcomes of the closure of Kimberley Centre had its genesis in a meeting between Hon. Ruth Dyson, then Associate Minister of Health and Minister for Disability Issues, Dr Anne Bray, then Director and Peter Cartwright, then Trust Chairperson, Donald Beasley Institute, in June 2002. The focus of the discussion was on the need for disability research in New Zealand. The Hon. Ruth Dyson asked whether the Institute was prepared to undertake research around the closure of Kimberley Centre. She was aware of the Institute's previous research [funded by the Health Research Council (HRC)] into the closure of Templeton Centre, near Christchurch.

On the advice of the Minister, a research proposal was submitted to the Deputy Director-General, Disability Issues Directorate. The proposal emphasised the need to establish the independence of the research, anticipating that many potential participants would differ in their perspectives of the Ministry of Health and its role in the closure of Kimberley Centre.

Consultation with Kimberley Centre Families, the Public Services Association (PSA) and New Zealand Nurses Association (NZNA), Kimberley Centre Management, Te Timatanga Whanau Group and other stakeholder groups began in November 2002. The aim of the consultation process was to refine the project prior to its submission for ethical approval.

The Kimberley Centre Research Project was conceived of as having two separate phases. Phase One involved speaking to family members, Kimberley Centre staff and building a picture of the day-to-day lives and adaptive competencies of people while they lived at Kimberley Centre. In Phase Two, the impact of resettlement on the life quality of family, staff and residents would then be assessed by repeating the same measures following resident's move to their respective community based services. The Ministry of Health provided funding for Phase One of the project and under the HRC Partnership Programme funding for Phase Two was provided by the Health Research Council.

The Kimberley Research Project: Examination of the outcomes of the resettlement of Kimberley Centre received ethical approval from the Manawatu-Whanganui Ethics committee in July 2003 and Phase I began with the first family interviews in October 2003.

2.2   Kimberley Centre Research Project aims

The overarching aim of the Kimberley Centre Research Project was to provide a comprehensive analysis of the outcomes associated with the closure of Kimberley Centre. The closing of Kimberley Centre represented a watershed moment in the history of support for people with intellectual disabilities in New Zealand and a moment of major social change for residents, their families and staff who shared a common connection to Kimberley Centre.

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

Exploring the impact closing Kimberley Centre had on the lives of the men and women who lived there is the primary focus of this report. The key research objectives related to Kimberley Centre residents were:
1. To compare how life changed for Kimberley Centre residents within the core QOL domains advanced as contributing to a full and interconnected life between Kimberley Centre and the community-based services they were resettled to. Where possible the study was also to be informed by residents' own assessments of what gave their lives personal meaning in and then out of New Zealand's last institution.
2. To identify the impact of service change on the adaptive and functional skills of Kimberley Centre residents including the prevalence and service response to challenging behaviour. Determining whether competency losses or gains were sustained over time and understanding what elements of service delivery contributed to the acquisition or extinction of skills and behaviours.
3. To identify any issues of service quality or gaps within community-based services, with a particular focus on understanding variability in QOL outcomes and what supported or frustrated resident's ability to live valued lives.

Two further project aims influenced the research design. In the deinstitutionalisation literature, the residents who populate institutions are sometimes characterised in ways that deny their heterogeneity. In addition to the aims above, we were interested to learn whether the closure of Kimberley Centre was a similar experience for residents with dissimilar support needs.

Secondly, as noted previously, the last two New Zealand institutional closure programmes have incorporated larger cluster house sites as service placement options. Bigby argues that understanding what lies behind the increased demand for services that approximate

institutional care has important implications for people with an intellectual disability given research findings that suggest poorer QOL outcomes for residents supported in Cluster House settings.[7, 40] Comparing QOL outcomes for residents resettled to Cluster Houses and Community Group Homes was another key aim of the Kimberley Centre Research Project.

2.3   Kimberley Centre Research Project research design

To evaluate the impact of deinstitutionalisation within the lives of Kimberley Centre residents the Kimberley Centre Research Project employed a prospective longitudinal research design. A prospective design is a forward looking research strategy that involves identifying a population prior to an environmental change and collecting data for key outcomes before and after the critical moment of change. For Kimberley Centre residents, this involved recruiting a representative sample of residents and their families and building a picture of their lives while they lived at Kimberley Centre. By repeating the same measures 3-6 and 12 months after resettlement, life at Kimberley could be compared to life in residents' community-based services.

Collecting information about resident's separate journeys out of Kimberley yielded three important axes of comparison. Capturing and comparing data drawn from the eight measures chosen as indicative of life quality (Figure 2.1) permitted analysis of the way life had changed for residents between institutional and community-based support settings. Comparisons were also made between the outcomes associated with resident resettlement to either a Cluster House or Community Group Home. And finally, by using villa type as a short hand for the primary support need of Kimberley Centre residents, it was possible to explore whether the costs or benefits of deinstitutionalisation were similar for people with dissimilar support requirements.

2.4   Kimberley Centre Research Project data collection methods: Objective QOL Measures

a) **Adaptive Behaviour Scale – Residential and Community**, 2nd edition (ABS-RC:2)   Definitions of adaptive behaviour and attempts to measure adaptive skills emphasise the manner in which people cope with the natural and social demands of their environment.[41] Poor adaptive functioning is reciprocally understood as limitations in an individual's ability to meet the standards of maturation, learning, personal independence or social responsibility expected of an individual's cultural and chronological peers.[42] The belief that promoting an individual's ability to manage environmental stressors and exhibit social responsibility within community settings supported the "social invisibility" of people with intellectual disability ensured its prominence in early deinstitutionalisation research.

One of the most widely used instruments used to measure adaptive and challenging behaviour is the American Association on Mental Retardation's (AAMR) Adaptive Behaviour Scale – Residential and Community, second edition (ABS-RC:2). Two previous versions of the scale were reconstructed to improve overall reliability and the discriminative power of the measure for institutional and community living. The ABS-RC:2 was normed on over 4000 adults with intellectual disabilities living in the United States and Nahira

Figure 2.1 — The Kimberley Centre Project Quality of Life measures
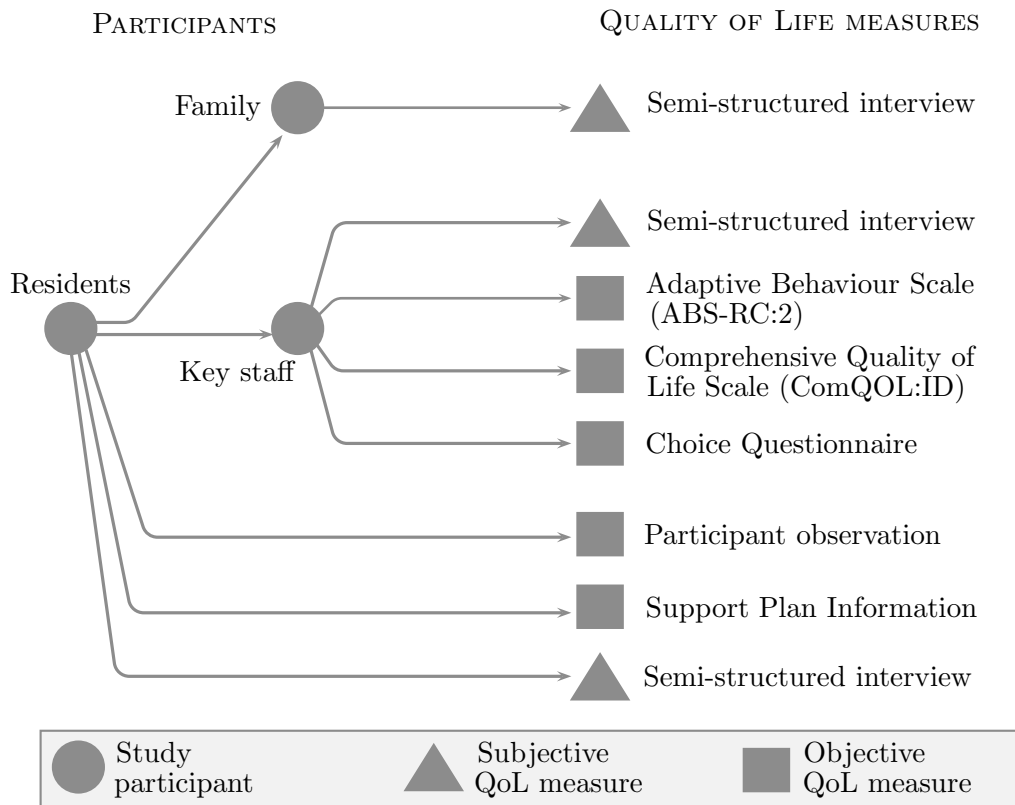
PARTICIPANTS

QUALITY OF LIFE MEASURES

Family — Semi-structured interview

Residents

Key staff — Semi-structured interview

Adaptive Behaviour Scale (ABS-RC:2)

Comprehensive Quality of Life Scale (ComQOL:ID)

Choice Questionnaire

Participant observation

Support Plan Information

Semi-structured interview

| ● Study participant | ▲ Subjective QoL measure | ■ Objective QoL measure |

et al. (1993) outline a number of studies that affirm the scale's construct and content validity.[41]

The Scale is divided into two parts. Part One focuses on personal independence and is designed to evaluate coping skills considered important to personal independence and responsibility in daily living. In Part One, 73 item scores are incorporated within the ten adaptive skill domains of *Independent Functioning*, *Physical Development*, *Economic Activity*, *Language Development*, *Numbers and Time*, *Domestic Activity*, *Pre-vocational/Vocational Activity*, *Self-Direction*, *Responsibility* and *Socialization*. The item scores in Part One have also been factor analysed to yield the three general adaptive behaviour categories of *Personal Self-Sufficiency*, *Community Self-Sufficiency* and *Personal-Social Responsibility*.

Part Two of the ABS-RC:2 is concerned with social behaviours, grouping 41 items scores into the eight challenging behaviour domains of *Social Behaviour*, *Conformity*, *Trustworthiness*, *Stereotyped and Hyperactive Behaviour*, *Sexual Behaviour*, *Self Abusive Behaviour*, *Social Engagement*, *Disturbing Interpersonal Behaviour*. The item scores in Part two have been factor analysed to yield the two challenging behaviour categories of *Social Adjustment* and *Personal Adjustment*.

At each phase of the project, key staff identified as knowing a resident well completed the scale, guided by a member of the research team. One hundred and thirteen ABS-RC:2 scales were completed (90% return) over all three phases of the project.

b) **Observations of daily life**   Running records are sometimes described as participant observations.[43] They provide a rich source of descriptive information, able to capture important dimensions of complex social phenomena. Descriptions of competencies, body language, facial expression and responses to stimuli can be incorporated in running record

narratives. Stretching over time, a running record also captures environmental antecedents to behaviour and the immediate consequences that flow from it.

Six half-hour observations were conducted at randomly assigned times for every resident at each phase of the project. Observations took place in settings where a participant would ordinarily be at the designated time. This occasionally meant observers had to follow a participant if they moved during the course of an observation. Observers positioned themselves in ways that minimised the potential for interaction with participants but assumed an identity that reduced the potential for their presence to be intrusive. Sometimes this meant engaging briefly with a participant or others who shared a particular setting with them. The role of the observer was to generate a record of participant behaviour and the context in which it took place. Running records were used to capture a continuous stream of participant behaviour, including interactions with other people and significant events within a setting that were perceived to have had the potential to alter behaviour. Each observation was prefaced with a description of the setting, providing an equally rich source of information about the lived experience of participants and the context to their behaviour.

To analyse the observation data, the running record narratives were post-coded into a coding schedule that summarised key elements of the day to day lives of residents including; where residents learnt, worked and recreated, what activities filled their day, who they got to know, how they were communicated with and how often they engaged in self-abusive or maladaptive behaviour (Appendix 2).

To capture a snapshot of the geography of residents' lives, the settings they occupied during observation intervals were described in the vernacular of the setting. Similarly the activities that residents engaged in from moment to moment were transposed from the running record on to an activity typology that blended McDonald's (1997) five activity opportunities (Disengaged, Leisure, Domestic, Personal Care and Vocational) with the finer discrimination in activity types identified in Sparrow and Sharp's (1991) eight-fold typology.[44,45] Residents were recorded as engaging in either *Sedentary*, *Wandering*, *Indoor–Passive*, *Indoor–Active*, *Social*, *Outdoor Active*, *Domestic*, *Personal Care*, *Assisted Personal Care*, *Employment*, *Vocational/Educational* or *Voluntary activity* in every minute of the 30-minute observation. A picture of the day-to-day social interaction was built up by recording with whom and how long residents were included within the socially orientated communication of others. Interaction could be verbal or non-verbal but excluded surveillance. The proportion of interaction initiated by residents and the communicative intent of each partner to an interaction was also recorded, including communication events that were not responded to by one or other of the intended communication partners. The coding categories were an adaptation of the typologies used by Light and McDonald,[45] cited in McDonald (1997), and included *Instruction*, *Responding to Instruction*, *Social Closeness*, *Seeking Information*, *Giving Information*, *Acknowledgement* and *Not Clear* when the intent was unobserved or ambiguous. The presence of five types of maladaptive behaviour were also coded for, including behaviour assessed to be *Self-Injurious*, *Stereotypical*, *Harmful to Others*, *Vocalisations* not part of ordinary language or communicative in intent and *Other behaviours* inappropriate to the context.

The locality, activity type, communication event and maladaptive behaviours were recorded if presented in every minute of the 30-minute observation, yielding an index of event frequency and duration for all coded variables. The research team all had previous experience using running record observations and received two days training to improve the inter-rater reliability of post-coded narratives.

Six hundred and seventy one individual observations were completed yielding 20,130 minutes of recorded activity over all phases of the project (89% return) and inter-rater coding reliability (extended Cohen's κ statistic 85–95%) and intra class correlation (ICC) were satisfied for all phases.

c) **The Comprehensive Quality of Life - Objective Scale** The Comprehensive Quality of Life Scale (ComQol-ID) has historically been one of the most widely used instruments employed as a measure of "whole of life quality." The Comprehensive Quality of Life Scale exists is three parallel forms, enabling the life quality of people with intellectual disabilities (ComQol-ID) to be directly compared to adolescent children and the general population on an equivalent measure. In its original construction the scale contained two axes, one to measure objective QOL and the other to measure subjective QOL within the seven core domains of *Material Wellbeing*, *Health*, *Productivity*, *Intimacy*, *Safety*, *Place in the Community* and *Emotional Wellbeing*. Within the objective axis, three item questions, scored on a 5-point Likert scale, contribute to the domain score. Whilst the ComQol-ID had established utility as a quality of life measure and had proved to be valid, reliable and sensitive to change,[46, 47] Cummins (2002) would subsequently abandon the composite scale, primarily because of conceptual and methodological flaws in the subjective axis of the scale.[47] Because the study had already received ethical approval to use the tool a decision was made to continue to use the objective axis of the ComQol-ID only, which Cummins (2002) described[47] as providing a "good general overview of objective life quality".

At each phase of the project, key staff identified as knowing a resident well completed the scale, guided by a member of the research team. One hundred and fourteen ComQol-ID scales were completed (91% return) over all three phases of the project.

d) **The Choice Questionnaire** Personal freedom and the ability to exercise control over decisions that affect one's life are cherished rights and widely recognised as an essential component of life quality.[48, 49] Most conceptualisations of the QOL construct include self-determination as a core domain. Despite its acknowledged centrality to life quality, the ability that people with intellectual disabilities have to exercise authority over their own lives in New Zealand[9] and internationally[50–52] remains limited and well short of the normal experience anticipated by deinstitutionalisation.[5]

The Choice Questionnaire is a 26-item scale designed to assess the degree of choice available to people with an intellectual disability across various life domains including; *domestic matters*, *staff*, *money and spending*, *health*, *social activities*, *community access*, *personal relationships*, *work or day activities* and *general choice making*. The measure has demonstrated sound reliability and construct validity and satisfactory test-retest reliability, internal consistency, inter-scorer agreement and content validity. Because the ability to make choices is known to be strongly influenced by adaptive skills,[48, 53] the adaptive competency of residents was controlled for in any un-paired comparisons by using participants ABS-RC:2 adaptive behaviour score for that phase of the project.

To avoid modality and response biases, key staff identified as knowing a resident well completed the scale as proxy informants, guided by a member of the research team at each phase of the project. One hundred and sixteen Choice Questionnaires were completed (93% return) over all three phases of the project.

e) **File Information** Detailed information relating to each resident participant was transposed from their individual file at Kimberley Centre and 12 months after the move to their new community-based service. Data collection was managed using a FileMaker Pro database and organised around the core QOL domains. Data included diagnostic information, medication and medical history, outpatient records, support plans, resident

goal setting, programmes, intervention protocols, special incident reports, property inventory and notes related to material wellbeing, visitor records, evidence of community participation and indicators of acknowledgement of consumer rights.

2.5 Kimberley Centre Research Project data collection methods: Subjective QOL Measures

a) **Key staff interviews**   At each phase of the project a staff member identified as knowing a resident especially well contributed a semi-structured interview. The aim of the interview was to capture complementary qualitative information about the lifestyle, idiosyncratic indicators of life quality and support needs of each resident and how well they were supported in each setting. Key staff were also invited to reflect upon how the particular support environment advanced or suppressed life quality and what impact Kimberley Centre's closing was perceived to have had on resident participants. Core domains derived from the QOL construct provided the interview framework, but staff were equally free to guide the interview in directions they felt were important to a deeper understanding of a resident's life quality.
A semi-structured interview format was chosen because open-ended questions allowed the dialogue to remain focussed upon 'understanding' the lived experience of residents and the culture in which support was embedded. Key staff interviews were taped, transcribed and sent back to informants so they could correct and self-edit their narrative. One hundred and sixteen interviews were volunteered (93% return) yielding in excess of 10,440 minutes of interview time.

b) **Resident interviews**   Until very recently, the stories of the people making the journey out of institutions have been excluded from the discourse of deinstitutionalisation.[54] With the approval of welfare guardians, residents judged able to give informed consent both by staff and a member of the research team were also given the opportunity to contribute a semi-structured interview. The interviews mirrored key staff interviews in so far as the core QOL provided an organising framework, but residents were also invited to tell the interviewer what was most important to making their lives good and to discuss the hopes and fears they held related to the transition from institutional to community based support settings. Four Kimberley Centre residents were able and took the opportunity to tell their own story at each phase of the project.

c) **The Personal Wellbeing Index**   In the original study design the Personal Wellbeing Index (PWI) was chosen as the most appropriate empirical measure of resident's perceived life quality. The tool comes with a pre-test protocol designed determine if respondent's understand the nature of the task or exhibit known response biases (recency and acquiescence) to interview questions. Only two Kimberley Centre resident participants passed the pre-test protocol in Phase I and the measure was subsequently abandoned.

2.6 Employing the QOL construct to investigate the outcomes of closing Kimberley Centre for long-term residents — Method Summary

From the Kimberley Centre Research Project's inception a decision was made to employ the QOL construct to facilitate a 'whole of life' exploration of the impacts of closing Kimberley Centre. The core principles related to the conceptualisation and measurement of life quality

Table 2.1 — The number and return rate of Objective and Subjective QOL measures collected over all phases of the project.

| | Objective QOL Measures | | | | | | | | Subjective QOL Measures | | | |
| | Observations | | ABS-RC2 | | ComQol | | Choice | | Key-Staff interviews | | Resident interviews | |
	N	%	N	%	N	%	N	%	N	%	N	%
Phase I	260	94	43	93	44	96	44	96	45	98	4	100
Phase II	189	79	33	83	34	85	34	85	36	90	4	100
Phase III	218	93	37	95	36	92	38	97	35	90	4	100
Total	**667**[*]	**89**	**113**	**90**	**114**	**91**	**116**	**93**	**116**	**93**	**12**	**100**

[*] To preserve comparability four observations were excluded from the analysis.

articulated at the IASSID World Congress 1996[55] have all been incorporated within the overall study design.

Cummins' (1997) QOL domain taxonomy was adopted as an overarching evaluative framework, with information drawn from all of the data collection measures contributing to a 'thick description' of life quality in the domains of Material Wellbeing, Health, Productivity, Safety, Intimacy, Place in the community, Emotional Wellbeing and Overall quality of life.[46,56]

A key focus of the data collection strategy was the collection of both objective and subjective data within the core domains promoted as a first level deconstruction of life quality (Figure 2.1). The emphasis on pluralistic methodologies was also accommodated by a multi-method research design that allowed findings to be approached from different perspectives.

And finally, the formally marginalised voices of people with intellectual disabilities and those who knew them well were fore-grounded as a way of acknowledging the unique lived experience of men and women whose entire adult lives had unfolded Kimberley Centre and the highly personal nature of their journey out of New Zealand's last total institution.

2.7 Data analysis (Quantitative)

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

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

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

And finally, multiple linear (continuous data) and logistical (dichotomous data) models were employed to explore the strength of association between a range of potential explanatory vari-

ables (independent variables) and changes in Quality of Life outcomes of interest (dependent variable). Important independent variables included:

* the length of time a resident had lived at the Kimberley Centre;
* whether a resident's welfare guardian was a parent, sibling or other relationship;
* the distance a resident was from their welfare guardian;
* which type of villa residents lived in at the Kimberley Centre (multiple disability, challenging behaviour or lifestyle villa);
* what model of support they were resettled to (Cluster House or Community Group Home);
* the age of a resident;
* the sex of a resident.

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

2.8   Data analysis (Qualitative)

A general inductive approach (Thomas, 2006) was used to analyse data collected from resident and key 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 to capture residents', families' and staff's experiences of deinstutitionalisation. Transcribed interviews were analysed using a qualitative research software programme (HyperRESEARCH) that broke interview narratives into key research themes identified as emerging from within the data.

2.9   Resident participants

In August 2003, 349 Kimberley Research Project – Study Information Packs were sent to the welfare guardians of residents who remained at Kimberley Centre. Families who were interested in participating in the project could indicate their interest by returning a Participant Interest form. Every family that expressed an interest in informing the project was contacted by a member of the research team to clarify any questions and ultimately to work through the process of obtaining informed consent. Family members who were also the welfare guardian of Kimberley Centre residents gave proxy consent for their relative to be included in the study. The process was slightly different for potential participants that self identified as Maori. Initial contact with residents' whanau was made by telephone or letter by a Kimberley Centre Maori staff member identified as knowing the resident and their whanau well. This initial contact was to seek permission for a "kanohi ki te kanohi" (face to face) visit by a member of the Te Timatanga Whanau Group who gave the whanau information

about the project. If permission was granted, the meeting took place and consent forms were either completed on the day or left with the whanau according to their wishes.

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

Indicative of the more general gender skewing of institutional populations, twenty-nine male (63 percent) and seventeen female (37 percent) residents contributed data during Phase One of the project. The age of male participants ranged between 31-62 years with their mean age (M=44.50, SD=9.59) only marginally lower than female participants (M=44.9, SD=6.64) whose ages ranged from 35-59 years (Figure 2.2).

Resident participants had lived at Kimberley Centre for an average of approximately 38 years (M=37.68, SD 8.51). Males tended, on average to be slighter older in age when first admitted to Kimberley Centre (M=10.72 years; SD=9.21) than female participants (M=7.94 years; SD=5.22) and similarly, had spent fewer years living at Kimberley Centre (M=36.40 years; SD=12.54) than female participants (39.80 years; SD=9.82).

Most participants had first entered Kimberley Centre as children and lived their entire adult lives at Kimberley Centre. By the time the research team met residents, male residents had, on average, spent 80 percent and female residents 87 percent of their lives living at the Centre.

Participants were drawn from all 12 villas that remained open at the Kimberley Centre at the start of the project (Table 2.3). At the Kimberley Centre, residents were assigned to villas according to an assessment of their primary support need. Residents were understood as residing either in Challenging Behaviour, Multiple Disability (Frail health) or Lifestyle villas. Staff and residents shared a common understanding of the distinctions between villa types. The nature of resident support need and the social practices of care differed between villa types according to the common cultural understanding of the function of the villa. As residents left Kimberley Centre, villas were sequentially closed as part of process of managing the transition to community-based services. During the course of the project, therefore, staff and residents were reassigned to different villas, changing their composition as resettlement gathered momentum.

Residents differed little in mean age between the different villas types. Residents in Challenging behaviour villas tended to be a little younger and residents in Lifestyle villas a little older than the overall sample mean but no statistically significant differences emerged in mean age between villa types (Table 2.4). Because of the more general gender skewing within the Kimberley Centre population, the number of male participants was greater than the number of female participants in all villa types. The ratio of males to females was, however, much larger in the Challenging behaviour villas, where male participants outnumbered female by a ratio of 2.67 : 1. The genders were most evenly balanced in the Multiple disability villas where males outnumbered females by a ratio of 1.29 : 1.

Figure 2.2 — Age/Sex profile of the Kimberley Research Project resident participants (October 2003).
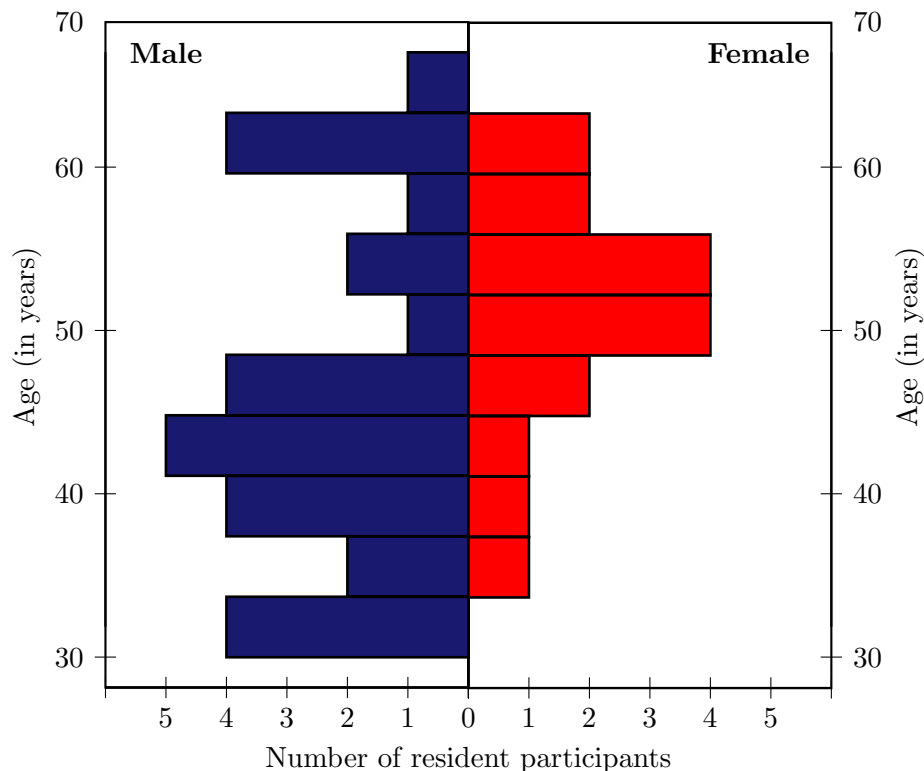
Figure 2.3 — The villa assignment of participants by villa and villa type (October 2003)

Challenging Behaviour		Multiple Disability		Lifestyle	
Hawea	3	Awatea	4	Monowai	6
Ward 5	4	Ianthe	6	Hostel	1
Ward 7	2	Kaniere	6	Rotoiti	6
Palm Grove	2			Wanaka	3
				Ohau	3
Total	**11**		**16**		**19**

Residents living in Multiple disability villas were typically admitted to the Kimberley Centre at a younger age than other villas types. The mean age at admission for residents living in the three Multiple disability villas was 6.83 years. Residents in Challenging behaviour villas, for example, were admitted 4.9 years later (95% CI [0-10.23], $p = 0.07$). Whilst this result did not achieve statistical significance at the ($p < 0.05$) level, the test was influenced by a relatively large variability in age of admission for all villa types and the small size of the population sampled.

Residents who resided in Multiple disability villas also tended to have lived at the Kimberley Centre a little longer than other villa residents. On average, people who lived in Multiple disability villas had lived at Kimberley Centre for 42.1 years, 4.21 years longer than residents in Lifestyle villas and 8.83 years longer than residents who lived in Challenging behaviour villas.

Figure 2.4 — Participant demographic details by villa type

	Challenging Behaviour		Multiple Disability		Lifestyle	
	Mean	S.D.	Mean	S.D.	Mean	S.D.
Age	42.82	7.88	44.50	8.07	45.94	9.47
Male:Female ratio	2.67		1.29		1.71	
Age at admission	11.73	8.04	6.83	3.66	10.22	9.64
Length of residency	33.27	12.16	42.10	11.33	37.89	11.03
Distance from WG (km)	163.32	136.56	278.20	190.23	179.63	201.46
Parent:Sibling ratio	10.00		1.33		1.25	
Adaptive behaviour	123.57	55.58	39.25	30.33	108.11	42.67
Challenging behaviour	40.79	23.82	14.22	10.62	26.72	22.26

Women tended to have been admitted to Kimberley Centre earlier than their male peers regardless of the villa type. This finding is at odds with family narratives that often emphasised difficulty mitigating the impact of the challenging and/or unpredictable behaviour of son's as contributing to decisions to seek out of placement. The pattern of later male admission is, however, most exaggerate for residents in the Challenging behaviour villas (Figure 2.5). The earlier admission and longer length of residency experienced by women participants may be partially explained by their being under-represented in Challenging behaviour villas where residents tended to be younger and admitted later. Whilst clearly beyond the scope of this study, the pattern of earlier admission of girls with an intellectual disability may also reflect an expression of broader socio-cultural values about gender and impairment.

Participants who lived in Multiple disability villas tended to live further from their welfare guardian. The mean distance separating people living in Multiple disability villas from their welfare guardian was 278.20 km. The welfare guardians of residents who lived in the two other villa types were almost half the distance from their welfare guardian while they lived at Kimberley Centre. For example, the welfare guardians of residents who were supported in Challenging behaviour villas, on average lived 114.88 km closer to their family member than the welfare guardians of residents who resided in Multiple disability villas (95% CI [-14.73-244.49], $p = 0.8$).

Of the 11 residents who lived in Challenging behaviour villas, only one person had a sibling as their welfare guardian. This differed markedly to other villas where the ratio of sibling to parental welfare guardianship was much more equitable. As noted above, residents in Challenging behaviour villas tended to be slightly younger in age, had been admitted to Kimberley Centre when they were older and had spent less time living at the Centre. Parents may also, therefore, have been younger and/or more immediately engaged in their support. Other factors may also have contributed to the more limited inter-generational transference of support including historical differences in the experience of visiting or disposition towards familial contact either over time or between the different villa types.

2.10 The representativeness of Kimberley Research Project participants

The number of residents who contributed to the project represented approximately 13 percent of the total population of men and women who lived at Kimberley Centre when the project began in October 2003. Determining how representative the study sample was of the wider

Figure 2.5 — The proportion of Kimberley Centre residents and research participants residing at Kimberley Centre in November 2000
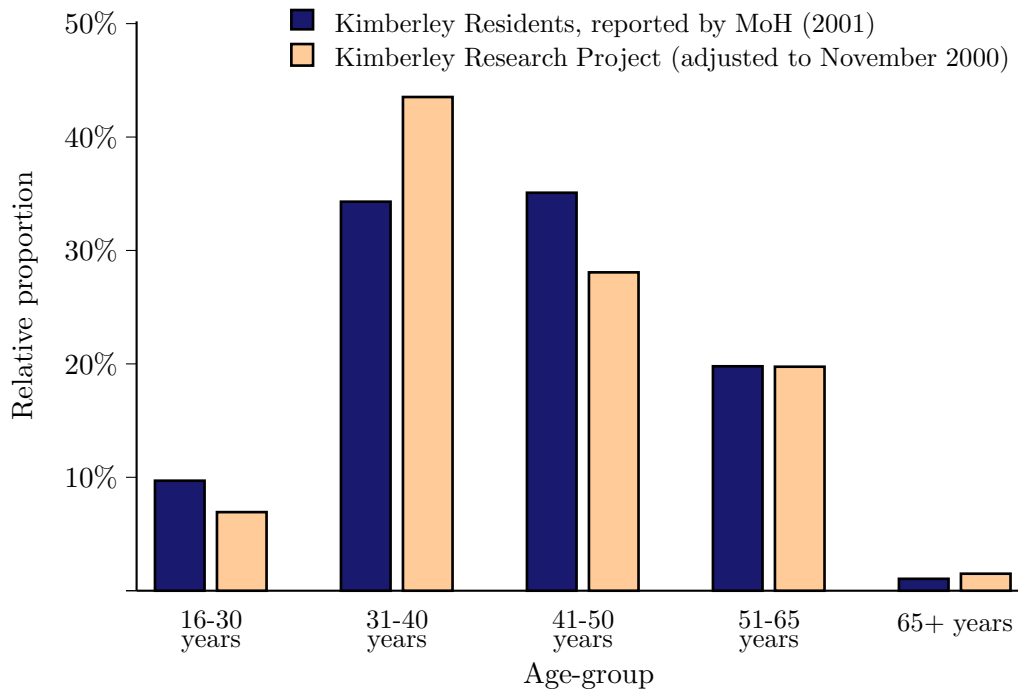
Kimberley Centre population was problematic given the lack of comparable publicly available data. The Ministry of Health's (2001) report to the Ministers of Health and Disability Issues *Preferred Future Service Provision for the Residents of Kimberley Centre* provides the most recent demographic data.[35] In that report, 379 people were stated as living at Kimberley Centre when the survey was conducted in November 2000. At that time, the average age of Kimberley Centre residents was reported to be 42 years (Minister of Health, 2001), almost exactly the same mean age of the participants who informed this study when adjusted for the time difference in sampling (M=41.68 years). A comparison of the age profiles of Kimberley Centre residents as described in the Ministry of Health (2001) report and the adjusted age of research participants reveals a similarly high level of correspondence between the two populations (Figure 2.5).

In the same document, the Ministry of Health also reported the results of the Needs Assessment process conducted at Kimberley Centre in April 2000.[35] Kimberley Centre residents were classified according to support need. Six classification categories were used and are listed in Table 2.2 together with the percentage of residents within the categories that conform most closely to the villa typology used in this study.

Comparing the respective population percentages reveals an almost exact "fit" between the proportion of total Kimberley Centre residents assessed as being most independent of support need (SNC: A; B; C) and study participants drawn from Lifestyle villas. On the basis of this comparison our population sample may, however, be slightly skewed towards residents with higher medical support needs. It is not unreasonable to suggest that part of the skewing has occurred because of the imprecision of dissimilar typologies. Residents assessed as having both behavioural and high medical support needs (SNC D1/2), were coded as equivalent to Challenging behaviour villa residents when collapsing the categories into villa types,

Table 2.2 — The number of the Kimberley Centre residents by needs assessment (2000) category and the Kimberley Centre villa type

Kimberley Centre Needs Assessment (2001)				Kimberley Centre resident participants		
Category	Description	N	%	N	%	Villa
SNC D1	High behavioural needs	95	33.77	11	23.9	Challenging Behaviour
SNC D1/2	Behavioural & medical needs	33				
SNC D2	High Medical Needs	89	23.48	16	34.8	Multiple Disability
SNC A	Independent Functioning	5				
SNC B	Verbal prompting needed	42	42.74	19	41.3	Lifestyle
SNC C	Physical assistance needed	115				

potentially excluding residents who may actually have been assigned to Multiple disability villas. An alternative explanation is that parents with family members perceived to be more vulnerable because of higher medical support needs may have been more motivated to participate in the research project.

2.11 The historical representativeness of Kimberley Centre: An institution in terminal decline

At its peak, the Kimberley Centre was the largest specialist institution in the Southern Hemisphere. The Kimberley Centre was home to 759 men, women and children in 1979 and in the 1980, it was estimated that 15% of all New Zealanders identified[19] as having an intellectually disability resided there* and for two decades the Kimberley Centre was epicentre of best practice for people with intellectual disability.

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

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

The broad aim of the Kimberley Centre Research Project was to accurately document the impact of closure during this process of change through direct observation and measurement. The narratives of residents, their families and key staff provided additional historical insight

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*Estimates of the highest resident population at the Kimberley Centre vary, some sources suggesting in excess of 1000 may have lived there at one time. Hunt[19] is cited here as a reliable secondary source.

into the way all three groups interpreted the changing character of Kimberley Centre and the impact they believed living, visiting and working in an institution had made to their life quality. Although directly comparable to existing deinstitutionalisation research, the generality of the research findings reported are restricted to the five years the research team watched Kimberley Centre close and former residents begin lives support from community-based service settings.

3

Re-locating Kimberley Centre residents

3.1   The distance between family members

In 1992, the Manawhatu-Whanganui Area Health Board made an application to the Family Court to place Kimberley Centre residents under Personal and Welfare Guardianship orders. Their application reflected a more general concern that, after the enactment of Protection of Personal and Property Rights Act 1988 (PPPR Act), residential disability support services had become exposed to complaints to the Health and Disability Commissioner to the effect that they were acting unlawfully in providing treatment to informal 'patients' in the absence of informed consent.[57]

Typically in 'blanket orders' a member of each resident's family was appointed as welfare guardian and a standard court order made authorising continuing care and a requirement to reside at Kimberley Centre.

One of the effects of the orders was to place families at the centre of decision making related to the future placement of their relative. In the wake of the Minister of Disabilities' announcement that Kimberley Centre was to close in 2001, families played a key role in determining the geography of resident resettlement. A number families welcomed their centrality. For them it offered an opportunity to make the sorts of decisions that were a more truthful reflection of their unbroken regard.[58] For others, it offered moments of control within a resettlement process they felt had been imposed upon them.

For some families, however, the role and responsibilities of welfare guardianship remained shadowy, carrying echoes of accountability for the future welfare of family members they had been dislocated from for many decades.

In this chapter the range and pace that Kimberley Centre resident participants were resettled to community-based services is described. We also explore whether any factors appeared to influence the decisions welfare guardians made about how close or what model of community-based support they chose for their relative. The chapter concludes by documenting how families described the positive and negative consequences of a general trend to resettle their relative closer to home.

Table 3.1 — The distance between Kimberley Centre residents and their welfare guardian by relationship type

Relationship	Number	Percent	Average distance	s.d.
Parent	28	60.9	173.4	186.1
Sibling	16	34.8	269.8	183.1
Other	1	2.2		
Missing	1	2.2		
Total	**46**	**100.0**	**212.5**	**188.5**

3.2 Who acted as resident participant's welfare guardian and how near were they before resettlement

In the Kimberley Centre Research Project, 28 parents (60.9%), 16 siblings (34.8%) and one non-family member (2.2%) acted as court appointed welfare guardians for the Kimberley Centre residents who informed the study[*].

The families of residents who participated in this study were scattered throughout the North Island, living at distances from Kimberley Centre that ranged between 3 – 717 km. Before resettlement, the average distance separating Kimberley Centre residents from the relative acting as their welfare guardian was 212.5 km (SD=188.5). Parents tended on average to live nearer Kimberley Centre (M=173.4km, SD=186.1) than sibling participants (M=269.8km, SD=183.1). Although parents were, on average, 96.4 km closer to their relative, the difference between parents and sibling was not statistically significant, (95% CI [0–214]; $p = 0.1$), partly as a consequence of the wide variability in proximity and small study sample size (Table 3.1).

Residents who lived in Multiple disability villas tended to live furthest from their welfare guardian. Residents with more profound physical impairments were, on average, 98 km further from their welfare guardian than residents who lived in Lifestyle villas (95% CI [-233.59 – 36.45]; $p = 0.15$) and 114.9 km further from residents who lived in Challenging behaviour villas (95% CI [- 244.49 – 14.73]; $p = 0.08$). When the differences in distance separating the families of residents who lived in different villas were compared, the type of support needs residents were understood as having approached but also failed to achieve statistical significance.

As noted previously, residents who lived in Multiple disability villas tended to have been admitted to Kimberley Centre at an earlier age and had lived at the Centre longer. Conversely, residents who lived in Challenging behaviour villas were more likely to be admitted later in their lives, suggesting that the length of time residents were separated from their family and difficulties in sustaining meaningful familial relationships while their relative lived at Kimberley Centre may have influenced decisions that affected the physical proximity of family members (Table 3.2).

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[*]A number of Kimberley Centre residents did have court appointed non-relatives named in personal orders. All of the residents who participated in this study, however, either had a family member or person who acted as surrogate family appointed to be their welfare guardian. Because welfare guardians and their immediate family contributed 'family interviews' during the project, they are generally referred to as 'family' in the discussion that follows

Table 3.2 — The distance between Kimberley Centre residents and their welfare guardian by villa type

Villa type	Number	Average distance	s.d.
Challenging behaviour	11	163.3	136.6
Multiple disability	16	278.2	190.3
Lifestyle	19	179.6	201.4
Missing	—	—	—
Total	**46**	**210.0**	**187.2**

3.3 The pace of resettlement

The first residents recorded as leaving Kimberley Centre as part of the planned closure left for their community-based service in April 1983. Their departure heralded the beginning of a process of resettlement that ended in October 2006, but which in reality started three decades before with the implementation of the *Community Care Programme* in the 1970s.

The flow of residents who participated in this study to their community-based services mirrored the pace of general resettlement reported by the Ministry of Health (2005), except that the acceleration in departures that occurred after June 2006 was slightly more exaggerate in the study population. Over half of the residents who participated in the Kimberley Centre research project continued to reside at Kimberley Centre in the four months that preceded eventual closure* (Figure 3.1).

Figure 3.1 — The pace of resettlement of Kimberley Centre Research Project and Kimberley Centre residents during the study period in three-month long ranges.

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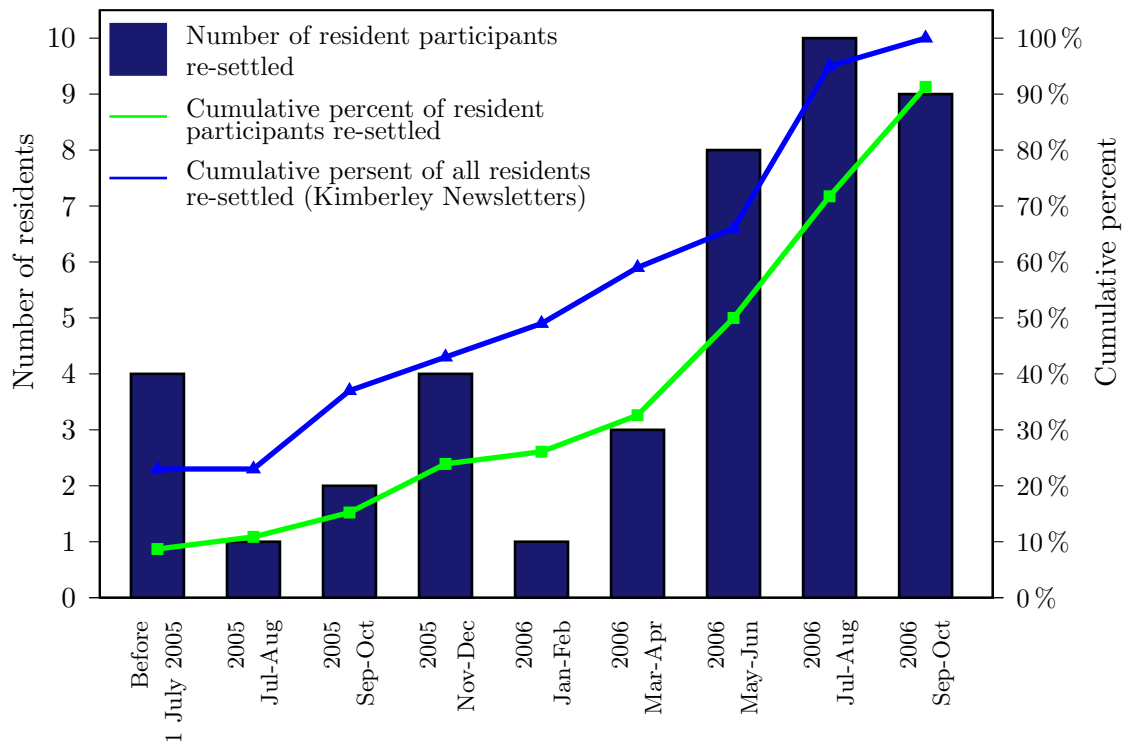
*The cumulative frequency of study participants falls short of 100% because three residents died at Kimberley before they were resettled to community-based services.

A multiple linear regression model was used to explore the strength of relationship between a number of key factors and the length of time it took residents to be resettled to their respective community based services. The sex, time spent at Kimberley Centre, relationship to welfare guardian, Kimberley Centre villa type, and the community service model chosen were selected as possible predictors of the pace of resettlement. A number of different regression models were employed and three variables consistently emerged as having a decisive role in determining the moment of resettlement. The community service model chosen, time a resident spent at Kimberley Centre and their sex accounted for approximately 50 percent of the variance in the data.

Of the three variables, the type of community-based service chosen emerged as the most powerful influence over the pace of resettlement. On average, residents resettled to Community group homes were resettled 4.6 months earlier than their peers (95% CI [2.5–6.8]; $p < 0.001$). Delays amending court orders and difficulties Housing New Zealand experienced altering and obtaining resource consent for sites were cited as slowing the resettlement process.[59] Residents and their families were affected by the speed at which houses met code of compliance requirements and became habitable. As the two Cluster Housing sites at Levin and Palmerston North became available towards the end of the closure programme, it was reasonable to expect an association between the model of support and date participants were resettled.

As had been the case for the distance between residents and their welfare guardians, the length of time residents had lived at Kimberley Centre also affected how quickly they were resettled.

During the consultation process, families identified the potential for deinstitutionalisation to disrupt lives lived almost exclusively at Kimberley Centre as an important concern. Kimberley Centre was perceived to have provided a safe and happy "home" for longer term residents, with little to be gained by separating them from familiar people and patterns of care.[37,60] The longer a resident lived at Kimberley, the slower they were to leave (Figure 3.2). For every 10 years a resident spent at Kimberley Centre their departure was, on average, delayed by 1.5 months (95% CI [0.5–2.5]; $p = 0.004$). Women also tended to be resettled 2.5 months ahead of their male peers (95% CI [0.1–4.6]; $p = 0.039$).

As noted previously, families also worried about the suitability of community-based care given an understanding of their relative that tended to emphasise their potential vulnerability.[37,60] This understanding seemed not, however, to have influenced the eventual timing of resettlement. Had fears about the safety of residents weighed on families minds in ways that influenced how quickly they sought to resettle, the type of villa residents lived in and the relationship residents had with their welfare guardian ought to have emerged as explanatory variables. The lack of association between these variables and the pace of resettlement offers little support for the argument that differences in the perceived vulnerability of residents or the experience of being a parent or sibling contributed to the speed at which resettlement was embraced.

Figure 3.2 — The relationship between the number of years residents had lived at Kimberley Centre and the pace of resettlement.
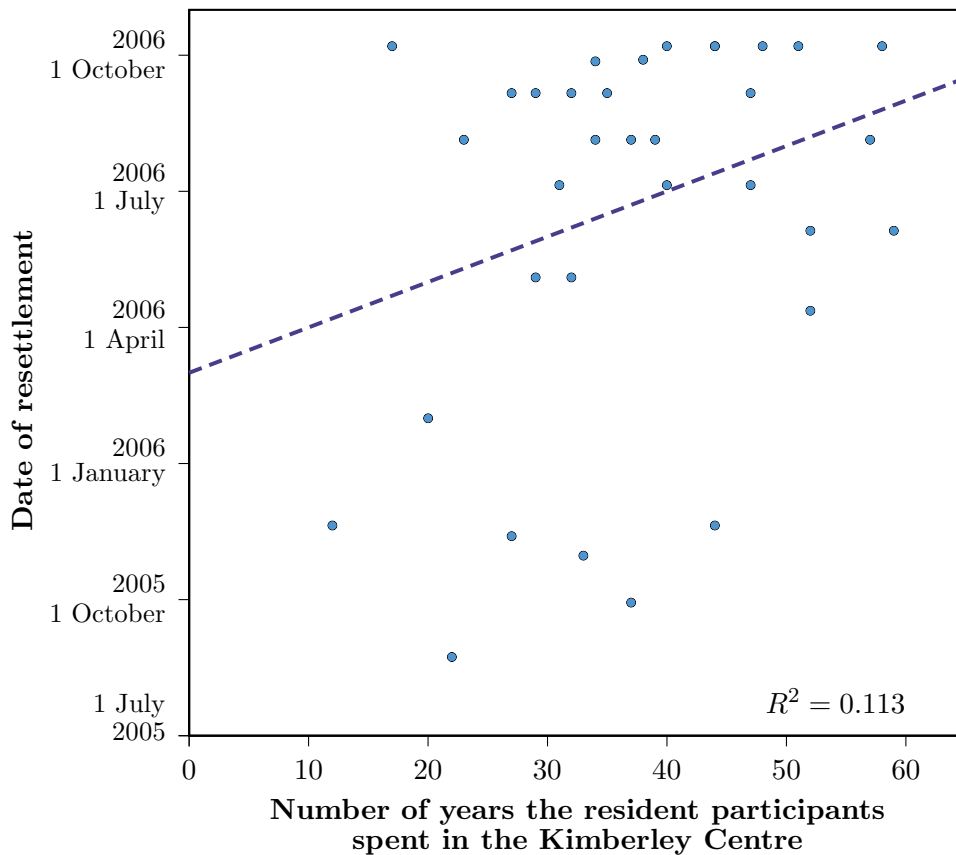
3.4   The re-location of Kimberley Centre residents

Unlike the more regionally circumscribed resettlements of other institutional closures, the Kimberley Centre diaspora* had a broad geographic reach. Residents who participated in the Kimberley Centre Research Project were resettled to services as far north as Kaikohe and as far south as Lower Hutt (Figure 3.3). Levin and Palmerston North dominated as placement destinations, but largely because families that chose services from these locations had prioritised Cluster Houses as their preferred model of residential support. Sixty-nine percent of participants resettled to Levin and 71 percent of participants settled to Palmerston North moved to Cluster Houses. The change that occurred to the geography residents' relationship with their family emerged as one of the most significant impacts of Kimberley Centre's closing. The trend for all but one resident was for families to close the distance between themselves and their relative. Before resettlement, less than 10 percent of resident participants lived less than 40 km from their welfare guardian. After Kimberley Centre closed, 50 percent of participants lived within that ambit. Conversely, before closure, 45 percent of resident participants were separated by more than 140 km from their welfare guardian. After

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*Conventionally the term 'Diaspora' is used to refer to the dispersion of Jews outside of Israel from the sixth century b.C., when they were exiled to Babylonia, until the present time. However, in this context we use the wider definition for the term 'diaspora' which means the dispersion or spreading of something that was originally localised (as a people or language or culture) – dispersion, distribution- the spatial or geographic property of being scattered about over a range, area, or volume; "worldwide in distribution"; "the distribution of nerve fibers"; "in complementary distribution".

Figure 3.3 — The destination of the Kimberley Centre Research Project participants following resettlement
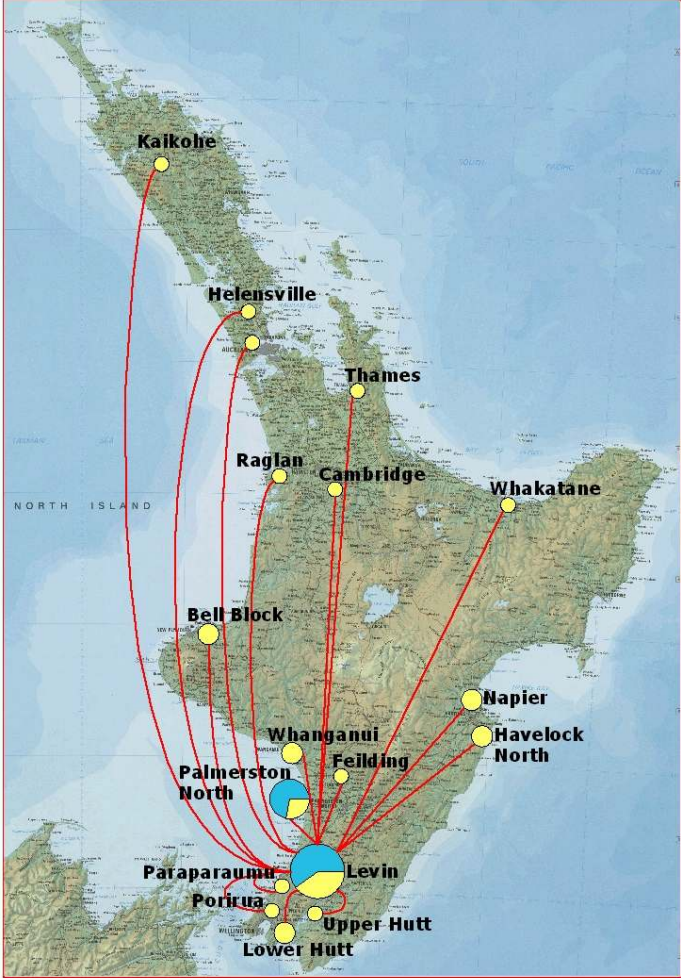
resettlement, only 21 percent remained beyond 140 km (Figure 3.4). The average distance separating family members more than halved, falling from 186 km to approximately 82 km (Table 3.3).

Kimberley Centre residents who lived in multiple disability villas tended to move the furthest, but, as discussed previously, they also tended to be located at greatest distance before resettlement. We would expect, therefore, the trend to be most marked in this cohort.

Whether the person making the placement decision was a parent or sibling also appeared to make a difference to the final destination of residents. Siblings were typically both further from their brother or sister while they lived at Kimberley Centre and more likely to resettle them near by (Figure 3.5). Before Kimberley Centre closed, no siblings lived less than 40 km from their relative. During the resettlement process approximately 62 percent of siblings brought their brother or sister within that circumference.

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Figure 3.4 — The distance separating the Kimberley Centre resident participants and their welfare guardians before and after the re-settlement.
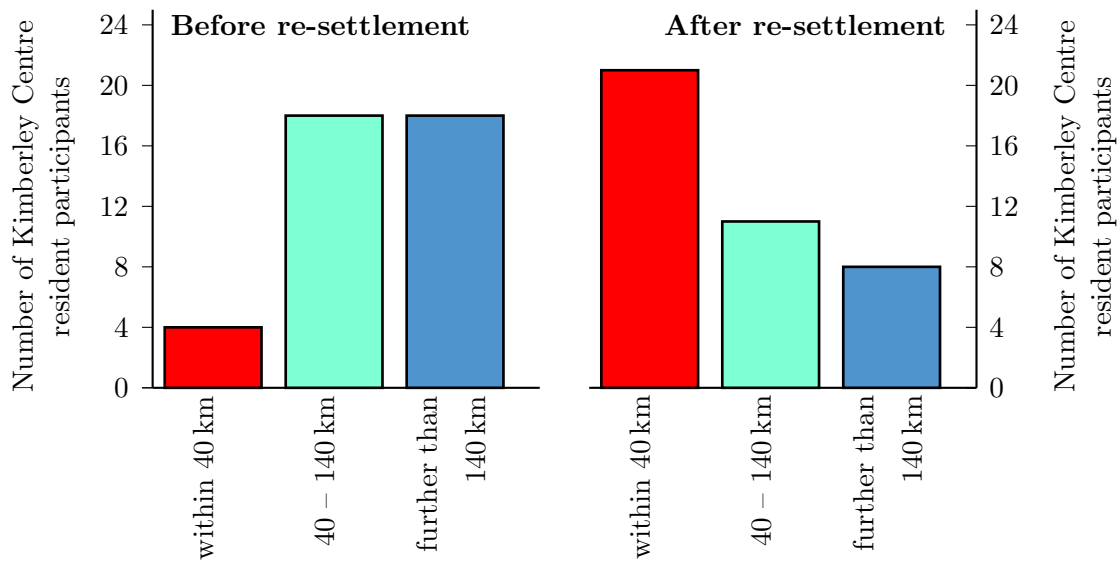
Table 3.3 — The distance between Kimberley Centre residents and their welfare guardians before and after resettlement.

Villa	Distance from welfare guardian before resettlement		Distance from welfare guardian after resettlement		Change in distance after resettlement	
	mean	s.d.	mean	s.d.	mean	s.d.
Challenging behaviour	163.32	136.56	106.51	128.21	56.81	107.17
Multiple disability	243.61	162.65	115.54	111.47	127.07	178.76
Lifestyle	164.38	195.69	47.29	56.64	117.09	188.63
Total	**185.60**	**171.82**	**82.34**	**99.21**	**103.26**	**165.85**

3.5 Cluster House or Community Group Home? Who chose which model of community-based support

At the conclusion of the 1996 consultation, Kimberley Centre families succeeded in their efforts to incorporate the right to choose services perceived to best meet their relatives' needs and the need for support and security to be guiding principles in the process of deinstitutionalisation.[35] The two principles reflected a strong preference many families had to approximate the support they had always trusted at Kimberley Centre.[58] The precedent for Cluster Housing had already been established at Templeton Centre* and the fight for a sheltered village was, for many, a caring readjustment to the inevitability of the Kimberley Centre's closing.[20]

Other families conversely saw in deinstitutionalisation, an opportunity to re-locate their relative back within the frame of their family by bringing them nearer.

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*See Chapter 9 for a more comparative discussion.

Figure 3.5 — The distance between residents and their welfare guardians before and after resettlement by type of relationship.
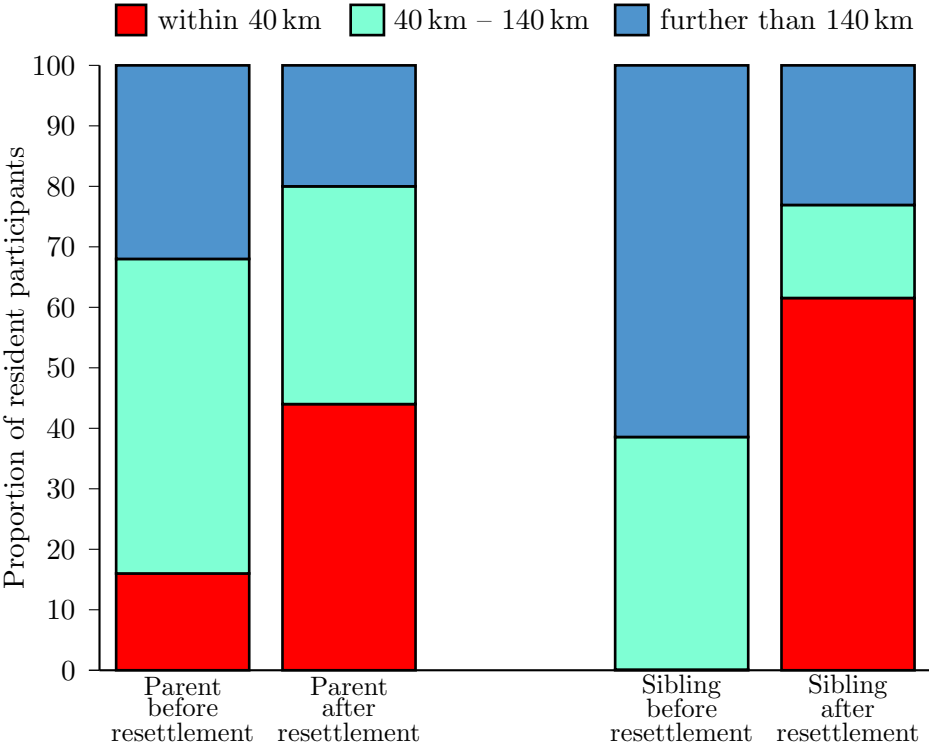
Choosing a location and model of support for their relative at Kimberley dominated the discussions families had with the Needs Assessment Coordination Service (NASC) regarding the community-based service provider the Kimberley Centre residents would ultimately be resettled to.

Despite initial resistance to dispersed Community Group Homes, the majority of Kimberley participants were resettled to services providing this model of support. In sharp contrast to the 70 percent of families who expressed a preference to either preserve the status quo or approximate institutional care in Clustered Housing sites,[20] 64 percent of residents participants ultimately moved to a Community Group Home.

The preference for a Community Group Home model of support was strongest amongst siblings. Ninety percent of siblings chose to resettle their family member into Community Group Home (Table 3.4), suggesting siblings may have been more predisposed towards community based care than parents.

Being a brother or sister to a family member with an intellectual disability is not only a qualitatively different relationship to parenthood but the relationships exist largely unfettered by the decision to seek out of home placement and the stresses parents were responding to. In her analyses of sibling's experiences of the resettlement of Templeton Centre, Mirfin-Veitch (2005) reported siblings' narratives incorporated both an unbroken positive regard and an enduring sense of sadness and guilt at the radically different course their brother or sister's life had taken.[32] The attitudes of parents and siblings towards impairment and appropriate support were also forged at different moments in time. Parents lived in an antipodean post-war era in which an aspiration for perfection often found expression in the stigmatisation of difference.[24]

SISTER   She is not being naughty as my parents thought. People used to say to my mother and this is a very sad thing to, you must have done something really bad to have a child like that because in the 40s people didn't recognise children like that. Mum got some terrible things said to her and she couldn't drive a car and she used to come home pretty well in tears because people used to be so terrible to her. Said you must have been a very bad woman to have a child like that. It wasn't [Sister] being naughty, it wasn't [Sister] being naughty, it was [Sister's] only way of asserting her personality. Stating how she felt but the way she asserted it was not acceptable to normal people.

Parents also often lacked a ready template for community care. In addition to their own experience of an historical lack of community-based support, parents would often equate community-based residential support for people with intellectual disabilities with well publicised moments when community based mental health support was perceived to have failed service-users or the community.[37] Siblings greater exposure to alternatives to institutional care and the presence of people with intellectual disabilities in ordinary mainstream community settings may have made them more likely to recognise and embrace the opportunities a new model of support offered their family member.

SISTER-IN-LAW Yeah, and you've got parents that possibly are of the same age basically as [Brother's] mum and dad would have been – or a bit younger, who thought, like [Brother's] mum and dad that their child was going to be safe there for the rest of their lives you know. And it's incredibly emotional.

RESEARCH   And thinking about the end of their lives

BROTHER   Who's going to look after their child.

SISTER-IN-LAW Who's going to look after their child if suddenly they're out in the community, which if you read the papers and listen to the television, it's not a safe place. To my knowledge and it's limited – there's never been a huge scandal attached to Kimberley. Like, so therefore parents have felt a safeness. That their child was safe there. I've never felt like that with [Resident] because she's not my child. The sibling responsibility I feel is like one step removed from a parents. You can only do the best that you think.

For a few families, the reality of resettlement exposed differences in the way the dislocation of a loved family had been experienced. In the field-notes below, the researcher reflects on an account the sister of a Kimberley Centre resident gave of the difficulty she had tempering a life-long advocacy for her brother to respect the way their mother had coped with the loss of her sibling.

> To [Sister] [Brother's] resettlement "couldn't come soon enough." In spite of her aspiration to resettle [Brother], [Sister] had not pursued placement with great vigour because of the impact his moving would have on their mother. [Brother and Sister's] mum lived in a rest-home in [Town]. . . She had told none of her friends about her son in Kimberley Centre, which [Sister] attributed to residual shame, because of the way disability was stigmatised back then. Throughout her childhood, [Sister] described continuing to advocate for her absent brother, insistent that "You are going to bring him home this time," at her father's. . . visits to Kimberley.
> The sadness for [Sister] was that her mother's reluctance to close the physical distance separating her from her son meant that she died without also closing

the interpersonal distance between them. [Sister] and her mum were not able to share a common understanding of [Brother]. [Sister] said [Brother] had taught her much. [Sister]'s frustration was that her mother did not see [Brother] with her eyes. Because [Brother] had been resettled after his mum had past away, his death would finally occasion physical proximity. [Brother] and his parents lie at opposite ends of the small cemetery as you wind your way out of [Town].

As noted previously, siblings also tended to live further from their brother or sister (Table 3.3). Living at a distance from the proposed sites for Cluster Houses meant that if siblings wanted to relocate their relative back nearby, welfare guardians had no alternative but to choose a Community Group Home as the model of support.

Comparing the demographic characteristics of residents resettled to either model of community-based support revealed that the two populations were remarkably similar.

Residents resettled to Community Group Homes or Cluster Houses differed little in their age, sex or length of residency at Kimberley Centre. On average residents who lived in Cluster Houses tended to be only slightly older (3.97 years), were admitted to Kimberley Centre a little earlier in their lives (1.25 years) but had lived at the Centre for fewer years (1.23 years). They also differed little in the assessment staff made of their adaptive behaviour (Table 3.4).

Residents did, however, differ greatly in the distance that separated them from their welfare guardian before leaving Kimberley Centre. The men and women that came to live in Community Group Homes were, on average, 254.3 km distant from their welfare guardian. Kimberley Centre residents who moved to Cluster Houses were, on average, only 76.9 km from their welfare guardian before resettlement. This finding suggests that the family members who ultimately chose Cluster Houses had remained in close proximity to their relative. Living near to Levin and Palmerston North meant that when the need to select a community-based service came, they did not have to decide between prioritising proximity or the model of support. Families who had remained close to their relatives also tended to chose the closest approximation of the institutional care they knew and trusted. When the opportunity was available to choose a service model without compromising accessibility, the aspiration to maintain the status quo families had communicated throughout the consultation process continued to be reflected in their placement decisions.

The other interesting finding was that, whereas the Kimberley Centre residents that had been assigned to either challenging behaviour or lifestyle villas tended to be more uniformly present in each of the two community-based support models, a far greater proportion of residents assigned to multiple disability villas would eventually be resettled to a Community Group Home. At first reading, this finding seems counter-intuitive, given that lobbying for the inclusion of Cluster Housing as a placement option focussed on the need to acknowledge the greater vulnerability of Kimberley Centre residents. Families had initially hoped that by continuing to aggregate people with similar support needs they could preserve the skill set and resources they perceived characterised institutional care within residential enclaves. As noted previously, however, the men and women who lived in multiple disability villas also tended to be those at greatest distance from their welfare guardian (Table 3.2), and here again, families who wished to relocate their relative within their ambit of care had no alternative to the Community Group Home. The aspiration of families to reduce the geographic and psychological distance that separated them from their family member emerged as an more important influence over placement decisions than the apprehensions previously held about the appropriateness of community-based care.

Table 3.4 — The demographic characteristics of residents resettled to Community Group Homes and Cluster Houses.

	Community Group Home				Cluster House			
	N	mean	%	s.d.	N	mean	%	s.d.
Number of residents	25				14			
Age (October 2003)	24	39.43		9.5	14	43.43		7.19
Male/female ratio		2.28				1		
Age at admission	22	8.68		5.77	14	7.43		3.63
Length of residency	23	39.43		11.63	14	38.29		9.14
Distance from welfare guardian (km)	25	254.32		183.23	14	76.96		52.5
Change in distance to welfare guardian (km)	25	166.91		181.98	14	9.97		20.41
Proportion of parents	12		50%		12		50%	
Proportion of siblings	10		91%		1		9%	
Proportion from Challenging behaviour villas	6		60%		4		40%	
Proportion from Multiple Disability villas	7		70%		3		30%	
Proportion from Lifestyle villas	10		59%		7		41%	
Adaptive behaviour score (Phase 1)	24	85.54		53.94	14	88.36		52.93
Challenging behaviour score (Phase 1)	24	37.83		33.22	14	20		12.3

3.6   Moving closer to families

Within the lives of residents and their families, social and emotional closeness, not kilometres, was a more appropriate metric for proximity. For many, closing geographic distance was more than dissolving a barrier to contact. It was a way to renegotiate family roles after the dislocation of institutionalisation.

Many families reported that it was difficult to maintain contact with their relative while they remained at Kimberley Centre. Milner and Mirfin-Veitch (2007) argue that the reality of institutional living challenged the tenacious love families held for their relative.[58] Physical distance and the situating of major institutions along the fringes of local towns could act to compound grief and a sense of abandonment. It also made travel arduous and expensive, especially for aging parents. Institutions were largely deaf to families' efforts to communicate moments of important family history. Attempts to personalise their children through gifts of clothing or other symbols of continued affect were also difficult for institutions to accommodate. Institutions instead privileged a different understanding of sons and daughters and the vision of the institution as a miniature and self-sufficient community able to meet all of a resident's needs could physically and emotionally marginalise families from the lives of their relative.

In spite of this, staff would continue to report that family were the most important people in the Kimberley Centre residents' lives.

RESEARCHER Who are the most important people in her life?

STAFF Her family. The only reason why I say that and that's understandable, because every time [Brother] comes in and I mean I have seen it, and then I saw it when I took her up to her mum's funeral, I saw that, and she knows her family. They would be the most important people. As you said, you only have to mention [Brother's] name and her eyes, her whole face lights up.

Kimberley Centre was a difficult place to declare individuality. Residents had few possessions, places or activities to call their own and families stood as a beacon of individuality and identity. For Kimberley Centre residents visits from family members were special interruptions to the rhythm of institutional life and home for most continued to be the places they grew up and shared with families as sons and daughters.

RESEARCHER I was thinking where is home. Where do you think of as home [Kimberley Centre resident]?

RESIDENT Um... [Town]... the farm house.

RESEARCHER You still think of that as home.

RESIDENT Yes.

RESEARCHER Do you go there very much?

RESIDENT No... um... I used to, I used to. But sometimes I do and they just have me for the day.

For many residents, moving from Kimberley Centre meant moving towards a 'place' inside of families that they had always held dear.

BROTHER Very strong on family, loves photos. Every time you go down there, she always asks for photos whether you bring them down or not.

RESEARCHER Well that's quite an achievement really. I mean I've been looking at the photos on the wall, you seem to have a fairly big family. Does [Resident] know all of her nieces and nephews and...

BROTHER Not the latest little girl, because there's no photos sent down to her yet have they?

SISTER IN LAW No, but she's met the three older girls and because as a family we go down for celebrations. [Name] was a small baby and the oldest of the boys, but she knows I always put who they are and their relationship to [Resident] on the back of the photo you know, so that the staff are able to flesh that out for her. But they all live here in [Town] and they are really looking forward to her coming up here.

Proximity also facilitated access to extended family as, like the narrative above, welfare guardians often acted conduits to brothers and sisters and their children reconnecting families and introducing nieces and nephews to people and life stories beyond each others compass. Occasionally welfare guardian's and their placement decisions reconnected residents with the people and places they were originally displaced from. In the first flush of deinstitutionalisation, families' ability to colour residents' life before institutionalisation became part of a wider process of re-visioning that was highly valued by staff who tended to meet Kimberley Centre residents as strangers. And sometimes they supported a re-visioning by those who assumed they knew residents well.

STAFF His sister is on the family property. The original house, I think she said it burnt down but when [Resident] was 20 and Kimberley Centre went on

	strike he actually came to that house that [Sister] lives in and I think his mother was still living there then.
RESEARCHER	So in a round about sort of way, when he visits he is actually reconnecting with his childhood.
STAFF	Yes, and he knew the truck. When he saw it, we would say to him, there's dad's truck and he would go to the truck, he recognised the truck. I am sure he recognised the tractor and he just loves that tractor and you just wonder does he remember. [Sister] said dad used to sit him on it and hook something on to the steering wheel and then he would feed out, and [Resident] would be doing the steering at six years old, so then - I really believe that he is recalling some of the things that went on.

Once the adjustment to the Kimberley Centre's closing had been made, many families identified resettlement as an opportunity to rekindle family roles. A number of families described in their interviews acknowledging the re-inclusion of their family in fresh portraits that hung prominently in lounges and living rooms.

PARENT	Mm...I guess I get emotional when I go out there.
RESEARCHER	Do you? In what way?
PARENT	Because I love him and it is good to have him home again.

To mothers especially, the return of their sons and daughters was often equated with the completion of a long struggle to preserve family integrity that had begun with their efforts to keep their children from an institution.

RESEARCHER	On the phone call I made before coming up here, [Resident's] mum said, I have waited 54 years for my son to call me 'mum' I think they are incredibly proud. I think they are proud about what they have accomplished.
STAFF	It was like at the birthday, what did she keep calling him, my big fella, my big fella, oh you are doing well my big fella

Being close, however, also meant that residents could reciprocally add value to the lives of those they cared about. Services attentive to the opportunity found ways for residents to add value to the lives of members of their own family.

RESEARCHER	So how much family contact would he have?
STAFF	From his mother? Quite a lot. She was in hospital for a little while but we took [Resident] up to the hospital to see her.
RESEARCHER	Yes what a brilliant thing to do, she loved it, she absolutely loved it.
STAFF	Did she? Oh that's good, well that's good because he would have loved going up there as well. I wasn't the one that took him but I know that he went up there to see her and he would have loved that.

3.7 The counter narrative of families who also experienced living close negatively

Every story of deinstitutionalisation was different. A small number of families spoken to before resettlement viewed deinstitutionalisation positively, expressing an optimism they could work in partnership with services to support their family member. A year after resettlement, some reported a waning of their optimism and a failure of services to share their vision. The narrative below captures a mothers disappointment at the way things had

worked out. When the interviewer first met this parent, she spoke enthusiastically about the possibilities she saw for her daughter, animating the conversation with a sweep of her arm, as if relocating her daughter within the circumference of her care. Following placement she, like many, had become increasingly concerned about the lack of staff training. She was also concerned that staff did not 'see' her daughter and the causes of her frustration the same way that she did and was similarly disappointed that the range of activities she thought possible had not materialised. Typically, she said, she would arrive to find her daughter sitting in her lazy-boy while staff ran the house. Not wanting to be perceived as demanding, the mother described feeling 're-marginalised' from her daughter's life.

RESEARCHER   I got the impression from in our earlier interview was that you were actually enjoying the process of being involved in her needs assessment and being able to say what [Daughter] wanted

MOTHER   Oh yes, I remember that.

RESEARCHER   Yes and you seemed to be very involved in thinking about what [Daughter] wanted in those earlier days and there was some sense of you know, feeling empowered back then

MOTHER   But not now.

RESERACHER   Now we are talking about a year later.

MOTHER   Yes, I know, I know, yes I do have that um, mm, yeah, I suppose I do have the feeling that I don't have any power down there if you can say power, that's a bit strong isn't it. Yes, I have felt the way it is going is that this is what we are doing with [daughter], not how would you like or anything. I just tend to get the feeling that the staff are doing what they are there to actually do and, it might be harsh saying this, take it or leave it sort of thing, but what we said or wanted, didn't matter because they are the ones looking after them all or looking after them all day and all this sort of thing you know, it is just getting stronger.

A small number of families reported feeling excluded from an active support role in much the same way as institutional care had confined the relatives' care to the professional Kimberley Centre community.

MOTHER   Well I just...I just [*laughs*] I feel if I go down and do too much moaning and everything...um...I won't get the support that [Daughter] needs, you know that you get a bad name if you are picky all the time...I didn't feel I had the right to.

In houses where there was a steady stream of staff resignations and exits a number of families spoke of feeling distanced by having to continually redefine their place and reinvest their faith in new support relationships.

On the whole, however, the move towards family that occurred as a consequence of Kimberley Centre closing was generally positive for residents and families alike. Living closer typically led to more frequent, intimate and informal family contact, and the ordinary events that accumulate to build family history. In the narratives below, support staff at Kimberley Centre and in a community setting are asked a similar question about one resident's relationship with their family. The difference in accessibility and implications for life quality captured here were representative of most participants' experience of moving from Kimberley Centre.

In Kimberley Centre

STAFF	I haven't seen his family down here for ages. They used to have a lot of contact, really nice people, a lot of people and I am sure if they could they would get down and see him more often.
RESEARCHER	Does he recognise them?
STAFF	He used to, yes. I used to watch him, he used to run out there and meet them.
RESEARCHER	He used to?
STAFF	Well I haven't seen them recently. They haven't visited for many years I don't think. And I am sure he would recognise them again.

Beyond Kimberley Centre

STAFF	Yeah, and for family too, their perspective, they don't have to travel all the way down to Levin to visit [Resident], he is here so we have also got a choice that they can come and go whenever they please. If they can't get over here, like [Resident's] mum or a phone call. It is not a toll call, it is just a phone call.

4

Assessing the impact of institutional closure on the adaptive competencies of the Kimberley Centre residents

4.1 Kimberley Centre Research Project aims in the area of adaptive behaviour

This chapter presents findings related to resident adaptive behaviour in Kimberley Centre. The capacity people have to adjust and adapt their behaviour to the ever changing social and physical reality of daily living can be an important determinant of their ability to respond appropriately to others and meet their own needs. Evidence suggests that people's level of adaptive competence is also amongst the most powerful predictors of a presence in ordinary community spaces, the ability to participate in meaningful activity and decisions that affect life quality.[61–63] People with lower adaptive skills tend to be marginalised from the worlds of choice, employment, productive activity and inclusive community relationships.

The impact of institutional and community-based support on the ability people with disabilities had to learn and expand social and adaptive competencies has been to the foreground of debate that has driven people in and then out of institutional settings.

A belief that specialist institutions liberated people with disabilities from unsuitable life circumstance to produced miraculous improvements in skills and manners through specialised education and discipline contributed to the institutionalisation of people with an intellectual disability.[17,64]

Half a century later, concern about the impact living in institution had on the adaptive functioning of the people who lived there featured prominently in the discourse that argued for institutional closure. In an influential meta-analysis of American deinstitutionalisation research, Larson and Lakin (1989), for example, included findings of decreased intelligence, loss of adaptive abilities and more frequently disordered personalities as evidence that institutions were harmful compared to community-based alternatives.[65] Furthermore, as the

philosophy of Normalisation became the dominant philosophy of support, approximating the ordinary rhythms and customs of wider society came to be seen as the way to lift the acquisition of adaptive skills and support the greater 'social invisibility' of people with intellectual disabilities within their community.

Given its role in influencing major disability related social policy, and the centrality of adaptive behaviour to the life quality of men and women who depend on services for support, evaluating the impact closing Kimberley Centre had on the adaptive competences of the residents who moved was a key objective of this research.

Included within the formal objectives of the Kimberley Centre research project was the following aim.

> **To identify any changes in adaptive behaviours and daily functional skills among residents which occur during the resettlement phase**

4.2   Measuring adaptive behaviour

The American Association on Mental Retardation's (AAMR) Adaptive Behaviour Scale – Residential and Community, second edition (ABS-RC:2) was the quantitative instrument employed to measure and compare the adaptive competence of Kimberley Centre residents before and after resettlement.

The ABS-RC:2 is the most recent of the AAMR's adaptive behaviour measures. Two previous versions of the scale were reconstructed to improve overall reliability and the discriminative power of the measure for both institutional and community living populations. The ABS-RC:2 was normed on over 4000 adults with intellectual disabilities living in the United States and Nahira et al. (1993) outline a number of studies that affirm the scale's construct and content validity in Chapter Six of the Administration Manual.[41]

The ABS-RC:2 Scale is divided into two parts. Part One focuses on personal independence and is designed to evaluate coping skills considered important to personal independence and responsibility in daily living. Seventy-three item scores are grouped to contribute to the ten Adaptive Behaviour Domains described below.

Independent Functioning (IF) Explores people's ability to take care of their personal needs autonomously. Eating toileting and self care skills are measured together with the ability to use transport and other public facilities.

Physical Development (PD) Assess a person's sensory and motor abilities.

Economic Activities (EA) Measures people's ability to manage their financial affairs and act as consumers. Money handling skills, and an individuals ability to use banking service, budgeting running errands and purchasing goods are examined.

Language Development (LD Proficiency receiving, expressing and using communication skills in social situations is explored in this domain.

Numbers and Time (N/T) Explores basic mathematical comprehension, particularly skills related to everyday living.

Domestic Activity (DA) People's ability to take care of their living environment are explored in this domain, in particular their ability to clean, cook and perform ordinary domestic routines.

Prevocational/Vocational Activity (PVA) Measures people's tardiness, habitual absence, and care as behaviours indicative of an ability to adapt to vocational environments.

Self-Direction (SD) Explores an individual's initiative, perseverance and use of leisure time as behaviours likely to contribute to the maintenance of an active or passive lifestyle.

Responsibility (RE) Taking care of possessions, and demonstrating responsibility with regard to carrying out instruction, punctuality and self control are explored as indicative of an individual's dependability.

Socialisation (SO) This domain examines an individual's ability to socially interact with others cooperatively and with consideration.

Part Two of the scale highlights social behaviours and in particular, aptitudes related to social expectations the authors felt were placed on people with intellectual disabilities in community and service settings. Behaviours are organised into eight domains, which measure adaptive behaviours that relate to the manifestation of personality and behaviour disorders.

To aid interpretation of the findings, this chapter draws upon a number of other data streams. A deconstruction of the Observation running records as well as thematic analysis of key staff, resident and field-note narratives are to build a 'thicker' description of the way learning and personal development is nurtured or frustrated in the places people lived.

4.3   Resident adaptive behaviour in Kimberley Centre

Part One ABS-RC:2 scores are designed to capture the range of conceptual, social and practical skills learnt by people that assist them to function in their everyday lives. Adaptive behaviour is a multi-domain construct reflective of the range of different competencies that contribute to an ability to cope with the natural and social demands of our environment. Domain raw scores are converted to standard scores based on a normal distribution of adults with an intellectual disability living in residential or community settings with a mean of 10 and standard deviation of 3. Standard scores that range between 8-12 are considered to represent an *average* performance relative to the adaptive skills of other adults with intellectual disabilities. Standardised scores that fall between the ranges of 6-7 are described as *below average,* (83.88 percent of the normative group achieving equal or better performance), scores at or below 4-5 considered to be *poor,* (ordinarily be exceeded by 93.13 percent of the normative population) and 1-3 described as *very poor,* (exceeded by 97.66 percent of other people with an intellectual disability).

Figure 4.1 describes the average, standardised adaptive behaviour scores of residents recorded while they lived at Kimberley Centre. Compared to the subset of all people with intellectual disabilities, residents who had lived at Kimberley Centre, on average, fell below the mean adaptive behaviour of their peers on all domains (Table 4.1). When standard scores were averaged for all participants, the only domain to breach the threshold of below average performance was the Physical Development domain (M=9.33, SD=0.45).

Physical development is not an adaptive behaviour. This domain measures participant's sensory, and motor capacities and is included in the ABS-RC:2 because learning and the manifestation of appropriate adaptive skills is often dependant on performance in these areas.[41] In general terms therefore, physical development can bee seen as indicative of the potential to learn new skills. The fact that Kimberley Centre residents should approximate the average level of physical development and yet fall below the average level of adaptive functioning on all other domains suggests that something, either about the disposition of

Figure 4.1 — Mean standardised adaptive behaviour domain scores (ABS-RC:2) at the Kimberley Centre
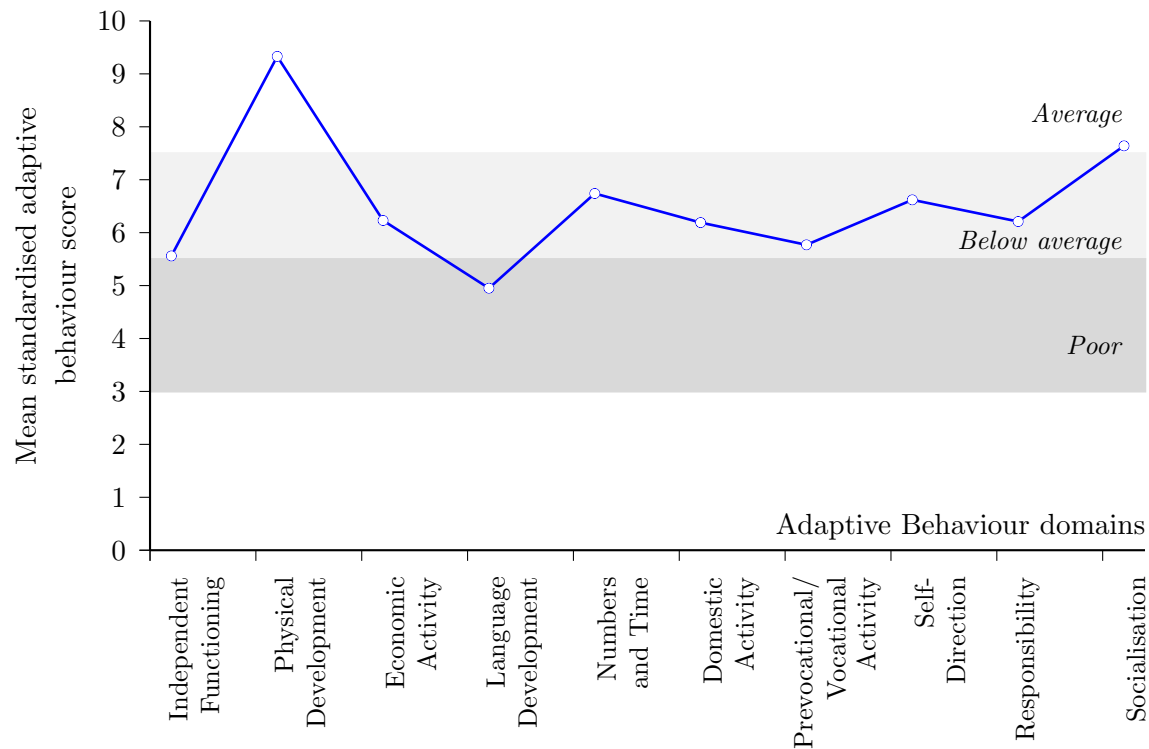
Table 4.1 — Mean standardised adaptive behaviour domain scores at the Kimberley Centre

Part One Domains	mean	s.d.
Independent Functioning (IF)	5.56	0.55
Physical Development (PD)	9.33	0.45
Economic Activity (EA)	6.23	0.08
Language Development (LD)	4.95	0.51
Numbers & Time (N/T)	6.74	0.23
Domestic Activity (DA)	6.19	0.31
Pre-Vocational Activity (PVA)	5.77	0.45
Self-Direction (SD)	6.62	0.46
Responsibility (RE)	6.21	0.40
Socialization (SO)	7.64	0.47

Kimberley Centre residents or the day to day reality of living at the Kimberley Centre, may have frustrated the development of adaptive competence.

An examination of the profile of adaptive behaviour domains recorded for different villa types provides a partial explanation for the elevation of the physical domain scores relative to the level of adaptive behaviour recorded in other domains. Kimberley Centre residents were extremely heterogeneous, differing widely in degrees sensory and motor functioning. Residents in Multiple Disability villas tended to have much higher physical support needs with a below average mean adaptive behaviour score (M=6.44) whereas residents assigned to Lifestyle (M=10.41) and Challenging Behaviour villas were (M=12.22) at and beyond the standardised mean for the general population of people with an intellectual disability (Figure

4.2). The higher levels of physical development of residents living in Lifestyle and Challenging Behaviour villas had the effect of lifting scores in this domain relative to other competencies

A high standard of physical care may also have lifted assessments of physical development relative to other domains. Maintaining physical wellbeing was central to the social practices of the institution. Consistent with a biomedical understanding of the primary support needs of the people that lived at Kimberley Centre, staff activity appeared especially attuned to meeting the physical care needs of the resident population in a timely and efficient rhythm. The cadence of villa activity was regulated to meet the personal and physical care needs of villa residents in a well-practiced routine

STAFF   You have got 10 residents per 2 staff so obviously you need to have a routine - I think for something like feeding you both have to be there, for safety issues, So you have got to do other work around these times.

RESEARCHER   Do you think the routine helps? You were talking before in terms of staff that staff need a particular job done [before shift change] so they can recognise whether people haven't had enough to drink or been changed.

STAFF   Yes, well it is because as I say quite often, you do work as a team, and if someone is held up, you carry on with their work.

Figure 4.2 — Mean standardised adaptive behaviour domain scores (ABS-RC:2) at the Kimberley Centre by villa-type
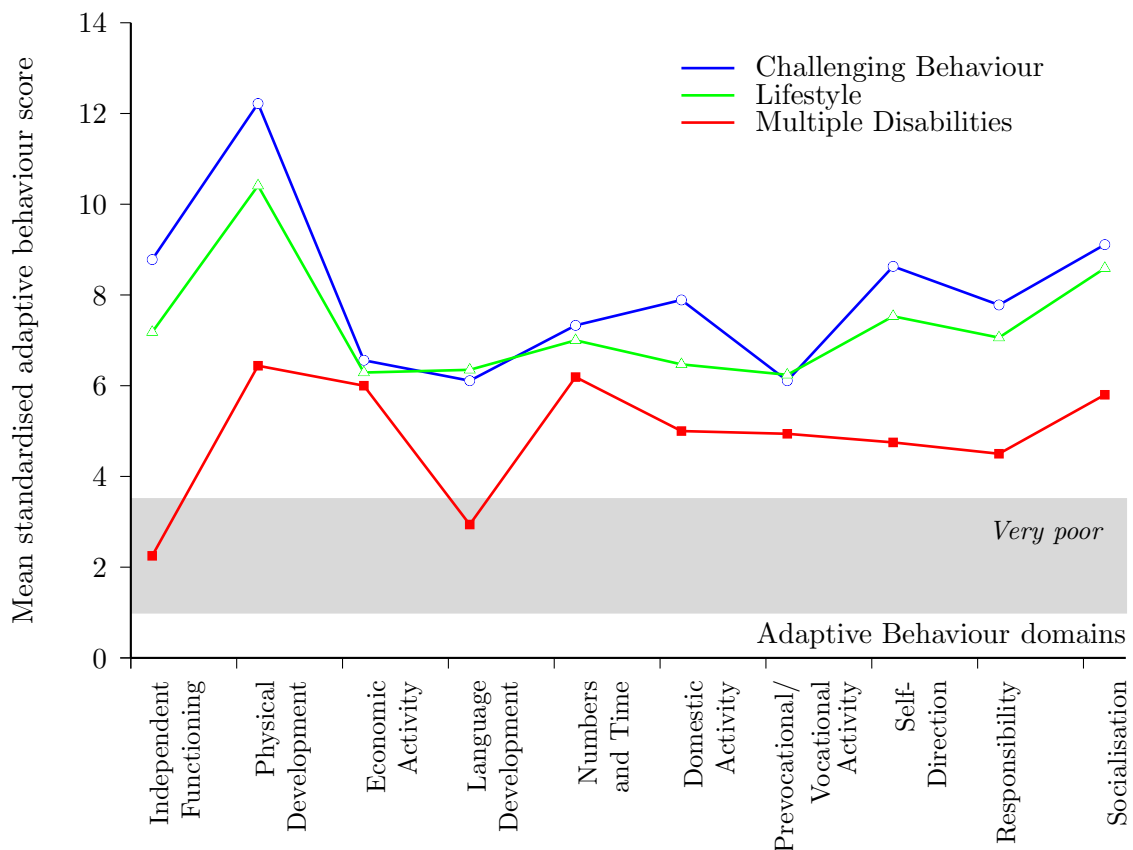
Moments of personal care similarly punctuated the day to rhythm and staff took responsibility for making sure participants' meals were nutritious and that they ate and drank healthily. Residents at Kimberley Centre lived under the watchful gaze of staff for most of the day and

staff took great pride in being able to discern moments of discomfort or ill health from the subtlest behavioural indicators.

KEY STAFF   Generally he does keep good health, he can go down quite quickly if he becomes sleepy or anything we actually get him to the doctor straight away – it is usually a chest infection or something and he comes down with those probably about 3 or 4 times a year and he will just be as good as gold and the next minute he is sleepy and you take him to the doctor and yes, he has got a chest infection.

Kimberley Centre residents had on-site access to a medical care and other health related services. A podiatrist visited wards on request, dental care and some specialist services were attended to on-site and the Kimberley Centre doctor had a patient knowledge that for some residents stretched to their admission as children.

For that period in Kimberley Centre's history that the research team was able to observe villa culture however, maintaining day-room equilibrium and attending to the physical wellbeing of residents appeared to regulate support practice. Villas were staffed at levels that denied contemplation of a much wider vision of what contributed to life quality and staff had become acculturated to the established pattern of day-to-day activity and a narrower understanding of their role.

RESEARCHER   What is the role of a psychopaedic assist?
STAFF   Mostly employed to meet their needs. Basically you are like a baby sitter. You are going to make sure that they all go to their different areas. Make sure that they are toileted, make sure they are clean, you shower them, you dress them, you feed them, you don't have to feed them all but you observe and watch the ones that are known chockers or the ones that have different meals and you have just basically got to look after them.

One of the consequences of a support practice dominated by the routine of institutional living was that residents were less likely to experience activity that might lead to new learning or opportunities to challenge and confound disabling social constructions. At Kimberley Centre staff often reported that residents were beyond further developmental potential or alternately that they lacked the time required to embed improvements in adaptive behaviour.

RESEARCHER   So I was just thinking about [Resident], we were talking before about his [hand] signing and I guess in a way I am kind of thinking about his life skills as well. Do you have much scope to work on those sorts of things?
STAFF   Yes, it doesn't happen all the time, if you are one to one you would most probably get more out of him.
RESEARCHER   I was meaning do you get that time?
STAFF   No, you don't. Because you are on a frail ward to start off with, you have got more things are happening. Like with [Villa resident], there are two of us tied up with him, so you get that during the day and you get the same thing out there.
RESEARCHER   You said something really interesting the other day, you were saying that they had a go at colouring.
STAFF   Oh yes, the colouring in book
RESEARCHER   Yes, and then you said oh it is probably too late for him now, do you want to tell me a bit more about that?
STAFF   Well I suppose if it was 10 years ago and he was a bit younger.

An examination of the adaptive scores recorded at Kimberley Centre for residents assigned to different villa types reveals a less benign finding. In Figure 4.2 we see that even though residents in Challenging Behaviour and Lifestyle villas exhibited average physical development, their performance on all other domains fell below average except for the *Self-direction* of residents in Challenging Behaviour villas and the *Socialization* skills of residents assigned to both Challenging Behaviour and Lifestyle villas. Within the domains of *Economic Activity*, *Numbers & Time*, *Domestic Activity*, *Prevocational Activity* and *Responsibility*, residents who had the physical capacity to learn new skills did little better than the most profoundly disabled Kimberley Centre residents. For these residents, living in an institution appeared to suppress the acquisition of skills particularly in these 5 domains.

A number of environmental factors appeared to contribute to the limited development of life skills. Firstly, the physical separation of Kimberley Centre from wider community relationships and entrenched support practice limited the ability staff had to individualise activity or accommodate differences in residents learning style or potential. A few residents, typically those from Challenging Behaviour villas had managed to 'negotiate' jobs and roles with the Kimberley Centre Day Support Service (DSS) that acknowledged their personal preferences and aspiration to do more. But for most, coffee club, the daily trek for breakfast, lunch and tea, participation in group activity programmed by DSS and the occasional weekend van-ride were welcome interruptions to a lives predominantly spent sitting around the perimeter of the villa dayroom. The life-spaces and day-to-day reality of institutional living varied little for residents whose personal histories, values and capacity to learn life skills differed greatly (Figure 4.3).

Figure 4.3 — The relative proportion of observed time residents were engaged in types of activity at the Kimberley Centre

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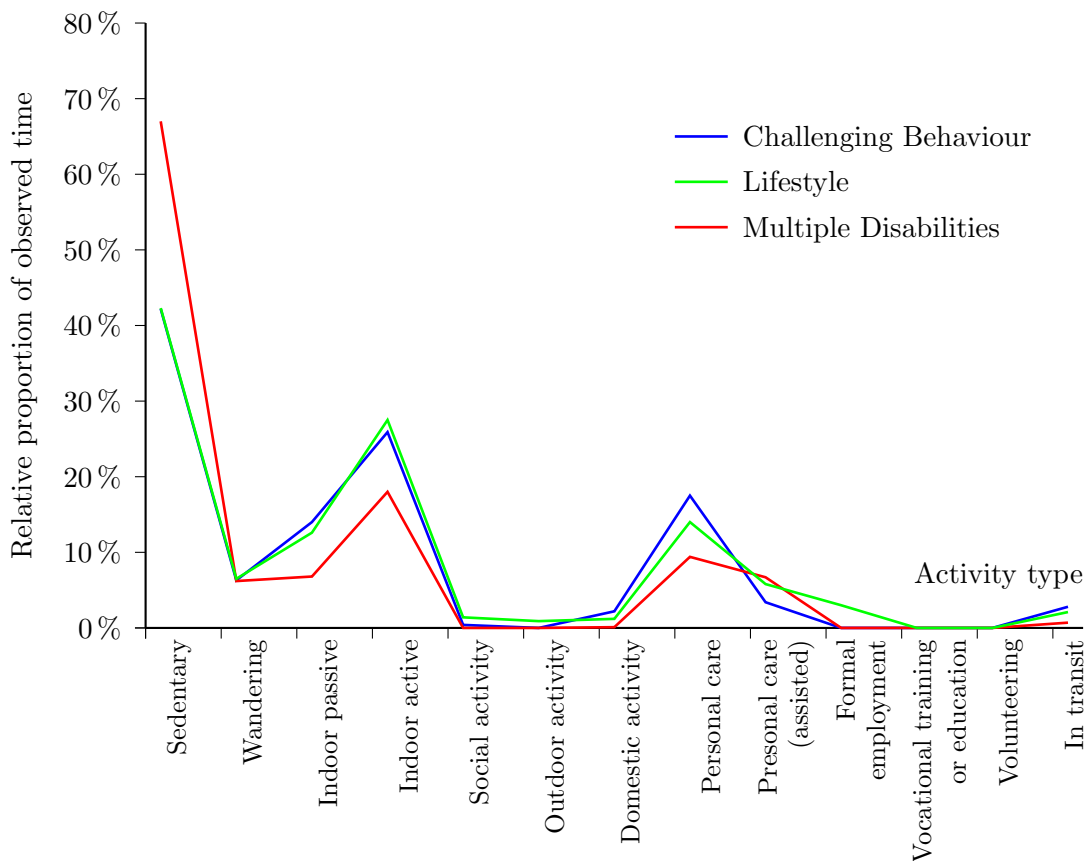
Over 40 percent of residents' time was spent doing nothing, sitting, staring, standing and snoozing (Sedentary Activity) with the overarching institutional rhythm meaning that the pattern of day-today life looked much the same in any Kimberley villa.

An extremely limited set of Service Support Plan Goals for Kimberley Centre residents was reflective of the circumscribed ability staff at Kimberley Centre had to respond within the broad sweep of activities and preferences that could have made life good. Hand and foot rubs, an outing once a month and walks around the grounds were both ubiquitous and indicative of the pre-eminence of physical well-being as a service performance outcome.

RESEARCHER You were saying, day support has kind of drifted off for [Resident]. What sort of goals would you find on her support plan?

STAFF Do you mean what she is having now? Well the hand rubs, make up.

RESEARCHER But it wouldn't be like the movies - what about life skills and things like that - has there been any effort to do that or communication or like any of those sort of more holistic

STAFF No.

RESEARCHER Can you say why?

STAFF No I don't know. It just hasn't happened I suppose, like a lot of things.

By October 2003 Kimberley Centre was already an institution in terminal decline and families and staff were quick to remind the research team that the Kimberley Centre was a shadow of its former self.[37] As the institution downsized, villas closed, programmes retrenched and the role of management was said to have drifted away from service innovation to effective management of the closure process.

RESEARCHER Has whatever has been happening here helped him acquire new skills?

STAFF I think it is just the repetition and the routine. The routine that they have every day, I am sure it is just the routine that has helped him do that. As far as new skills, he hasn't really learnt any new skills because we haven't actually had the facilities not for a long time - we used to have a good training area here, and I am sure he did used to go to training but we just haven't had them for years. We have got day support but they don't do a lot of actually skill work especially with the likes of our Palm Grove behavioural and [Resident] especially.

The shrinkage of DSS, and a culture that supported a role division between villa staff – whose primary orientation was meeting the physical and emotional welfare of residents – and vocational staff – that ran and triaged residents into exercise, music and other programmatic vocational elements – further frustrated a well informed picture of the developmental potential of residents. Improving adaptive behaviours appeared largely to be the domain of day support services (DSS) and the formal programme. Busy ward staff often appeared to know little of residents programme or of the competences exposed beyond villa life.

Of all residents the men and women assigned to Multiple Disability villas did the least. Before Kimberley Centre closed, few residents left their villas either to participate in the vocational programme or trips beyond Kimberley's gates.

STAFF Nothing very exciting ever happens. She is always awake when we go to do her cares so that would be about 8.30 I suppose in the morning. She is showered, all her personal needs have to be done for her so she is showered, dressed, put in her chair and she is fed by a nasogastric tube so that's put on and there [Resident] stays. It is Kimberley Centre, you

have only got so many staff, and you have got so many residents. Like the day support people, I mean they do the best they can but they have to rotate people and they do but it all boils down to what we can do in a given amount of time I suppose and because these guys too are classed as frail, they kind of get overlooked. They are sort of never taken over to the Monowai house there and I don't know - you can talk to the people about what they do over there, listen to music and things like that I guess whereas if they were more mobile they probably would get that.

The residents who were supported in Multiple Disability villas, on average, scored very poorly in the domain of Independent Functioning (M= 2.25 SD=2.24). Approximately 98 percent of people with an intellectual disability would be expected to score higher than their peers in the Multiple Disability villas at Kimberley Centre.

The Independent Functioning domain is conventionally understood as indicative of an individual's need for direct support. The domain measures an individual's ability to perform personal cares and navigate within the environment with a degree of independence. Hunt noted that in 1982, the medical superintendent had asserted almost 50 percent more "severely handicapped" residents lived at Kimberley Centre than the Department of Health national average for similar institutions.[19] It is reasonable to assume that the more profound impairments of resident's in these villas contributed to the low scores. However, being denied appropriate opportunities to perform or practice skills in a sustained or individualised way can suspend people with intellectual disabilities in perpetually dependent relationships. The press of time and limited expectations relating to the capacity of residents to learn conspired to limit the opportunity for staff to notice and build upon latent potential.

STAFF   Like he doesn't eat for himself now, like you feed him most of the time.
RESEARCHER Well do you think there is scope in [Resident] for learning new skills? Do you think he can learn them?
STAFF   I think he could. You know the first appearance, because there will be a time factor, because everything is rush, rush, rush, but if it was a one on one, you could actually get him to do things.

Recent evidence suggests that the more intimate and informal learning that takes place when staff participate with people in ordinary activities in ordinary ways, may advance the acquisition of personal and domestic competencies more than programmed learning.[66] Little opportunity existed at Kimberley Centre for staff to engage participants in this way. In the everyday lives of participants, most of their personal care activity appeared to deviate little from an efficient, aggregate and unchanging institutional routine. Residents were therefore denied access to roles, responsibilities and experiences that would underscore the relevance of learning from within other domains too. Even the most ordinary and unappealing of domestic activities were the domain of staff alone,

STAFF   He doesn't get a lot of chance to do that sort of thing. I am sure he would be able to do simple chores around in a household, like set tables and things, and he would love to do it. Because I am sure he would just love to help, he just likes for people to say to him you have done a good job, thank you. It is really hard to sort of explain when you have known they have only lived in a place for years but I am sure he would be able to - with the right staffing, he would be able to do it.

Being trusted with broom or dish-cloth conferred upon residents the adult role of worker, marking them out as residents of status and competence.

RESEARCHER What else would you like to be doing in your new house.
RESIDENT Just jobs and that. Yes, and I love working.
RESEARCHER [Staff Person] was saying to me that you hate not doing anything, Can you do much here at Kimberley Centre, do you ever get the ironing or the cooking here at Kimberley Centre?
RESIDENT No the staff do it. They bring our lunch in to us.

Whereas the poorer scores of residents in Multiple Disability villas acted to lower the average performance of Kimberley Centre residents in the domain of Independent Functioning, residents from all villa types scored poorly in the Language Development Domain (Figure 4.2). The average adaptive behaviour score of residents who lived in Challenging Behaviour and Multiple Disability villas was lowest in the Language Development Domain and approximately 93 percent of people with an intellectual disability would be expected to score in excess of the average Kimberley Centre residents recorded in this domain (M=4.95; SD=0.51).

At Kimberley Centre 63% of observed communication events lasted less than a minute Figure 4.4). Residents typically had few opportunities to engage with others in their everyday lives and moments of shared communication tended to be ephemeral in character and unlikely to generate any expectation that reciprocally valued communication was desired. Interaction was fleeting. Busy day staff acknowledged residents as they passed en route to somewhere else. Communication tended either to be instructional or inquisitive in tone, as staff sought information or guided behaviour that aided staff related tasks. Embedded within most interactions were subtle verbal or non-verbal cues that suppressed rather than invited further dialogue

Running record narrative: Kimberley Centre (25/2/04)

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Staff    Are you alright there? [focus Resident]
         [Resident] steps forward and grins.
         Turns in a circle. Staff moves off.
         Finger in mouth, pulls lip, grins and turns circle.
         Bends and pulls fluff off the floor.
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McDonald (1997) notes that an absence of communicative purpose or lack of opportunities to refine communication skills by monitoring whether exchanges effect environmental change can inhibit the development of communicative competence.[45] Neither attributes of communication tended to be present in the limited communicative exchanges that were observed for many Kimberley Centre residents.

Little concerted effort appeared to have been made to discover or transcend barrier to effective communication. No communication technologies were evident, no sign practised – even for deaf residents, no choice-boards were available and no systematic attempt to improve literacy other than what might occur opportunistically in participant's day programme. Staff often spoke of it too difficult to improve language and in many interviews they expressed a view that the communication skills of residents had deteriorated over the years they had known them at Kimberley Centre.

A pervasive acceptance of the reality that many residents had entered Kimberley speaking, but would leave silent represented a quiet but distressing everyday denial of personhood,

Figure 4.4 — The length of communication events involving the Kimberley Centre residents as a proportion of total time observed communicating
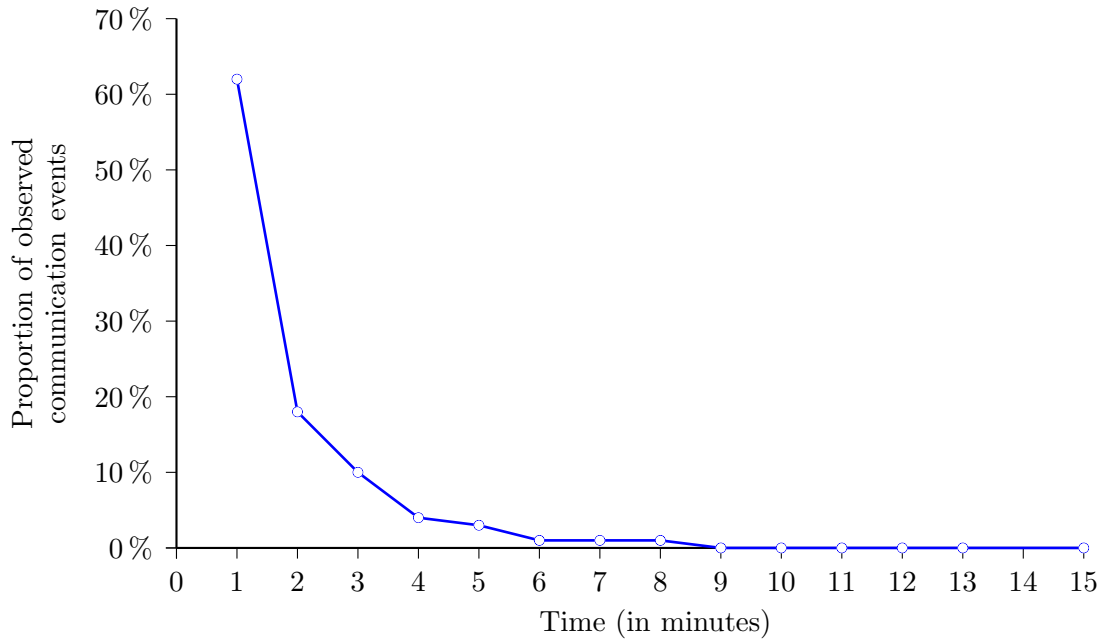
suggesting as it did that Kimberley Centre residents could find little use for self expression through language.

STAFF   A lot of these residents here, I can't understand why they don't talk more. If they can put a few words together, they should be able to do more than they do. I think it is just chosen, they just choose not to say anything, I really do.

RESEARCHER   Why?

STAFF   I don't know, probably because I don't know, maybe it is because they have been told to be quiet and shut up over the years and just decided that is the best thing to do.

The lack of developmental momentum in most adaptive behaviour domains, coupled with the improvement in adaptive behaviour that was observed in community-based settings after resettlement strongly suggests that the day to day reality of living in an institutional setting contributed to the poor performance of study participants relative to the adaptive competence of their peers.

In Chapter 5, the changes that were observed in resident adaptive behaviour during the course of residents' first year beyond Kimberley Centre are described including an exploration of what factors appeared to influence learning. The possible improvements in service delivery that may help sustain the sense of people with an intellectual disability as developing people are also discussed.

5

Resident adaptive behaviour beyond the Kimberley Centre

5.1 Resident adaptive behaviour beyond Kimberley Centre

Calls for the dismantling of major institutions were influenced by a simple, deterministic logic that changing the environment in which people lived, worked and recreated would influence their capacity to learn and adjust to the ordinary places and activities of the communities from which they were segregated. Although little research exists in the New Zealand context, the great weight of international deinstitutionalisation research suggests that a general, though not inevitable, improvement in the overall adaptive behaviour ought to be evident in community based settings with improvements in the domains of self-care, domestic and social skills to the fore. Chapter 4 examines resident adaptive behaviour following their move from Kimberley Centre.

When the performance of Kimberley Centre residents before and after their move were compared, an improvement in the average overall, standardised adaptive behaviour was observed 3-6 months after resettlement with the improvement persisting when residents were followed up one year after leaving Kimberley Centre (Figure 5.1).

When the standardised scores were summed to give an overall measure of adaptive behaviour the average score rose from a 147.3 (SD=21.8) at Kimberley Centre, to 150.8 (SD=25.6) in Phase 2 and up to 154.0 (SD=26.0) in Phase 3.

A two-tailed, paired t-test was used to explore possible significant differences between changes in the overall standardised adaptive behaviour scores for each resident at all phases of the research (Table 5.1). Although the increase in adaptive behaviour scores between consecutive phases failed to reach statistical significance, the 6.59 point increase in reported scores between Kimberley Centre baseline the end of the first year in a community-based service was statistically significant (95% CI [12.6–0.6]; $p = 0.032$).

Figure 5.1 — Mean overall standardised ABS-RC:2 domain scores by research phases.
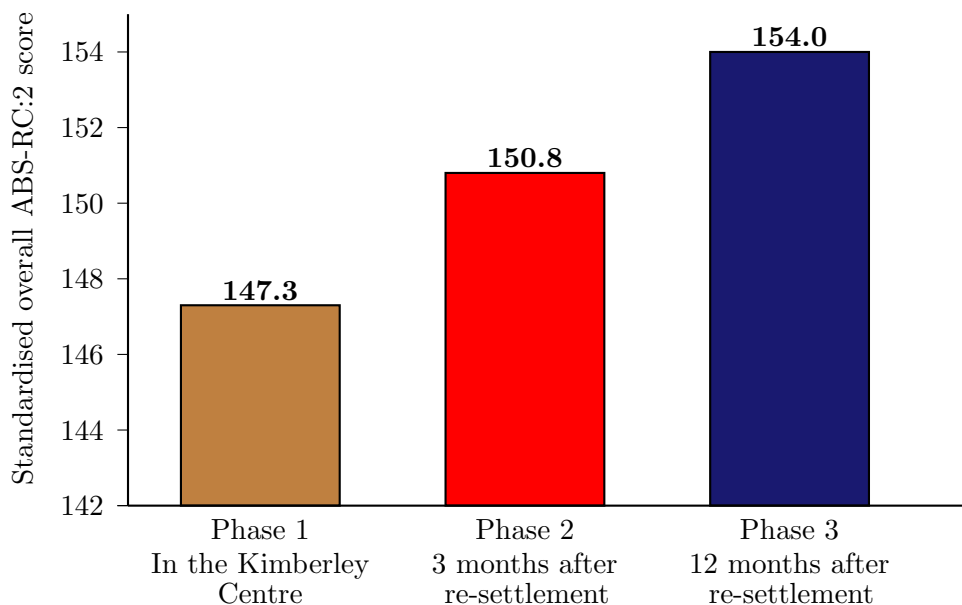
Table 5.1 — Paired differences in overall standardised ABS-RC:2 domain scores between research phases.

Phase pairs	Mean of paired differences	s.d.	t	p
Phase 1 – Phase 2	4.53	14.8	1.7	0.105
Phase 1 – Phase 3	6.59	17.2	2.2	0.032
Phase 2 – Phase 3	2.40	13.1	0.9	0.374

These findings are consistent with the international literature, adding further support for the association between the movement of institutional populations to community-based support settings and improvements in overall adaptive behaviour.

It is important to note, however, that the mean improvement in overall adaptive behaviour diminishes over time (Table 5.2). The mean of paired difference between scores recorded at Kimberley Centre and 3-6 months after resettlement (M=4.53; SD=14.8), is nearly twice as large as the mean of paired difference between scores recorded between 3-6 and 12months after resettlement (M=2.4; SD=13). This reduction in adaptive behaviour change is also consistent with research that suggests the positive gains adaptive skills following resettlement plateaus (levels off) after the first year living beyond the institution.[51,59,67,68]

A disaggregation of the data permits us to see in what particular ways the shift to community-based services appears to have improved or suppressed the development of adaptive competence in particular life skill domains. Figure 5.2 describes the average standardised scores recorded for the ten adaptive behaviour domains sampled at each phase of the project.

The general trend was for improvement across all but one domain over time, with the increase in adaptive behaviour sufficient that by the end of 12 months living in a community-based setting, no average standardised domain score remained *poor* relative to their peers and two domains were elevated sufficiently to be considered as average relative to other people with intellectual disabilities of a similar age. At Kimberley Centre, the Physical

Figure 5.2 — Mean standardised Adaptive Behaviour domain scores (ABS-RC:2) for each phase of the Kimberley Centre Research Project.
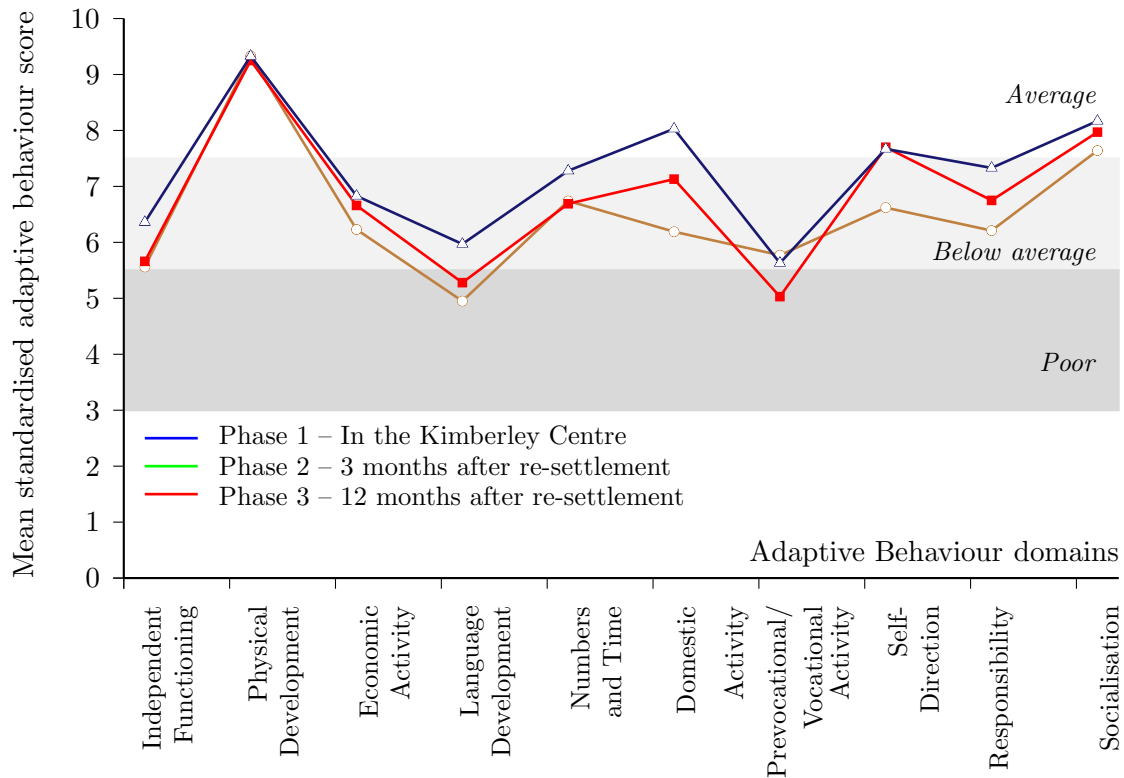
Development domain was the only adaptive behaviour score to approximate residents' age related peers. Twelve months after resettlement, the average *Domestic* (M=8.03; SD= 2.83) and *Socialization* (M=8.17; SD=3.04) skills of residents were assessed as having recovered to being little different from other people with an intellectual disability (Table 5.2). Community living appeared advantageous with respect to learning a particular set of adaptive skills. Two-tailed paired t-tests revealed statistically significant improvements in resident' scores in five of the ten competency domains twelve months after their move to a community-based service. Community living appeared to lead to significant improvement in the adaptive behaviour of residents in the domains of *Economic Activity*, *Language Development*, *Numbers & Time*, *Domestic Activity*, and *Responsibility* (Table 5.3).

5.2 Improvements in the domestic and community literacy skills

The most dramatic improvement in adaptive performance was observed in resident abilities related to taking care of the living environment and performing ordinary domestic routines. The move to a community setting was accompanied by an average increase of 2.62 in resident scores within the Domestic Activity domain of the ABS-RC:2 twelve months after resettlement. This improvement in performance was statistically significant (95% CI [1.25 – 3.98]; $p < 0.01$), adding to the body of literature that has consistently demonstrated improvements in this domain following resident's move from institutional settings.[1,4,65,69]

One of the most commonly advanced explanations for this, now robust, research finding is that the more homelike setting afforded by smaller, architecturally typical community-based

Table 5.2 — Paired differences in overall standardised ABS-RC:2 domain scores between research phases*.

Part One Domains	Phase 1 In the Kimberley Centre		Phase 3 12 months after resettlement	
	M	SD	M	SD
Independent Functioning (IF)	5.56	0.55	6.36	3.21
Physical Development (PD)	**9.33**	0.45	**9.33**	**2.72**
Economic Activity (EA)	6.23	0.08	6.83	1.13
Language Development (LD)	4.95	0.51	5.97	3.19
Numbers & Time (N/T)	6.74	0.23	7.28	2.21
Domestic Activity (DA)	6.19	0.31	**8.03**	**2.83**
Pre-Vocational Activity (PVA)	5.77	0.45	5.63	2.83
Self-Direction (SD)	6.62	0.46	7.67	3.44
Responsibility (RE)	6.21	0.40	7.33	3.20
Socialization (SO)	7.64	0.47	**8.17**	**3.04**

*Mean standardised domain scores classed as *average* relative to age peers with an intellectual disability are recorded in bold font.

Table 5.3 — Paired differences in ABS-RC:2 domain scores between Kimberley Centre and 12 months after resettlement*.

Phase pairs	Mean of paired differences	s.d.	t	p
Independent Functioning (IF)	0.12	14.17	0.05	0.96
Physical Development (PD)	-0.71	2.68	-1.54	0.13
Economic Activity (EA)	**1.06**	**2.26**	**2.74**	**0.01**
Language Development (LD)	**1.94**	**4.88**	**2.32**	**0.03**
Numbers & Time (N/T)	**0.59**	**1.31**	**2.63**	**0.01**
Domestic Activity (DA)	**2.62**	**3.91**	**3.91**	**0.00**
Pre-Vocational Activity (PVA)	0.12	2.20	0.32	0.75
Self-Direction (SD)	1.59	6.12	1.51	0.14
Responsibility (RE)	**1.24**	**2.18**	**3.31**	**0.00**
Socialization (SO)	1.76	6.49	1.56	0.13

*Statistically significant paired differences (α=0.05) are recorded in bold font.

settings permits a greater opportunity for people to participate and practice activities that would lead to an increase in competence in this domain.[70, 71]

At Kimberley Centre, performing domestic duties like cleaning, washing or setting the table had become the preserve of the truculent and privileged few who were able to keep the cadence of the institutional rhythm. The closure of smaller villas and withdrawal of ancillary services denied opportunities for residents to participate in ordinary domestic activities like food preparation, laundry or other household chores. Kimberley Centre staff would frequently report a belief in the latent potential of residents to either learn or demonstrate domestic competence, could not be expressed in residents "villa lives."

RESEARCHER Her daily living skills – how would you rate her daily living skills?

STAFF She is actually pretty good really but doesn't get the opportunity to, like practice cooking she can boil water and things like that but she could probably learn. I would say she would be able to cook her own toast and make herself a cup of coffee without too much trouble. It is just that she doesn't really get the opportunity.

RESEARCHER How much has she learnt in her time at Kimberley Centre?

STAFF I don't know. Not really, I think we sort of take that away from them. Just the way things are structured, the time frames when things have got to be done so we have probably not as much as what she could - does that make sense?

In community-based settings the immediacy and more flexible routine of household activity greatly expanded the opportunity residents had to become actively involved in domestic tasks. Whereas at Kimberley Centre the ordinary rituals of meal preparation, table setting, doing the washing or the vacuuming tended to happen beyond resident's influence and often gaze, in community settings the same domestic activities were part of the everyday culture of a home-life that residents were emersed in. The disparity of opportunity, residents had to demonstrate or improve domestic skills and that staff had to support independence in this domain, is evident in the narrative below. Here staff are contrasting answers staff when asked to describe the repertoire of life skills the same individual had in and then out of Kimberley Centre.

At Kimberley Centre

RESEARCHER How would you describe her daily living skills?

STAFF Well basically apart from her going out to programmes she will wander in, Hi [Pet name] and she will sit here with her pile of magazines and her women's weeklies and then she will just wander off again. So she wanders from A to B.

Beyond Kimberley Centre

RESEARCHER One thing I haven't asked about is her repertoire of life skills and stuff like that. Have they increased, stayed the same or decreased.

STAFF I think they have increased. When [Resident] came in, [Resident] would come to the table for a meal and everything about that meal you had to support [Resident] with. Putting on her what she calls pinnie, her feeder, to - don't get me wrong, we have still got to help her sit up and get her in the right position. Once she finished her meal it was straight off into her chair. Now when she goes for her meal, she will try and slip her own pinnie

on. She feeds herself totally. Once she is finished, if the others, because she is usually around about last. She will then stand up, go around the table, push all the chairs in. Try and pick up whatever coasters or place mats are on the table. Take up her plate and knife and fork and that, and her cup. Take off her pinnie, go out in the laundry, put it in the basket, the right basket too and then go back to her chair. Just the other day, the first time I had seen her do it and I asked the other staff if they had seen her do it and they hadn't, after the meal and some of the dishes were washed and left on the bench, she got the tea towel and dried eight cups and then put them away too which was great, it was, that was really good. But I mean she tries to make her bed and it is the same for all of them, if they make their bed and make the attempt to make their bed, then however it is we will leave it like that. When we first started we would tidy it up.

In the more intimate community-based support setting, residents were less divorced from the action at the heart of home-life and had the chance to witness and participate in the entire sequence of ordinary domestic activity that led to meals, clean clothes and tidy houses.

STAFF   I found out that when she was at Kimberley she helped with the laundry but all she ever used to do was help chuck them in to their trolleys and push them back to the wards. Well now she sees the whole process, dirty clothes going in to the machine, being washed, being hung out, being brought in and folded up.

The difference was most dramatic for people with multiple disabilities, where motivated staff could find opportunities for people formally suspended in a highly dependent role to become active participants in the normal routines of daily living.

RESEARCHER Is it reasonable or unreasonable to talk about building competencies with [Resident]?
STAFF   Well she is never going to do the chores of the household. I mean you have got to be realistic about that, I don't think she will, but she can be involved. You can fold the towels and put them on her, she can watch but she is never going to actually physically do the towels herself so yes, she can be involved, she can observe. She sees all of the vacuuming and all those sorts of things.

Being causal in the process of seeing washing safely back to the linen cupboard, placing 'pinnies' in the correct laundry basket, unceremoniously drying stray dishes and making your bed to your own particular specifications, embody more than a demonstration of domestic competence. They represent acts that accumulate to change the phenomenological meaning of a support setting by transforming a dwelling into a person's "home".

"Home" is perhaps the most basic and potent of living spaces.[72] Beyond its geographic centrality, the home is also at the epicentre of psychological and social meaning.[73] As unassuming as they were, small domestic roles may have assumed important psycho-social meaning for Kimberley Centre residents. Taking responsibility for clearing the table might have contributed to a sense of home ownership and permanence. Selecting the correct laundry bin may have emphasised the physical and social knowledge that communicated a belonging to place. And quietly doing the dishes may have represented an expression of affect, humanising social relationships within the home with a moment of reciprocal thoughtfulness.

There is little doubt that the acquisition of some, seemingly small competencies, had great personal significance to a number of residents, contributing immeasurably to their life quality.

Henry* was visually impaired and music was his passion. Kimberley Centre staff spoke freely about using music as a pacifier for Henry. Provided he was in earshot of the stereo, Henry was content. In his villa, the stereo was kept behind a locked cupboard. Henry generally spent his days at Kimberley Centre sitting where he could monitor the cupboard because his vigilance determined whether the music played or not. Despite impairment, Henry had emancipated himself from the musical tastes and timing of staff' entrances by teaching himself how to work his own stereo within a few months of resettlement.

RESEARCHER   Henry had no control over the stereo at Kimberley Centre. It was in a locked cupboard and staff would turn the music on or turn the music off, now I watched him do it.

STAFF   I know, its fabulous, like if he can't find the right CD, coz, he puts them down on the floor or they fall off his chest of drawers he goes down and he is looking for them and then he will put his CD in and he turns - he can change the channels as well. If he doesn't like that music, he tells you he doesn't like that music, I mean I go in and sing with him, I mean he likes it and when he has had enough he will stand up and he will grab you by the arm and he will say out so you just go, otherwise he will start laughing and he will sing along with you. He has done it all for himself. He used to ask, when he first started here he used to ask, he would drag you along in there because he wants the radio on and you run your hands, and you quite often see him run his hands and he is feeling things and you bring his hand along and he is feeling and he is taking in what you are doing.

The disposition of support staff towards engaging residents in the running of their own home and commitment to increasing core competencies varied greatly in community settings. The sharp social divide between client and service provider that existed at Kimberley Centre often followed residents into their community-based settings. At many sites, staff continued to fill the active role of provider of care and residents the more passive role of recipients within their own homes. The continual ebb and flow of people in houses struggling to retain support staff and a reported absence of values based training meant that well intentioned support staff were given few opportunities to confront or challenge this understanding of their role. Providing good material and physical support was perceived to be of paramount importance, often distancing residents from opportunities to learn or feel a sense of proprietary over the houses they lived in, even in community-based settings.

STAFF   He doesn't have those opportunities to prove anybody wrong, he is not having the opportunities, he is not, no, because he is put where he is even though it is a lovely home, there is not the opportunity for him, there isn't. He is not learning other things. He is not, he's is getting dressed, showered, fed, put in to the lounge, occasionally going out, he just gets up and sits in the lounge and so there is nothing for him to learn.

A number of other factors appeared anecdotally to have contributed to the observed variability in support culture as well as the statistically significant improvements in the adaptive

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behaviour domains of domestic competence, *Economic Activity* (95% CI [0.27–1.85]; $p = 0.01$) and *Numbers & Time* (95% CI [0.13–1.04]; $p = 0.01$).

Smaller services with less horizontal distance between residents and management appeared to accommodate greater staff initiative and more flexible service practice, enhancing the ability that direct support workers had to bend their support to fit the personal preferences and learning styles of residents. The personal motivation of residents to learn was often a powerful, but unquantifiable determinant of adaptive behaviour gain. In places where the culture was most supportive of residents' capacity to learn, the people who lived there had helped to define the social practices of home.

RESEARCHER   What accounts for [Resident] working so hard to learn.
STAFF   My theory is that the example set for her by the ones such as [Flatmate 1] and [Flatmate 2] and [Flatmate 3], especially [Flatmates 1 & 2]. They want to do everything from the dishes to sweeping the floor to the laundry, to the vacuuming and they set the example for her every day. It just doesn't come once a week, they want to do it every day and that has rubbed off on all of them.

Six months after resettlement, the increase in domestic adaptive behaviour slowed. A number of studies have reported the potential for adaptive behaviour gains to plateau a year after resettlement. The finding has tended to be attributed to the initial expansion of competence, reflecting an increase in the expansion of opportunity to demonstrate skills, rather than the any inherent difference in the ability of community-based settings to nurture learning. The decelerated pace of adaptive behaviour gains in key domains and staff who tended to describe an unsystematic approach to skill development, found in this study, would appear to lend weight to this argument.

Moreover, a correlated trend was observed in the amount of time residents were actively engaged in life domains like domestic activity. For example, the average amount of observed time people participated in domestically related activity doubled post-resettlement but similarly plateaued twelve months after resident's move to their community-based service (Figure 5.3). A weekly routine in which staff assumed responsibility for most of the domestically related activities had become embedded in most settings by the end of the project.

5.3   Improvements in language and self-expression

As noted above, as a support environment, Kimberley Centre tended to be insensitive to the need of residents to be active and valued communication partners. The infrequent and fleeting character of most interaction inhibited opportunities for meaningful self-expression and appeared to suppress the development of linguistic competence. Of all the adaptive behaviour domains sampled for in the ABS-RC:2, residents performed most poorly on indicators of *Language Development* (Figure 5.2). Approximately 93 percent of people with intellectual disabilities would be expected to score better than their age peers at Kimberley Centre and stories of residents who formally spoke, falling silent over the years staff punctuated staff the narrative of the Kimberley Centre.

Twelve months after resettlement, residents had on average, increased their standardised score within the *Language Development* domain by 1.94 points. This was a statistically significant improvement in resident performance (95% CI [0.24 − 3.64]; $p < 0.03$).

Figure 5.3 — The relative proportion of observed time residents were recorded as engaged in domestically related activity
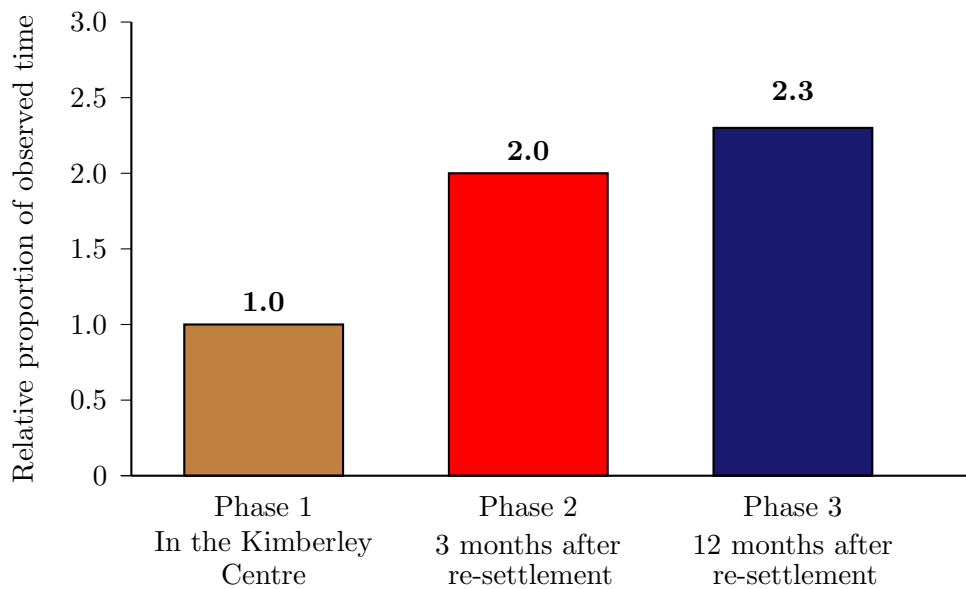
The observed recovery in proficiency related to the reception, expression and use of communication skills might reasonably be attributed to a number of differences between the two support environments. At Kimberley Centre the press of time and number of residents limited moments of interaction and opportunity for self-expression. In addition to having to calibrate interaction to meeting the personal support needs of up to 14 residents whilst keeping in step with the rhythm of institutional living, managing the equilibrium of villa dayrooms often meant rationing attention. In the smaller and more home-like community settings, residents were included in a communicative event more than twice as often as they were while they lived at Kimberley Centre (Figure 5.3).

Living, eating, sharing daily chores, shopping, and recreating "inside" of the lives of the people staff supported in community services enhanced opportunities for conversation. In addition to providing a greater chance for staff to learn more about each other, sharing lives also infused communication with residents' personal history.

In the first flush of deinstitutionalisation, a sense of discovery appeared replete in resident–staff interpersonal interaction. Staff and Kimberley Centre residents typically met as strangers, and discovering the boundaries of aptitude became an important way staff and residents got to know each other. Unearthing buried competence was strongly reinforcing and the recovery of language emerged as amongst the most powerful of staff motivators.

STAFF   Sometimes when she is angry, the words come out, they are clear, 'leave me alone', 'go away' and it is amazing and her mum is the same. We sort of all live in hope that one day her speech is going to return. You know it is there but it is her choice, but it is when she is angry. It is like a little sentence strung out and she puts all these words together and it is as clear as a bell.

John O'Brien (2003) has suggested that the moments of discovery and types of relationship that lead to good support are constructed on "wasted time.[36]" Time spent hanging out talking about ordinary stuff, noticing extraordinary things about each other. The greater "wasted time" afforded in some community contexts appeared to increase the likelihood

Figure 5.4 — The duration and average number of communication events observed in each project phase.
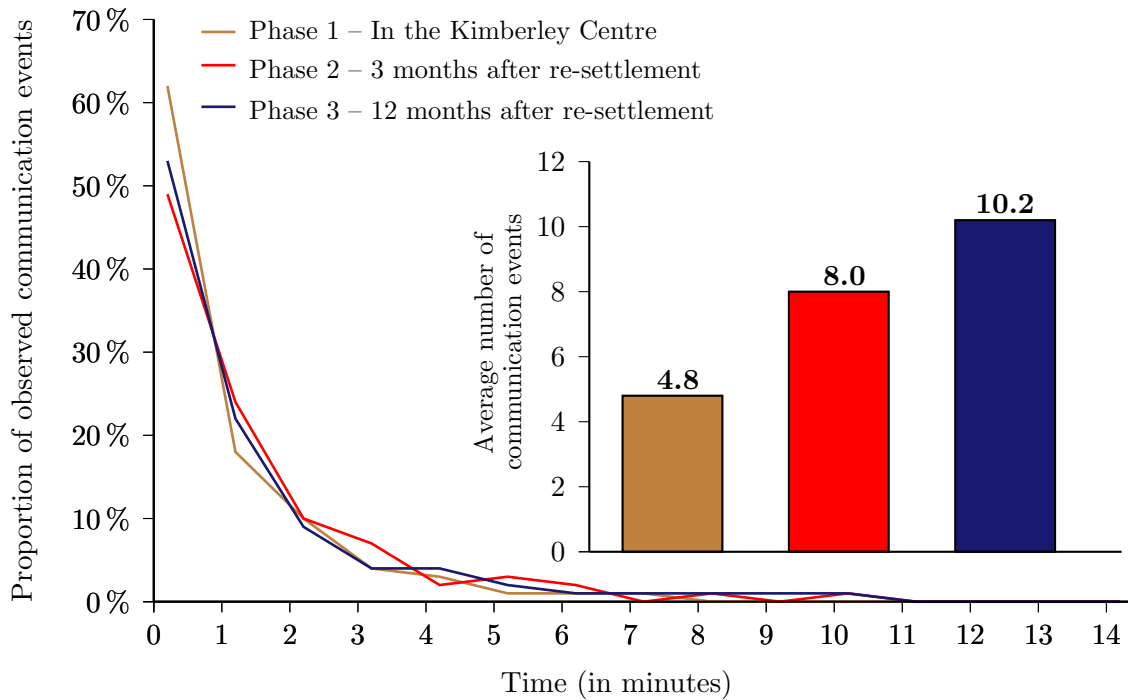
of disclosures of hidden linguistic competence and of staff noticing such moments. The following extract is drawn from a running record narrative. It captures a staff person and resident hanging out in a reading pit at the local library. Although "counted" as vocational in orientation the support staff also lived with the resident and the service had adopted naturalistic community participation as an extension of home-life as the model of day-support rather than the conventional vocational programme.

In a corner of a community library this Kimberley Centre resident had inclined affectionately towards his staff person as she quietly peeled back horizons of complex linguistic knowing. For many Kimberley Centre residents, the unearthing of latent competence changed the way they were socially constructed in self-fulfilling ways. Coupled with staff who found the process reinforcing, the first six months of resettlement saw an accelerated increase in the acquisition of this and other adaptive behaviours.

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Running Record 10.25am; 21/8/07
Location: Community Library
Sitting in reading pit leaning in against staff.
Book open on table in front of [Resident].

27min    [r] turns page.
         [s] 'It's a story about bears
         [r] What's that?' points to page.
         [r] 'Policeman'
         [r] whispers inaudibly
         [n] laughs.
         [n] 'What are they doing. Making a well to get some water.'
```

```
       [r] points
       [n] 'Right'
       [r] points at page 'Hot'
       [n] 'But what's happening?'
       [r] 'Rain'
       [n] 'Yeah it's raining - What's that?'
       [r] 'Lightening.'
       [n] 'Up there in the clouds. Do you know that word,
             What's he doing in the water.
       [r] points to page
       [n] pats hand, 'That's water, what's he doing though?'
       [r] 'Dancing...'
29 min [n] 'What's that?'
           'Train,' pointing 'Bike' lifts hands imitating
           steering wheel,
       [n] 'What is it?'
       [r] 'Motor car' Smiles
       [r] Begins volunteering in quick succession 'Dishes, Bread' lifts
           index finger to mouth.
       [n] Kai yes,
       [n] & [r] laugh.
       [n] touches [r]'s elbow.
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RESEARCHER Yes, if I walked in the house not knowing [Resident], what would you tell
            me about [Resident]?
STAFF   Oh that's a good one. He is real teachable. He loves encouragement, he
            tries new things he does. He is lovely, he has got a funny sense of humour.
RESEARCHER When I first came here somebody said to me oh [Staff] is so proud of
            [Resident].
STAFF   Yeah, I am, because he has really changed.

Beyond Kimberley Centre, the centrality of families to a collective process of discovery and the rapid and evolving repertoire of competence unearthed in the first months of de-institutionalisation challenged notions families had of the fixed developmental potential of their relative too.[58] Borrowing the phrase from Bogdan and Taylor[10] (1989), Mirfin- Veitch (2005) suggested that exposure to the flourishing of new competence in the first months of resettlement had led the Templeton Centre families she followed to re-attribute qualities of shared humanness. A similar observation could be made of Kimberley Centre families, with language gain proving an especially potent antecedent.

FAMILY   [Resident] is doing really well, He's changed, They say he's speaking more.
RESEARCHER I can remember in our first interview you saying to me at various stages
            in the interview, I am not sure how much more [Resident] can develop.
FAMILY   But as [Family friend] said to me, I don't think they – it is not that they
            didn't want to teach him to talk, they haven't got the time at Kimberley,
            that's what it is, and this place where he is now, it's different.
RESEARCHER What do you think [Resident] likes about being there?

FAMILY   I don't know what [Resident] likes. He settled down and I am sure they
              said they'll teach him to say different words so I have got my trust in
              them that they will do that.

Whereas for other domains, the pace of adaptive behaviour change appeared to plateau twelve months after resettlement, the trend for increasing linguistic competence was sustained between phases. A closer examination of how resettlement affected the language skills of different residents revealed that the *Language Development* domain scores of people who moved from Multiple Disability villas improved in the first six months, but plateaued thereafter, but the scores of people resettled from Challenging Behaviour and Lifestyle villas increased more evenly, at both phases in the project (Figure 5.4 and inset).

Although the average frequency with which people were engaged as a partner to a communication event increased at every phase of the project to eventually double by the end of the first year in community-based services, deinstitutionalisation made little difference to fleeting character of resident interaction (Figure 5.4). Most interaction events, whether at Kimberley Centre or in the community lasted less than two minutes. Opportunities for self-disclosure and the deepening of social knowing that occurs through sustained dialogue were infrequent, despite direct support staff expressing a strong desire to improve resident's communication skills. Communication aides, choice boards, New Zealand sign and staff training in facilitating communication continued to be absent in community-based settings.

5.4 What impact did residents' level and type of support need have on the acquisition of adaptive competence following resettlement?

People with multiple and profound disabilities typically live lives with lower opportunities to express preferences or make choices, have more limited access to community resources and intimate relationship and are more marginalised from productive activity and staff attention in community-based services.[74] One possible implication of these, now well replicated research findings, is that people with multiple disabilities are unlikely to share evenly in any benefits associated with institutional closure.

On the other had, preliminary analysis of observations and key staff narratives volunteered in Phase I of the Kimberley Centre Research Project suggested that the lives of people supported from Multiple Disability villas varied little from day to day and were most compromised by the retrenchment of ancillary support services as Kimberley Centre sequentially closed. As a consequence, this cohort potentially had most to gain from Kimberley Centre closing.

To the author's knowledge, no published research has explored whether residents with different support needs benefit equally from institutional closure. Figures 5.5 and 5.6 describe changes in staff assessment of residents adaptive competence in all 10 domains between Phases 1 – 3 and Phases 2 – 3. In figure 5.5 the average change in standardised scores recorded twelve moths after resettlement is plotted for residents originally assigned to Challenging Behaviour, Multiple Disability and Lifestyle villas. The centre circle represents each cohort's baseline Kimberley Centre score with the strength of adaptive behaviour gain indicated by the distance the mean score extends beyond the circle's circumference. The distance each domain score dips inside of the circle similarly indicates the strength of adaptive behaviour loss.   Differences emerged in the patterns of adaptive behaviour gain, suggesting the personal characteristics of residents and their experience of living in community-based

Figure 5.5 — Mean change in ABS-RC:2 standardised domain scores between Phase 1 and Phase 3 of the Kimberley Centre Research Project. (The circle represents the zero change.)
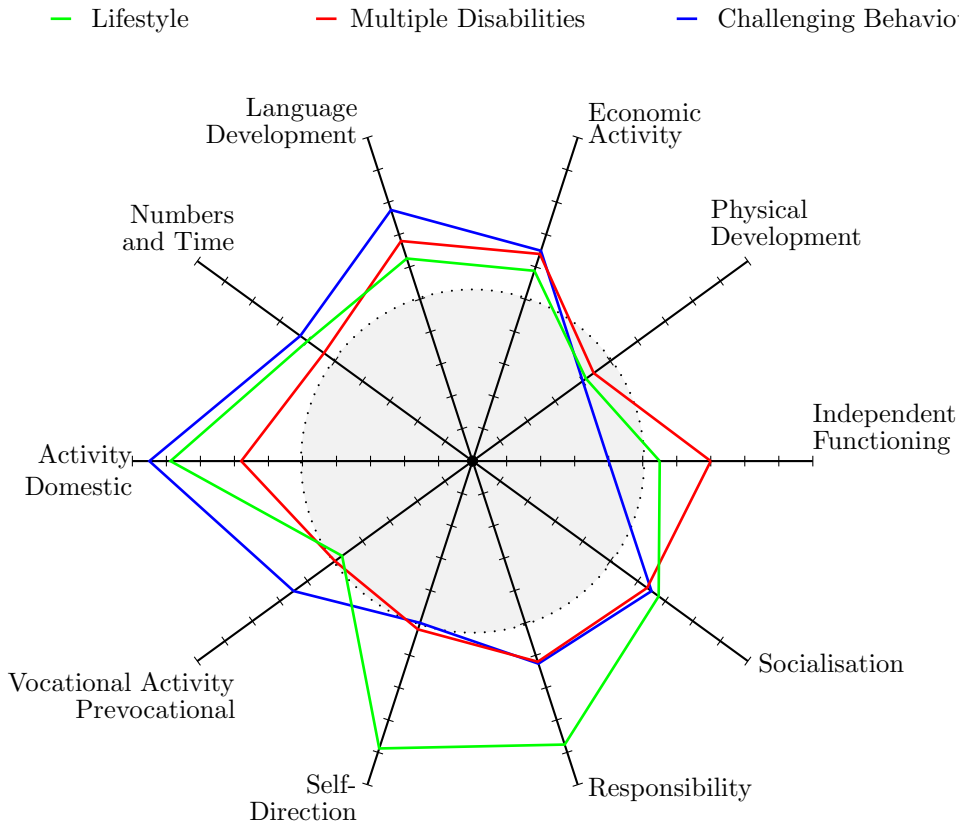
services may have intersected in ways that advantaged the acquisition of particular life skills in distinctive ways for people with different types of impairment. For example, freed of the unerring rhythm of institutional living, residents resettled from lifestyle villas appeared more able to demonstrate evolving initiative, perseverance, self-directed use of their leisure time and responsibility in interpersonal transactions. Conversely, the men and women resettled from either Multiple Disability or Challenging Behaviour villas were recorded as exhibiting very similar adaptive skills in the *Self-Direction* and *Responsibility* domains as those reported at Kimberley Centre. For these individuals, it is likely that both impairment and the response of services to their perceived support needs limited the ability this subset of Kimberley Centre residents had to demonstrate an equivalent adaptive behaviour change to that demonstrated by their peers resettled from Lifestyle villas.

As noted previously, the average standardised scores for all resident cohorts increased in the domains of *Domestic Activity* and *Language development*, with the residents resettled from Lifestyle and Challenging Behaviour villas benefiting most from access to new opportunities to demonstrate and develop latent domestic competence. On the other hand, people from resettled from Multiple Disability villas appeared to benefit most from resettlement in the domain of *Independent Functioning*. At Kimberley Centre residents were occasionally described as the object of peoples work. Contorted limbs or people that found it difficult to sit or lie still were *"not user friendly,"* in the rush to complete personal cares, whereas in the less hurried atmosphere of community based services, staff had more time to notice and improve

self care skills. Improving independence in eating and basic self care skills also featured prominently in resident support plans as individualised lifestyle planning goals.

STAFF   She has lots of new skills. Lots of new skills. She has learnt to eat slowly. She has learnt to set her own place. She has learnt to brush her teeth. Wash her hands. Lots of skills, important little things.

Other than a slight dip in the Physical Development domain that probably reflects a reduction in sensorial or motor abilities as people aged, residents, on average, exhibited positive adaptive behaviour change in all domains during the course of their first year beyond Kimberley Centre. What is less obvious, however, is that the momentum for adaptive behaviour change generally occurred in the first six months after resettlement.

Figure 5.6 — Mean change in ABS-RC:2 standardised domain scores between Phase 2 and Phase 3 of the Kimberley Centre Research Project. (The shaded disk represents zero change.)
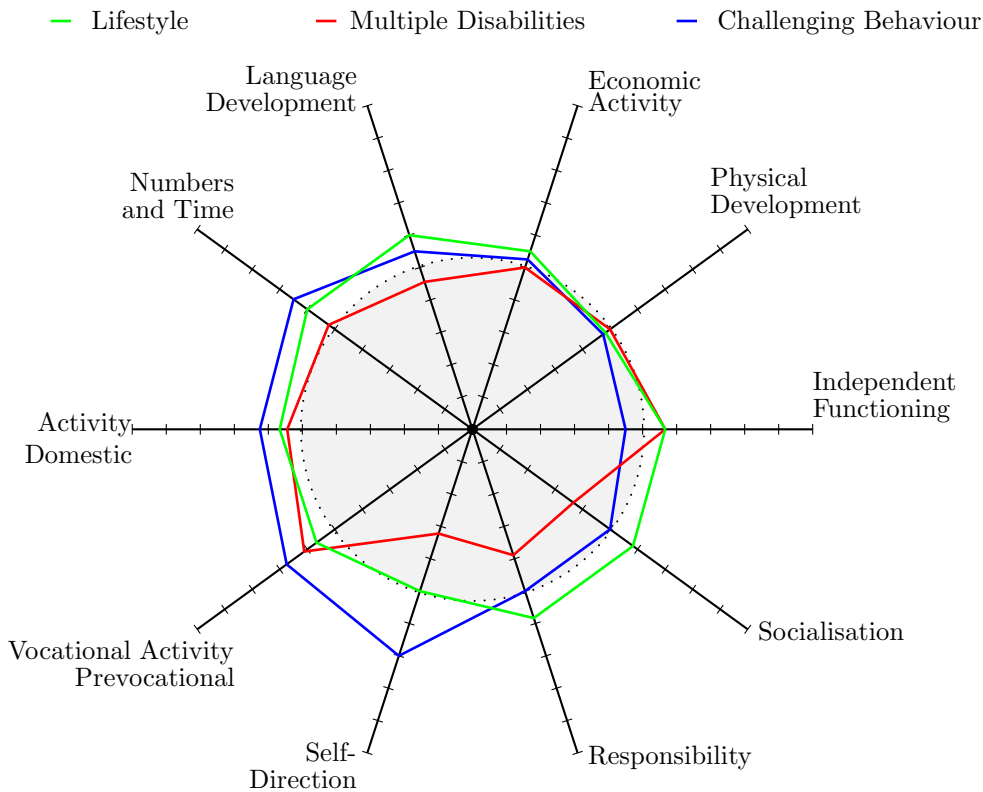
Figure 5.6 describes the mean adaptive behaviour change in standardised scores that occurred between Phases 2 and 3 of the Kimberley Centre Research project. The clustering of change in adaptive behaviour scores about the zero axis is indicative of a pervasive arrest in the pace of resident learning after the first six months of the resettlement.

As noted above, researchers have generally attributed the plateauing of adaptive behaviour gain to an initial expansion of opportunity to acquire adaptive skills.

Anecdotal evidence suggests that a coincident change in the culture of support may also have contributed to the stalling in adaptive behaviour gain. As described previously, support staff and residents tended to meet as strangers. As the daily routines and idiosyncratic cultural practices of each setting bedded in, the "sense of discovery" and acuity to exposing latent

competence that seemed so powerfully reinforcing in the first flush of resettlement appeared to have been replaced by a "sense of knowing." Whereas discovering new limits to personal competence had formally been powerfully reinforcing to staff, predicting, anticipating and managing became the new markers of professional competence by years end, leaving residents exposed to the risk that their potential for new learning could be defined by the perceptions and self-reinforcing behaviour of support staff. People with multiple disabilities were most vulnerable to being 'cast' in this way and it is interesting to note that their aptitude in the domains of self-direction and responsibility was assessed as falling in the last half of their first year out of Kimberley Centre[*].

5.5 What anticipated the emergence of adaptive behaviour following resettlement?

Given the variability in adaptive behaviour gain hinted at by differences in the scale of change experienced by residents resettled from different villas, the research team was interested in knowing whether it was possible to identify any factors that made the acquisition of new adaptive behaviours more or less likely.

Research that has attempted to account for variability associated with Quality of Life outcomes for people with an intellectual disability has tended to focus upon aspects of service design (including variables such as the physical design and location of settings or the number of residents and staff ratio in settings), service processes (including variables such as staff training, whether staff practices are individually or institutionally organised and other working methods and procedures adopted by staff) and the individual characteristics of residents[59,63] (including variables such as the type of impairment, adaptive or challenging behaviour, age and type of support that preceded residential care).

In this study, a multiple linear regression model was used to explore whether welfare guardian's choice of either Cluster House or Community Group Home or the level of impairment were associated with any differences in residents' propensity to learn adaptive skills. The model of community-based support chosen by families and the Kimberley Centre villa residents moved from were selected as possible predictors of the change in overall adaptive behaviour twelve months after resettlement. Other variables selected included, age, sex, time spent at Kimberley Centre, family relationship and the distance to residents welfare guardian. A number of different regression models were employed and two variables consistently emerged as having a decisive role in influencing the overall standardised adaptive behaviour score. The distance relatives were from their welfare guardian and the nature of the relationship accounted for approximately 25 percent of the variance in the data. Of the two variables, the proximity of a family was the most important. When all other factors were held constant, being close to a family member lifted the change in residents' overall adaptive behaviour in their first year beyond Kimberley Centre. On average, every kilometre that separated residents from their welfare guardian lowered the change in overall standardised adaptive behaviour by 0.07 points (95% CI [-1.38 – -0.004]; $p = 0.037$). Residents also benefited from being close to their parents. Having a mother or father as welfare guardian also supported learning. On average having a parent as welfare guardian improved the change in overall standardised adaptive behaviour score of residents by 10.37 points (95% CI [-0.62 – 21.36]; $p = 0.064$).

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[*]This theme is discussed in greater detail in section 8.8.

For Kimberley Centre residents, it mattered little whether they were resettled to Cluster House or Community Group Homes. Moreover, differences in the personal characteristics of residents exercised no significant influence over residents' capacity to improve overall adaptive behaviour post-resettlement. Their age, sex, type of impairment or the length of time they had lived at Kimberley Centre failed as explanatory variables. What mattered most was the qualitative attributes of familial relationship.

This finding is challenging to the disability sector for two important reasons.

The distancing of people with intellectual disabilities from their families represents one of the most pervasive consequences of the sustained policy of institutionalisation. In the residential reform that followed, the physical, procedural and socio-cultural attributes of alternative service models have monopolised both the disability and Quality of Life discourse. The potential role families can play in sustaining the life quality of people with an intellectual disability has remained at the margins of intellectual and service attention.

As noted in Chapter 3, many families came to embrace deinstitutionalisation as an opportunity to relocate their relative back within the frame of their family and to participate as partners to a community of support about their relative. Aside from other benefits of embracing this vision, the findings of this study suggest that continuing to marginalise families from their aspiration to be engaged in the support of their relative disables people with intellectual disabilities by denying them access to a greater opportunity for personal growth and development.

The second reason is that if we fail to acknowledge the potency of families to learning we may also be blind to a real possibility that the seeds of best support practice may lie in emulating family support. For the residents who moved from Kimberley Centre to community-based services, families exposed residents to experiences that enhanced the acquisition of adaptive competence.

Two attributes of family support suggest themselves as possible explanations for the benefits to learning of being close to one's family. Families tended to lend the voice of advocacy. Many demonstrated an ability to recognise even small opportunities to add quality to the lives of sons and daughters as well as confront practices they perceived to threaten their relative's wellbeing. Being present kept services honest and attuned to families' wider aspiration for their relative to learn and be loved.

Families attentive nurturing and pleasure in personal growth, is the second attribute of familial care that warrants wider discussion.

In New Zealand's Pakeha support services, individualised support, self-determination and respect for the rights of the individual tend to be emphasised as core service values. This implicit focus on the individual as an island of wellbeing is, however, not common to all cultures. In a comparative study of residential services in London and Milan, Carnaby (1997, 1998) observed that Milanese service providers used the family as a template for service delivery.[75, 76] Families were acknowledged as having the greatest potential influence upon a person's psychological wellbeing and support was orientated towards empowering family relationships. Where service users lived beyond the reach of their family, support was expected to emulate family care, with operational policy directing staff towards the need to offer a *loving presence* to service users. In Kaupapa Maori services, family is also placed at the heart of service delivery. Locating people within the loving presence of whānau (family) and on beyond to their spiritual connection to tipuna (ancestors) are understood as central to wellbeing. The support relationship typically resonates with the nomenclature of family, and

like the Italian model of support, service practice emphasises whakapono (faith), tumanako (hope) and aroha (love) as core service values.

Because relationships are the medium of human support, the wellbeing of residents who left Kimberley Centre was in no small measure influenced by the quality of interpersonal relationships they met in services on the other side.

Direct care staff act as conduit to support through their relationship with service users. They tend to gate-keep meaningful activity and reflect back through interpersonal interaction and physical care, a social construction that informs recipients of care of their sense of self and self worth.[77,78] Marquis and Jackson (2000) concluded, after interviewing 26 Western Australian service users about their daily experiences and perceptions of support that the importance to service users of the interpersonal qualities of their transactions with support staff, greatly exceed the technical or procedural dimensions of care giving. What mattered to people who depended on disability services were acts of support that communicated *care for* and not *care of* themselves. People said quality support was effected by staff who were prepared to transcend the formal and task orientated focus of their role, with the *right attitude* experienced when interaction fostered feelings of attachment, inclusion, equality and a sense of being liked and respected. Self-disclosure and *normal talk* characterised dialogue infused with the vocabulary of friend and mateship. *Sharing the Inner Circle* was the moniker Marquis and Jackson (2000) used to describe relationships at the apex of an experiential hierarchy. Relationships between staff and service users categorised as falling within the inner circle had life sharing capacity with patterns of interaction extending beyond work-time, expanding the role of both partners within an ethos of friendship or extended family.

The insight of the Western Australian service users who spoke to Marquis and Jackson (2000) held true for Kimberley Centre service users. The most marked changes in life quality, including the potential for growth through new experience, occurred when both partners to the support relationship demonstrated a familial like commitment to advocacy and left room for the vocabulary of love to punctuate their relationship.

STAFF   I took [Resident] to [City] for Guy Fawkes. He was very vocal all around the wharf. He came with my family. My husband pushed him around. Anyway, we got our spot and [Resident] was looking up at the sky with one eye when the fireworks went off like a canon. Well. [Resident's] mouth dropped open. I spent the next 8 minutes thinking I had killed him. He never moved or blinked. After that we got him Chinese to eat and he farted all the way home. My kids were not impressed. I laughed my head off. The following week I took [resident] to [town] beach. We watched the fishermen with their rods, fishing, so I went garage-saleing and I brought [Resident] two fishing rods. We haven't been out yet because [Resident's] health deteriorated. [Resident] has been in hospital going on 3 weeks. I've been in hospital every single day to do his cares on him and feed him. He is puckering up for a kiss and looks real good. His eating has got so much better and I'm thinking positive all the time. I really love this old man. My husband told me off. I go up and do his cares on my days off. He came up with me last time and when we got back he said you really shouldn't hug [Resident] like that – he's not your family. I said yes he is. Till the day he dies he's my old man.

5.6 Sustaining the sense of viability as developing people

When the Western Australian service users spoke to Marquis and Jackson (2000) about the relational context of human support, they described experiencing good support in the communication that expressed an orientation towards their continued viability as developing people.[78] The importance of a sense of purpose and momentum to lives has been reported elsewhere. When New Zealand service users spoke to O'Brien et al.[1,74] (1999, 2001) about what the closure of a North Island institution meant to them they identified a sense of pride in the skills they had acquired since moving to community settings as amongst the most important benefits of deinstitutionalisation. Similarly, in their collaboration with Milner and Bray (2003), people who used a New Zealand vocational service described the lack of expectations held for people with impairments as pervasively disabling.[79]

As outlined above, the first months of resettlement were characterised by a flourishing in the adaptive competence of most Kimberley Centre residents. By the end of the year, however, the average change in adaptive behaviour had stalled and in many settings residents and staff had become acculturated to the traditional roles of passive recipient and active and empowered providers of support.

Environmental and relational factors appeared to contribute to the observed deceleration in learning, but during the course of the project, a number of possibilities suggested themselves as ways to sustain the sense of discovery that infused service delivery in the first flush of deinstitutionalisation

Community-based services were generally slow to embrace individualised support planning. Larger services in particular appeared overwhelmed by the logistics of managing the resettlement of Kimberley Centre residents and the process of identifying key workers and setting lifestyle goals typically occurred towards the end of residents first year in their new homes.

RESEARCHER How would new learning take place? Is it something you talk about as a team?

STAFF Again we haven't had meetings unfortunately but hopefully this will happen again.

RESEARCHER I am kind of getting a sense that it hasn't flowed in to goal setting either.

STAFF No, none of that. As I say starting off at the beginning of the year, hopefully their things are becoming more structured and as I say more training for staff and hopefully they are on the right track now.

Staff were neither trained in the process nor encouraged to think critically about the role of lifestyle planning or its strengths and potential pitfalls.

RESEARCHER The lifestyle plan was written only a month and a half ago [14months after resettlement].

STAFF Yes, and I didn't know how to do it, I just worked it out in my head. [Service Manager] she said we had to do it and we had to call the family in and she said she wants it done within a month and I thought oh shit, so I got all the papers and I sat down and read them and I thought okay, I had better do mine because I like to get my work out of the way, so I did mine and I said I don't know how to do one but I will do it anyway.

RESEARCHER So you had no training.

STAFF No, nothing like that, mate.

Although the range of goals that appeared in resident's support plans were much broader in scope than the ubiquitous hand and foot massages and walks around the Centre, confusion existed as to purpose of the process. Often resident goals reflected a transposition of the biomedical focus as central to the support role. For many the Lifestyle Planning process had become a way to monitor and manage the quality of staff performance on these circumscribed indices of life quality.

STAFF   Goal two and three – to assist [Resident] to maintain a healthy sleep pattern. Three to dressed at all times. Goal five – to maintain a good health and optimum weight. Goal six – to ensure regular assistance and support is given. Goal seven - to monitor and support pleasure activities. Goal eight to monitor and support and minimise UTI, URT, upper respiratory infections. Goal nine to ensure safe and comfortable transfers. Goal ten [Resident] has all his medications administered.

The failure to invest in training and a perception that residential settings were not resourced in ways that allowed the degree of individualised support required to achieve personally valued outcomes tended to dispirit support staff.

STAFF   In saying that I think I would be speaking for most of the staff who work for [Service Provider] in saying that we really want these people to grow and achieve a full life and in order for that to happen I believe there needs to be more staff in the houses. Some might need just one more staff in the house or some might need two but I think that's the key. Like I can give you an example. Lifestyle planning, if we wish to achieve a goal for one person, for one of their goals, we have to include all of them. We cannot have one of our support workers going off with one of them and leaving five with the others, you are not allowed to do that. That just can't happen. So a lot of the goals would be achieved because we are all in the van and we are all doing it whether that is – not so much as not getting in the van, no matter where you go, but what I am saying is you can't work on one goal specifically for one person.

And the pre-eminence of service goals as a quality assurance measure slewed the process towards being understood as a formal and inflexible service protocol rather than a way to connect people and their natural supports to a shared vision of each resident's authentic hopes and aspirations.

STAFF   It is, it is like their personal goals, goals that we have to do and come and think up things that are going to make their lives a little bit better or something they can learn from and everything else and in the end that goal just becomes one more hassle for the staff would be the thing. We don't see it as something that is good for them. I think we see it as a funding tool. That's a bit sad really isn't it. It is supposed to be a formal procedure where everyone sits down, the key workers and the clinical manager and team leader and they come up with what they feel is a good goal for that person, a smart goal, something they can achieve. The actual reality of doing it was nothing at all like that. It was somebody was pressured to come up with the ideas all in a hurry because we didn't have the clinical manager available. Didn't have the RN available, and everything had to be trotted off to the typist so there is a certain format and way of doing things. The goals had to be come so that's it.

Residents tended instead to be excluded from the process entirely.

RESEARCHER You had a meeting yesterday, do you know what that was about?
RESIDENT   No
RESEARCHER I think it was about your lifestyle planning meeting and so who was at the meeting?
RESIDENT   Um, meeting, my mother was, and a few others that I know.
RESEARCHER And where were you? What were you doing?
RESIDENT   Down here with my grandmother.
RESEARCHER In your room?
RESIDENT   Yes.
RESEARCHER Do you know what goals that they decided on, like for the year? Do you know what they are?
RESIDENT   Yes.
RESEARCHER What did they decide?
RESIDENT   They didn't tell me.

Finding new ways for people to express and translate personally valued aspirations into collaborative support and holding the vision central to support practice would seem a productive way to sustain personal growth and development. It has the added advantage of fostering innovative service delivery. To be consistent with the vision of individualised support, the process of lifestyle planning would be neither formulaic nor procedural but rather reflect the same heterogeneity as the people who found it a useful way to hold support accountable to their sense of what made life good. Some examples of potentially useful directions to contemplate emerged during the research process.

Aware of the need to consult with families but ignorant of the lore of Lifestyle Planning one resident's key worker organised an informal meeting with a resident's family to discuss what possibilities for their daughter's future excited them. The meeting took place at the family home and when it came time to establish goals, family members assumed responsibility for an even share of the objectives, inverting the arrow of support by requiring the service provider to help the family achieve the vision for their daughter they had all settled upon. Conversely the family had also took a role in supporting the service achieve the goals that they had taken responsibility for. Over a cup of tea the key-worker had transcended the historical understanding of professional services as sole provider of lifestyle support and unwittingly begun a process of community development.

RESEARCHER When I read through the goals that had come out of the life style plan, the family are actually contributing to the goal setting. They read as if there is an expectation on the family to deliver on some of those short term goals. [Mother] was looking in to like a holiday camp – and so [Mother] is doing that and [Sister] and [Key-worker] are supporting each other to have [Resident] home. It is the first time I have seen families so intimately involved in the planning process.
STAFF   Oh, okay, because we had the meeting at [Sister's] place. We actually went to her place and there was [Team Leader], myself and [Sister] the clinical leader and we sat around the table. [Resident] was there, she was present and we had the meeting there, at their family home.

As noted above, staff in residential settings also expressed a view that houses were staffed to meet the physical and not the social support needs of residents. The group was prioritised over the individual, making it difficult sometimes to achieve goals that were best met with one-to-one support. The problem was however, broader than a resource issue because it reflected a more intractable segmentalisation of residents' lives. In many respects the role division between villa staff, primarily responsible for meeting day-to-day residents' physical and emotional support needs and day support services, responsible for providing interludes of sensory and intellectual stimulation had followed residents from Kimberley Centre into the community. What this meant was that services, often unconsciously, narrowed their support horizon, making it difficult to take a wider, more holistic compass to assessments of residents' life quality.

As well intentioned as they were, the programmatic activity of most vocational centres made them unlikely contexts to embed learning.

In the first place the nature of activity that took place in Vocational Centres appeared not to have deviated far from a "psychopaedic" understanding of people with intellectual disabilities.

Men and women who were able to work or who had previously participated in complex "work-like" activity at Kimberley Centre, cut and pasted, cooked, went out in the van to town or the beach, participated in music therapy and completed puzzles, often in crowded and noisy day-base rooms. Vocational activity tended, therefore to reflect the therapeutic horizons of traditional vocational practice, not the participatory aspirations of service users. Men, for example, had limited options other than to engage in typically feminised vocational activities.

STAFF	Well they [Vocational staff] get paid well to play with them. We get paid not so well to look after them.
RESEARCHER	It is activity on masse and its not very natural learning in normal places
STAFF	That's right the finger painting and the crayoning and the pasting. That's just play school.

Rather than being reflexive and person centred, learning had to take place in the context of congregate care. Vocational Centres similarly divorced people from the natural contexts to learning. Residents baked collectively at the day-base but never cooked for their flatmates at home. They went shopping by the van-load, denying opportunities to seed a relationship with the store owner or rehearse money handling skills with an empathetic support person. And they were read to in groups, not alone and inclined in towards a support person intent on unearthing buried competence in a quiet corner of the local library.

People did enjoy the stimulation of day-bases, meeting people they knew and the structure, purpose and colour attending vocational centres added to their day, but these attributes of vocational support could be incorporated within a re-visioning of vocational service provision that accommodated a holistic vision of individual support needed for residents to feel a sense of the viability as developing people.

6

Where residents lived, worked and played at the Kimberley Centre

6.1 Assessing the "Ordinariness" of life-spaces

The deinstitutionalisation of Kimberley Centre's was the last in a long sequence of institutional closures that occurred in New Zealand. Consistent with the international experience, widespread acceptance of the principle of Normalisation featured prominently amongst the constellation of factors that led to the process of deinstitutionalisation gaining momentum.[11, 32, 35] Central to the principle was a belief that best practice required the rehabilitation of people with intellectual disabilities in normal community spaces.[27]

Normalisation became both the goal of deinstitutionalisation and a principle of service practice.[11] As a result, the scope of the first wave of deinstitutionalisation research was widened beyond its focus on adaptive and challenging behaviour and new ways were sought to measure how well the lives of residential service users approximated ordinary lives.

John O'Brien's (1989) influential monograph *What's worth working for?: Leadership for Better Quality Human Services* shaped thinking at this moment in time.[80] O'Brien (1989) argued that service providers affect the daily experiences and future prospects of the people with intellectual disabilities by influencing;
* Where a person lives, learns works and plays,
* What activities fill their day, and
* Who the person gets to know and where the person experiences a sense of belonging.

Milner and Kelly (in press) argue that intellectual threads of normalisation, are still detectable in contemporary social policy.[81] Normalisation acted to elevate the importance of the physical presence of people with disabilities in the ordinary spaces and rhythms of community life. In New Zealand, disability related social policy is currently informed by the social model of disability.[82] The social model of disability asserts that people in a society are *disabled* when physical, social and structural barriers deny full and active participation within the community.[18] Consistent with both the social model of disability and the aims of normalisation, notions of integration and participatory citizenship find direct expression in the

New Zealand Disability Strategy's vision of transforming New Zealand into a non-disabling society by enhancing the participation of disabled citizens in mainstream community spaces and activities.[82]

Given the status of *an ordinary life,* as indicative both of the broader goal of deinstitution-alisation[5] and of the vision of people with an intellectual disability experiencing *valued lives,* O'Brien's (1989) typology of the way human support services can shape the lives service users is used in this chapter as a framework for assessing the impact closing Kimberley Centre had on the day-to-day lives of former residents.

Participant observation and semi-structured interviews with Kimberley Centre staff and residents are drawn on to build a picture of where Kimberley Centre residents lived, worked and played while they lived at Kimberley Centre. In Chapter Seven, the same sources are used to establish how life changed in community-based service settings.

6.2 Where residents lived, learnt, worked and played at the Kimberley Centre

The physical separation of people who live in institutions from the community about them is commonly thought definitive of institutional living. Kimberley Centre residents were dislocated from the world beyond the Centre's expansive grounds. During Phase 1 of the project, only 1.1 percent of the of the 129 hours residents were observed occurred beyond Kimberley Centre's gate (Figure 6.1).

To residents, going for rides or visits home meant stepping beyond a circumscribed life-space and the ordinary, scripted routine of villa life. They were prized moments, perhaps all the more important because their relative infrequency amplified the contrast between being in and being out of Kimberley Centre.

RESEARCHER Are you enjoying life?
RESIDENT   Yes thank you
RESEARCHER What do you especially like doing?
RESIDENT   Going out for rides and I like going home and I like going to things
RESEARCHER How often do you go out of Kimberley?
RESIDENT   Out of Kimberley to town - not very often.

Few opportunities existed for Kimberley Centre residents to be present in ordinary community places and those that did were typically ritualistic in character and initiated and moderated by staff.

Motivated villa staff might select residents in lifestyle villas for a van ride in the weekend. In one behavioural villa, for example, a Sunday trip to the Warehouse had become cemented in as part of villa culture and residents went on alternate weekends. Occasionally residents made the Day Support list for a breakfast at the Levin Cobb and Co and a small number regularly attending the Stairways dance, were they met Kimberley Centre residents that had left and were now living in the community.

STAFF   Currently he [Lifestyle villa resident] has been going out on the weekend, Saturday or Sunday – it's become a regular thing just of late so he would either go out on the Saturday or the Sunday but on average I suppose he would be going out once a fortnight I guess, outside the centre. And

Figure 6.1 — Mean proportion of total observed time resident participants were recorded in different activity spaces at the Kimberley Centre.
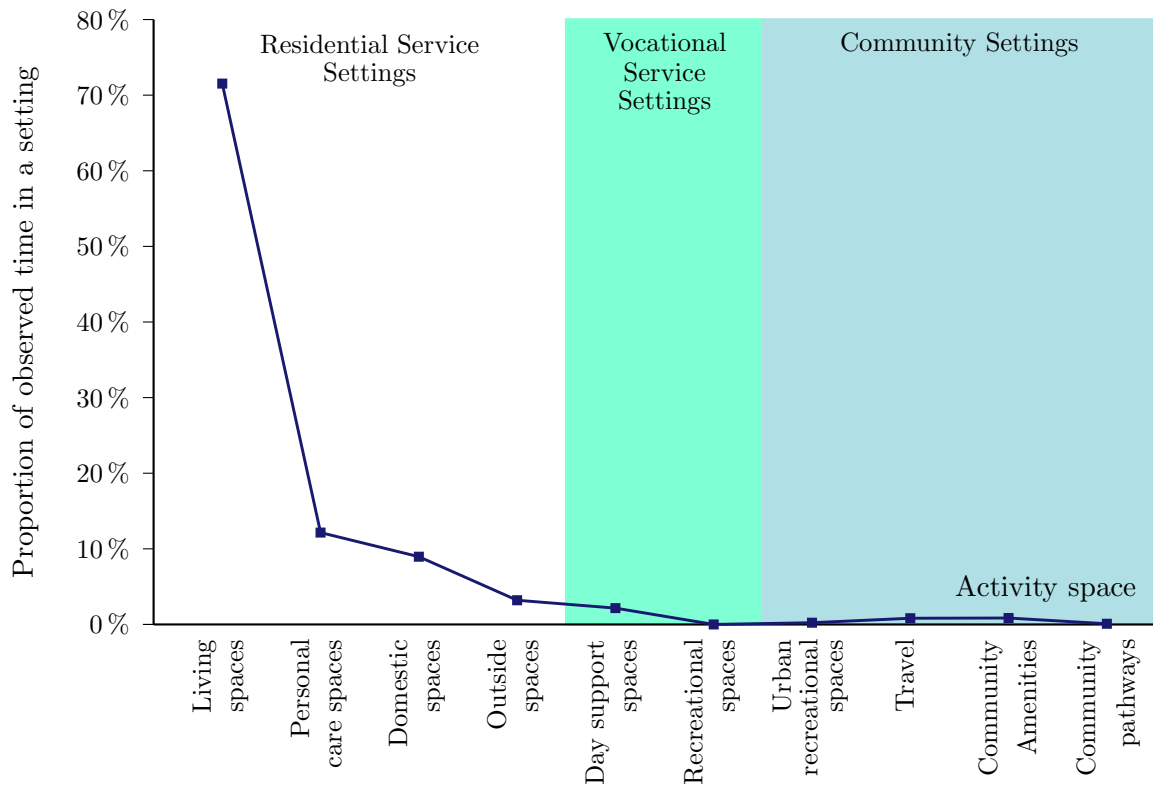
> then he has got his mother of course that he sees a little bit less regularly, but he also goes out maybe to the Cobb & Co for breakfast, that sort of thing, on a rostered sort of system. He gets out now and again. The weekend thing is something that is sort of organised by the staff. There are a few guys here that like to get out because the guys, a lot of the guys here they seem to enjoy just going for a ride and driving around so a few of the guys here who quite enjoy organising that and they go out in the morning or the afternoon and then the next day they change it around so everyone gets a bit of a go.

Families were often the conduits to the wider community. A small number of families were able to take their relative home for short breaks, reconnecting them with family lore and the places and patterns of life they knew before admission. Elderly mums took care of sons or daughters without support, maintaining for residents a highly valued sense of familial belonging. Families able to make the journey also tended to take their relative to town or out for a picnic when they visited. But for most residents, life unfolded almost exclusively within the boundary of Kimberley Centre.

RESEARCHER Participation and activities in the broader community, you are saying most of her life happens around here other than mum taking her out to the bach and stuff like that. Do they do other stuff? Do they go out?

STAFF No she doesn't. I do believe she might experience that sort of thing when mum takes her out but no, it doesn't happen for her here at Kimberley, no.

The only time residents tended to go beyond Kimberley Centre with one-to-one support was for hospital or other specialist appointments. Generally they experienced the community as part of a large group of Centre residents, often skirting town for the countryside that rolled past the windows on a weekend van-ride. Residents who were perceived as challenging or whose medical needs made transport difficult had the smallest life-spaces. In the three years prior to closure that the research team observed Kimberley Centre residents, a number of participants never left the Centre.

STAFF   There are other staff and they don't like him, they will sit him in a chair and he doesn't like that, so yes, what else would I like for him. I don't know how he is for rides and that. I don't know if he has done that, we had one girl – her mother was having a birthday party over in [Town] and him and another resident went for a little ride over there and apparently he was fine with that. He hadn't been out for a ride for the whole of the year, that was his first ride out of the unit in a year.

The potential of institutions to sever people from the community is commonly acknowledged. Less well documented is how circumscribed resident's lives can be inside the grounds of institutional settings. Kimberley Centre's immaculate and expansive grounds contributed to the illusion of spaciousness and activity. When families first spoke of the immanent closure of Kimberley Centre, the loss of the sense of freedom communicated by the size and openness of Kimberley Centre often featured in their narrative.

FATHER   As soon as you drive in the gate, it is lovely, it is a beautiful space, but every building you come to it had atmosphere, it was well built, there was no glass, they were well laid out, there's trees and lawns and those sort of maintenance are very high these days trying to maintain those – I don't know how big it is but I think it is more than 10 acres, it might be 20 or 30 acres, but anyone can find their way to any of the villas. I can't see that sort of happening again in a city where they will find that amount of room. You know you go in the grounds there, there is an area that has got a beautiful garden for the disabled set up for the kids and they have everything there, the aviary, bird cages, the birds and things. Now there is nothing. It is very appropriate for some of them who are in there and that's including our son.

The reality for residents was that most of their lives were lived out in relatively few and well populated spaces. The villa was the pre-eminent location. Kimberley Centre residents spent, on average, 95.6 percent of the time they were observed within the villa environment (Table 6.1) and were only ever fleetingly present in either vocational (3.2 percent) or community settings (1.1 percent). Although the pattern of being confined to the villa was generally consistent for all residents, differences did emerge in the geography of people's lives that reflected the way they were understood.

People perceived to be *challenging* appeared to have the greatest degree of freedom within villas, but spent most of their day locked into them. On average people living in Challenging Behaviour villas spent 97.4 percent of observed time somewhere in their villa. Staff were quick to point out that this had not always been the case for these men and women, but with the closure of workshops retrenchment in Day Support programmes, limited opportunities existed to meet the intellectual and recreational needs of Kimberley Centre's most adaptively competent residents.

Table 6.1 — Mean proportion of total observed time residents were recorded in activity spaces at Kimberley Centre by villa type

	Challenging Behaviour villas		Multiple Disability villas		Lifestyle villas		Kimberley Centre total	
	M	SD	M	SD	M	SD	M	SD
Living spaces	80.0	2.7	69.8	29.5	66.1	22.3	70.5	23.0
Personal care spaces	3.8	5.6	25.1	32.2	6.7	9.3	12.6	22.0
Domestic care spaces	11.5	6.4	2.0	4.2	14.7	14.4	9.5	11.5
Outside spaces	2.1	6.5	0.4	1.5	5.5	12.6	2.9	8.9
Total in Residential Setting	**97.4**	**3.5**	**97.4**	**5.6**	**93.1**	**12.5**	**95.6**	**9.0**
Total in Day Support	**0.1**	**0.4**	**2.4**	**5.3**	**5.5**	**11.7**	**3.2**	**8.4**
Recreational spaces	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Urban recreational spaces	0.5	1.6	0.0	0.0	0.3	1.1	0.2	1.0
Vehicle	1.9	1.9	0.2	0.6	0.8	1.2	0.8	1.4
Community amenities	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Community pathways	0.0	0.0	0.0	0.0	0.2	0.9	0.1	0.6
Social spaces	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Total in Community Setting	**2.4**	**3.1**	**0.2**	**0.6**	**1.2**	**2.1**	**1.1**	**2.1**

RESEARCHER How often would he go to Day Support?

STAFF 1 Not very often because his well they are categorised in to what classes they can provide for them and it is not many that they can provide for him that he would even be interested in.

RESEARCHER So who makes that categorisation?

STAFF 1 Well DSS do on assessments. He used to be heavily involved in cultural things but then through restructuring and stuff like that we have lost some of those services. More often than not [Resident] is managed here in the ward and even our options are limited to what we can offer him but what he does request we give. He does enjoy reading and that's just magazines that he just flicks through. He is not reading the words but he is looking at the pictures.

STAFF 2 He has been away on lots of trips and for a lot of the guys here they have and he loves that and he has performed really well. It is sometimes quite a surprise how much of New Zealand a lot of these guys have seen.

STAFF 1 No it has been pretty good, and that just goes like I was saying before about the way [Resident] changes when he is out in the community based environment, or a function of some sort, he is completely different, he is more excitable, more happy, more laughing and all that sort of stuff.

RESEARCHER Do you think there is something he has got to look forward to therefore, you know like if these things are more accessible to him in the community? Do you think it will happen?

STAFF 1 Yep it will.

STAFF 2 He has just come to exist out here and that's it.

People supported from within Multiple Disability villas were the least likely to get beyond Kimberley Centre. Day support would sometimes visit villas and a few residents would "go

out" for an hour or two each week for sensorial programmes, but for most, days rolled on in the same settings. During Phase 1 observations, 98.5 percent of resident time was recorded as spent in either residential or vocational service settings (Figure 6.2). Residents in Multiple Disability villas tended to be understood as frail and meeting the physical and intimate care needs of villa residents took precedence over all other support needs.

Figure 6.2 — Mean proportion of total observed time resident participants were recorded in activity spaces at the Kimberley Centre by villatype.
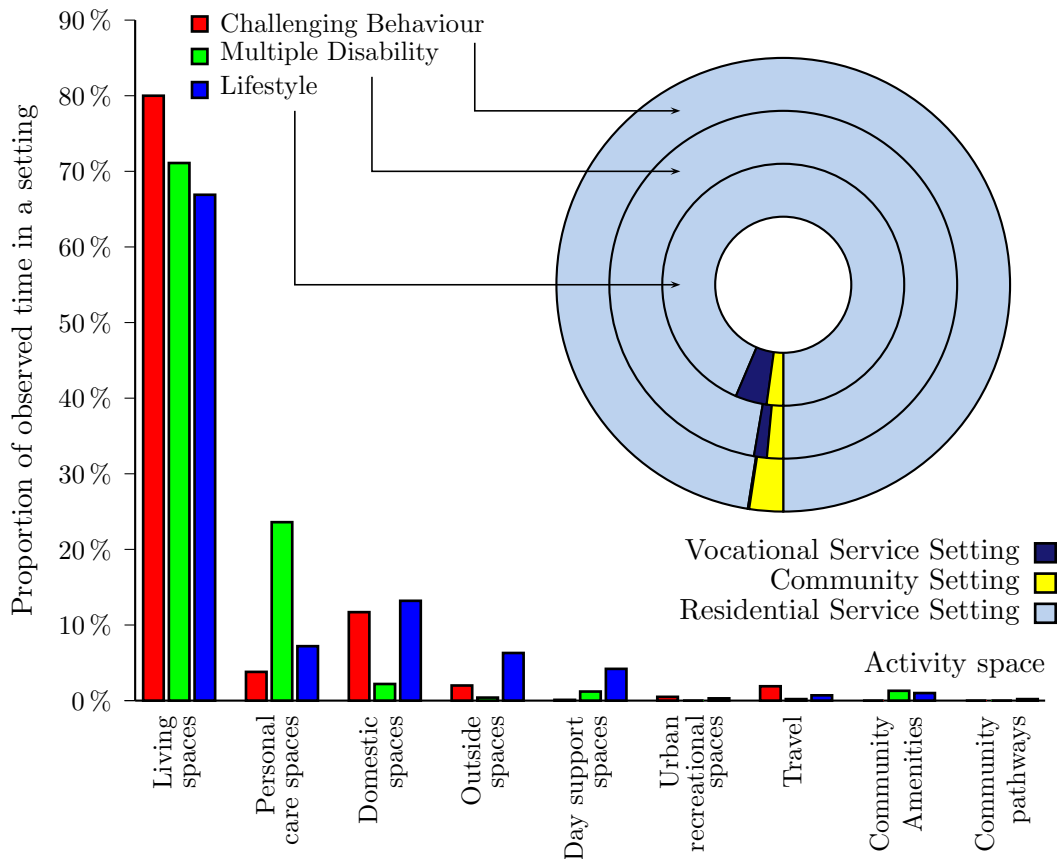
A more fine grained analysis of residents' activity spaces reveals that even within the villas, a single location tended to be pre-eminent. For people in Multiple Disability villas, the dayroom (63.5 percent) and dormitory (15.0 percent) emerged as primary locations. Together, residents on average spent 70 percent of observed time in these two settings, attesting to their highly sedentary lives.

For residents in Lifestyle and Challenging Behaviour villas, the dayroom (65 percent) also featured most prominently in their life-space. Participants would most often be found in "their" chairs in the day and dining rooms. Explanations by staff for the selection of particular chairs by residents usually indicated a high degree of sensitivity to the subtle ways places were nuanced for residents. For example, staff would speculate that a resident could *watch down the corridor from there,* or *hear the radio in that seat,* or *watch who comes and goes from the cupboard.* Many participants appeared to be habituated to particular locations and were supported to exercise proprietorial rights over small areas of personal space within the villa.

Figure 6.3 — Mean proportion of observed time resident participants were recorded in different villa spaces (Phase 1 – In the Kimberley Centre).
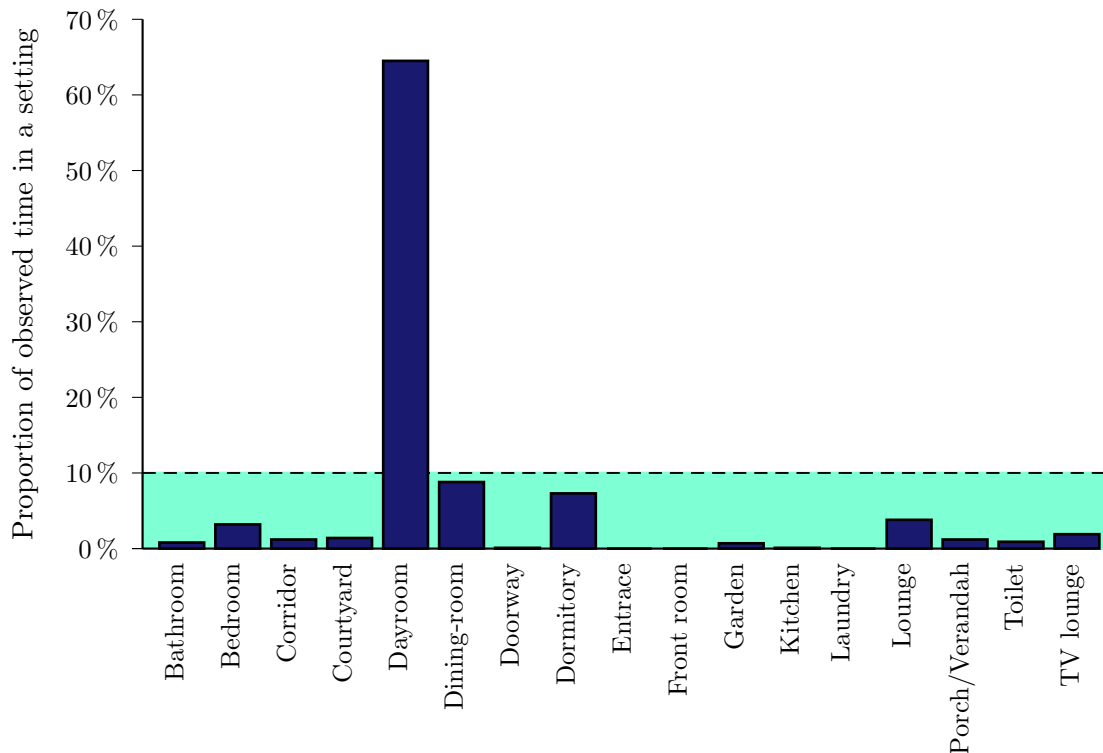

```
Villa dayroom
2.47    Shuffles back to chair, Pulls sleeve of resident sitting in chair
        to remove him. No dialogue. Encouraged by staff to evict:
        ''That's right, pull him out of your chair.''
        Vocalises (unheard).
        Pushes himself backwards into vacated chair. Grins, crosses legs.
        Brief rocking. Coughs and turns to monitor staff conversation.
```

In villa dayrooms second hand seats and couches lined the walls. A table, where staff would read or write and to which residents might drift if they wanted to engage staff also tended to be sited towards the outside of the room. In some villas a single resident might use the table for a programmed pot of tea in the interludes between staff paperwork. Between was an expanse of floor that residents would periodically wander or sit in. A muted television or radio usually played. Some residents paid fastidious attention, but for most it was the auditory backdrop to their continual monitoring of the ebb and flow of villa activity. The rooms were warm, bright, generally quiet and looked out towards the well kept but unpopulated Kimberley Centre grounds. The number of residents in a villa dayroom did not exceed 13, but fluctuated depending largely on who was away with Day Support Services. Villas were staffed at a ratio of 1:5, but breaks, paperwork and the need to meet individual support needs demanded staff time, often leaving one person to staff an entire dayroom.

STAFF   There is not all that great a variation (to people's days). There used to be a lot more van rides at one time. But for whatever reason they have stopped. You have got 2 staff looking after 10 residents, we used to have 2 staff looking after 12...so it actually doesn't actually enable you to have

much variation when each resident is supposed to be sighted every 4-5
minutes.

RESEARCHER So does (resident) get beyond Kimberley very much?

STAFF Not these days I don't think. No it would be a rarity I think.

Staff appeared to act as keepers of dayroom equilibrium, including maintaining the well established rhythm of the institution. Residents whose vocalisations or behaviour was considered disruptive tended to be directed to enclaves within the dayroom, typically either the sunroom or small villa balcony. The preamble to a running record below is a typical prelude to observations that took place in villa dayrooms.

```
[Resident] hides his face and lies down on couch in enclosed veranda.
Three other residents in there, one sitting (strapped) into arm chair.
One man wandering and sitting and 3rd in a wheelchair with tray attached.
This man grinds his teeth.
Focus person has a plastic bottle that he is popping bits off.
5 other men are in the day room with TV going.
One wanders, the rest sit around the walls.
One staff is working in there.
Looks up from his paper periodically to talk to residents.
```

There were no dayrooms in some wings of villas where people with multiple or more profound disabilities were supported. Here, living spaces were configured much as a hospital ward. The main dormitory was flanked by residents' beds, separated by room dividers. An isle that bisected residents' beds, acting as the main thoroughfare to the ward. An effort had been made to personalize these spaces with photographs, soft toys, ornaments and colourful duvets bought in by the residents' families. At the southern end was a small, sometimes windowless lounge, usually furnished with a television (going), a selection of toys, comfortable chairs and space enough to take a few wheelchairs. Residents who lived in the wings of these villas generally spent their time either in bed or with their wheelchair parked alongside their bed or in the small lounge. In contrast to other villas, staff were the most lively actors, ever moving in a seamless cycle of monitoring drips, flushing, moving and attending to the personal care needs of residents. On breaks they sat with each other, outside with a cigarette and coffee and in lull times they would sit in the small lounge and watch television with the cluster of residents that were in there that day.

As noted above the range of locations in which activity took place within villas tended to be related to the adaptive functioning of residents and the social practices that contributed to villa life. Participants in behavioural villas were observed in a greater range of locations than other participants, whereas the lives of people with multiple disabilities unfolded almost entirely in the dayroom or dormitory (Figure 6.3).

For people supported in Multiple Disability villas, most of the other locations in which resident activity occurred was associated with moments of personal care. Participants in behavioural villas spent 11.5 percent of their observed time in the dining room and 1.3 percent in the bathroom and participants in lifestyle villas 13.8 percent and 0.7 percent of their time in these locations. The principal way that days at Kimberley Centre appeared to be metered out was by the distance to or from moments of orchestrated personal care. Showering, dressing and undressing, ablutions and meal times divided the day up. Morning and afternoon tea came to residents on a trolley but breakfast, lunch, dinner and sometimes supper involved a communal walk to the dining room.

```
Villa dormitory
9.47     What's the time Nurse. Pulls on ear, moans.
         Smiles calling out to staff: ''Coffee?''
         Staff: ''Not yet, it's not long since you had a coffee.
               Not till morning tea time.''
         Staff walks out to attend to another resident.
         [Resident] continues to talk aloud about ''lady making coffee
         for her at morning tea time...''
         Calls out: ''What time make coffee nurse?.''
```

Staff generally controlled the timing of personal care and migration to and from the dining room, but the rhythm seemed to have been built up over years of finding the most efficient way to meet residents' needs quickly. Both staff and residents anticipated the subtle environmental cues that signposted these events.

```
Villa dayroom
3.42     Leans right forward. Spots drinks trolley.
         Stands immediately.
         Takes bag off crosses the floor quickly with other residents...
         [Resident] drinks quickly, puts cup down on the table and
         walks back inside (villa dayroom).
         Sits in ''his'' seat, pats chest and vocalises, spots observer
         Laughs and fingers in ears, head back opens mouth,
         turning head from side to side.
```

Similar chronologies were used to calendar longer periods. Residents that were able located themselves within a week through their day programme or, for the group of men in one of the behavioural villas, how many days they had to go before their regular Sunday trip to the Warehouse.

There were few places that residents could choose to go at their discretion. One participant was at liberty to visit other villas. His bike could occasionally be seen propped up in unpredictable places. However, for the most part, participants' days were programmed and other locations, including the expansive Kimberley Centre grounds, were simply places of egress to predetermined destinations.

Paradoxically, residents of behavioural villas, who lived behind locked doors, had the most autonomy within villas, many being free to come and go from their bedrooms. Some expressed a desire to go for a walk or visit the canteen, but staff, mindful of staffing levels and the need to sight residents regularly, were typically unable to accommodate such requests. Moments of personal care therefore represented the primary way residents could interrupt the stretch of time between the predictable elements of their day, and staff exhibited great empathy and insightfulness to facilitate independence in meeting individual personal care needs promptly.

```
Villa dorm
11.30    [Resident] ''Help please,'' gets up independently.
         Bends to put book down.
         Staff anticipates and guides [Resident's] hands to her back.
         [Resident] leaves with staff towards the toilet.
         Walks with a rocking but steady gait,
```

```
talking as she goes about ''being good...''
Led back to chair, bends to pick up book.
Asks staff ''Nurse, can you put my book back?''
''Please.''
Continues gesturing, open palms, hands towards face.
```

It must be acknowledged that sampling limitations may have led to a failure to capture the entire range of places participants living at Kimberley Centre experienced. Alternative locations feature infrequently in residents' life space and weekend observation, when residents were more likely to be beyond Kimberley Centre were under represented in the sample. Missing, occasional destinations included engagement with the Day Support Services programme, which varied greatly for participants. Some went nearly every week-day and impatiently waited out the weekend for their programme to restart. Programme elements included art or themed conversation. Other residents might be taken by day support staff to beat an accompaniment to music with other residents in a vacated villa or visit a room set up to provide sensory stimulation for more disabled residents. One participant went once a week to an on-site therapeutic pool and two other participants belonged to the "Kimberley Centre Chimers," who met regularly to practice their bell ringing. People with multiple disabilities seldom went anywhere.

Like other major institutions, Kimberley Centre had historically promoted itself as a *self-contained village,* but in Kimberley Centre's formative years, the first superintendent, Charlie Guy described attempting to *open the gates a bit wider for the man in the street*[19]. Hunt (2000) argued, a community presence had contributed to the humanising of resident care at Kimberley Centre.[19] Families and the Horowhenua community had historically supported church, youth, sport and cultural clubs at Kimberley Centre. Vestiges of the culture of self-sufficiency remained. Day support continued to organise summer and winter festivals. Dances and movies were routinely held in the hall and some residents attended church on Sundays. Social events provided an opportunity for residents to meet staff and residents that they had become separated from by the circumscribed and timetabled culture of villa life, giving events additional resonance.

STAFF   Because he has been here for such a long time, he knows a heck of a lot of people and staff and when he goes to these places he doesn't get to see them a lot of the time unless he is going past going from one area to another area that's the only other time that he can catch up with a lot of people. He has what he deems to be his peers here. The other residents that he comes in contact with are past acquaintances and friendships that he has had over the years. They are like family

RESEARCHER   They come from another time?

STAFF   He goes up 'aaahh' and waves to those people and that's him, he just sits there and has a jolly good old time, he likes music, he likes to have a dance, he likes to just be a part of the festivities. He is really in to that sort of stuff.

A small number of residents had also carved opportunities for moments of genuine privacy and the ability to self-determine activity beyond the gaze of staff.

STAFF   I would stay interaction is the main thing, he gets to meet the variety of staff that come through the place. The friends he has around the centre. I think he enjoys the – I mean it is a big premises and he enjoys the freedom

of being able to go out by himself. When he goes for his walks, he goes
by himself, takes himself out and goes over maybe to the chapel, he goes
to church on Sunday so he has that so I suppose it is like his community
here really isn't it. His work, his friends, his social side. And I think he is
someone who likes to – I think when he gets more community aware and
gets out and about a bit more, I think it might take him a bit of time
to adjust and become comfortable in the surroundings, I suppose he has
been used to these surroundings for so long.

The Kimberley Centre chapel was a different space where the ordinary power relationship
between staff and residents was inverted. Residents had more active and staff more passive
roles in the ministry and in supporting people to attend. The church was also a place where
the lives of people from communities beyond Kimberley Centre intersected with the lives of
people within, but in a context where residents had the greatest cultural insight. At the
funeral of one of the study participants, for example, fellow residents took centre stage in the
celebration of his life and in keeping the important cultural rituals of the chapel, ringing the
chapel bell to herald his leaving the Centre for the very last time.

7

Where residents lived, worked and played beyond the Kimberley Centre

7.1   Finding a place beyond the institution

Progress towards the vision of a non-disabling society is benchmarked in the New Zealand Disability Strategy against the presence of people with disabilities in mainstream community contexts. Research suggests that whilst the policy of deinstitutionalisation has increased the presence and use of common community resources by adults with an intellectual disability[67,83] they have typically remained absent from the types of social relationships that would impart a sense of community membership and belonging. Three separate investigations into the community experiences of New Zealand men and women with disabilities all characterised the social position of people with an intellectual disability as being *in* but yet to be *of* their communities.[9,74,79]

In order to determine what impact leaving Kimberley Centre had on the spatial and social integration of former residents, the measures used to explore where residents lived worked and played at Kimberley Centre were repeated in Phases 2 and 3 of the project. In this chapter, data drawn from participant observations and the narratives of Kimberley Centre residents and their support staff provide a picture of changes in the cardinal life-spaces of home and the vocational centre following resettlement. Participant narrative, direct observation and data from the ComQOL-ID is also used to explore how well Kimberley Centre residents were embedded into the communities to which they moved.

7.2   Where residents lived, learnt, worked and played beyond Kimberley Centre — Residential settings

The longer residents were in a community-based service the more likely they were to be observed beyond the residential setting. Despite spending an increase proportion of their time in vocational (4.8 percent) and community spaces (10.4 percent), however, the residential

service setting continued to be the cardinal space in resident's lives a year after resettlement. On average, residents were recorded as being in their home for eighty-five percent of the total time they were observed in Phase 3 of the project (Figure 7.1).

Figure 7.1 — Mean proportion of total observed time resident participants were recorded in different activity spaces at and beyond the Kimberley Centre.
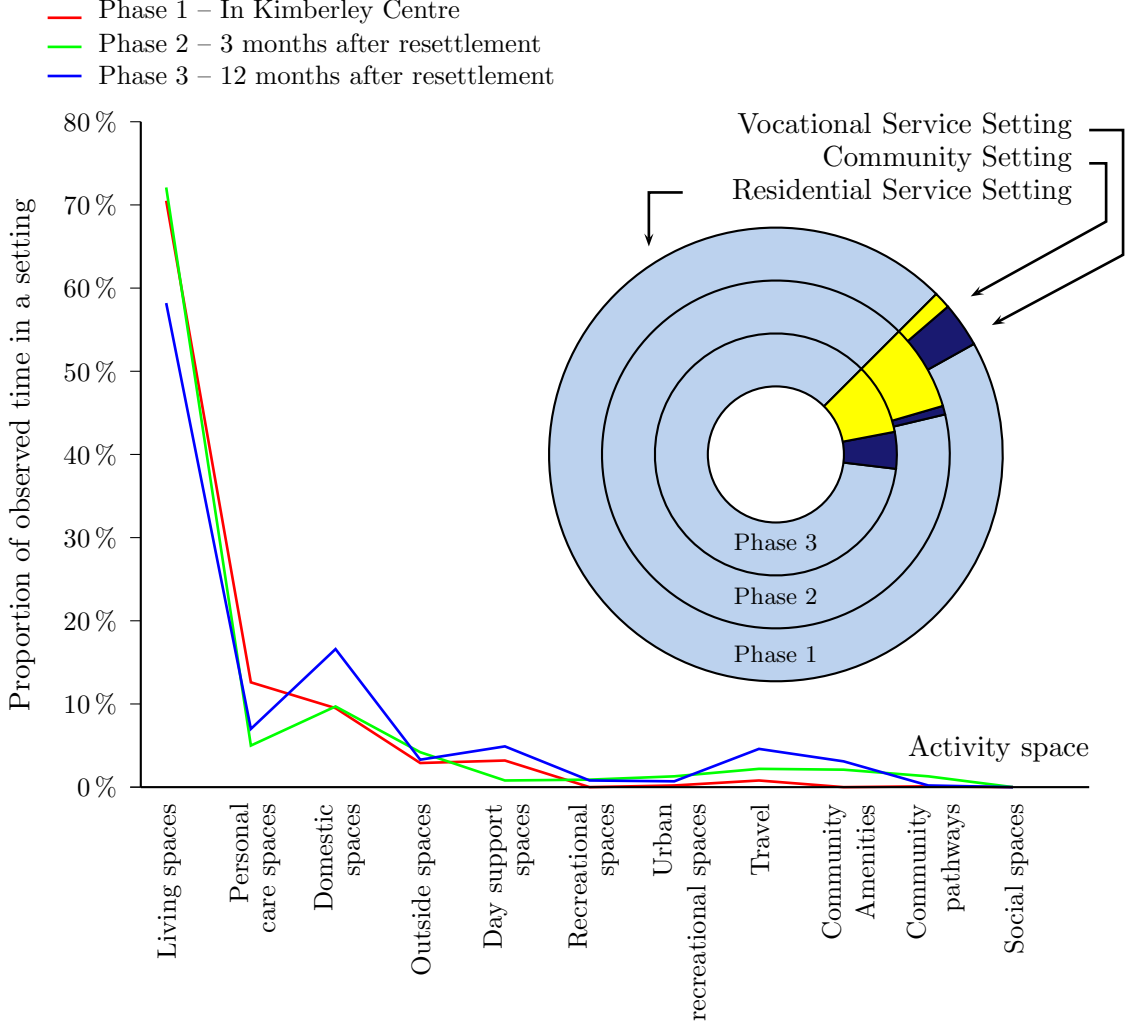
Being in a community-based residential setting was, however, was a qualitatively different experience. Consistent with the normalisation principle, residents were resettled to architecturally typical dwellings within ordinary neighbourhoods. The houses tended to be large and well appointed, although most were fenced and gated. At Kimberley Centre, villa lives severed residents from normal domestic routines. Because most community-based settings were open plan, even the most impaired residents were vicariously engaged in normal day to day household activity. Residents heard the throb of the washing machine, smelt lunch being prepared and were occasionally able to monitor the ebb and flow of the neighbourhood beyond.

STAFF   Yes, but just that whole surrounding was more light and airy. I think when the light is going in there, it is quite bright, light and airy and with all the people around, I think it has got a good atmosphere. And I like the layout of the house because when you are in the kitchen, she can see

in the kitchen, she can see in the dining room, she can see us going up and down the corridor. I just think it is a great open, because we move the chairs around to different positions and things so I think that actual layout is really great. I think the environment is one hundred and fifty per cent better. I mean she comes out here and sits on the deck and when she meets up with friends. That's definitely a bonus because they can actually see town life. Do you know what I mean, if you are in a cul de sac and there are just the other houses whereas if you go to a café or just go for a walk around town, you see people, there's cars, do you know what I mean, you feel an atmosphere of town which is different from a suburban street.

Researches have argued that "home" has a symbolic function, acting as an interlocutor between an individual and the community by conveying messages about the self identity and social position of the people who live there.[73] Residents able to express their thoughts verbally generally communicated a sense of pride in their new homes, suggesting in terms of the wider symbolic meaning of "home," their new living situation communicated radically different social makers of themselves as men and women.

RESEARCHER Do you like your new home [Resident]?
RESIDENT   Yes
RESEARCHER What do you like about it?
RESIDENT   It's good value. It has got ranch sliders
RESEARCHER Its quite flash isn't it, a big lounge
RESIDENT   Yes, my own bedroom. I had it before I left, I was in [Villa] but I had my own room in the end.

Those unable to communicate verbally found other ways to express their pleasure.

STAFF   She found her way to her bedroom which we used to just leave open and had a throw over on top of her duvet and quite often she would just go and lay on her bed which she does like that too. That's another place where she found she needed peace and quiet was to go and lie on her bed. Her family had been in and put all these photos up on the wall so she lays in bed, and she does, she lays there and looks at them and you go in there sometimes early in the morning and she is propped up on her pillow looking at them with a big smile on her face. I just really believe that it has been the best move ever for [Resident].

When families and staff were asked about what impact the move to community-based had made to the life quality of Kimberley Centre residents, having their own bedroom featured prominently as a perceived improvement in life quality.

STAFF   He has got his own room, he has got his own clothes in there and he is quite happy really and he potters around in his room a lot and he loves it. He will strip his bed and then remake it, he will look in his wardrobe with his shirts and things hanging in the wardrobe and he likes that and he feels they are his own and he gets a smile on his face and that's nice, that's a positive thing.

For many residents their bedroom represented a sanctuary for reasons that went beyond its ability to provide privacy. Tall men got large beds and bedrooms became the repositories of all that was uniquely a resident's own. The portraits that hung on walls belonged to

no other family and the furniture and treasured possessions were now unequivocally private property.

RESEARCHER Like what do you think [Resident] likes about here [Staff]?

STAFF Her own bedroom, her own stuff. Her own stuff and knowing that nobody is going to go in to her room and touch her stuff. None of her stuff is going to go missing. She has a space for her different clothes and she knows that although she tends to mix them all up but just yeah, very much her own space. She has a nice room. She likes her room, she does.

Many residents, and especially those previously supported in Lifestyle villas, had few possessions at Kimberley Centre. Some jealously guarded toys they had spirited from Day Support, secreted objects in fresh hiding places or carried items of significance about the centre in bags kept within easy reach. Having one's treasured possessions so publicly and yet inaccessibly displayed in residents' bedrooms may therefore have communicated something of the permanence and social value that O'Brien (1994) argued was an important psycho-emotional functional home ownership.[22] The bedroom also represented a space into which residents and their families could write something of resident's unique personality with furnishings and care.

The more home-likeness of the community-based service and opportunity for the individuality of residents to find public expression confronted negative or biomedical understandings of Kimberley Centre residents. At Kimberly Centre, some families found it difficult to *see* their relative behind what one family member coined the "Kimberley uniform."

SISTER The kids were all – some of them were half dressed, some of them were not dressed but they were all sitting there rocking and yelling with maniac screams and yells which [Resident] up until she went in – she did scream but not like these people. They all had a unified voice and had all become a copy of each other and they had all become one person. Her identity and her personality got stripped away. . .

The inviting and well-appointed community-based houses made it easier to humanise relatives. When Mirfin-Veitch spoke to the family members of residents resettled from Templeton Centre, she reported that siblings in particular, had enduring memories of family visits to their brother or sister living in the institution. Mirfin-Veitch (2005) described sibling recollection of visiting as often freighted with a sense of sadness, perturbation and guilt that made visiting difficult.[32]

The brothers and sisters of Kimberley Centre residents told similar stories.

RESEARCHER And when you visited, your impressions of Kimberley at the time, how did you see it.

SISTER Very frightening, I mean we were only kids and it was very frightening because in those days I mean the children were all walking around the enclosure and that, they had a bit train at Kimberley and we would go and sit there and all of a sudden all these kids would come to look at me and it was very very frightening but over the years you got used to it but I never went in to her room on the wards, you didn't go in there.

Having comfortable homes made it easier for residents to host their family member. The experience described above of *never (going) to her room on the wards* was not atypical. Many families preferred to take their relative out, to walk the grounds or to meet their family member in the visitors lounge. Visiting community-based homes was a different

experience. Family members stayed for a cup of tea or shared a meal, getting to know their relative's flatmates in the process, sometimes incorporating them within an expanding field of care.

RESEARCHER   Can you tell me about Christmas. I understand you spent the day at [Son's]

MOTHER   He enjoyed his day, he really was happy [Staff] rung me on the Saturday to talk to me about that money that I said I didn't know about and then she said the staff asked if you would like to come up and spend Christmas day with [Son] and have dinner with him and she said in fact you can stay the night because they have got that room there and I thought well I might take you up on that. I said normally I would usually have [Son] up here, I would do Christmas dinner and I was worried about how I was going to manage because I didn't have much strength in that. . . I also gave them some money actually because it was nice of them to ask me to go and there was something they wanted to get for the house and I told [Son] I was coming and he was happy. It took ages to get there but I got there and [Son] was at the door with a box of chocolates for me and it was wrapped up and he had a parcel for me so he was so thrilled.

RESEARCHER   Did you enjoy being there?

MOTHER   Yes, yes it was nice, yes, they did a nice dinner.

RESEARCHER   I was just thinking that is a real contrast isn't it because would you have felt able to do that at Kimberley.

MOTHER   No I wouldn't have done anything like that. Yes, they invited me to stay so I said I will stay the night and so his face lit up, he was really happy. He played his musical thing. I put it up later in the afternoon because the others don't take much notice and that's when I said about [Flatmate] joined in when I said about it and I pushed the button and played Waltzing Matilda and her voice from there and I said would you like to come and sit over here and she came but she just had her head down and then I said now we will have this one, Waltzing Matilda and I pressed the thing and she started singing and her hands went up, I was really thrilled, this was amazing really, because I had never seen her do anything before, she had just always got her head down.

Living in beautiful houses also appeared to dim what O'Brien (2007) coined *the bright line* separating staff from residents.[84] In the ordinariness of family homes, it was easier to acknowledge the shared humanity of people who lived and worked together. A number of staff supporting people in community-based settings had formally supported the same residents at Kimberley Centre. In the narrative below the staff member describes how her understanding of a women she supported in both contexts was informed by differences in the limits to which she could express her care.

RESEARCHER   You said yesterday "we knew residents as individuals in Kimberley." I wouldn't wish to contradict that at all but I was just wondering whether it was easier to get to know people here [community-based setting] When we stood in [Resident's] room you said "look it is more personalised, it is more individualised."

STAFF   It is, she had a curtain and a cubicle. Where could she stick a television, – it is more individualised and personalised. I mean I know that we had

individual toiletries but half the time we just tended to use whatever was closest but now she has her toilet bag in her room. She has her own little toilet box with her toiletries in, she has her hair dryer sort of thing, it is more personalised. When we go shopping, we don't go shopping for all five at once, they take her, and they shop for [Resident], do you know what I mean, it is [Resident's] shopping day.

RESEARCHER   As opposed to. . .

STAFF   As opposed to the clothing lady going and buying ten people's at once, so that's what I mean by more personalised and more kind of things like when you go shopping you are thinking of [Resident] and you might have [Resident] with you and you might not but it is all about [Resident].

Residents contributed to the dissolution of social distance too. Sharing the same spaces and routines gave residents the opportunity to contribute to the maintenance of their own home and the wellbeing of those they shared it with in ways that were difficult at Kimberley Centre.

STAFF   She's just getting used to setting the table with place mats and that sort of thing. She is very good at bringing things to the table. She is one that will go in to the kitchen and watch the staff and bring out food. She likes to do that.

And the ease of egress meant that people were at liberty to come and go in ways that were similarly denied by the regimented regime of villa life.

RESEARCHER   What do you think [Resident] likes about living where he is living?

STAFF   That he can decide where to go within his home, he can decide where to go and what he wants to do next. If he doesn't like there was – I remember the other day when something was put on the table and he just shoved it aside saying I don't want that, I don't think so, and he just walked off and then come back and that's not his only chance to get something, if he wants something he will come back and get something else, it is not you eat now and that's it for the rest of the – until the next sitting you can have. [Resident] is able to make his own mind up and then he will walk out of his room and he will go in to the barn, and go in to the lounge, he can go outside without having to have staff follow him.

7.3   The limitations of architectural typicality

Consistent with the principle of architectural typicality, domestic spaces in community-based settings were modelled on an able bodied template. For some residents, therefore, the physical design of properties that should have been their home failed to accommodate for their impairments. For people in wheelchairs or who had difficulty moving limbs ordinary domestic tasks became extraordinarily difficult. Sinks and oven tops were above eye-line and cupboards and phones beyond arms reach, reinforcing the conventional roles of staff as providers and residents as passive recipients of professional support. Small architectural features, like the lip at the bottom of ranch-slider doors could have major quality of life implications confining people in wheelchairs to the interior living spaces of their homes.

The physical location of houses could also severe people from their community. Most houses tended to be situated away from local amentities in commuting neighbourhoods on the

outskirts of town. They fringed cul de sacs or were amongst the last houses going out of town. Being beyond easy walking distance to a local shop other civic amenities, denied residents the continuity of presence likely to lead to their becoming assimilated into the social landscape of the community. It also made it difficult for residents to seed relationships or achieve the valued social roles of neighbour or community member. When staff were asked about the potential for residents to develop relationships of place many commented on the lack of contexts or opportunities for interaction within the neighbourhood.

STAFF   No we don't have any of that out there other than probably the mailman.

There were few opportunities to develop relationships of place and few opportunities for the community to become comfortable and confident with their new neighbours. Some exceptional services had found inclusive community contexts where people were beginning to develop relationships through a sustained presence, but the geography of resettlement meant that many residents were as socially isolated from their local community as ever they were at Kimberley.

STAFF   They never stay in one place for long because the only outings that we take them are you know like dentists, doctors, hairdressers, they only have to do the job and they are gone and if we take them somewhere it is really just with them and their picnics and that and then they go straight back home again so there is no real way for them to get out and meet other people, there isn't, no, there isn't, because I thought about that. Yes there isn't, there is no way for them to get out and meet other people.
RESEARCHER   You don't even have a neighbour.
STAFF   No, nothing. That is a bit closed off, yes it is, definitely.

Cummins and Lau describe social relationship and the sense of communal belonging it engenders as the *heartland of life quality*[85]. The siting of most community-based residential services made it difficult for services to support Kimberley Centre residents locate themselves within the social heartland of their community. The impact is perhaps best illustrated by contrast. Two smaller services providers were supporting residents with significant care needs in houses located on the very edge of the shopping centre of their rural town. Staff would, without question, take one person with them every time they went to post a letter or choose vegetables for tea or stroll to a café for lunch. Because being with staff in town had become an ordinary day-to-day occurrence, staff and residents were recognised personalities incorporated within the community townscape.

RESEARCHER   Can you describe [Resident's] typical day.
STAFF   Depending on the weather really. She might get up, have her shower, she will talk and chat to the staff, she will watch what is going on, she might spend her morning in her lounge chair, she might go in her wheel chair in the afternoon, she has a little break. She might go out for a walk, occasionally she will go out walking and in the evening she might go down and get a few vegetables and come back with the staff who have gone shopping, just down at the New World supermarket.
RESEARCHER   Can you explain the might's, how do they happen.
STAFF   Well it depends on what we need. If we need groceries we might look around and we might think who is in the wheel chair, who went last time and who hasn't gone this time and we will take this person. If it is raining we are not going to go out walking, if it is a nice sunshiny day then they will come out on the deck. If it is the weekend, that is the day we usually

> dye her hair because we don't have to get anybody to day services so
> Grocery shopping, if she is in her wheel chair and she hasn't gone she
> goes. If we are going for a walk if the weather is nice and we have to go
> and get stamps for envelopes, who is in their chair, [Resident], your turn
> to go sort of thing.

In the same way that institutionalisation dislocated people with intellectual disabilities from the community, the segregation of institutional lives also denied the citizens of New Zealand communities, relationships with disabled men and women. The more Kimberly Centre residents participated in their local community, the more they transformed them by being there.

STAFF   I think the more people in the community see them, the more they will
          be accepted.
          Do you know what I mean, we will, we will, because I mean a lot of people
          didn't even know we were here or who was coming and we have started
          to slowly meet the neighbours and the people in town. It takes time to
          break down the barriers., I took out someone walking and she went second
          hand shopping, that's how we met another neighbour because she went
          second hand shopping and the lady worked in the second hand shop and
          she said are you in that house, I am your neighbour from across the road
          and I mean that's how we will be integrated but it will be slow. When we
          go walking they will begin to recognise us going up and down the road, I
          wonder where they are from, do you know what I mean, it will get people
          talking the more they see us out. She has actually got a community on
          her doorstep where she hasn't lost her sense of community because she
          has got one only 15 minutes down the road so she is lucky that her house
          is in town I suppose you could say. Imagine if she was out in the country
          with no footpaths. The church down the road put a flier in our letter box
          and said they were most welcome to come to church if any of them wanted
          to come and they have wheel access.

7.4   Where residents lived, learnt, worked and played beyond Kimberley Centre — Vocational settings

Developing suitable work and activity programmes for residents who were moving from Kimberley Centre was integral to the planned closure programme . When Kimberley Centre residents moved to community-based services they brought with them funding to purchase an assessed number of half day support hours from a vocational provider. During the closure process vocational services were to develop in parallel to the provision of residential support. By the end of their first year beyond Kimberley Centre most residents had placements with a vocational service provider.

Although differing in size and occasionally in orientation towards particular support needs, most vocational centres deviated little from historical vocational service support practice. Activity within vocational centres tended to be programmatic, rotating through scheduled elements that incorporated music or other forms of sensory stimulation, handicrafts, walks that looped about the day-base, van-rides to public spaces, cooking and story-telling. Day-bases were staffed at a similar ratio to institutional settings and service users were collectively,

rather than individually engaged in programme elements. During the day, morning and afternoon tea and the entrances and exits of service users interrupted units of activity as residential services ferried residents to and from the day-base.

RESEARCHER She goes to [Vocational Provider] during the day. Do you know what she does there?

STAFF Um it can vary from painting, to mobiles, making mobiles, um, cutting out pictures, all those sorts of things.

RESEARCHER Does she seem to enjoy those from what you said?

STAFF Yes.

The authors were aware of alternative vocational models. In a few communities no vocational service had been established as part of the closure process or existing vocational services lacked capacity or inclination to absorb Kimberley Centre residents. In such circumstances residential providers were funded to provide vocationally orientated day activity. Only one, smaller service had pro-actively chosen to mentor residential support staff to provide flexible, community-based activity. Four of the thirty-nine participants that began Phase 2 were not receiving support from contracted vocational service provider for the duration of the project.

In the months following resettlement, the number of residents accessing vocational support dipped below the levels recorded at Kimberley Centre.

Kimberley Centre residents were, on average, observed in vocational setting for 2.2 percent (SD=7.8) of the total observed time (Figure 7.1). Between 3-6 months after resettlement, the average proportion of total observed time that residents were recorded in community vocational settings fell (M=0.9, SD=4.7). The reduced presence of Kimberley Centre residents in vocational settings immediately after resettlement probably reflected a number of coincidental factors. Managing the transition to community based services required effecting a balance between reaching a critical mass of service users to be viable whilst at the same time maintaining the ability to accommodate the flurry of resettlement that occurred towards the end of the closure process. In some communities a delay existed between people moving out and their ability to access vocational services. In the first six months after resettlement, no vocational activity was observed for people who moved from Challenging Behaviour or Multiple Disability villas (Table 7.1), suggesting that residential services may also have contributed by taking a cautious approach to vocational placement. There is a possibility that the decrease in the proportion of total observed time may also have been influenced by the study design. Participant observation sampling methodologies can be less sensitive to activity that occurs more infrequently and direct observation in vocational settings may have been more difficult to organise initially as researchers worked to establish a rapport with community-based service providers.

A year after leaving Kimberley Centre the average proportion of total observed time residents were recorded in vocational settings had rebounded (M=4.8, SD=9.9) to be more than twice the level recorded at Kimberley Centre (Table 7.1). Residents resettled from all villa types were observed participating in more vocational activity at the close of their first year beyond Kimberley Centre (Figure 7.2). Although the percentage of time spent in vocational settings increased for all residents, the increase was most dramatic for residents who had formally lived in Multiple Disability villas. The proportion of time residents were observed in vocational settings is, however, a poor measure of the impact the addition of this life-space made to the quality of residents' lives. Going to the day-base added structure, purpose and momentum to the lives of residents, replicating the ordinary diurnal rhythm of work and home life in the community beyond. Going to the day-base also offered residents an opportunity to share

Table 7.1 — Mean proportion of total observed time residents were observed in vocational settings by villa type

	Challenging Behaviour villas		Multiple Disability villas		Lifestyle villas		Overall proportion of time	
	M	SD	M	SD	M	SD	M	SD
Phase 1 In the Kimberley Centre	0.1	0.4	1.2	3.7	4.6	11.4	2.2	7.8
Phase 2 3 months after resettlement	0.0	0.0	0.0	0.0	1.8	7.0	0.9	4.7
Phase 3 12 months after resettlement	0.8	2.6	4.4	7.3	7.5	13.0	4.8	9.9

Figure 7.2 — Mean proportion of total observed time resident participants were observed in a vocational settings by the Kimberley Centre villa type.
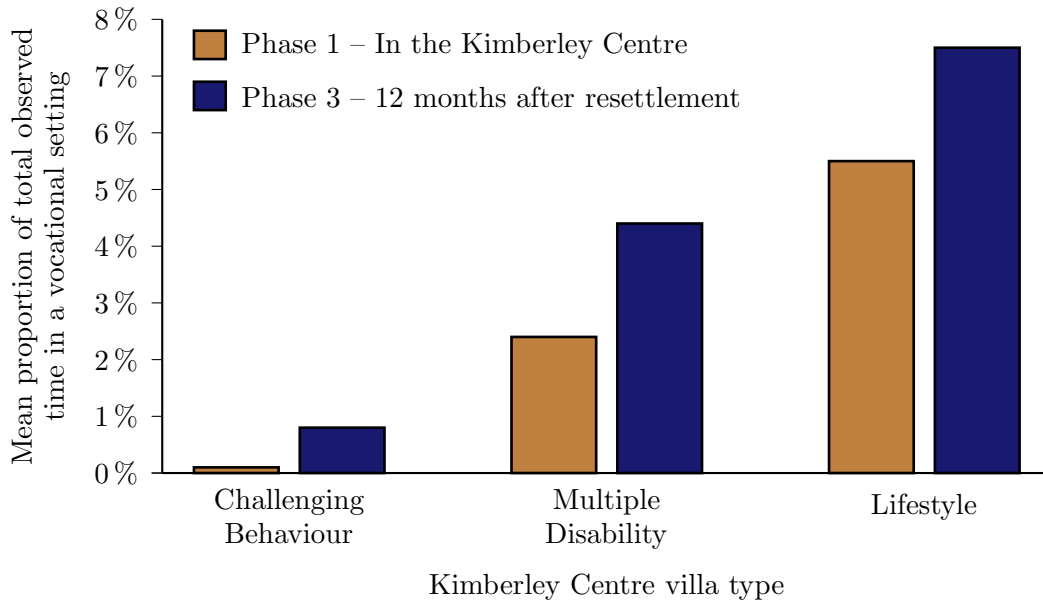
common community with other people with intellectual disabilities and the chance to catch up with friends, adversaries and people that were part of the narrative of residents' lives. Day-bases also offered a commitment to the personal development of individuals and an oasis of stimulation, especially to those men and women that had formally spent long hours passively sitting around the walls of their villa dayroom or whose life kept the cadence of feeding, flushing and changing in Multiple Disability villas or hospital dorms.

STAFF   Mm, I think it would be nice if we could achieve really great things for all of them. I mean I suppose if you looked at all the positive things that have happened since they have come out. One of them is [Flatmate], who never went to vocational service for years and he is enjoying it and loving it and going out whereas in Awatea he sat there and he spent most of the time in bed. It's good to see him lighten up.

7.5 Meeting the wider aspirations of deinstitutionalisation in vocational settings

In spite of the positive contribution attending a vocational centre made to the life quality of service users, a number of attributes of the experience of being in vocational settings confounded the broader aspirations of deinstitutionalisation. Bigby and Fyffe (2006) distinguished between the processes of deinstitutionalisation and institutional closure. Deinstitutionalisation, they argued, was a more complex process, requiring individualised support to embed former residents within communities as valued and contributing members and support lives that were consistent with individual aspiration.[39]

In their present configuration, the programmatic, collective and scripted character of vocational support denied people the opportunity to participate in activity that genuinely interested them.

STAFF   It's quite sad, they do nothing. And like [Flatmate] will go there and of course we have been trying to get him in to something that would suit him and he just wanders around aimlessly with no interaction with anyone and now they are wanting to put [Resident] in there which will mean that probably a staff member will have to go with him but you will be busy watching the behaviour instead of them teaching new skills. And they are in a room half the size of this, people in wheel chairs, and if [Resident] acted out, he can bang the wall and go over and hit somebody in a wheel chair.

RESEARCHER And they will offer him craft, I mean [Resident] is a bloke.

STAFF   He is not a craft person.

RESEARCHER He likes tractors.

STAFF   Yes, I would love to take him around a second hand place where there are vehicles and wandering around and let him have a look see.

As is noted by this resident's support person, the confined spaces, press of people, structured and therapeutic activity made day-bases difficult spaces for people with different learning styles and lifestyle preferences. They were especially difficult for men whose behaviour was perceived as challenging. Services experienced greatest difficulty finding appropriate vocational placements for people resettled from Challenging Behaviour villas, and even beyond Kimberley Centre, residents were, on average, only recorded in vocational settings for less than 1 percent of the total observed time (Figure 7.2).

Service users remained in the shadows of decision-making in vocational settings with little control over the range and timing of day-base activity. All activity was organised and moderated by staff and, as had been previously reported for other New Zealand vocational service users, the narrow and inflexible pattern of activity appeared to reflect the horizons of service culture rather than individual aspiration.[79] For service users with a wider vision for their lives the experience could be dispiriting. In the narrative below a Kimberley Centre resident expresses the hope that she can continue to feel valued and productive by replicating roles she had managed to forge while she lived at Kimberley Centre.

RESEARCHER When you move from Kimberley what would you like to do?

RESIDENT   Go shopping. Work in a coffee shop.

RESEARCHER You have work doing lunches and at coffee club here don't you?

RESIDENT   Mmmm...

RESEARCHER Is there anything else that you might like to be doing when Kimberley closes?

RESIDENT   Kitchen, work in a kitchen. Going out to lunch. Go home and see mum and dad. They can come and see me in my new home. if they want to and have a coffee with me.

When we met again, beyond Kimberley Centre, staff said she had become despondent at her inability to interest others in her vision.

STAFF   Okay, well say for instance, going to vocational, you know going to work, she was really really looking forward to it. I don't think [Vocational provider] has any expectations of what she feels its job should be. She has become very despondent with the whole place.
            She has become a bit despondent with that and we have had some behaviours because she is really now not wanting to go to be there.

The lack of alternative approaches to advance the pre-eminent vocational goals of *increasing the participation of people with disabilities in employment and in their community* (Minister of Disability Issues, 2001; p6) and a pervasive perception that people were compulsorily required to choose and attend from within the limited palette of vocational options similarly contradicts the service goals of self determined and individualised support outlined in the policy document, Pathways to Inclusion.[86]

For some, it also represented an erosion of the personal autonomy they experienced at Kimberley Centre.

STAFF   When he decides he is not going to be doing something, it is going to be that so he can definitely make his needs known. For example, if I said to him you have got art this morning and he had a look outside and saw it was a bit wet, he might decide, no I don't think I will go today, its raining. And he will just chill out and get his board and do what he wants to do there. Choice I think is very important for him.

RESEARCHER What sorts of things does he exercise control over.

KEY STAFF   I think if you look at most of the parts of his living, he makes clear what he likes and what he doesn't like and is offered choice in most things, take art for example, you have got art this afternoon do you wish to go and most of the time he is happy to go but sometimes there might be a reason that he decides he would rather stay back, it could be the weather, it could be that somebody is coming to visit him, it could be the fact that he just doesn't feel like it. It is a big premises and he enjoys the freedom of being able to go out by himself. When he goes for his walks, he goes by himself, takes himself out

To this man, his ability to choose elements of the vocational programme that interested him and his emersion in a culture that supported his right to choose when he attended were cherished liberties. Beyond Kimberley Centre, the requirement of services to meet different performance indicators, threatened to swamp the freedom he had acculturated to with an alternative vision of life quality.

KEY STAFF   The ideal place for him would be somewhere that is close enough that he can actually access these services for himself but how that would work is going to be a tough one for them to work out. I would say if they were picking him up in vehicles to take him, that is going to limit his choices. If

a vehicle comes to pick you up to take you somewhere and he doesn't feel like going, they are probably going to load him on anyway. Those kind of things could be issues for him. He is such a polite person that when he is taking himself over to art he thinks if I don't want to go I won't wheel over. But if someone comes to pick him up he is probably going to be - he won't say to it them.

The programmatic character of vocational settings also represented a poor approximation of ordinary community living in two other important respects.

The issue of how far to stray from *mainstream* activity referents to accommodate the differences of intellectual impairment has always been contentious. In the narrative below a staff person advocates for an elderly and unwell man who is habitually taken to his day programme. Two things concern her. Firstly that his right to refuse service provision is neither communicated nor respected, and secondly that the activity similarly fails to acknowledge the man. For this staff person, the mainstream referent was her father.

RESEARCHER The other thing I noticed about his lifestyle is that he continues to go to his day base throughout.

STAFF Yes, and we have fought about that too. Sometimes the weather is absolutely atrocious and I have fought the team leaders, all of them on this.. I have said to them with weather like that, it is disgusting. It is cold out there. It is foul. I wouldn't let my father out there yet you make [Resident] go across. It should not be. And they go, "he has got to go, it is being funded" I can't stop it and he is not well and they still send him there in the rain, hail and snow and they shouldn't and I said have we got no say. The caregiver should be the one that makes that call because we are their voice, they can't talk. We are trying to get [Resident] to say no, but see [Flatmate] said no and they still forced her across there. [Service provider] policy clearly say, that they have rights. No means no, if they don't want to go across there, well [Flatmate] went no and she was forced across there.

However, well intentioned, day after day this 60-year old gentle man would find himself pushed about the neighbourhood in his wheelchair by staff chaperoning a group of other service users about the day-base neighbourhood. On other days he would be invited to contribute to a cacophony of instruments by striking out at a xylophone or cut images from a Women's Weekly, none of which fit the man this staff person thought she saw, nor the man she knew her father to be.

The segregated nature of vocational settings and the atypical way people were fleetingly escorted to public community spaces also marginalised residents from the ordinary ways people daily seek out and nurture common community. In the absence of an established vocational service provider the narrative below describes how a space was left open for families to support natural forms of community participation. Here, a mother swam alongside her son twice a week after being separated for more than thirty years and brothers went to lunch together, with the trust they shared sufficient for a profoundly autistic man to only see his sibling and not the complexity of the local mall.

RESEARCHER Can we go back? I think what you were saying was, you don't want the people in the house locked in to disability services?

STAFF   They can go there from time to time, but they shouldn't have all their
                 programmes with other disability services. They have come to the com-
                 munity to get out in the community, that's how I look at it. Mixing with
                 their families or other families. I take them to mum's, she doesn't mind.
                 She thinks they are lovely. She has always got something there for them.
RESEARCHER   Well some of the families I have spoken to talk about trying to develop a
                 partnership with services. That you collaborate in the care of their sons
                 and daughters. That is difficult if they spend all their lives in services.
STAFF   At the moment we have got a programme in place on taking him to
                 Country and Western in the evening and [Resident's mother] she would
                 be there as well, we would meet at the country and western together.

Self authored, ordinary community participation happened serendipitously, beyond the stric-
tures of the formal vocational setting.

STAFF   Yes, she does five half-days, and she will come home and as soon as she gets
                 home she will have lunch and of course they have turns staying at home
                 because she is home during the day there will be one of the others there
                 with her and it means [Resident] will get to do whatever is happening in
                 the afternoon. Some days we go shopping or something like that. We go
                 for coffee and cake, not too often so it is a treat rather than an addiction.

A number of key attributes appeared to characterise those services able to provide most
effective support to resident's aspiration to construct personally valued forms of community
participation. Smaller services, able to support activities that authentically reflected individ-
ual passions and preferences fared better. Being flexible enough in service delivery to capture
mercurial opportunities to try new things or deepen relationship helped the evolution of
community too. Services able to draw in families and other valued non-service relationships
also provided more effective individual support by introducing residents to the communities
they brought with them. And services that focussed on qualitative indicators of belonging
and membership, including building reciprocity, shared history and emotional consequence
into relationships rather than auditable metrics of time and place were more effective at
embedding residents in the communities they moved to.

STAFF   What can blow that routine out are things that we need to urgently go
                 to, say a tangi or something. Things out of the square. I don't know, we
                 have got a sports day down in Auckland, and we are going to go down a
                 couple of days before and take them to places like Kelly Tarleton's. We
                 actually stay in a Marae, all our houses do and then we generate all our
                 activities around that and it is all about fun. What happens when we go
                 in there, his sister and his brother-in-law always come to the marae and
                 they have a meal with us and they stay till really late and they attended
                 the ball with us and it is about stuff like that for [Resident]. We try to
                 find what he likes out in the community. I think one of them was playing
                 pool at the RSA, we also had a literacy tutor They have got a lady that
                 does cooking lessons up in [Town] and she is going to come and do some
                 sessions with our guys in their whare and that's not just a – cook a pizza,
                 she actually cooks real whole meals like summer meals, plus a pudding It
                 is more looking for things they can actually do in their age. We go fishing
                 and then they go here. That's what they do, they go fishing, they go
                 eeling. [Kaimahi/Staff] usually takes them eeling. I suppose it is just an

experience for them. I mean even just a drive out to the beach. They go up to [Town] They go up to the marae out there and if there is anything on, like festivals or whatever – there is an [Tribal] festival, we actually take our mokopuna to, and a lot of the community know them. There was second hand place where they used to go and pair all the shoes off and put them in. They do some volunteer work down there. I mean you know when the Maori queen died, two of them said to me, can we go? And I said what - to Ngaruawahia and they said yeah, and I went I don't see why not and the house keeper looked at me and smiled and said we all want to go, because this is their cup of tea, they get right in to mihis and going to maraes where there are big crowds and even though there were thousands and thousands of people going to Ngaruawahia when our Maori queen died, our matua wanted to go, so they went. We organised for them to stay in Auckland and they went down like everybody else. They went and they stopped at the gate and waited like everybody else. We knew our matuas would love that and they love just sitting there listening to our kaumatua mihi and it doesn't matter what the occasion is for. They love to sit there and listen or just get up or sing or even sing with everybody else, they love it, whanaunga you know. We will go to the marae to learn about certain things like where they have been, their whakapapa, and how they are related to this area and that area and this land and that family from their own family.

This particular service had made a conscious decision to mentor residential support staff to incorporate forging community as intrinsic to their role. As a consequence, support staff were encouraged to develop a holistic understanding of each resident's total support needs, including a focus on naturalistic and self authored forms of community participation. Their pursuit of more effective ways to nurture more inclusive community, including giving better effect to people defining and directing their own support outcomes ought to be part of a wider re-visioning of vocational funding and service delivery. Without it, the less palatable alternative will be the translocation of the day support residential divide that characterised institutional care and an entrenchment of the segmented and socially marginalised service lives that have been the historical experience of people with intellectual disabilities.

STAFF   The thing too, all these people as you say go to vocational services and the whole house is out all day, do they actually want to be out all day?

RESEARCHER I know, as opposed to going somewhere fishing or sitting in a coffee shop and having a cup of coffee with your mates. The day bases to me look a lot like, well they look exactly the same as.

STAFF   Kimberley day support. Yes, there are no differences at all.

RESEARCHER So how does the typical day go?

STAFF   Yes, get him up in the morning, he goes on the toilet first, and then we start showering them all and breakfast, drugs, two of us go out in the van and take three of them down and then we come back doing the shopping while we are out or banking or whatever. The person who is staying here carries on and does the housework and stuff like that and we have got about an hour and a quarter in between that time and then it is back to picking him up for his lunch and then come back and change them and take them back again. It is an unchangeable rhythm.

RESEARCHER   One of the consequences is, the guys actually don't get to do their own shopping do they.

STAFF   No, definitely not. Just the physicality of actually getting them there and because they are funded to go to the day base so that means [Resident] and [Resident] are there every morning, so that's three of them gone, and that only leave [Resident] in his cot here, and then in the afternoons we have got [Resident's] turn and [Resident] still goes and [Flatmate] by the time she has had her drugs, and sleeps for the rest of the afternoon and [Flatmate] won't stay in his chair after lunch. So we are regimented by basically the day base and their needs...Well they [Vocational staff] get paid well to play with them. We get paid not so well to look after them...the finger painting and the crayoning and the pasting, That's just play school.

7.6 The meaning of "community"

The concept of *community* is a contested construct. What is meant by the term, has been the focus of much debate and a considerable body of theoretical discussion. In the field of disability research, what is meant by *community* has been further complicated by an inclination to present the construct as the antithesis of the historical segregation of people with intellectual disabilities in *special* facilities.[79]

When Ozanne et al. (1999) reflected upon what drove the process of deinstitutionalisation, they concluded that the death knell eventually tolled for institutions because, the reforms which occurred in 1960-70s, could not change the reality that living in an institution made it difficult to establish local community linkages or opportunities for individual control of daily life.[25] *Community* subsequently became an epithet for any context beyond the shadow of segregated care and decreasing the barriers to the presence of marginalised populations to *mainstream community* spaces has remained as the unifying principle of social policy in the United Kingdom[87] and in New Zealand.[79]

Milner & Kelly (in press) have recently argued that as a consequence of the historical origins of the nomenclature of community, the construct has tended to be thought of in spatial terms within the disability discourse. Service practice and service audits emphasise location as the primary indicator of inclusion and not the how people are experiencing community spaces. The need to incorporate qualitative indicators of community meaning is intrinsic to the understanding of community beyond the disability discourse. Almost all commonly held definitions acknowledge the multifaceted nature of the construct and incorporate the inter-related elements of *people* and a *sense of belonging* together with affect for *place* as central to an understanding of community. The people places and sense of membership and belonging Kimberley Centre residents experienced in the communities beyond Kimberley Centre are incorporated in this exploration of the impact of institutional closure.

7.7 Where residents lived, learnt, worked and played beyond Kimberley Centre — Community settings

Comparing the average proportion of time residents were observed in different life-spaces at Kimberley and one year after resettlement reveals that the closure of Kimberley Centre was associated with an increase in the presence of residents in community spaces. In Figure 7.3 the average proportion of time residents were observed in different living spaces is represented by the area of the each circle. As noted in Chapter 6, residents were seldom observed beyond their villa while they lived at Kimberley Centre. Long dayroom hours were interrupted by moments of personal care or a scheduled exodus to the dinning room at meal times. Residents were only episodically observed beyond Kimberley Centre's grounds.

A year after moving from Kimberley Centre the lounge and dining room had replaced the villa dayroom as the cardinal space in residents lives, but people were observed in residential living space more infrequently in community-based settings. Two-tailed, paired t-tests were used to explore possible significant differences between changes in the proportion of total observed time that residents were observed in different life spaces. The 14 percent reduction in time residents were observed in residential living spaces was a statistically significant reduction in average observed time (95% CI [-6 – -22]; $p < 0.01$). While residents were in their own homes, they also spent less time in a single location. The time residents spent in domestic spaces increased by 5 percent. This also proved to be a statistically significant change associated with the move to a community based services (95% CI 0.0 – 10.0]; $p = 0.04$).

On average people were observed in their community homes 9.1 percent less than the proportion of time they spent in or about their villa, with almost all of this statistically significant difference (95% CI [-3.2 – -15.1]; $p < 0.01$) being accounted for by a commensurate increase in time spent in the community. Twelve months after resettlement the average proportion of time residents spent in community based settings had increased by 8.2 percent. This was a statistically significant increase in the proportion of observed time (95% CI [4.5 – 12.0]; $p < 0.01$) with the difference being most marked in the proportion of time residents were observed travelling (95% CI [1.0 – 6.0]; $p < 0.01$) and visiting civic amenities or other community facilities (95% CI [1.0 – 6.0]; $p = 0.01$).

Although deinstitutionalisation changed the material circumstances of all residents, people resettled from Challenging Behaviour villas experienced the most dramatic transformation in the types of spaces their life subsequently unfolded after Kimberley Centre closed. Figure 7.4 describes the average change in the proportion of time residents resettled from the three Kimberley Centre villa types were observed in different locations 12 months after moving. Scores above the shaded circle represent increases in the proportion of time residents were, on average, observed in particular locations and scores that dip below the circle circumference denote decreases following the move to community-based settings.

After resettlement, people who moved from Challenging Behaviour villas spent dramatically less time in residential living spaces, reflective of their liberation from the locked villas they were hemmed in to at Kimberley Centre. Interestingly, this cohort spent proportionately more time in open settings, exchanging the villa dayroom for time outside in the garden or beyond the dwelling and out in the community visiting civic amenities and public spaces. Their sustained, relative absence from vocational settings may also have contributed to the more significant increase in the proportion of time these men and women were present in community settings (Figure 7.4). Not surprisingly, all residents spent more time in the domestic locations

Figure 7.3 — Average proportion of total time residents were observed in different life-spaces at Kimberley Centre and 12 months after resettlement.

At the Kimberley Centre

12 months after resettlement
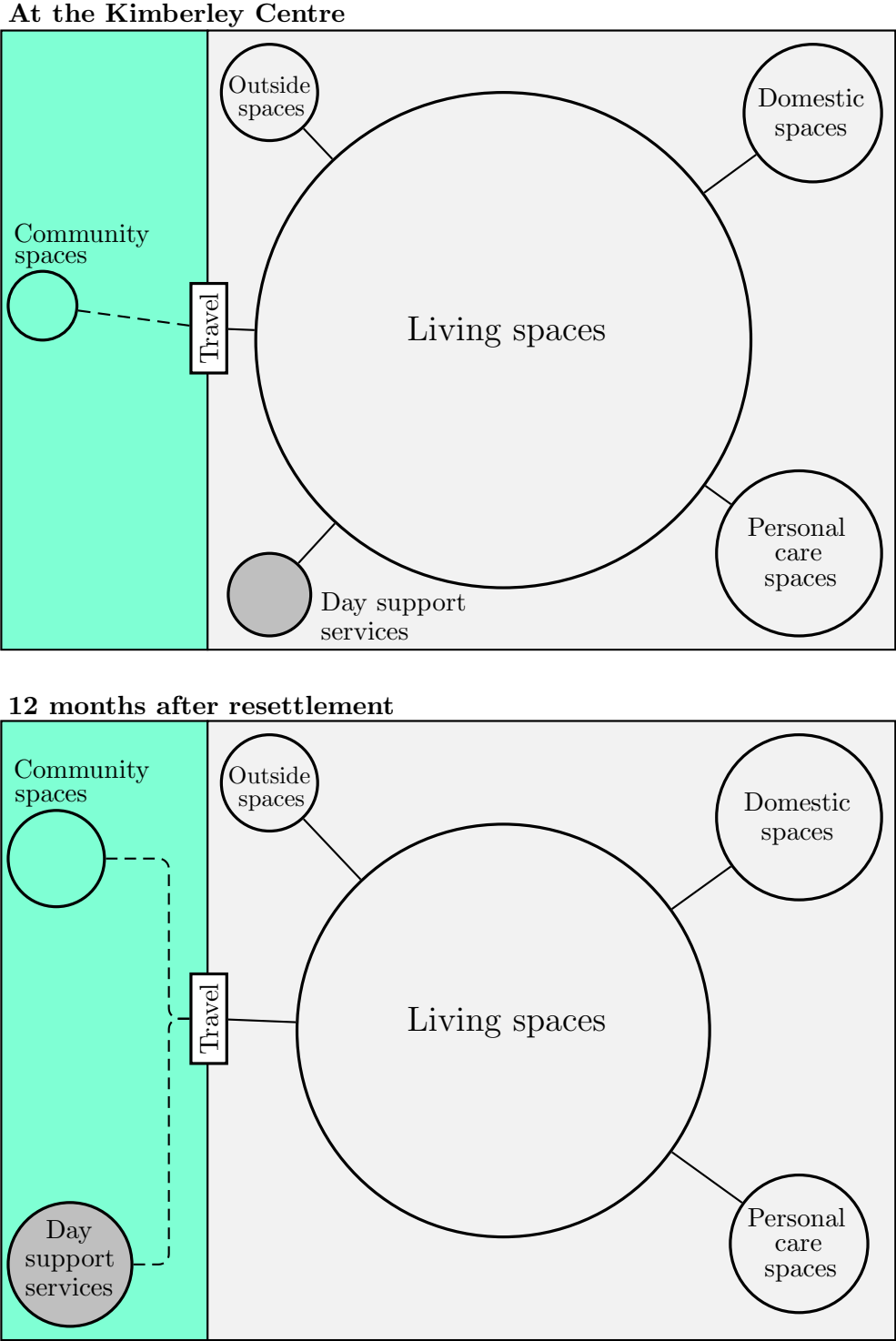
largely denied by villa life, but also spent proportionately more time visiting civic amenities, going out for haircuts, swimming at a local pool or visiting the community doctor.

Table 7.2 — Paired differences in the proportion of time residents were observed in life-spaces at Kimberley Centre and 12 months after resettlement.

Phase pairs	Mean of paired differences	s.d.	t	p
Living spaces	**-14.0**	**23.0**	**-3.65**	**0.00**
Personal care spaces	-2.0	10.0	-0.97	0.35
Domestic spaces	**5.0**	**15.0**	**2.17**	**0.04**
Outside spaces	1.0	10.0	0.43	0.67
Total Residential Spaces	**-9.1**	**17.8**	**-3.13**	**0.00**
Total Domestic spaces	1.0	12.2	0.49	0.62
Recreational spaces	-1.0	3.0	1.41	0.17
Urban recreational spaces	0.0	3.0	0.81	0.42
Travel	**4.0**	**7.0**	**3.28**	**0.00**
Community amenities	**3.0**	**7.0**	**2.58**	**0.01**
Community pathways	0.0	1.0	0.57	0.58
Social Spaces	1.0	2.0	1.61	0.12
Total Community Spaces	**8.2**	**11.3**	**4.32**	**0.00**

The pattern of time spent in other locations did not differ significantly from general pattern of life at Kimberley Centre. Residents remained absent from the less public, socially intimate spaces of visits to friends or family. The research team were aware that a number of residents were supported to visit family members, some on a regular basis. However, the arrow of social intimacy tended to point towards residents and moments when residents went out to visit their family or friends occurred with such irregularity that they were not observed in any of the three phases of the project.

The trend for people to be more present in community spaces after their move to community-based services did, however add greatly to life quality. At Kimberley Centre trips beyond the institution grounds were welcome and eagerly anticipated interruptions to the tedium of villa life. Being in a community-based service did little to extinguish the pleasure resident's experienced simply going somewhere beyond the daily round.

STAFF   He has got to go to the dentist soon, he has been to the hair dresser's and we take them out on little trips as well but virtually his day is spent in the lounge. The outings would be the high point of his day if anything.
RESEARCHER Where do you normally go and what does he do.
STAFF   On a fine day we got to the beach. If it is a wet day we usually just drive them around, take them places, you can't really take them out of the van, we just go for a drive to parks and stuff like that.

Being in community-based services greatly increased the array of community contexts that residents were exposed to. Their smaller size, location, dependence upon community resources and the regular ferrying to and from day bases contributed to an erosion of the material barriers to being present in ordinary community spaces. It also displaced the culture of self-sufficiency. Most residents went out to the hairdresser and the dentist, and shared the shops other community resources with members of their own community, rather than having them provided for on-site.

Figure 7.4 — Mean change in the proportion of total observed time in different life-spaces between Phase 1 (In the Kimberley Centre) and Phase 3 (12 months after resettlement) by different villa type. The shaded disk represents the zero change. One unit on the axes corresponds to 5% change in the given activity.
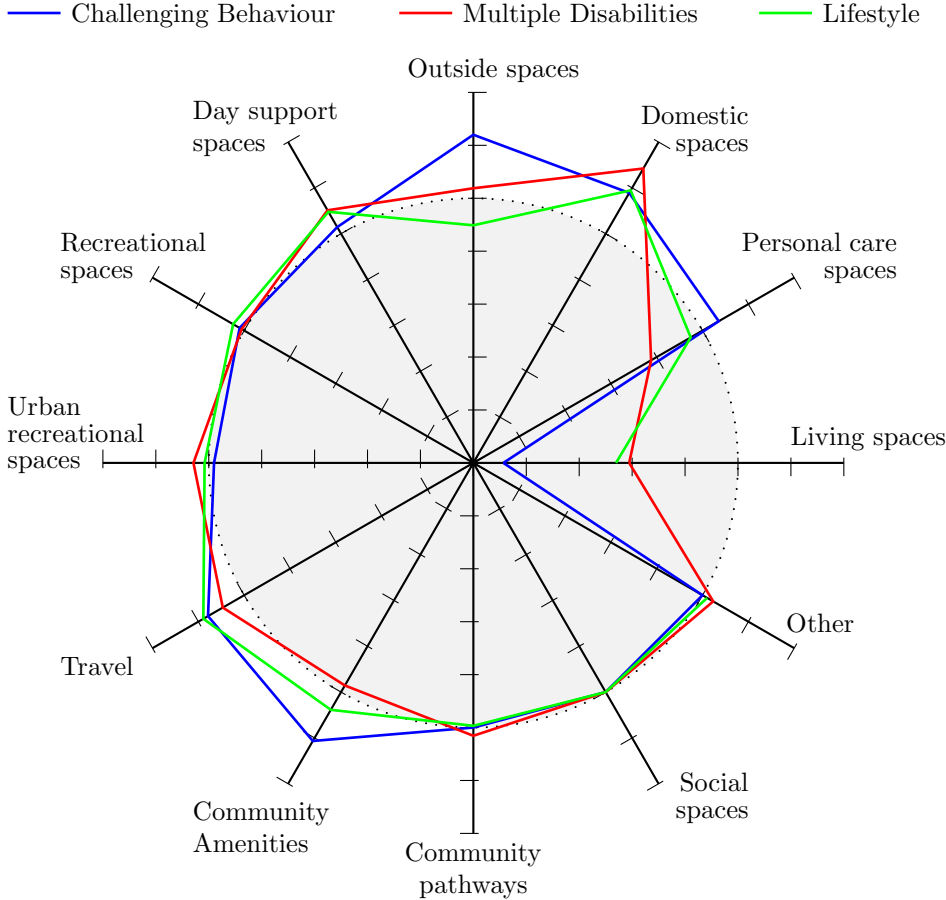
STAFF   We go to the Warehouse down at the shopping centre, we go to church, we go to town, we like to go to different coffee shops, we don't like going to just the same one. Yes, we have got baking days and trips to the hair dressers to have our hair coloured and here we are under the dryer and all sorts of things. We're making Christmas presents so we off we go for decorations.

The greater accessibility of community contexts appeared to have a wider, psycho-emotive meaning too. When residents reflected on their personal journey out of Kimberley Centre, many included the vocabulary of liberation.

RESEARCHER What is the best thing about living in the community? What is the best thing that wouldn't have happened if you were still living there.
RESIDENT   Being out.

The sense of personal liberty experienced by *being out* in the same community spaces as others New Zealanders echoed the feedback 14 Kimberley Centre residents heard self-advocates express at the consumer forums in held in August 2000 as part of the consultative process prior to the Working Group's recommendation to close Kimberley Centres.[88] In the quote below, a Kimberley Centre resident reflects on the mixed emotions he experienced revisiting

the staff and residents that remained behind in his old villa. Whilst pleased to see old staff and residents, his expression of empathy is strongly evocative of the story self advocate Robert Martin told of his friend who summed the difference between living in and out of an institution with the single descriptor *freedom*.[23]

RESEARCHER Okay, so did you feel a bit sad about going in there and seeing your friends.
RESIDENT Yeah, they are all locked up and I have got a free world.

7.8 The hospitality of North Island communities to Kimberley Centre residents

Prior to its closure, many families expressed a fear that communities beyond the enclave of an institution could be hostile and unwelcoming to people with an intellectual disability.

The experience of those residents who contributed to this study was that the communities to which they were resettled were unevenly accommodating of their participatory aspirations. By the end of the first year after moving from Kimberley Centre, a few residents had found a place inside of community groups and become incorporated as social identities within the social fabric of the group. A small number of elderly men and women had joined age related community support groups, one house had become regulars shooting pool at their local Returned Servicemen's Association (RSA), one resident took turns as a volunteer at a second hand store and a few residents patronised local Country and Western nights. Given the opportunity residents fought for ways to add value to the communities that had included them.

RESEARCHER I have seen some of the best support ever from two kuia who sat at the table with [Resident]. They were patient, they wanted to know this man and [Resident] was giving them something back too. We got served puddings and the two old ladies couldn't finish theirs. My response was to take them away but [Resident] cracked a joke about his nana not letting food leave the table. He spoke in Te Reo, and these women loved it, They laughed about him carrying on the old ways and of course [Resident] swells up. [Flatmate] is helping deal cards and [Resident] is helping with the puddings and taking these lovely women back to their childhood.

In the few inclusive contexts that were observed, residents also appeared to work particularly hard to acquire the social conventions of place.

RESEARCHER At Tai Chi, he is watching so carefully to fit in, to acquire the customs.
STAFF Yes, he does a lot of assessing and I don't blame him because he has had a lot of time to do that but I suppose it is that fit in kind of thing.
RESEARCHER Yes, but he is motivated to do it.
STAFF No he is
RESEARCHER At Kimberley, he sat in the shadows. I don't see that at all. I see a man who is willing to know how to belong.

Residents' desire to decipher and perfect the social customs of community contexts was often supported by staff efforts to act as social interpreters or through their efforts encourage socially appropriate behaviour. The support tended, however, to be unplanned and reactive. Despite evidence that carefully constructed interventions can support the acquisition of greater social confidence and social interaction amongst people with significant intellectual

or behavioural support needs,[62, 89] supporting the development of pro-social behaviour in an concerted way did not appear to feature as an intentional element to support.

Contexts where residents were included as active and valued members were, however, atypical. The community appeared less porous to Kimberley Centre residents for a number of related reasons. Sometimes the physical environment made community spaces difficult to access. The curbing in *ordinary* streets made it tricky for people in wheelchairs to navigate their neighbourhood, isles were too narrow or it was a long way to an accessible toilet. Often public amenities lacked the facilities to support participation.

STAFF [Resident] swims once a week at the moment but hopefully we might be able to get down there twice a week because he loves it.

RESEARCHER I think it is been important for his mum too.

STAFF Oh yes, she calls him the man you know and he floats round and he loves it. It is hard work but it is worth it. The facilities aren't that great, we have to take our own hoist in the van, that means the van is gone, once [Resident] goes in there the van is gone. They mix with other people down at the pool. People who have had operations and need moving around and stuff like that down at the pool, it is very nice.

And occasionally, community indifference and intolerance socially marginalised residents.

RESEARCHER I have heard people say with [Town] being so small, there isn't a lot of community activities that people can link in to.

STAFF That is right, there is no group, that is right, yeah that is right because it is a small community. We had [Resident] going to a chat group. It wasn't only for disabled, anybody could go but after two sessions [Resident] had to stop going just because they said they were tired of her repetitive speech.

Clement suggests that service values that emphasise *full participation, community inclusion* and *participatory citizenship* obfuscate the less palatable reality that people with intellectual disabilities experience subtle forms of social segregation as part of their daily lives.[90] In many ways the sustained policy of institutionalisation acted to marginalise communities from valued relationships with the people with intellectual disabilities who would otherwise have lived amongst them. The imposed separation of New Zealand citizens, each from the other, may have contributed to the social distance which underscores what Reid and Bray (1998) coined the *normality* of personal exclusion.[91] Despite an undertaking in the 1994 protocol adopted by the Central RHA and MCH that; *Public awareness programmes will be developed to promote the strengths, rights and needs of people with intellectual disability and to provide information regarding disability-related issues.* Kimberley Centre residents and their allies have hitherto stood alone in confronting community prejudice.

7.9 The influence of service practice in defining community

Consistent with international[67, 83] and New Zealand research[1, 9, 74, 79] Kimberley Centre residents greater community presence typically failed to translate into relationships likely to engender a sense of community membership or belonging. A number of researchers have begun to suggest that the support practices of human services may represent a barrier to the evolution of community relationships.[79, 92]

A more fine grained analysis of the types of community spaces resident were recorded as being present reveals that residents tended to participate in community activities of a particular type. When the weekend chores were finished and the weather was friendly, residents went as a group for a van ride. Each week the destination was different as staff struggled to think of new beaches, parks and picnic spots to try to entice residents from the van.

STAFF   Around about 10ish, if we are going for a ride in the van, that's when we go. They are asking from the time they get up to the time we say van ride, all of them, they know on Saturdays I am going in the van.

RESEARCHER So where do you go?

STAFF   That's a good question, we are running out of places to go. Parks, beaches, places like that. We will ask them and they will always say the same place, the beach, but once you get there they don't want to get out. Yeah, no matter what the weather.

Figure 7.5 — Mean proportion of total observed time residents were recorded in community settings 12 months after resettlement
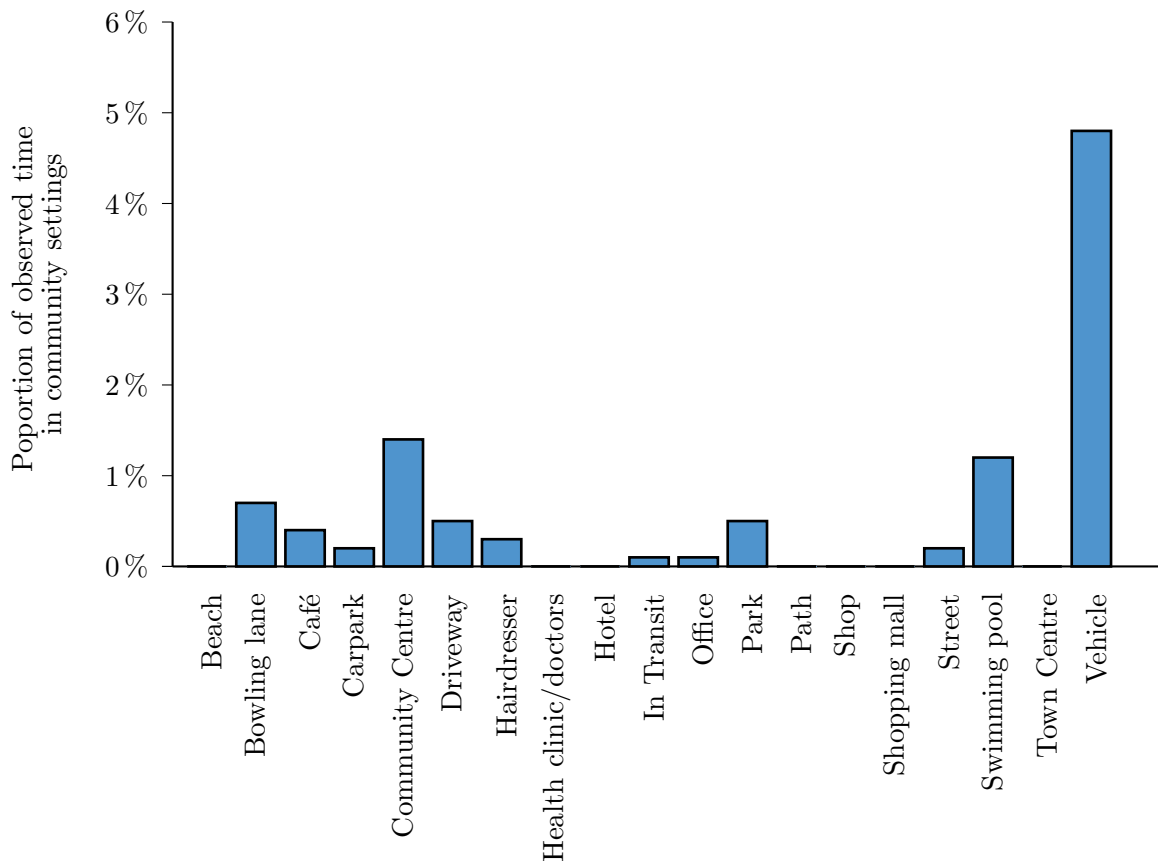
During the week, residents went with day support service users as a group in the van, either to the same beaches, parks and picnic spots, or in chaperoned visits to the community library, art gallery or shopping mall. In all these contexts, residents only ever made brief and infrequent visits. Their fleeting and irregular presence meant that residents generally came and went from community settings without any opportunity to engage others in ways that may lead to ongoing social relationships. The most frequently recorded community location was the van that ferried residents to and fro (Figure 7.5).

RESEARCHER	What about opportunity to create new relationships, has he had any of those?
STAFF	No, not really, he doesn't really have the opportunity to create new friends, no, no he doesn't.
RESEARCHER	What about inviting other people to his home.
STAFF	No, that's a sad part. If we could visit other homes and meet other people there and it would be like an outing and then maybe they might meet new friends there but there is no other home. I don't think there is. It would be good to be able to take them out to a place where there is other people, definitely, that would be really good.
	They never stay in one place for long because the only outings that we take them are you know like dentists, doctors, hairdressers, they only have to do the job and they are gone and if we take them somewhere it is really just with them and their picnics and that and then they go straight back home again so there is no real way for them to get out and meet other people.

Residents who were only ever in the community as part of a group of other men and women with an intellectual disability were similarly denied the opportunity for members of the public to recognise and acknowledge their individuality. Residents seldom engaged each other. Being in the community without your flat or work mates was, for most, therefore, qualitatively different experience than being their collectively.

RESEARCHER	And he looks as if he anticipates, he quite likes going out.
STAFF	Oh yes he loves it, he loves it all the more if you have a one on one with the staff rather than everybody. There again it is the loner part coming out I think, he feels more comfortable with the one on one. That really hit home the other day when I took him out and he was animated and happy, it was nice to see.
RESEARCHER	You should put it to the test more often.
STAFF	When I can. There again it comes down to staff numbers if you are able to do it isn't it. If there are two of you on and there is a work load to be done and you always feel guilty leaving the other person behind with the five clients that are left and the jobs that have to be done. I mean there are jobs, but I am sure it will happen.

As discussed previously, increasing the flexibility of vocational funding to permit opportunities for people to seek out and nurture their own communities of interest would add greatly to the life quality of the residents who participated in this project.

In her analysis of the parliamentary debates that foreshadowed the construction of the first generation asylums in the United Kingdom, Walmsley (2005) suggested the twin impulses of protecting society from the *menace of feeblemindedness* and protecting people with disabilities from a hostile community, laid the foundation for over a century of segregation.[15] At times, echoes of a the same protective logic was observed in the subtle ways staff steered residents to the shelter of the far end of the beach or the quietest cafés, even if it meant frustrating residents' aspirations to engage directly with the people they shared their community with.

STAFF	Out in to the community, we do try to watch that with the choices of what café she wants to go to, she may want to go to one that has got a lot of people there, that sort of thing, the staffing generally, we don't

want that. It depends on how well she is and I don't care, I just take her, probably a bit of the I am going in there.

Kelly Johnston (2005) recently argued that regardless of the way people characterise institutions, for the people who lived there, they often represented the whole of a persons adult life experience. New Zealand men and women with intellectual disabilities have themselves described in published accounts finding purpose and meaning to their lives through the places and people they shared Sunnyside,[93] Kingseat[94] and an institution near Wanganui.[95] When residents moved from Kimberley Centre to community-based services, their resettlement displaced a pre-existing community. Many left friends and activities that had historically added greatly to their life quality. A number of people had found it hard to replicate some of the ways they experienced community during the time they lived at Kimberley Centre.

RESEARCHER What about town, do you go to town very much?
RESIDENT Ah I used to
RESEARCHER Do you go to church any more [Resident]?
RESIDENT No I don't go to church any more. I used to.
RESEARCHER How do you feel about that. Would you like to go to church?
RESIDENT I wouldn't mind thank you.
RESEARCHER Do you feel like you can ask to go to church.
RESIDENT Ah, they will ask me.
RESEARCHER Do you still go to Stairways?
RESIDENT I used to. I used to.
RESEARCHER Before I asked you whether you went for a coffee or went and had breakfast in town any more like you did at Cobb and Co?
RESIDENT No I don't. I used to when I was in [Villa]
RESEARCHER What about shopping, do you shop for the house?
RESIDENT I used to, I used to shop for the house.
RESEARCHER The first time I met you at Kimberley, I went to push your chair and you told me not to. Do you remember that?
RESIDENT I remember, yes.
RESEARCHER You also used to go places by yourself. Remember at Kimberley you used to wheel over to [Staff] at the day base and I think sometimes you used to visit [Kimberley resident].
RESIDENT Yes, yes.
RESEARCHER Do you go places by yourself any more?
RESIDENT No, they arrange the van. I used to go down by myself when I was in [Villa] but they take me to the day base.

Figure 7.6 contrasts the average response staff gave to a question drawn from the Place in the community domain of Cummins' ComQOL-ID.[46] Staff were asked to rate how often each resident participated in a range of activities during a typical month at Kimberley Centre and 12 months post-resettlement. At Kimberley Centre staff reported that residents regularly attended a club/group/society. The high levels of participation recorded for this leisure activity (M=3.7, SD=6.7) is misleading as many staff included residents' compulsory attendance of *coffee club* in their assessment. Staff also included residents' attendance of "Stairways" in their assessment. Coffee club occurred up to three times a week and was organised by Day Support. The original intention had been for residents to improve social etiquette by sitting together to have a cup of tea and a biscuit, but it had become a tightly

scheduled exodus to the Day Support villa followed by an earnest attempt by residents to drink two cups of tea and an extra biscuit before the half hour heralded the arrival of the next villa dayroom. Stairways was a dance, held at a community hall in Levin the dance was organised by a local family and had been a place where Kimberley Centre residents could socialise and catch up with acquaintances that had left Kimberley Centre but remained in the district. With the exception of the inflated frequency recorded for attendance of a club/group/society, the pattern of participation in different activities was not dissimilar, suggesting that support practices may not have differed significantly in community-based settings (Figure 7.6). Beyond Kimberley Centre, residents chatted with a neighbour or

Figure 7.6 — Proxy staff responses to the ComQOL-ID question: *"Please indicate how often in an average month you take part or attend each leisure activity,"* in Phase 1 and Phase 3.
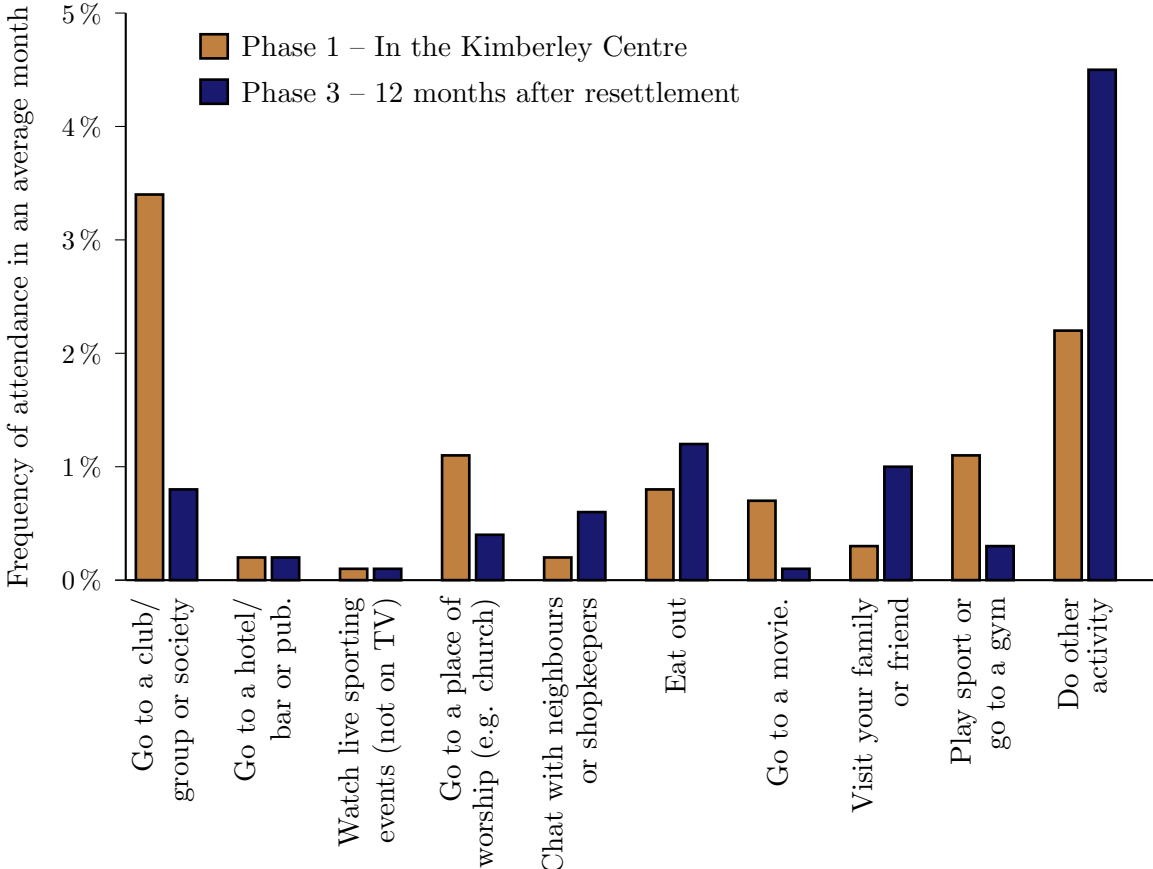
shopkeeper, purchased a meal and visited a friend or family member slightly more often. They were less likely, however, to attend church, go to a movie, play sport or attend a gym, all of which occurred within the confines of Kimberley Centre. In their consultation with disabled adult service users, Milner and Kelly (in press) report that people with disabilities prioritise the experience of being in place over the acculturative status of settings.[81] Leaving Kimberley Centre for some residents meant moving away from people and activities that had contributed to life quality. As noted previously, the Kimberley Centre chapel was a distinctive social space in which the residents had the dominant social voice and took leadership roles in defining and controlling the social customs. The same may also be said of the Kimberley Centre movies, which screened at the hall every month and the dances at Stairways that residents chose to attend with autonomy. Against the procession of visits to parks and picnics, and the coffee shops and malls it is easy to overlook the quieter moments of community experienced in

the segregated spaces of Kimberley Centre. Moreover, many of the qualitative attributes of community participation residents described experiencing at Kimberley Centre were absent in the assimilative spaces they were taken to by the community-based service.

Every resident's journey was different and no one person's experience adequately summed another's. For every resident whose social world had shrunk post-resettlement, there were an equal number whose relationships were characterised by deepening emotional and interpersonal intimacy. A small number had also begun to establish community connections. Having a more regular community presence increased the likelihood that people, who share the same community, would see each other more clearly and improve their ability to communicate. It happened in moments as undramatic as habitually picking up a favourite magazine.

STAFF   On a Monday she gets the Woman's Weekly every week which requires for us to actually take her to the book shop, she asks for that book, receives that book and usually when she is in there a couple of people at the counter will say hello to her and talk to her, have a bit of a yak to her.

Supporting people to select activities that authentically expressed their interest and permitting them the dignity of authoring their own presence supported the evolution of community too. Sometimes this meant going with flatmates or other service users and sometimes it was important to leave them behind.

STAFF   There are (five) hours when we can do one on one. You don't need to be dragging everybody else along if they don't want to do it. I know [Resident] wants to go to a concert and [Flatmate] and his key worker have gone to [City] and checked out the railways, he likes the trains.

7.10   The potential of staff to create community

Within the restricted social networks of people with intellectual disabilities, staff can occupy positions of paramount social significance.[96,97] Marquis & Jackson suggest that against the backdrop of their own materially enriched lives, support staff are sometimes unaware of the felt attachments of people living in services.[78] Families and staff often represent the only validating relationships in service users lives and through their relationship with service users, staff can expand (or restrict) the social worlds of people dependent on their support. Staff who enhance positive self-regard, seek out and nurture new community and transcend the formal role of care-giver seed community development.

Differences in the extent to which Kimberley Centre residents were engaged with their community could often be accounted for by the collective or individual actions of support staff. Some were potent social connecters, taking responsibility for establishing new relationships from people drawn from within their own community networks.

STAFF   We thought that would be good to try the Country and Westerns on a Sunday. So yeah, that was our thing [Resident] for this year, because it is held at two different places and we can get him in. There was a guy that I knew that was running the country and western so I need to go along and see if he's still – because he actually works for Māori community mental health from a Māori perspective, so he is a very patient sort of guy as well and some of our guys they get up and sing, quite a hard case thing.

And others widened their own "families," by broadening the horizons of all of the people who were closest to them.

STAFF One thing I must say [Researcher] is I say to anybody I love this guy, I love him as a son you know

RESEARCHER So you are modelling, unconsciously you are modelling a way of relating to [Resident] just doing that.

STAFF Mm, we went home, we went around to my boy's place and he said to me 'we are having a barbie this Saturday, are you working' and I said yes, and he said come over and he said you know that guy you look after, do you want to bring him? Yeah, yeah, I will bring him around so we went around there, but we had already had dinner and got around there and he said oh would he be hungry, I said oh yeah he has already eaten, just let him have some pork and potatoes, so he went around there and had a barbie with the family...I told him this is [Resident] – all my boy's friends were there and their wives and girlfriends. A little girl came running in and she said that man is sitting down in the garden and he was sitting in the garden so they laughed, but they think he is great and when they all come in they go all around him and see him in the kitchen, they all want to get a piece of him...The kids love him. Even though we were only there for about half an hour or so.

By introducing this man to his family, his staff person made a considered decision to narrow O'Brien's (2007) bright line of social distance and step beyond the narrow role descriptors of support. One of the consequences for this Kimberley Centre resident was that when he entered the community, he did so beneath the korowai (cloak) of his support staff's love and respect. There are dangers implicit in allowing support relationships to cross the boundaries of affect and services typically emphasise the risks as part of their practice. People with disabilities[23,78] and their families[37] tell us, however, that these are the support relationships that have historically added most to their life quality. Denying the inevitability of reciprocally valued relationships requires them to become subversive. Honest dialogue about the risks and benefits of including staff within the compass of community relationship has the potential to add to the life quality of people dependant on their support.

8

What activities filled a person's day within and beyond the Kimberley Centre

8.1 It's not where you are it's how you are in places that counts

John O'Brien (1989) suggests that one of the most important ways human support services affect the life quality of service users is by influencing the type of activities that fills their day.[80] Duffy (1997) similarly argues that because of the historical power imbalance between the providers and recipients of human support, services can loose sight of the way they unconsciously define the shape of people's everyday lives through support practice.[98]

The places that build to form an individual's sense of their place in the world resonate with meaning because of their event history.[99] Not surprisingly, therefore, people with intellectual disabilities tell us that it is not so much the *where,* but the *how* they experience being in the community that counts to them.[79,81] New Zealand adults with an intellectual disability, however, have struggled to be active in ways that lead to valued social roles[1] or the sense of membership or belonging beyond segregated service settings.[81]

In this chapter, participant observation, ComQOL-ID domain scores and the narrative of Kimberley Centre residents and their support staff are used to explore whether Kimberley Centre residents were similarly displaced from meaningful roles by focussing on what activities filled their day, in and then out of Kimberley Centre.

8.2 The activities that filled a person's day at Kimberley Centre

At Kimberley Centre, life for most appeared to be characterized by long periods of inactivity interrupted by brief and largely scripted flurries of activity. On average, exactly half of the time residents were observed at Kimberley Centre, they were recorded as engaged in no form of (obviously) purposeful activity (M= 5.0; SD=0.26). Figure 8.1 plots the average proportion of total observed time that residents were recorded as engaged in a particular activity type.

Figure 8.1 — Mean proportion of total observed time residents were engaged in different types of activity at the Kimberley Centre.
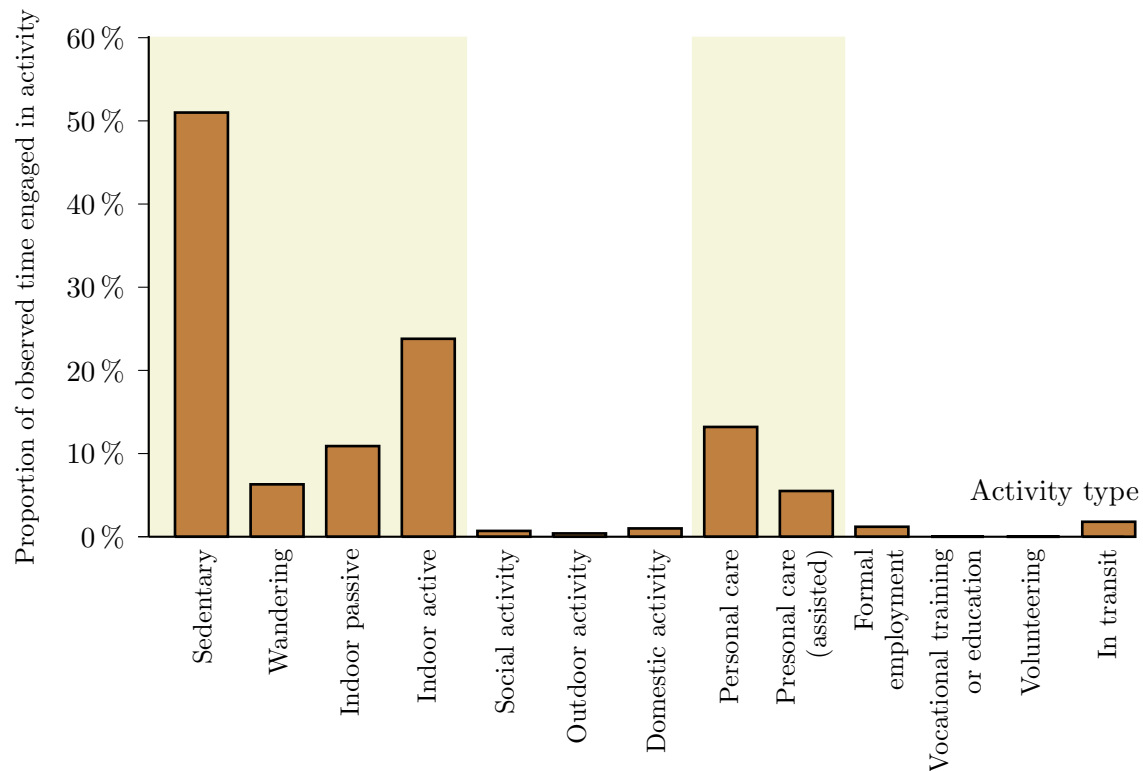
Clearly described are the long hours participants were observed sitting or standing, doing little. On average, fifty percent of the time, participants were judged to be engaging in sedentary activity. Sedentary activity was the least stimulating of all of the activity codes. Participants were observed as disengaged and either sitting staring, standing or snoozing for an interval to be coded as sedentary. If wandering (6%) and moving between predetermined locations (2.7%) are added to the total, nearly sixty percent of the time participants were observed could be said to have been engaged in relatively purposeless activity. Often participants were recorded as having engaged in sedentary activity uninterrupted by anything or anyone for the entire 30-minute observation. The following extract is typical of resident activity captures in many running records.

```
2.06     Rubs face with left hand.
         Begins grinding teeth.
         Lifts both hands and rubs temples above ears
         Finger drifts to across forehead and begins circling hair.
         Grinding teeth and pulling hair.
         Motionless (inattentive to staff' entrances or exits.)
         Eyes close, cupping head with hand.
         Opens eyes to look at observer, turns to TV and back to observer.
         Eyes close.
         Inserts finger in ear...
```

When staff were asked as proxy respondents, how often residents would feel as if they had nothing much to do in their spare time, 39 percent selected *almost always* as the most appropriate response and 75 percent responded at or above *usually,* (Figure 8.2).

Figure 8.2 — Kimberley Centre staff proxy responses to the ComQOL-ID question *"In your spare time, how often do you have nothing much to do?"*
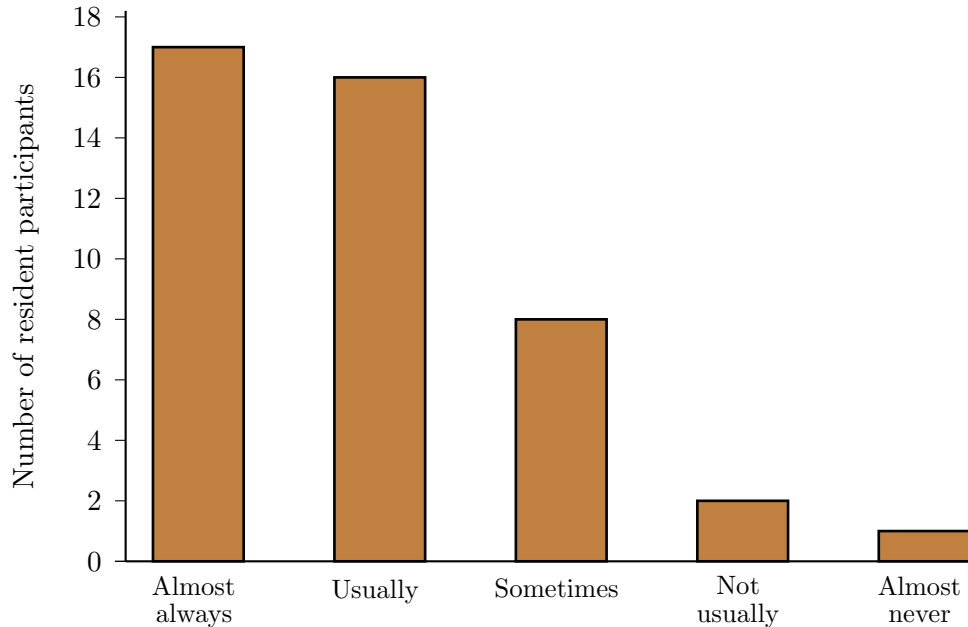
Even the most industrious of staff seemed resigned to the fact that the scale and less flexible rhythm of villa life meant that periods of boredom were an inevitable consequence of living in an institution.

> STAFF   I really think that boredom and an institution go hand in hand quite frankly, I really don't know how you can get around it unless you are going to spend tens of millions of dollars and have a one on one scenario or have two staff look after four residents.

A clearer picture of the lack of stimulation afforded residents emerges on closer inspection of the other coding categories. The minimal requirements for activity to be coded as *Indoor Passive* (M=5.1 percent; SD=10) and *Indoor Active* (M=24 percent; SD=18) were easily met. For example, *Indoor Passive* included watching television or attending to the radio and *Indoor Active* included, chatting or engaging with others or activities that appeared stimulatory but which may not in other contexts be considered as hobbies or otherwise purposeful activity. The resident in the following extract begins the observation, lying prone and popping bits off a plastic bottle. The appearance of the drinks trolley interrupts him and the extract starts towards the point when the resident is finishing his drink. Picking at the empty bottle and pulling the carton apart were both recorded as *Indoor Active* behaviour at Kimberley Centre.

```
2.47     [Staff] ''No you are not having it.''
         [Staff] explains to observer that [Resident] wants the empty
         soft drink bottle.
         [Staff] ''No, not till tomorrow.''
         [Resident] hovers around the trolley.
         [Staff] ''Go and have that drink'' (x2).
```

```
[Resident] sits...
Staff tells observer that he saves cartons for [Resident]
to pull apart.
Goes and gets carton and places it at [Resident's] feet.
Resident smiles and gets up.
Grabs the carton and begins pulling it apart.
```

Many other instances, like this, of staff attuned to and meeting idiosyncratic activity preferences were observed. Villa staff would, for example, save empty washing powder boxes for a resident to add to his collection, procure a clipboard to make it easier for someone who liked to scribble until a page was completely inked in, or make sure a supply of linen ties was kept up for someone to finger. Common to all of these tailored acts of thoughtfulness however, was a self-stimulatory dimension, deflecting rather than demanding staff attention. Villa staff were neither resourced nor expected to engage residents in ordinary activities at ordinary times or encourage ongoing learning. In the multiple disability villas a biomedical understanding of residents was emphasised and staff's understanding of their role narrowed to providing quality biomedical support.

RESEARCHER What do you think he likes about living at Kimberley?
STAFF   Ooh. I would I suppose be reluctant to say whether he does or he doesn't. The advantage I guess that exists for [Resident] and all others is at least there are pretty much always the same numbers of people on during any one part of the day. He will always have his cares met. He doesn't have to do anything for himself, some people see that as good.

And again:

RESEARCHER What do you think he likes about living at Kimberley?
STAFF   Well put it this way – well in my eyes he has got 24 hour care. He is bathed and fed, he has got a bed to go to every night, what more could you ask for.

In the lifestyle and challenging behaviour villas the emphasis appeared to upon maintaining the equilibrium of the dayroom and staff rationed their attention and animation to keep the ambience quiet and settled.

STAFF   Sometimes there will only be one staff in an area. It is supervising rather than doing.

Wandering sits on the cusp of what is conventionally considered maladaptive. On average, participants were recorded as wandering six percent of the time. However, most residents did not wander and a small proportion of the participant population accounted for most of this activity. Three participants wandered almost habitually. An impression that two appeared to wander in search of stimulation was supported by the location of pauses in their otherwise constant circumnavigation. One participant would squat, lingering at the intersection of corridors and in door jams where he had two vistas and the other began and ended his laps of the villa courtyard at a lamp-post which overlooked a staff car park at the very edge of a retaining fence.

```
3.55    Shuffling along fence perimeter looking out towards the road.
        Stops, stands hands clasped in front.
        Turns to watch staff drive out of car park beyond the fence.
```

```
Turns back towards observer.
Shuffles over to courtyard table before shuffling in an arch
back to the fence.
Vocalises staring out to the car park.
Hits head with the back of left hand following another
vocalisation.
Turns and shuffles to the gate as a staff person enters.
''Hello [Nickname].''
[Resident] vocalises and hits his head with the back of
his left hand.
```

The second most frequent activity engaged in by participants was *personal care.* Personal care was a rather amorphous code that included activities related to meeting participants' physical and personal care needs. Participants were engaged in activities like dressing, bathroom related cares, eating sleeping and grooming on average for 15 percent of the total time they were observed. For many residents, moments of personal care were associated with the most sustained interpersonal contact and great care and patience was generally taken in meeting people's intimate and personal care needs. The press to keep to the cadence of an institutional rhythm of care however undermined the opportunity to support greater competence in personal cares.

STAFF   This place is so – what's the word – well we are institutionalised and it
               is not just the residents, staff are too and it is a time factor. Staff can't
               be bothered taking the time. Taking time because it creates, it becomes
               a time factor, Everybody has got to be showered by 9 o'clock and that is
               quite easy too, because we are finished sometimes at 8 o'clock, a quarter
               past 8, things like that.

Time pressed on most care activities. For example the one-to-one assistance at meal times, though patient and empathetic, was often required as much by the need to make dining expeditious as by resident need. Communal hand washing and tooth brushing appeared similarly to represent the most efficient way for personal care to be accomplished.

```
2.46      Staff is giving drinks to residents.
          [Resident] calls out ''What about Mr [Name]?''
          Pulls [Resident] to sitting position.
          Bangs [Resident's] head on window frame.
          ''Careful.''
          Holds cup to [Resident's] mouth.
          Feeds whole cup in one go.
          Leaves and returns with a second cup which is finished in one go.
          [Resident] gets up.
          Staff moves to next resident.
```

Changes in location were also typically associated with moments of personal care. Morning and afternoon tea, supper, taking medication and occasionally grooming happened publicly in the dayroom in most villas, but all other moments of personal care occurred in other places, often requiring staff prompting to ensure the resident moved to the appropriate location.

8.3 Did the type of villa residents lived in make a difference to their activity?

Differences emerged in the activity patterns of villas, reflective both of residents' level of impairment and of the way they were socially constructed. Figure 8.3 plots the observed activity profile residents in the three villa types.

Given the heterogeneity of the resident population the similarity of the profiles is remarkable but perhaps not surprising given the way that the pattern of adaptive competence and location profiles of Kimberley Centre residents also tended to mirror each other regardless of villa type. This finding adds weight to prior conjecture that the cultural mores of Kimberley Centre were generally insensitive to individual difference and tended to press uniformly on the staff and residents.

Sedentary activity dominated all activity profiles, but the general trend was for the range of activities to be positively related to level of impairment. Residents with multiple disabilities were the most unstimulated, on average being recorded as engaging in sedentary activity 67 percent of the total time they were observed with residents in challenging behaviour (42.2 percent) and lifestyle (42.3 percent) almost a third less likely to be similarly disengaged.

Figure 8.3 — Mean proportion of total observed time resident participants were recorded as engaged in different activities at the Kimberley Centre by villatype.
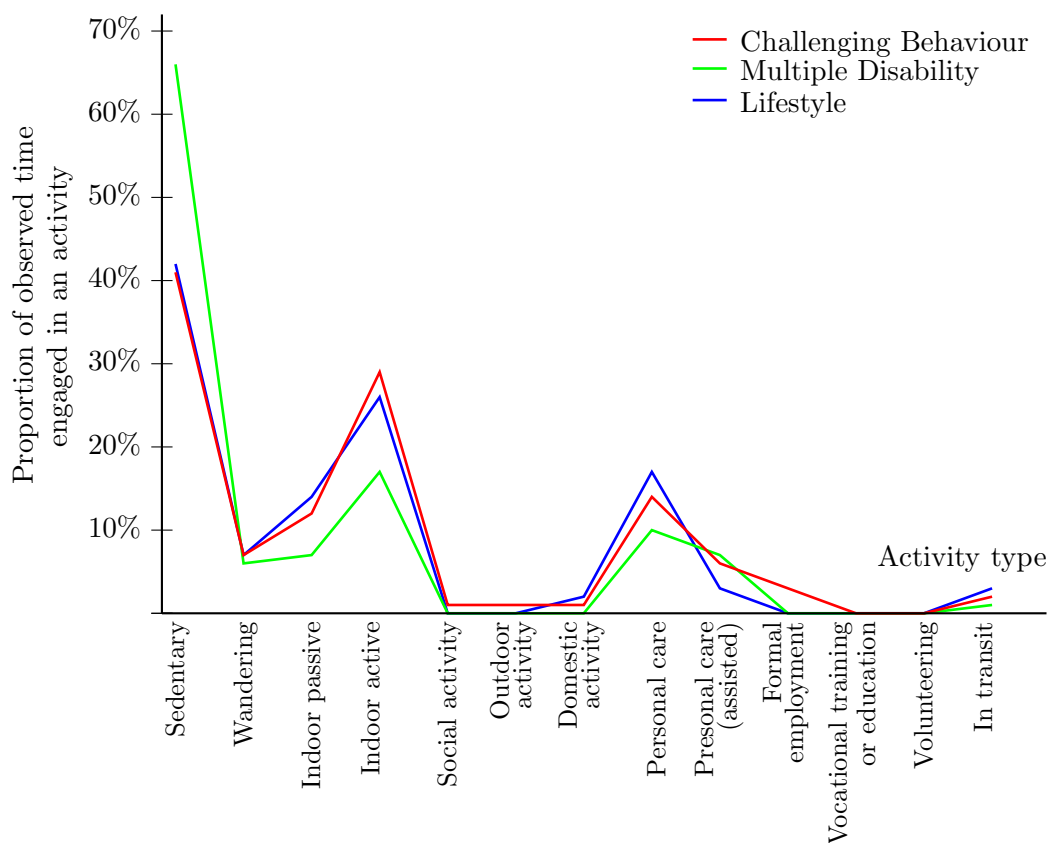
At face value these results are not surprising. We would expect that the types of activity participants engaged in might be compromised by severe impairment. However the more limited expectations held for people with multiple disabilities and consequential understanding

of staffs' role may also have influenced support practice in ways that made their unchanging lives a self-fulfilling and untroubling reality.

RESEARCHER What does [Resident] really respond to? What draws her out?
STAFF You are asking hard questions there.
RESEARCHER Do you know much of [Resident's] history prior to coming here?
STAFF No, but I don't normally check.
RESEARCHER It is pretty hard to know what her preferences are...
STAFF You are going to find that with a lot of residents, those who can't communicate – just use the odd body language, to determine likes and dislikes. It's very awkward.
RESEARCHER Do you think there are things he is proud of?
STAFF Again, it's so hard to determine what [Resident's] thought patterns are, so I wouldn't have a clue.

As a proportion of the total observed time, residents supported in multiple disability villas were less likely to be engaged in indoor active activity (18.0 percent) than residents in multiple disability (25.9 percent) or lifestyle villas (27.5) percent and less likely to be observed engaged in moments of personal care (9.4 percent) than residents in challenging behaviour (17.5 percent) or lifestyle villas (14.0 percent) too. The lower proportion of time observed in personal care is counter-intuitive given their greater support needs but probably reflects the number of residents who were naso-gastrically fed (and therefore not recorded eating) and their more limited ability to break the long stretches of doing little with trips to the toilet or personal grooming.

Common to all participants was the range of activities that were not observed at Kimberley Centre. Domestic activity barely featured. Residents were almost never observed engaged in social or outdoor activity, employment or other commonly understood moments of productive activity.

8.4   The activities that filled a person's day beyond Kimberley Centre

During the years residents were observed at Kimberley Centre, villa life for most was characterized by long listless hours interrupted by the predictable routines of resident care. The finding that residents lived largely sedentary lives was echoed by Kimberley Centre staff, 75 percent of whom estimated residents "usually" had nothing to do (Figure 8.2). Figure 8.4 contrasts the responses of Kimberley Centre and community-based staff to the same question.

By the end of the first year after resettlement, only 6 percent of staff estimated that the residents they supported "almost always" had nothing to do in their spare time. Community-based staff were, on the other hand, much more likely to report that residents were able to fill their spare time with purposive activity. Living in a community setting was associated with a statistically significant shift in staff assessment of how occupied residents were in their spare time (χ^2=25.7; $p < 0.001$). At each phase, staff's estimation of resident's purposive use of time improved, however, the only statistically significant change in assessment occurred between Phase 1 (at Kimberley Centre) and Phase 2 (3-6 months after resettlement).

Figure 8.4 — Mean proportion of total observed time resident participants were observed in a vocational settings by the Kimberley Centre villa type.
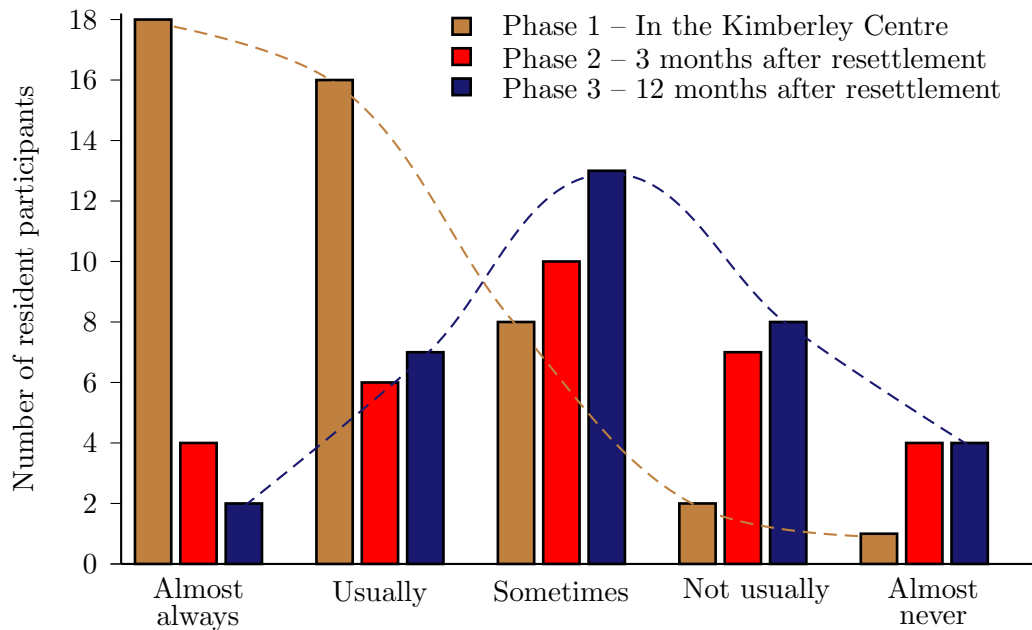
Table 8.1 — Pearson χ^2-test values for comparison between staff's assessments of how often residents had nothing much to do in their spare time at different phases of the project.

Phase pairs	χ^2	d.f.	p
Phase 1 and Phase 2	16.6	4	**0.004**
Phase 2 and Phase 3	1.1	4	0.900
Overall	25.7	8	**0.001**

This trend for significant change, followed by a plateauing in staff's assessment of residents' level of activity, is entirely consistent with an equivalent change in the observed activity patterns of residents discussed in more detail in sections 8.7 and 8.8.

When the everyday activity of Kimberley Centre residents was compared before and after their move to a community-based service, the overall pattern of resident's everyday appeared to change little, suggesting a similar culture of support may have followed residents into their new homes. Home was still the cardinal space in residents' lives and time spent there continued to be characterized by long periods, doing little (Figure 8.5). Similarly, the perseverance of residents' low level of engagement in domestic, social and outdoor activity also hinted that the historical roles of consumer and provider of care had been maintained in community settings. A number of important trends did emerge though, including some that were easy to miss. At Kimberley Centre a small number of residents were caught in a pattern of restless wandering. One year after resettlement the average percentage time residents were observed wandering diminished, falling from 7% at Kimberley Centre (SD=13%) to being less than half as prevalent by years end (M=3.0%, SD=8.0). Staff speculated that some residents listless wandering was self-stimulatory, and the more active and engaging community support milieu appeared to illicite a wider reduction in stereotypical behaviour*.

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*See section 9.5 for a more comprehensive discussion of observed change in stereotypical behaviour.

Figure 8.5 — Mean proportion of total observed time resident participants were recorded in different activities at the Kimberley Centre and 12 months after re-settlement.
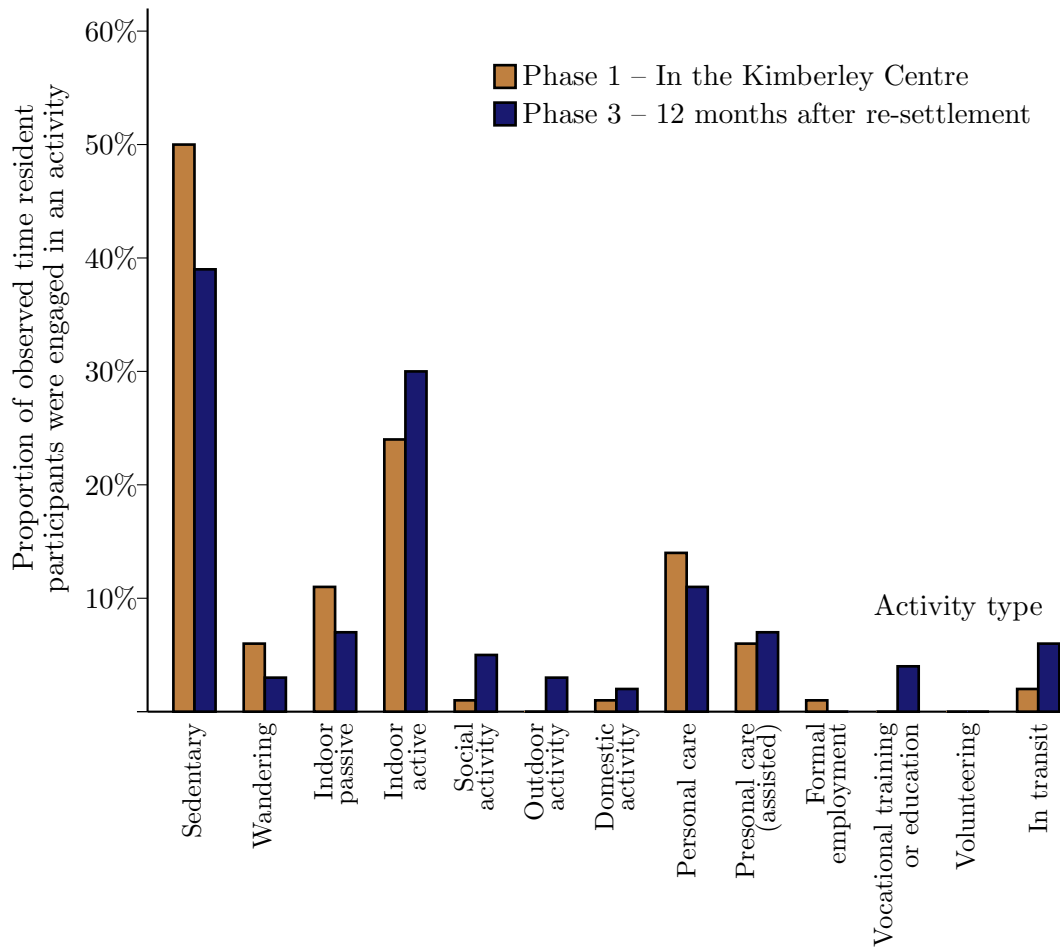
Conversely, although still small in the context of overall activity, the proportion of time residents were recorded as engaged in social activity rose during each phase of the project. Residents were, on average, only recorded as engaging in social activities for 1 percent of total observed time at Kimberley Centre. Twelve months after their resettlement, residents were recorded in social activity for more than five percent of the total observed time. Two-tailed, paired t-tests were used to explore possible significant differences between changes in the proportion of total observed time that residents were observed in different activities. The 4.7 percent increase in the proportion of time residents spent in social activity following their move was a statistically significant change following resettlement (95% CI [1.0–8.0]; $p = 0.01$). Social activities included being a passenger on trips taken for pleasure, visiting friends, attending organised events and participating in outdoor day trips, like picnics. The small but constant increase in this activity domain is coincident with the greater community presence of residents following their move to community-based services. A deconstruction of the community spaces residents were observed in after resettlement revealed an increase in the proportion of observed time residents were recorded out for drives and a greater presence in contexts such as parks, the community centre and bowling (Figure 7.1).

As discussed previously in section 7.9, being in these spaces had common experiential elements including that they tended to be organised and moderated by staff rather than self authored, were public rather than private social spaces and people came and went from

community contexts in ways that made it difficult to establish ongoing social relationship or become assimilated as *insiders* within the cultural landscape of particular community settings. Contexts where residents were included as active and valued members were scarce and even when staff included segregated and or atypical settings like Kimberley Centre coffee club and Stairways dance, the number of residents staff volunteered as belonging to a club, group or society remained low over all phases of the project (Figure 8.6).

Figure 8.6 — The relative proportion of residents whom staff, as proxy respondents, described as belonging to a club, group or society at all phases of the project.
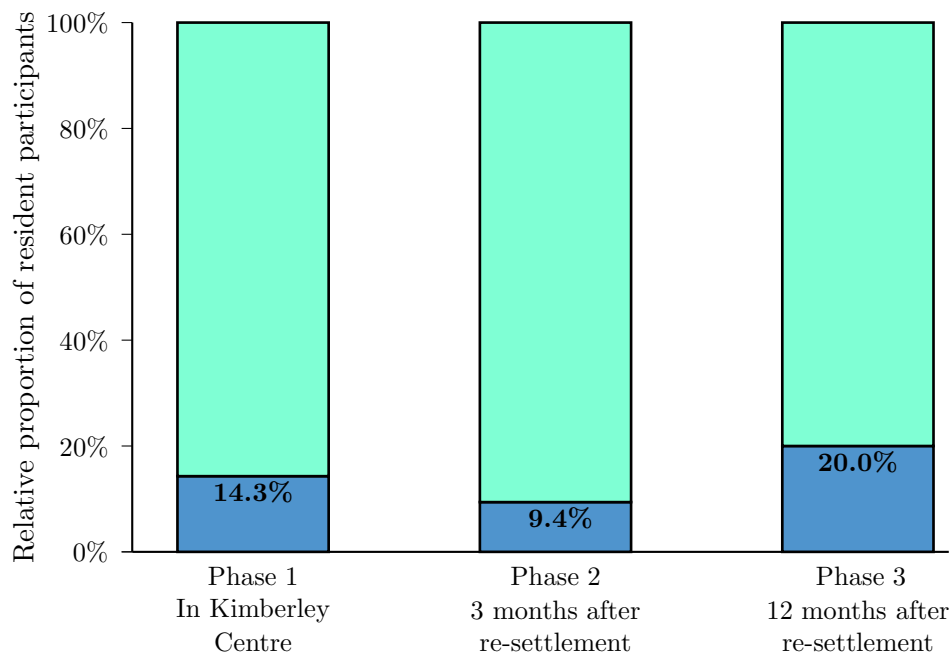
Consistent with previous New Zealand[9, 79, 100] research, the pattern of resident activity after resettlement could also be described as residents tending to live *in* without being *of* the communities they were resettled to.

At Kimberley Centre, the sedentarism of residents found expression in the relatively low frequency with which they were observed in transit between locations. Residents claimed and exercised territorial rights over chairs and staff worked hard to maintain the equilibrium in villa dayrooms. On average, residents were recorded as in transit for 2 percent of the total observed time while they lived at Kimberley Centre, typically during the scheduled exits and entrances for meals or personal cares. In Phase 3, the 4.1 percent increase in total observed time residents were recorded in transit was a statistically significant change following resettlement (95% CI [1.0–8.0], $p < 0.01$). In community based settings, a cultural shift towards fostering greater domestic independence, the smaller, less spatially distinctive activity spaces associated with a normal dwelling, greater domestic activity, daily trips to and from the Vocational Centre and residents' liberation from the inflexible institutional rhythm all contributed to residents being more frequently observed moving between locations.

The subtle life changes exposed by the greater mobility of residents in community-based settings is highlighted in the transcript extracts below. The two narratives capture staff responding to researcher questions related to how residents spent a typical day. The activities are the same. What differs is the resident's ability to determine the timing of activity. At Kimberley Centre she waits for breakfast. In the community based setting an ability to

author her own actions revealed latent competence and supported a greater involvement in the day-to-day routines of everyday living.

At Kimberley Centre

STAFF   [Resident] will get up at around 7 o'clock. She will have a shower or a bath whichever way she likes. Get herself dressed or she might want you to dress her but she can dress herself and then she will sit in there and wait for breakfast. After breakfast she gets her hygiene cares and then she will wander off to her placement.

Beyond Kimberley Centre

STAFF   Um, she likes to wake up and see a staff member so she will come out. Um, then she would like to have a shower, she likes to have a shower and shampoo her hair. She likes to choose her own clothing so we will choose the basics and she will replace it with what she wants. [laughs] And then she has a shower and she has breakfast. Again she chooses her own breakfast because that can vary from the choice that we have got, it is not always the same.

8.5   The ability to exercise choice in and out of Kimberley Centre

Personal freedom and the ability to exercise control over ones life are cherished rights within society.[48,53] Ryan (1997), for example, describes the freedom to participate in all dimensions of the social, political and community life as elemental to citizenship.[101] Research has consistently demonstrated that people with an intellectual disability make fewer choices than other citizens.[48,50,51,53] People with intellectual disability have themselves told us that their ability to author activity is important qualitative prerequisite to feeling a sense of community membership and belonging.[79,81]

Conversely, the loss of a progressive sense of personal identity through restrained and regulated circumstance was advanced by Goffman (1961) as one of the most disturbing consequences of living in an institution.[30] Improving the ability of people with an intellectual disability to exercise control over their lives became embedded as part of the wider vision for deinstitutionalisation[5,25] for people with intellectual disability.

At Kimberley Centre, outsourcing, the atypicality of the villa environment, an entrenched and unbending care routine, limited staff resources, a narrow understanding of the support role and a culture that staff said pressed on them not to do too much or do too little, conspired to suppress resident's ability to exercise meaningful control over ordinary life choices.

STAFF   Its a structured environment, it is a large environment, services are contracted in and out so that means that the opportunity sometimes to make choices is not easy. Sometimes it is exacerbated by the people that [Resident] lives with. You have to put systems in place to meet with what I call the lowest common denominator so that if you have someone who persistently decides I will go to everybody else's set of clothes – you have to prevent that happening, you have to put locks on. It takes the choice away. Meals are ordered from Horowhenua hospital. They are not what [Resident] would want, so yeah, the environment limits the opportunities,

there is no doubt about it. Nobody gives him the opportunity to choose. His clothes are made up by the night staff. His routine is followed rigidly really. He does get a choice occasionally from the canteen – He would choose everything anyway there and I just think it is Kimberley thing, there is not a lot of choice for them.

Choice making, for most, was limited to relatively artificial moments of self determination in which residents were able to act in proprietal ways within a small sphere of influence.

RESEARCHER Yes, she seems to have a lifestyle a little bit of her own choosing, like she has got her own chair

STAFF Her own chair is actually, have a good look at it, it has actually got a lap belt on it

RESEARCHER But she does go to it?

STAFF Quite often she will when she is in a good space, a good frame of mind she will take herself off to the couch and she will lie on the couch or something so no, she will choose other places to sit.

As was noted in section 6.1, however, for a small number of more able residents who had succeeded in gaining staff trust in their ability to navigate safely, Kimberley's grounds offered opportunities to slip beyond staff gaze in ways that would prove difficult to replicate in community settings.

STAFF She knows here boundaries here because we know that she won't go outside the gate, so it looks like she is taking off but she only goes under the tress. She does know the boundaries and she will find herself a spot. She is always back for lunch.

And unheralded moments of quiet self-determination that were also sometimes lost within the culture of community-based service delivery. The following transcript extracts capture the narrative of two staff reflecting on the same resident's ability to determine his day activity in and then out of Kimberley Centre.

At Kimberley Centre

STAFF He is actually very assertive. Certainly when he decides he is not going to be doing something, then that's not going to be it, it is going to be that so he can definitely make his needs known for example, if I said to him you have got art this morning and he had a look outside and saw it was a bit wet, he might decide, no I don't think I will go today, it's raining. And he will just chill out and get his board and do what he wants to do there. Choice I think is very important for [Resident], his ability to pick bits of pieces, a bit of empowerment in his life and he enjoys that, to have that.

Beyond Kimberley Centre

STAFF Why can't they have a choice [of Vocational Activities]? But no, they all go to [Vocational Service Provider] don't they. The contract says they have got the funding so they have to go and I suppose every time we don't turn up, it is a tick in the box, it is the same thing, it is all audited. They are getting paid to have them

RESEARCH So the pressure is on you to have them go...

For the majority of residents Kimberley Centre offered few opportunities to exercise control over their everyday lives. This reality was reflected in staff's assessment of the degree of choice available to residents across the six life domains sampled for in Stancliffe and Parmenter's Choice Questionnaire.[48, 53] Sample questions within the domains of *Domestic Activity*, *Money and Spending*, *Health*, *Social-* and *Community Activities* and *Work Activities* were scored from 1 to 3. A score of three indicated that resident was able to make a decision. Conversely, a score of 1 indicated the absence of autonomy or opportunity to decide.

In none of the individual domains did Kimberley Centre staff, on average, score residents more than 15 percent higher than the lowest level of individual autonomy (Figure 8.7).

Table 8.2 — Mean Choice Questionnaire domain scores for each phase of the project

Domains	Phase 1		Phase 2		Phase 3	
	M	SD	M	SD	M	SD
Domestic activity, staff and other people you live with	1.12	0.19	1.30	0.26	1.32	0.28
Money and spending	1.02	0.19	1.11	0.30	1.32	0.28
Health	1.07	0.43	1.25	0.34	1.30	0.47
Social activities, community access and personal relationships	1.15	0.44	1.34	0.43	1.51	0.54
Work/day activities	1.11	0.59	1.00	0.63	1.32	0.61
Overall choice	1.20	0.41	1.50	0.86	1.89	0.57

Figure 8.7 — Mean Choice questionnaire domain scores for each phase of the project.
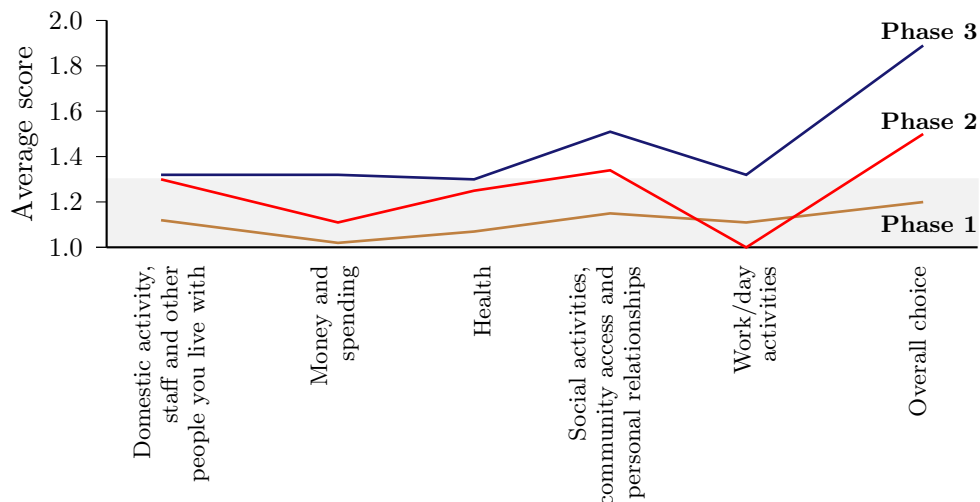
After resettlement, the ability residents were described as having to exercise choice improved in all six domains. Although self determination continued to remain highly circumscribed, a comparison of staff ratings at Kimberley Centre and 12 months after resettlement using a Two-way ANOVA revealed a small, but statistically significant increase in resident autonomy in the domains of *Domestic Activity* ($F = 8.70$, $p < 0.01$), *Health* ($F = 4.06$, $p = 0.02$), *Social Activity & Community Access* ($F = 5.65$, $p < 0.01$) and *Overall Choice* ($F = 12.31$, $p < 0.01$).

The small but significant increase in residents ability to be more self determining in areas of life related to their living environment, social and community activity and overall all choice

making appeared to be underscored by a number of changes associated with the move to community-based service settings.

More intimate settings, a smaller number of resident to attend to and a greater ability at home and in the community to be in contexts that offered opportunities for choice making, potentiated a widening of community-based staffs' understanding of their role. Many had come to see the facilitation of choice making as an important element to support.

RESEARCHER What choices can [Resident] make about her life?
STAFF   Anything that she wants, that's why I am here. If she wants anything
            done I try and make that happen for her. She makes choices in who she
            wants to assist her in the mornings. Who she wants around her, what she
            wants for breakfast, lunch and you know. So she makes all choices every
            day
RESEARCHER Mm, and she has made some choices about shopping purchases. When
            you have been shopping she has indicated what she likes.
STAFF   Yes, and what she wants, yes, and clothing, she makes choices in that,
            yeah so everyday living.

Similarly the architectural typicality and homeliness of community-based settings made it easier for services to impress on staff an equivalent right for service users to be self determining within the sacred space of their own home. Some staff spoke of the importance of *asking [Resident's] permission,* as the pre-requisite step to support.

Liberated from the routines of institutional care, community-based staff and former Kimberley residents also appeared to have greater freedom of movement and action within the places they spent most of their lives. As noted in section 7.2, the ability residents had to decide where to go and what to do next in their new homes was perceived by staff to contribute greatly to the life quality beyond Kimberley Centre. Research strongly suggests that opportunity to make choices is strongly correlated with activity.[102] Having the time to support the expression of individual choice-making appeared to contribute to resident wellbeing in other ways too. In the extract below the staff person clearly associates a commitment to taking the time for a resident to make clear her wishes with an improvement in her emotional wellbeing.

RESEARCHER That screaming, has that decreased?
STAFF   Yes it certainly has. It is not continuous and it is not an attention thing,
            she is not having to vie for attention or fight or battle for attention. She
            has got autonomy. She is independent with her clothing, ADLs* and we
            give her that power to be able to do that and yes, she certainly responds
            well.
RESEARCHER What do you think she likes about living here.
STAFF   I think the space and the individuality. That's what she enjoys. The fact
            that we can spend a lot of time with her.

8.6 Communicating care through personal support

Without the press of having to keep so strictly to the cadence of the institutional rhythm, staff could linger longer with the moments of personal support in community settings. Taking

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*abbreviation: Activities of Daily Life.

the time to keep to the pace and preferences of residents was assumed by direct care staff to be a marker of respectful care.

STAFF   You have got to be patient and wait for [Resident] when he has a drink, a sip at a time, and it takes an hour, still I will spend the hour on him, I don't care. I am there to do my job, I care more about the residents than I do about any of the house work and all the other bull shit they want us to do.

Twigg and Atkin (1994) argue that in a family context, providing and receiving intimate and personal support almost always occurs in a context of a caring obligation in which affect underscores the personal exchanges between the carer and the person being cared for.[103] Following in-depth interviews with three women with intellectual disabilities about their experiences of receiving intimate and personal care, Mirfin-Veitch, Conder and Bray (2004) found that the emotional context of care continued to be important to the way support was experienced when people were supported in services.[32] Mirfin-Veitch, Conder and Bray speculated that the process of receiving and providing personal care was a qualitatively different support experience in which the emotion context was central to the perception of support quality. Support that communicated affect through touch, friendliness and humour was highly valued. Conversely support perceived to lack emotional attachment contributed to a negative perception of the intimate and personal care people received. Feeling rushed or the object of others work were antithetical to the experience of good care.[103]

At each phase of the project, the average proportion of total observed time residents were assisted in their personal cares increased and whilst the 1.4 percent increase in observed time fell below statistical significance ($p = 0.08$), the qualitative experience of being cared for did appear to differ for the majority of Kimberley Centre residents.

8.7   Changes in the pattern of residents' activity in the first months of resettlement

In section 8.2 the differences between the pattern to activity observed at Kimberley Centre and community-based settings were tested. A small number of statistically significant differences emerged. Residents were less likely to be engaged in stereotypical wandering and more likely to be mobile or involved in socially orientated activity. Comparing the activity patterns of residents at the end of their first year beyond Kimberley Centre, however, masks an important flourishing and then retreat from more active resident lifestyles that occurred in the first flush of deinstitutionalisation.

Figure 8.8 plots the average change in the proportion of time residents were recorded in different activity types between Kimberley Centre and 3-6 months after their resettlement. As before, the circle describes the proportion of total observed time residents were observed at Kimberley, with scores above and below the circle circumference representing positive or negative changes that occurred in the first 3-6 months. The first six months beyond Kimberley Centre were characterized by a dramatic increase in the proportion of time residents were observed engaged in Indoor Active and a concomitant decrease in the proportion of sedentary activity residents were observed to be engaged in. Between Phases 1 and 2 the proportion of time residents were observed doing nothing, staring, standing or snoozing fell by 13 percent. A paired, two-tailed t-test found the decrease in sedentary activity between

Figure 8.8 — Mean change in the proportion of total observed time residents were recorded as engaged in different activity between Phase 1 (In the Kimberley Centre) and Phase 2 (3 months after resettlement)*.
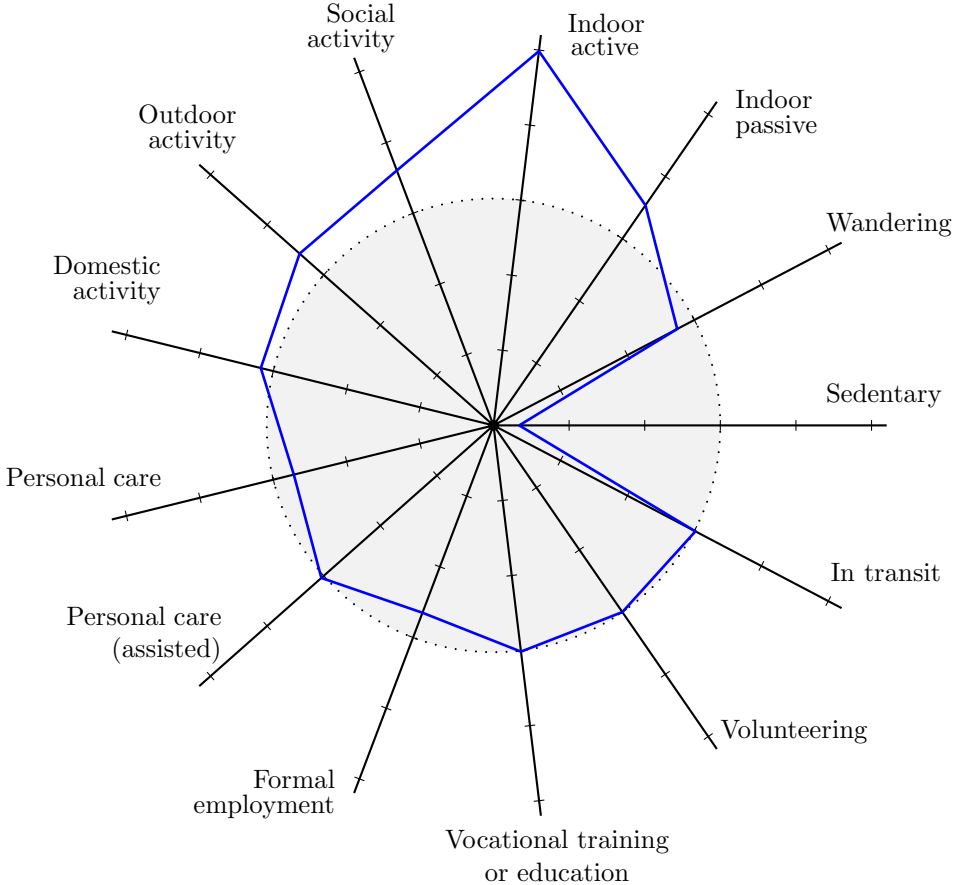
*The dotted circular line represents the zero change.
  One unit on the axes corresponds to 5% change in the given activity.

these phases was statistically significant (95% CI [-0.06 – -0.20); $p < 0.01$) with the move to community-based services strongly associated with a decline in disengaged activity.

Residents were less likely to be *doing little,* largely as a consequence of their greater propensity to be engaged in Indoor Active activity. In addition to a range of leisure pursuits, this activity type also included being communicatively engaged with other people and it was this aspect of residents that activity pattern changed the most after moving from Kimberley Centre.

Support staff were at the epicentre of most communicative events at Kimberley Centre and this pattern of dominating moments of interpersonal exchange became more exaggerate in community based settings (Figure 8.9). In Chapter 5 it was noted that both the frequency and duration of communication events increased following the move to community-based settings (Figure 5.5). Figure 8.9 plots the proportion of observed time residents were partners to a communication event during all phases of the project. It is disturbing to note that, despite the more intimate and homelike character of community-based support settings, the limited interaction between residents that occurred at Kimberley Centre was not improved by resettlement. At Kimberley Centre, many people were observed exhibiting a broad

Figure 8.9 — Mean proportion of total time residents were recorded as engaged in a communication event by communication partner.
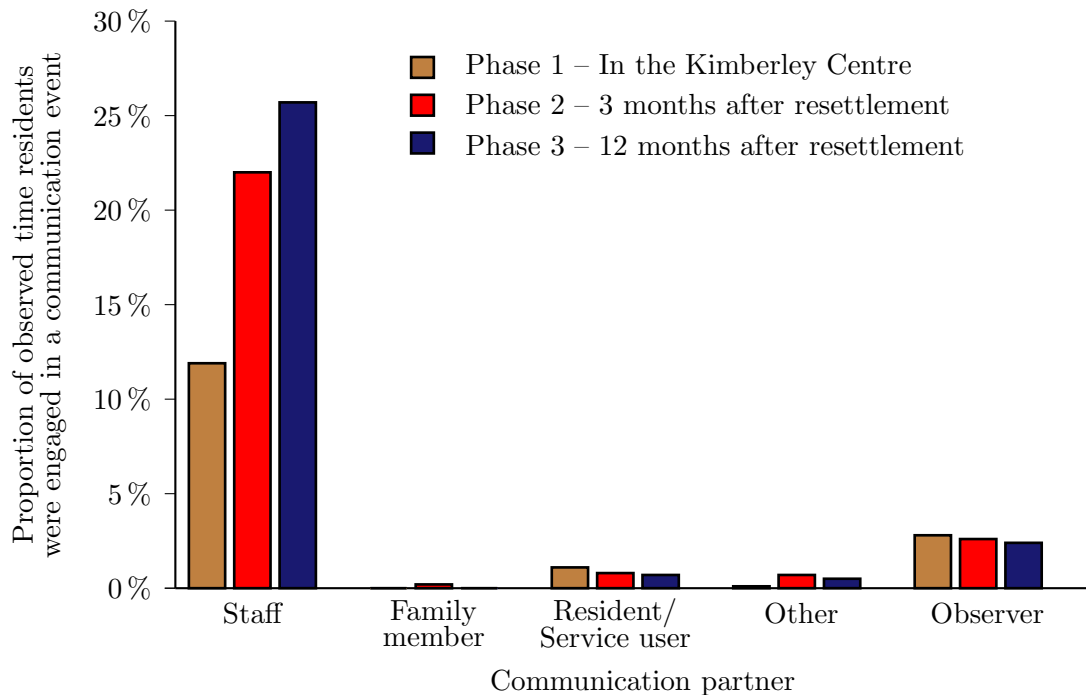
array of strategies to avoid engaging other residents, in a collective etiquette that included intimidation, body posturing and avoiding eye contact.

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Villa dayroom
10.55      Another resident sits beside [Resident] on couch.
           [Resident] sits up.
           Feet placed on floor.
           Taps floor with feet.
           Turns away from other resident.
           Leans back, crosses legs, screams 2-3 times.
           Other resident stands and moves away.
           [Resident] sits up, buries his head in the corner of the couch.
```

Living in community settings did little to extinguish the effectiveness of these strategies with most residents continuing not to engage those with whom they shared their home. In fact the proportion of observed time residents engaged other residents diminished at each phase of the project

Staff, on the other hand, occupied a more prominent social role in residents' lives, with the proportion of time staff were observed participating in a communication event more than doubling by the end of residents' first year beyond Kimberley Centre. At Kimberley Centre it was assumed that the central role staff played in controlling the flow of resources and institutional rhythm contributed to their pre-eminence in communication exchanges. Staff were typically the focus of residents' gaze.

RESEARCHER Who are the most important people to him?
STAFF   Staff, certainly staff, I would say.

RESEARCHER Why are they so important?
STAFF   Because they do things for him. And he will do things for them. What
            you do for me, I will do for you sort of thing.

In community-based services, staff remained the dominant social actors, continuing their control of the rhythms and tone of the house, but the nature of interaction had also changed. Communication events at Kimberley Centre tended to be fleeting in character. Busy day staff would acknowledge residents in passing. They might instruct or seek information that aided staff related activity. Or they could be a response to resident initiated behaviour calculated to return the villa dayroom to its normal equilibrium. Embedded in these exchanges were often verbal and non-verbal cues that suppressed rather than invited further dialogue.

With a lower staff ratio and more flexible day-to-day regime, staff were at liberty to indulge in the type of *wasted* and unproductive time that O'Brien (2003) argued was fundamental to the deepening of relationship and authentic exposure of the "light of some-ones being,".[36]

STAFF   She spends more time up rather than in her bed, that's for sure. We have
            a better ratio so therefore you can take her out for a walk. You can sit on
            her chair, you can chit chat with her. We can dye her hair, she has had
            her hair dyed. Like we bought hair dye and we dyed it out here on the
            deck one day sort of thing. There is all the extra time just to sit down
            and be with them. You don't have to rush, it is not so task orientated,
            like I have to got change her because I have got a change at 5, boom,
            boom, boom, so I wasn't so much for the person time, you couldn't take
            the time whereas here you can take the time, you can potter around, you
            can have a joke, you can spend more time with [Resident], you can talk
            about frilly things and talk about dolly and the newspaper and what do
            you think [Resident]. There is more interaction talking to her, with her,
            amongst it all.

And sometimes it was the doing nothing that counted most.

STAFF   He has really got to have one on one time. He loves to know you are
            there. Just to be around him, talking to him, touching him, read to him,
            just things like that but actual activities for him to do anything with his
            hands and that would be just about virtually impossible I think really.

8.8 A return to institutionalised care? — Changes in the pattern of resident activity towards the end of the first year in community-based settings.

When the research team returned six months later, a different pattern of activity had emerged. Figure 8.10 plots the change in the proportion of total time residents were recorded as engaged in different activities between 3-6 and 12 months after each resident had moved from Kimberley Centre. As noted previously, there was often a delay in residents attending vocational services as residential services waited for them to come on-line and support staff felt confident that residents were able to cope. As discussed previously, a greater emphasis on getting residents into community settings also contributed to an increase in the Vocational and In transit activity observed 12 months after resettlement (Figure 8.10).

Of greater import, however, is the fact that the initial trend of increasing indoor activity and decreasing sedentarism had completely reversed. The magnitude of the shift was sizeable enough to extinguish all of the initial gains that occurred in the first flush of deinstitutionalisation (Figure 8.8b), giving rise to a return to an activity pattern that resembled those first observed at Kimberley Centre (Figure 8.8c).

By the end of the first year no significant differences existed in the proportion of time residents were observed in either sedentary (95% CI [-16.0 – 2.0]; $p = 0.11$) or indoor active activity types (95% CI [-3.0 – 11]; $p = 0.22$).

Figure 8.10 — Mean change in the proportion of total observed time residents were recorded as engaged in different activity between Phase 2 (3 months after resettlement) and Phase 3 (12 months after resettlement)*.
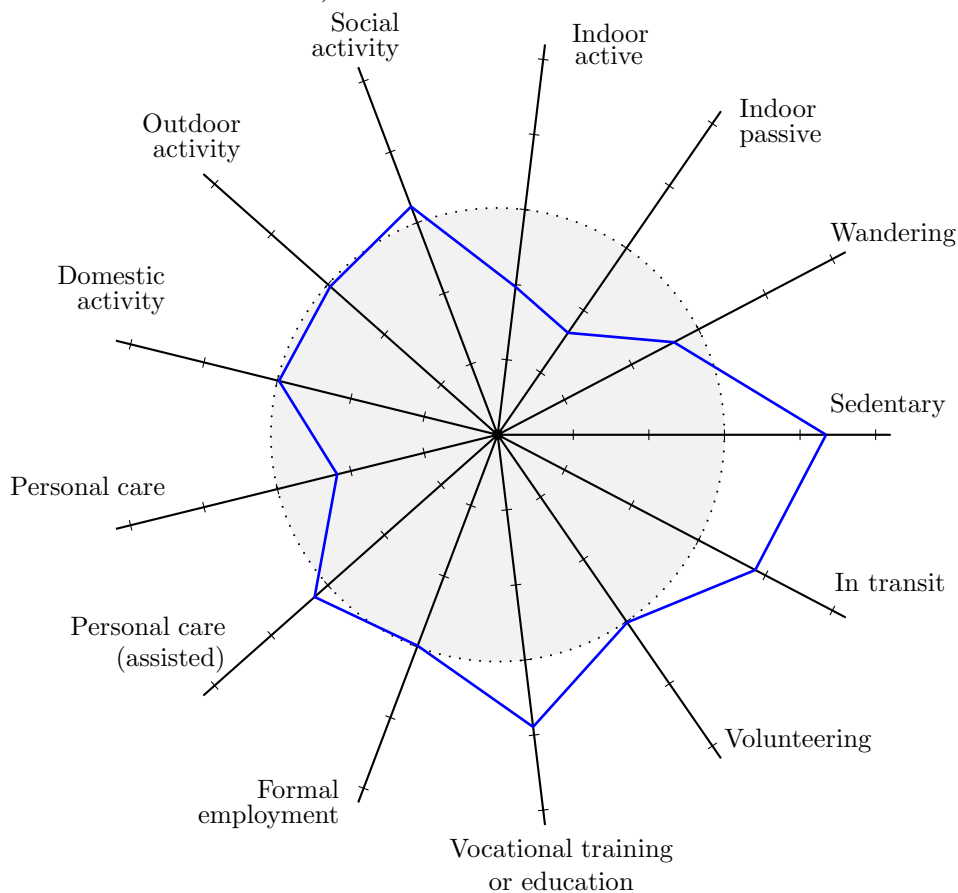
*The dotted circular line represents the zero change.
One unit on the axes corresponds to 5% change in the given activity.

The return to a pattern of resident activity that more closely resembled institutional lives might be accounted for by a subtle oscillation in the culture of community-based support. In the first months of deinstitutionalisation, services were galvanised by a determination to provide residents with new lives. They met each other as strangers and an *ethic of discovery* infused support relationships. Exposing latent competence and learning more about an individual's preferences and mannerisms became strongly reinforcing to staff and families. During this time support staff collaborated with families to learn more about each person

Figure 8.11 — Mean change in the proportion of total observed time residents were recorded as engaged in different activity between Phase 1 (In the Kimberley Centre) and Phase 2 (3 months after resettlement)*.
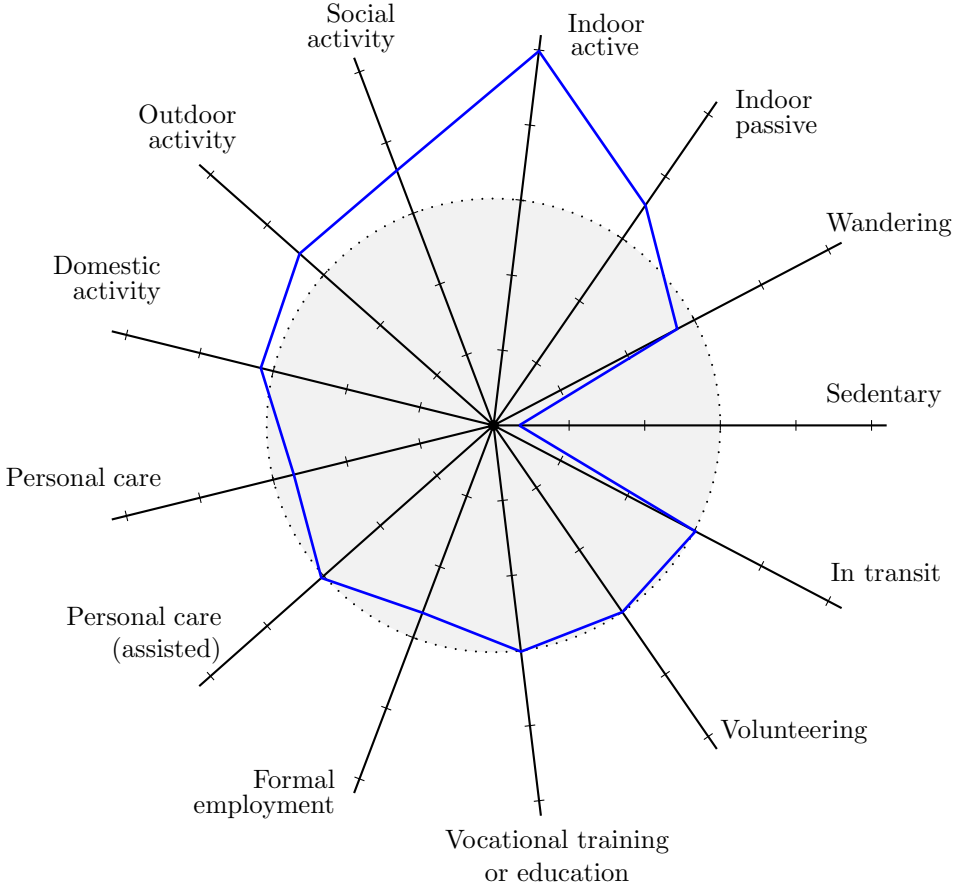
*The dotted circular line represents the zero change.
One unit on the axes corresponds to 5% change in the given activity.

and see beyond the paper of support plans and protocols to the men and women who they would begin new support roles with.

Expanding residents' horizons of experience was strongly motivating:

RESEARCHER Do you think it is important that his day does vary.
STAFF I think so, I think he needs - well to a point he needs to keep trying new things, yeah. To discove whether he likes them or not isn't it. I mean it is worth a try and if he doesn't, he doesn't, you have at least given it a go.

And staff took delight in the way new activity confronted old and disabling social constructions. This ethic of discovery was coincident with an increase in resident adaptive behaviour that families and staff both reported re-humanized Kimberley Centre residents. New activity and an attentiveness to the resident's responses suggested new possibilities for growth and personal development.

STAFF Yeah, I actually tried her horse riding on Sunday because I had seen a photo in her room and it was [Resident] in the photograph so I asked

about it and asked about it and I was continued to pursue it, I was very persistent and so they caved in and they said well pop out on Sunday so we did and again everybody's judgement of her, she actually, she put her hat on, she put her gumboots on and she hopped on the horse so that's an activity and she was smiling, she was really really happy on the horse, you could see it in her face and so we are going to continue with that for her maybe once or twice a week. So that's one thing we have got started.

The Kimberley Centre Research Project findings add to the research literature reporting a plateauing to the acquisition of adaptive competencies following deinstitutionalisation. Authors have generally attributed the initial flourishing of adaptive behaviour to the greater exposure people with intellectual disabilities have to learn or demonstrate pre-existing competence in the more culturally enriched and homelike community support setting rather than the conduciveness of support practice to ongoing learning.[51,59,71] Analysis of staff and family narratives in this study strongly suggest that a shift in service culture may also have contributed to a return to the activity patterns of institutional life and a concurrent slowing in the acquisition of competence.

Over time the vision of making a difference in the lives of Kimberley Centre residents became complicated by the realities of disability support practice and the ethic of discovery gave way to new markers of professional proficiency. Whereas unearthing competence was a powerful motivator in the initial phase of deinstitutionalisation, an antithetical knowing, anticipating and managing resident behaviour began to replace these values as reinforcing to staff.

Beyond the direct support relationship, elements of service culture also supported the shift in staff values.

Many of the community-based services that residents had been resettled to had bled staff. In a number of sites, none of the staff that had begun the support of Kimberley Centre residents in their new homes remained by the end of the first year. The staff that left took with them their vision of new community lives and their excitement at discovering new things about the men and women they had first met as strangers. Families became dispirited at continually having to establish relationships and reinvent their place in their relatives lives, especially when their choice of service was predicated on a faith they had in the energy and personal attributes of the people whom they original entrusted the care of their family member. Staff also became dispirited at the continual flux in middle management and in larger services, a belief that decisions of consequence were being made by people distant from an understanding of the consequences of their decisions inside of real lives.

Without the vision, new staff were inducted into services where the indicators of service quality emphasised the technocratic values of service protocol, policy and procedure, displacing making resident's unique aptitudes, preferences and life history visible as the primary goal of support.

Burden asserts that the excessive centralisation of decision-making has become the defining characteristic of community-based services. The effect of the bureaucratising of human support, he suggested is to suffocate spontaneity and creativity and emasculate the staff (and families) who held the most intimate knowing and strongest motivation to improve the life quality of people with intellectual disabilities.

Support for the argument that the a similar social construction of people with intellectual disabilities has permitted the social practices of institutional care to follow residents into community settings is evidenced by the continued resonance of Goffman's exposition of the

defining attributes of the 1950s asylum. Goffman (1961) described institutional care as characterized by:

* the loss of a progressive sense of identity;
* restrained lifestyles,
* the development of a professional hierarchy able to regulate life circumstance,
* the maintenance of social distance between staff and residents, and
* and the loss of the original vision of (deinstitutionalisation).

More than forty years later, the NHC (2003) would characterise New Zealand community-based residential care for adults with an intellectual disability with a similar set of attributes.[9]

The activities that filled the days of New Zealand's last institutionalised population changed significantly after Kimberley Centre closed. What they learnt, where they lived, worked and played and how they were engaged and understood by staff changed in quietly significant ways too. Quality of life improvements did not inevitably follow the move to community-based services as changed occurred through improvements in the way people who loved and cared about particular residents were able to express their affect through action. Nurturing communities of care and funding human support in ways that facilitate genuinely individualised service delivery would seem to an obvious way to continue the journey beyond institutionalisation. Doing so requires holding to a wider vision of deinstitutionalisation. One that sees people with intellectual disabilities stepping into the private social lives of other New Zealanders and shaping support to achieve self-authored lifestyles as indicative of stepping beyond the shadow of institutionalised care.

STAFF	I think probably when you are out it gives you a new lease too because it is different. I am saying from my experience, waiting for Kimberley to close, oh here is a nice new house, oh new people to meet, do you know what I mean, it is different. Kimberley used to teach you a lot because you had lots of new people coming in and staff changing and in the last years nobody came and the staff didn't change and the environment was the same, it just got worse, it deteriorated and the resources got less. But here, it is a new house, a new environment, new staff
RESEARCHER	Institutionalisation has nothing to do with bricks and mortar has it.
STAFF	It is what you think.

9

Cluster vs. Community Group Homes

9.1 The emergence of Cluster Housing as a placement option in New Zealand institutional closure programmes.

Here in New Zealand and internationally, the movement of people from institutions to community-based settings has not been uncontested.[6,104] In the swirl of politics that typically accompanies the closure of institutions, the voices of concerned families often feature prominently.[7,105]

Despite three decades of research describing generally positive outcomes for people who move from institutions,[65,67,83,106] family activism here and in Australia, has been addressed by a move towards institutional closure programmes incorporating larger scale replications of congregate care as placement options.[7] This trend is inconsistent with current New Zealand social policy that articulates a goal for disabled people to have their "own homes and lives in the community,[82]"

As noted previously in section 1.4, during the consultation rounds that preceded the decision to close Kimberley Centre, families expressed a strong preference for residents to remain at an upgraded Kimberley Centre or onsite in a Cluster House development. Their case was supported by disability discourse that emphasised the importance of individual choice and a precedent set in the deinstitutionalisation of Templeton Centre.

At an equivalent moment in the deinstitutionalisation of Templeton Centre, parents and families advocated for an on-site 'sheltered villa' concept, which they argued would provide a more normal environment than a traditional institution within the safe and secure grounds of Templeton Centre.[107] Buoyed by a statement by the Canterbury Area Health Board (CAHB) that a sheltered village was not necessarily incompatible with the principles of normalisation, subsequent plans to relocate only 150 residents to a re-modelled Princess Margaret Hospital Nurses' Hostel acted as the catalyst to protracted conflict between the CAHB (and later Southern Regional Health Authority (SRHA)) and the Templeton Centre Parents' Association. The Templeton Centre Parents' Association challenged the right of Health Link South and the SRHA to advocate on behalf of residents and submitted that the Princess Margaret site contravened the principles of normalisation.[107] Considerable political

and public pressure eventually brought a concession from the SRHA that the planned use of the Princess Margaret site would have the effect of 'trans-institiutionalising' Templeton and Sunnyside residents and the plan was abandoned in favour of setting up a sheltered village of 14 stand alone houses with communal living areas on a reduced part of the Templeton Centre site.[32, 107] Known as the Brackenridge Estate, this sheltered village would eventually become home to 80 Templeton Centre residents.

Throughout the resettlement process, the families of residents living at Kimberley Centre reacted in a similar way to the prospect of closure. Most families reported reacting negatively to the change, either disengaging or actively resisting the tide of deinstitutionalisation. When the inevitability of closure became undeniable, a number of Kimberley Centre families described reinvesting their energy lobbying for an on-site development like the Brackenridge Estate believing that it offered the closest approximation to the institutional care they had come to trust. During this time the Kimberley Parents and Friends Association (KPFA) became a valued ally in promoting Cluster Housing as a placement option.

MOTHER   I didn't actually think that it would happen. You know there were 900 residents down there when [Resident] went. I think there are still 360 but that's still a lot of beds to find, so the ones that are going to cope in the community have already gone. I have been totally opposed to deinstitutionalisation and as a group, the Kimberley Parents Association, we have been totally opposed to it, but we can see that it is actually going to happen now. For 20 years we have fought and fought and fought it and what we want now is a sheltered village.

Bogdan and Taylor (1989) argue that institutional care privileges a bio-medical understanding of the support needs of residents.[10] In her exploration of the impact of the closure of Templeton Centre on the families of Centre residents, Mirfin-Veitch (2005) reported that families often reflected back a biomedical understanding by constructing their relatives as 'severely disabled,' and lacking further developmental potential. Prior to resettlement, Templeton and Kimberley families would both assert that, deinstitutionalisation had come too late for their family member.[20, 32]

SISTER   I don't think she is going to improve any now and hasn't possibly for the last 5 years. Because her learning curve is finished, she can only accept life now, she can't possibly add to it or change it, she can only accept what is given to her. If [Resident] had been moved out at the time she was 30, yes, but now its too late, now its too late.

Kimberley Centre families also echoed a similar set of attributes they believed important determinants of resident life quality to those previously expressed by Templeton Centre families. Consistent with a sensitivity to the physical vulnerability of their relative, Kimberley Centre families emphasised the training and professionalism of staff, ready access to medical care and specialists, a sufficient staff presence to ensure vigilant monitoring and surveillance, a safe environment and the signs and symbols of service permanence as critical to the future wellbeing of their family member*.

When Mirfin-Veitch (2005) spoke to Templeton Centre families after resettlement, she found that whereas a similar set of service values continued to be emphasised by the families of residents resettled to the Brackenridge Estate, different makers of life quality had emerged as important indicators of life quality for residents resettled to dispersed community-based

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*see Chapter 5 in *The impact of deinstitutionalisation on the families of the Kimberley Centre residents.*

housing.[32] Milner and Mirfin-Veitch (2007) argue that the biomedical understanding of residents is contrasted in community-based services by the homelikness of the setting, unmasking of latent resident competence and the greater opportunity families have to reintegrate their relative within familial relationships. Within the narratives of Templeton and Kimberley Centre families a swift recalibration to incorporate these attributes as new makers of life quality was often heard.[58]

When the geography of resident resettlement was examined in Chapter 3, we noted that although residents resettled to Cluster Houses and Community Group Homes were similar in most respects, the average distance between residents and their welfare guardians prior to their move did differentiate between the two populations.

Before resettlement, the average distance between residents of Community Group Homes and their welfare guardian was 254 km, whereas residents resettled to Cluster Houses lived on average, 87 km from their welfare guardian (Figure 9.1). This statistically significant difference led to the conclusion that, when family members had the opportunity to choose a service without compromising proximity, they were more likely to opt for the Cluster House model of community-based support.

Figure 9.1 — The average distance between Kimberley Centre residents and their welfare guardian before and after resettlement.
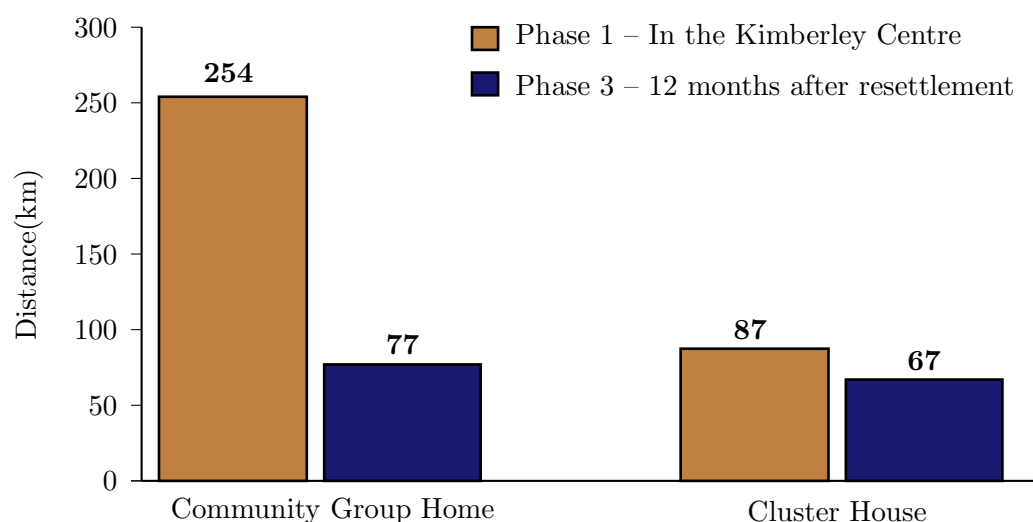
The conclusion is partially corroborated by the narrative of families as they reflected on their choice of service model. Many of the families that chose Community Group Homes spoke of 'bringing [their relative] home'. Siblings tended to live further away to begin with. Despite knowing a Community Group Home was the only service model available to them, siblings also appeared to be more likely to prioritise moving their brother or sister home

RESEARCHER Is there anything else that excites you about her future. Is there anything that you're looking forward to?

BROTHER It draws the family in.

RESEARCHER The other thing I was going to ask is how has this whole process affected your life?

BROTHER It's improved it. Having her come up here will take a lot of hassles – you see normally in a good year we only get down every three months. I just can't afford it.

SISTER-IN-LAW My daughters would love to take the grandkids around there. We'll be having Christmas with our sister. I mean, we've always been there for her birthday every year and when it was her 40th birthday we had a big family dinner because she's lucky in that she has cousins living in Levin, but this means she's got all these great-nieces and nephews who are going to have a birthday every year that she can be a part of.

In contrast, families that chose Cluster Houses tended to prioritise their relatives' history at Kimberley Centre and Levin. Families who chose Cluster Houses also included consideration for the relationships their relative had forged with staff and other residents as influencing their placement decision.

SISTER Why should she suffer being taken away from the environment she has known, she has lived in constantly since she was 7, why should she now go through it because somebody has said she has to move out and she can't make that decision for herself. Why should she have to leave the trees, the grounds, the whole environment she has known all her life because somebody else thinks she should. I take her into Levin and the people in Levin know her. She is known there and they know a lot of the residents come from Kimberley and there is a tolerance in Levin itself so there is a tolerance of people in the community of people like [Resident]. She is going on 60, she can't be deinstitutionalised. They can do a Cluster House, give her a nice little room, give her something nice, and let her stay at Kimberley.

For some, a belief that keeping Kimberley Centre residents together would ensure continued access to specialist services and a reservoir of psychopaedic insight represented another potent argument for choosing Cluster Housing.

BROTHER-IN-LAW We would like her to stay in Levin because that's where we feel the qualified staff are. Her lawyer is there, her doctor is there, her dentist and everything is there. We need somebody that we can trust with [Resident's] care and also too if we were to bring [Resident] up here and something was to go wrong, our doctor would probably refer us to the specialist back in Levin or Horowhenua, down there, where the specialists are so why not leave well alone. I mean if you went down to our local dentist with [Resident] to have something done, he would say no I can't touch it and right off to the specialist, and that's again down at Levin where they are. So that's why we opted to leave her where she can get quality of life from those that are qualified.

SISTER Because the specialists are in that area sort of thing, all right round in rural areas or even the likes of [City], they are all just GPs which cover a terrific range of ailments and bits and pieces just for normal people and so to take [Resident] in to our local doctor, it is just – well he is only human and there is only so much that he can learn or grasp in certain fields.

Families that preferred Cluster Houses could draw upon research that suggested that despite generally positive outcomes tending to follow people out of institutions, resettlement to dispersed Community Group Homes had fallen short of the wider aspirations of deinstitutionalisation in precisely these two quality of life domains. Within the deinstitutionalisation literature, a general consensus exists that limited progress has been made in relation to the promotion of more inclusive social relationships,[7,81,83,87,97,108] the opportunity to make

meaningful life choices[1, 51, 52, 67] and the wellbeing of people with intellectual disabilities across all health indicators.[6, 67, 104]

Originally founded on the philosophic principles of a previous generations of pioneers in the field of intellectual disability,[7] "cluster type" communities have recently been resurrected by families insistent on their inclusion in New Zealand's last two institutional closure programmes. Advocates for cluster or campus-style living arrangements for people with an intellectual disabilities have tended to cite cost effectiveness, and the ability to offer a better quality of life because of the greater spatial proximity of people with similar support needs as reasons for contemplating Cluster Housing.[6, 104]

In one of the few published studies to make a comparison between the quality of life outcomes associated with Cluster Houses and Community Group Homes, Emerson (2004) compared life quality as measured by a range of indicators between 169 adults with an intellectual disability living in Cluster Houses and 741 living in dispersed community houses in northern England.[6, 104] Cluster Houses were defined as accommodation located either as part of a campus development (three or more houses with an on-site day centre) or in a cluster of homes (a cul-de-sac or dead-end street with three or more adjacent homes). The residents who lived in Cluster Houses in Emerson's study were younger, reported as having lower levels of adaptive behaviour and higher levels of challenging behaviour and were more likely to have moved from a parental home or residential special school than their peers in community-group homes.

After statistically controlling for the effects of potentially confounding variables Emerson (2004) found that residents who lived in Cluster Houses were more likely to live in larger settings, be supported by fewer staff, be exposed to less stable living arrangements, be exposed to more restrictive management practices (seclusion, sedation, physical restraint, polypharmacy), lead more sedentary lives, be underweight, and participate in fewer and a more restricted range of leisure, social and friendship activities, including with other adults with an intellectual disability. Some of the potential benefits of living in a Cluster House included being more likely to be supported by staff with formal qualifications. Cluster houses were also assessed as having better internal procedures for assessment and staff training and residents living in Cluster Houses had more frequent contact with a psychologist or psychiatrist and better access to general health and vision checks.[6, 104] On balance, Emerson (2004) concluded, that Cluster Houses offered "a poorer quality of care and quality of life" when compared to dispersed Community Group Homes.

Emerson has been criticised, because the Cluster Homes he included in his study were unrepresentative of the first generation of intentional communities and because, even though he statistically controlled for confounding variables, the two populations differed in ways likely to affect the culture of support.[108] Emerson's (2004) study has, however, acted to refocus deinstitutionalisation research towards an exploration of the strengths and weaknesses of the types of housing and support models that are replacing institutional care.

In the sections that follow data from the Adaptive Behaviour Scale (ABS-RC:2) and participant observations are drawn upon to explore whether living in a Cluster House or Community Group Home influenced the adaptive and challenging behaviour, activity patterns and the geography of Kimberley Centre resident's lives after resettlement.

9.2 How different were the Cluster Houses and Community Group Homes Kimberley Centre residents were resettled to?

In the discussion that prefaced the closing of Kimberley Centre, Cluster Housing was represented as an alternative to community residential housing and defined[35] as "a purpose-built group of houses, each operating individually on one site, to provide residential services for people with an intellectual disability whose needs require 24-hour support". The anticipated number of houses to be sited in close proximity was anticipated as being between 3-8 dwellings.

Unlike the Templeton Centre closure, the two Cluster House options offered to families located beyond the grounds of Kimberley Centre. In Levin, 5 houses fringed a cul de sac towards the outskirts of town and in Palmerston North four houses shared a common driveway on a road going out of the city. Like many Community Group Homes, both sites were displaced from community amenities.

Other than being close to other residential support settings, Cluster Houses were largely indistinguishable from the conventional community group home. In both settings, residents shared their home with 4-6 adults with an intellectual disability. New Cluster Houses and Community Group Homes had *Housing New Zealand* as a common landlord, with their preference for the location and type of housing stock varying little between the two purportedly different service models. Cluster houses tended to operate individually, with little sharing of material or staff resources in evidence. Similarly, whilst living in a Cluster House meant that residents were more likely to neighbour people who had also lived or worked at Kimberley Centre, fences and a culture that emphasised dwelling autonomy meant that residents seldom interacted with their neighbours. Within cluster sites, each house tended to be a social-island in much the same way as villas separated people with shared history at Kimberley Centre.

RESEARCHER Does [Resident] have friends outside of the service and family? One of the things about Cluster Houses – the neighbours are people she formerly lived with. Is there much interaction between the houses?

STAFF Not really mainly because of the other houses, like the people they had in there are not very mobile. She doesn't know them on the right but she knows the ones across the road because they are the ones that used to pick her up and take her to day services.

And finally, the service providing Cluster Housing was also a major provider of residential disability support. As a consequence, pre-existing community-based support policy and practice tended to be transposed into the new support settings, further contributing to the similarity between the two models of community-based support.

Whilst no data about the composition of staff in community-based settings could be collected, anecdotal evidence suggests that the proportion of Kimberley Centre trained staff was greater in Cluster House settings and, by the end of the first year following the closure of Kimberley Centre, a specialist had been employed to support community primary health providers in Levin.

9.3 Who populated Cluster Houses and Community Group Homes?

Twenty-five Kimberley Centre resident participants were resettled to a Community Group Home, four of whom moved to a pre-existing service. Fourteen participants were resettled to a Cluster House. Residents resettled to Cluster Houses were, on average, only slightly older (3.97 years), had been admitted to Kimberley Centre at a slightly younger age (1.25 years) but had lived at Kimberley Centre for a little over a year less (1.23 years) than their peers resettled to Community Group Homes. None of these small differences approached statistical significance.

In Emerson's (2004) study, residents living in Cluster Houses were assessed as having lower adaptive but higher challenging behaviours. The reverse was true for Kimberley Centre residents who moved to Cluster Houses. Residents resettled from Kimberley Centre to Cluster Houses were assessed as having an average challenging behaviour score of 19.5. The average score for residents resettled to Community Group Homes was 37.9. A two-tailed t-test was used to compare the difference between the two populations and the 18.4 point difference in mean challenging behaviour recorded while residents lived at Kimberley Centre proved to be statistically significant ($t = 2.3$, $p = 0.03$). No difference was evident in support staff assessments of resident adaptive behaviour. Residents resettled to Community Group Homes were reported as having an average overall adaptive behaviour score of 84.9 and residents resettled to Cluster Houses 85.2. The 1.4 point difference fell well short of statistical significance ($t = 0.02$, $p = 0.99$).

Figure 9.2 plots the Adaptive and Challenging Behaviour scores reported by support staff while 43 resident participants lived at Kimberley Centre. An extremely weak positive correlation was observed between Adaptive and Challenging Behaviour ($R = 0.06$).

The distribution of adaptive behaviours reported for Kimberley Centre residents resettled to either model of community-based support was relatively uniform. The range of challenging behaviour scores, on the other hand, was more negatively skewed with the statistically significant difference in Challenging Behaviour between residents resettled to Cluster Houses and Community Group Homes accounted for by the fact that all of the residents with Challenging Behaviour scores above 50 were resettled to Community Group Homes (Figure 9.2).

9.4 Did living in a Cluster or Community Group Home make any difference to the acquisition of adaptive competence?

The move from institutions to community-based settings is typically associated with a cluster of lifestyle changes that have the potential to influence learning across a range of adaptive behaviour domains. Emerson's (2004) study suggests that, in the UK, the Cluster House and Community Group Home models of support are quantifiably different in service design and practice.[6,104] Examining the pattern of Adaptive Behaviour change representing a step to determining whether elements of service design or delivery inherent to Cluster Houses or Community Group Homes were more conducive to the exposure and support of new learning.

If Cluster Houses were, in reality, a closer approximation of the institutional support, it would be reasonable to expect that the repertoire of Adaptive Behaviours following resettlement to a Cluster House would most resemble those reported at Kimberley Centre.

Figure 9.2 — The relationship between residents' Adaptive and Challenging Behaviour scores reported by support staff while residents lived at the Kimberley Centre.
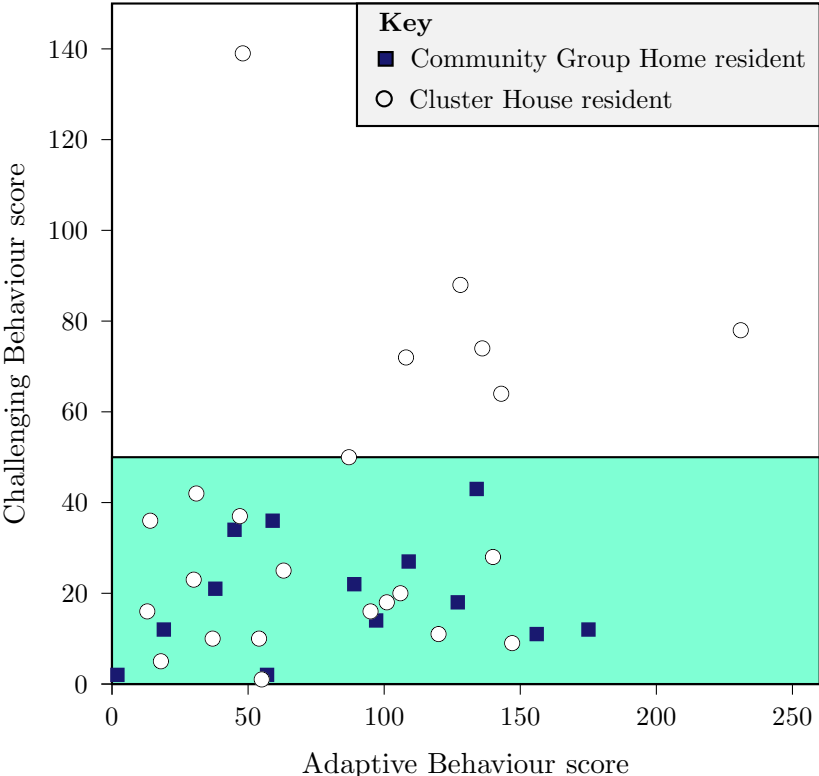
An examination of the change in overall standardised adaptive behaviour suggests otherwise (Figure 9.3). Whereas the reported overall Adaptive Behaviour of residents resettled to Community Group Homes changed little post resettlement, the average standardised Adaptive Behaviour of residents resettled to Cluster Houses improved by 7.5 points. Most of the Adaptive Behaviour change described in Chapter 5, therefore, can be attributed to the adaptive behaviour gains reported for people resettled to Cluster Houses. It may be significant to note that these were also the residents who tended to be resettled closer to their parents. Being close to a family member and a parent in particular was found to contribute most to the emergence of Adaptive Behaviour following resettlement*. These residents may have benefited more from the improved physical and social proximity to their families.

Another potential explanation for the disparity between the two models of support may be that learning was easier in Cluster Houses, or alternatively that different aspects of personal growth may have been emphasised as a consequence of individual differences in the two populations. Residents resettled to Community Group Homes tended to exhibit more challenging behaviours than residents resettled to Cluster Houses (Figure 9.7). Supporting people to make adaptive changes within these behavioural domains may have inhibited the acquisition of other competencies or featured more prominently in support practice in these settings. Mansell (2006) argues that people with intellectual disabilities can become trapped within their Challenging Behaviour if community-based services emphasise that aspect of their personality.[34] Furthermore, research suggests that people with challenging behaviours

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*See Section 5.6

are less likely to be present in their community[109] or make life choices likely to enhance ongoing learning.[110]

Figure 9.3 — Mean standardized overall Adaptive Behaviour scores reported for residents who moved to Cluster and Community Group homes over all phases.
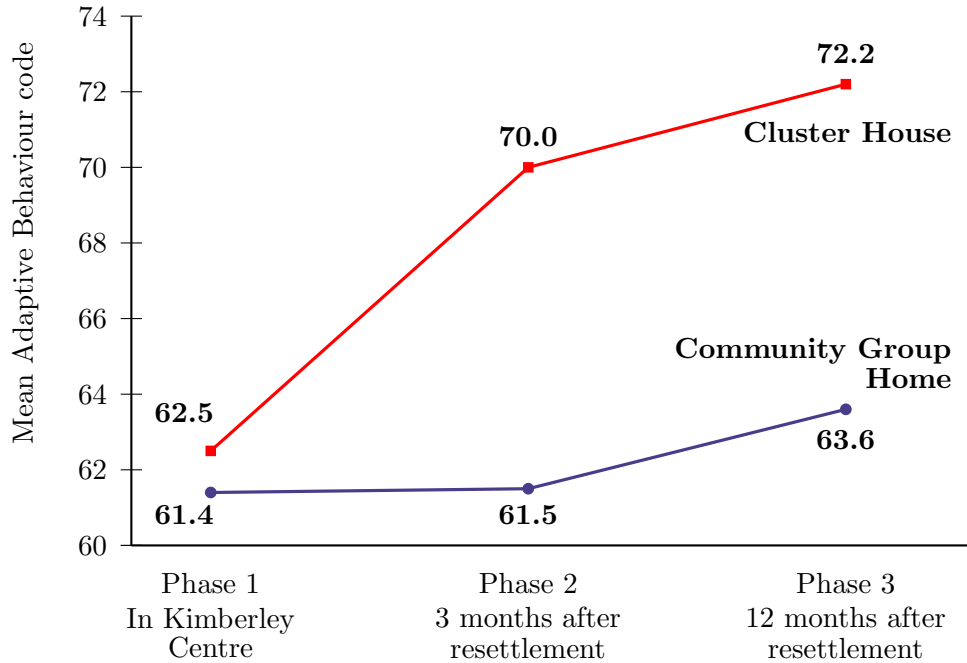
Despite the trend for more rapid adaptive behaviour gain for residents resettled to Cluster Houses, it is important to note that at no point did the divergence in adaptive behaviour between support models represent a statistically significant difference (Table 9.1). The difference between mean reported overall adaptive behaviour was greatest 3-6 months after resettlement, but the 8.46 point separation in scores fell well short of statistical significance ($t = 1.15$, $p = 0.26$).

Table 9.1 — Differences between the mean standardised overall adaptive behaviour scores reported for residents who moved to Cluster Houses and Community Group Homes over all phases.

	Mean ABS-RC:2 for Cluster House	Mean ABS-RC:2 for Community Group Home	Mean difference	t	p
Phase 1	62.55	61.43	1.12	0.15	0.88
Phase 2	70.00	61.54	8.46	1.15	0.26
Phase 3	72.18	63.57	8.61	1.12	0.27

A closer examination of the areas in which adaptive behaviour improvements were experienced reveals that living in a community-based setting was associated with positive adaptive behaviour gains in the domains of *Self-Direction*, *Responsibility* and *Socialisation*. Improvements in these domains occurred regardless of whether residents were resettled to a Cluster House or Community Group Home and most of the improvement in adaptive competence post-resettlement were reported in these three domains (Figure 9.4 and 9.5). In the first six months following resettlement, residents resettled to Cluster Houses experienced the most

rapid flourishing of Adaptive Behaviour in these domains (Figure 9.4) and although learning appeared to plateau thereafter, residents supported in Cluster Houses did not experience the shrinkage in competence community-based staff reported for residents resettled to Community Group Homes (Figure 9.5).

Figure 9.4 — Mean change in Adaptive Behaviour domain scores reported by staff for residents living in Cluster Houses at subsequent research phases.
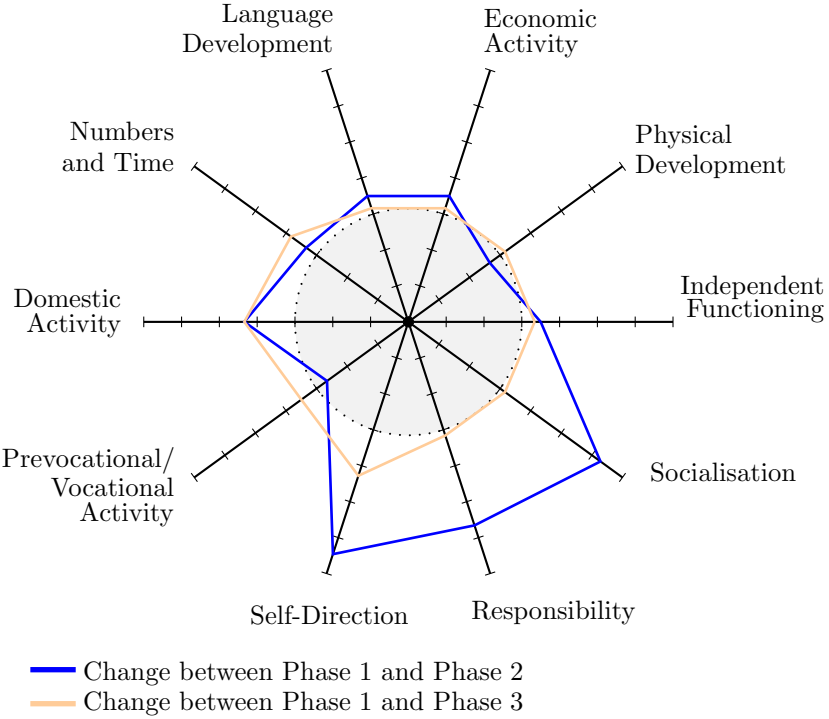
When the change in mean adaptive behaviour scores between the two models of community-based support were compared, residents resettled to Cluster Houses were found to have made the more substantial gains in the domains of *Independent Functioning*, *Physical Development*, *Self-Direction*, *Responsibility* and *Solicalization* (Table 9.2). By the end of the first year, a statistically significant improvement in *Self-Direction* was reported for people who moved to Cluster Houses ($t = 2.63$, $p = 0.01$).

Given the similarity between the two models of support, it would difficult to assert that any differences in the service design might explain this finding. As noted above, the literature suggests that people with more challenging behaviours can find themselves distanced from a community presence and self directed activity. The fact that differences should emerge in the pace at which competence was acquired in *Self-Direction*, *Socialisation* and *Responsibility* skills, lends weight to the proposition that the more challenging disposition of residents resettled to Community Group Homes changed the emphasis of service delivery in ways that made it more difficult to acquire the three types of competence most advanced community living.

Figure 9.5 — Mean change in Adaptive Behaviour domain scores reported by staff for residents living in Community Group Homes at subsequent research phases.

— Change between Phase 1 and Phase 2
— Change between Phase 1 and Phase 3
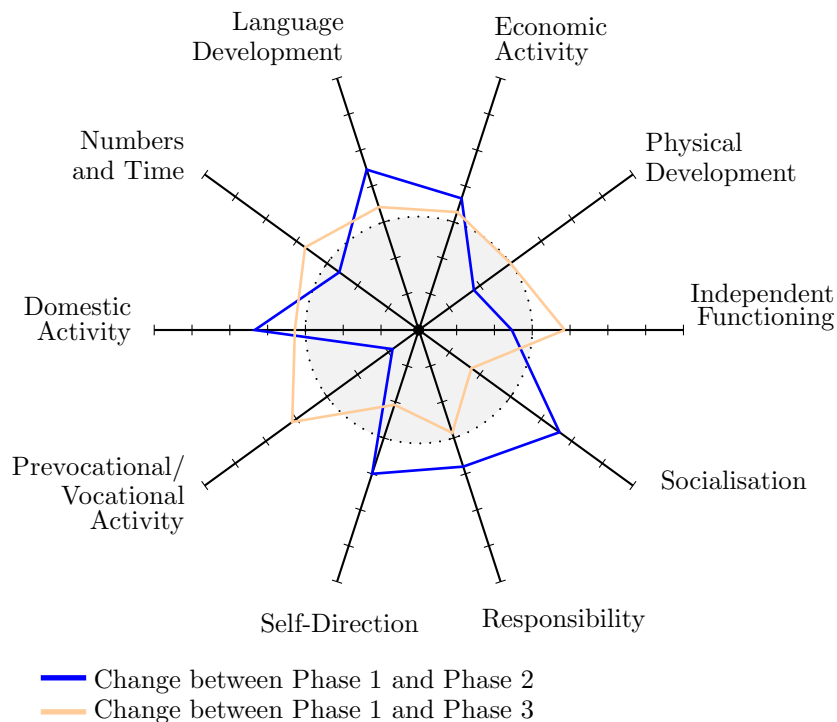
Table 9.2 — Differences between the mean standardised overall Adaptive Behaviour scores reported for residents who moved to Cluster and Community Group Homes between Phase 1 and Phase 3.

Adaptive Behaviour Domain	Mean ABS-RC:2 for Cluster House	Mean ABS-RC:2 for Community Group Home	Mean difference	t	p
Independent Functioning	0.75	0.21	0.54	0.81	0.43
Physical Development	-0.17	-0.47	0.31	0.56	0.58
Economic Activity	0.42	0.58	0.16	0.45	0.66
Language Development	0.50	1.16	0.66	0.91	0.37
Numbers and Time	0.25	0.42	0.17	0.52	0.61
Domestic Activity	1.42	1.74	0.32	0.43	0.67
Pre-Vocational Activity	0.08	0.33	0.25	0.29	0.77
Self Direction	**2.91**	**-0.05**	**2.92**	**2.63**	**0.01**
Responsibility	1.42	0.95	0.67	0.69	0.50
Socialisation	1.64	0.11	1.53	1.22	0.23

9.5 Did living in a Cluster House or Community Group Home make any difference to the prevalence of challenging behaviour?

Understanding what impact the move to community-based services had on the challenging behaviour of residents featured prominently in the first wave of deinstitutionalisation research. In spite of the number and array of studies, no clear picture emerged about the consequences of deinstitutionalisation for residents whose behaviour challenged support services.

In their original meta-analysis, Larson and Lakin (1989) noted considerable variation existed in the findings reported by investigators that had used a longitudinal methodology. An equal number of studies reported positive and negative change in resident adaptive behaviour after resettlement.[65] When they repeated their analysis 10 years later, the balance of published research still refused to fall in any direction. Ten of the studies that met their eligibility criteria reported improvements in challenging behaviour and six reported an increase in the prevalence of challenging behaviour post resettlement.[4] Kim et al. (2001) noted,[4] however, a trend towards more favourable outcomes in studies conducted after 1990, speculating that this may be reflective of a gradual improvement in the behavioural supports available to community services in the United States of America after deinstitutionalisation gathered momentum.

A similar lack of clarity about the effect of residential reform also characterised Emerson and Hatton's (1996) meta-analysis of published research from the UK and Ireland.[67] Emerson and Hatton (1996) reported that studies which compared information volunteered by direct-care support staff typically reported either no change (64%) or a significant increase in challenging behaviour following resettlement. In contrast, comparative studies that employed direct observation to gather information reported an overall reduction in Challenging Behaviour associated with the move to community-based services (64%). Like Larson and Lakin (1989), Emerson and Hatton (1996) believed that differences in the skill set, expectation and experience of key informants between the two service settings may have contributed to the more negative outcomes reported in studies that depended on key-staff as proxy informants.

In their investigation of the impacts of the Minnesota institutional closure program, Stancliffe et al. (2002) echoed the conclusions from both meta-analyses.[110] Stancliffe et al. (2002) found evidence for an initial increase in challenging behaviour in the first year following resettlement, but that with the exception of self-injurious behaviour, levels rebounded to be similar to those reported in institutional settings. Emerson and Hatton (1996) suggested the more complex socio-emotional demands experienced in home-like community settings may increase the frequency of events that illicite challenging behaviour or transform equivalent behaviour into more socially disruptive incidents in community settings.

When the mean standardised challenging behaviour scores of Kimberley Centre residents were compared, a slight improvement in challenging behaviour was reported in both Cluster Houses and Community Group Homes following resident resettlement* (Figure 9.7). This finding is at variance with studies reporting an increase in challenging behaviour after the move from institutional care[110] and previous studies that have used direct care staff as proxy informants.[67] However, none of the improvements in challenging behaviour observed in any phase approached statistical significance.

What does emerge is a remarkably similar pattern to improvement in challenging behaviour between cluster and community based support services. During the course of the first year beyond Kimberley Centre, the difference between the frequency with which challenging behaviour was reported by Kimberley Centre support staff for residents resettled to Cluster Houses or Community Group Homes varies little (8.56 – 9.73). The statistically significant difference in overall Challenging Behaviour score remains throughout the phases as a consequence of equivalent improvements in challenging behaviour during the "honeymoon" of resettlement and a coincident stalling of improvement towards the end of the year (Table 9.3)

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*Higher scores indicate less challenging behaviour on the standardised scale.

Figure 9.6 — Mean standardised overall Adaptive Behaviour scores reported for residents who moved to Cluster and Community Group homes over all phases.
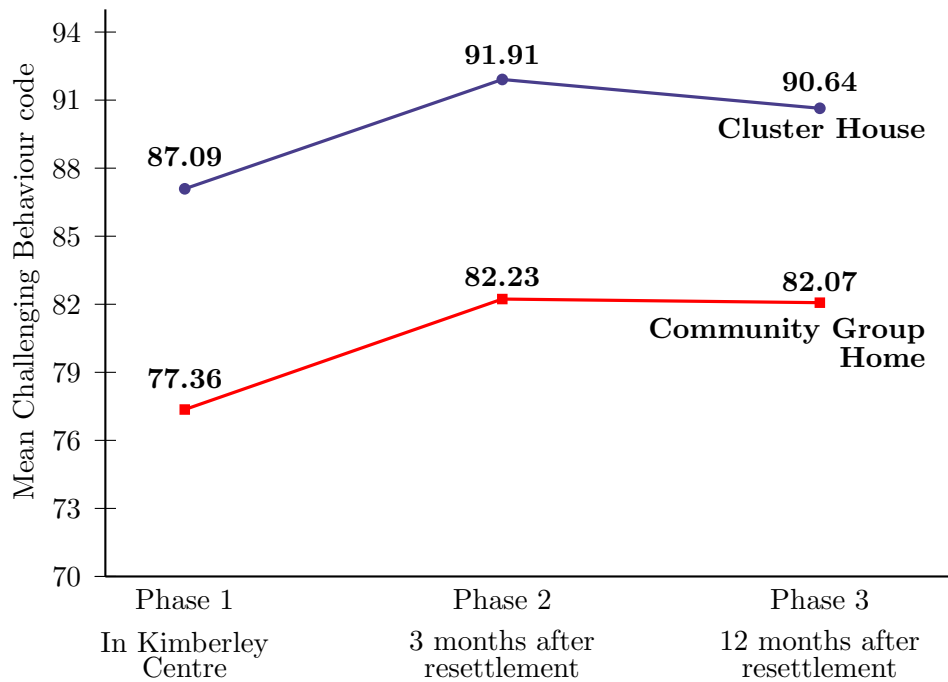
Table 9.3 — Differences between the mean standardised overall Adaptive Behaviour scores reported for residents who moved to Cluster Houses and Community Group Homes over all phases.

	Mean ABS-RC:2 for Cluster House	Mean ABS-RC:2 for Community Group Home	Mean difference	t	p
Phase 1	87.09	77.36	9.73	1.81	0.08
Phase 2	**91.91**	**82.23**	**9.68**	**2.14**	**0.04**
Phase 3	**90.64**	**82.07**	**8.56**	**2.25**	**0.03**

Residents resettled to Cluster Houses and Community Group Homes demonstrated the same pattern of flourishing and plateauing of behavioural improvement that characterised adaptive behaviour gain (Figure 9.7 and 9.8).

Consistent with the trend for more marked improvement in the Adaptive Behaviour domain of *Socialisation*, residents were similarly reported as being less likely to withdraw or be socially unresponsive in community-based settings. In the first six months after resettlement, residents were also less likely to be engaged in *Stereotyped*, *Hyperactive* or *Self-Abusive Behaviour*. Stereotyped and hyperactive behaviour is often postulated as being self-stimulatory and reported improvement in these three domains is likely to be reflective of the more socially enriched environment inherent in the smaller, more homelike community-based service settings.

Whilst no statistically significant differences emerged in the reported average change in challenging behaviour domains between Cluster Houses or Community Group Homes (Table 9.4), it is interesting to note that the only domains that Community Group Homes were less

Figure 9.7 — Mean change in Challenging behaviour domain scores reported by staff for residents living in Cluster Houses at subsequent research phases.
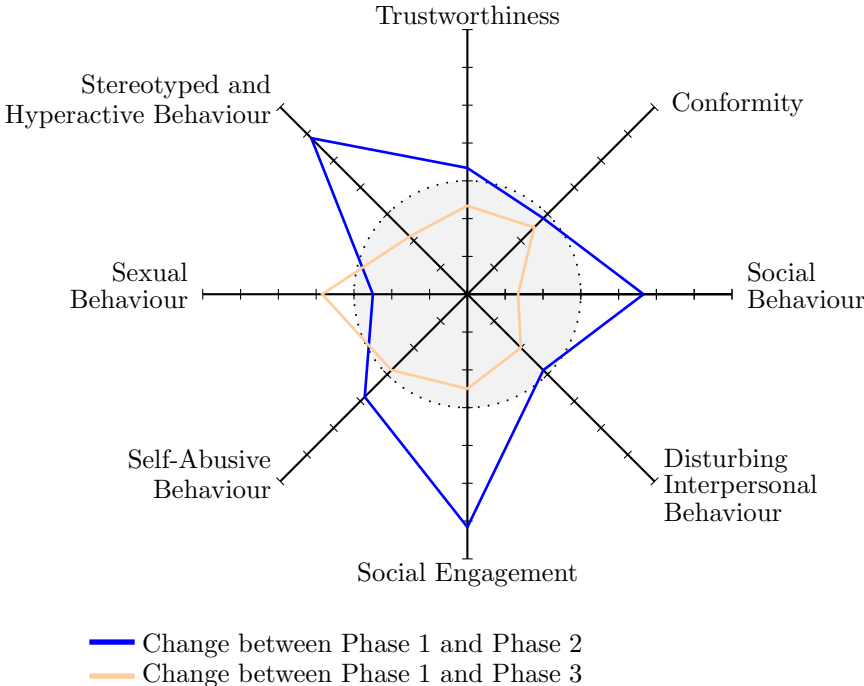
Figure 9.8 — Mean change in Challenging Behaviour domain scores reported by staff for residents living in Community Group Homes at subsequent research phases.
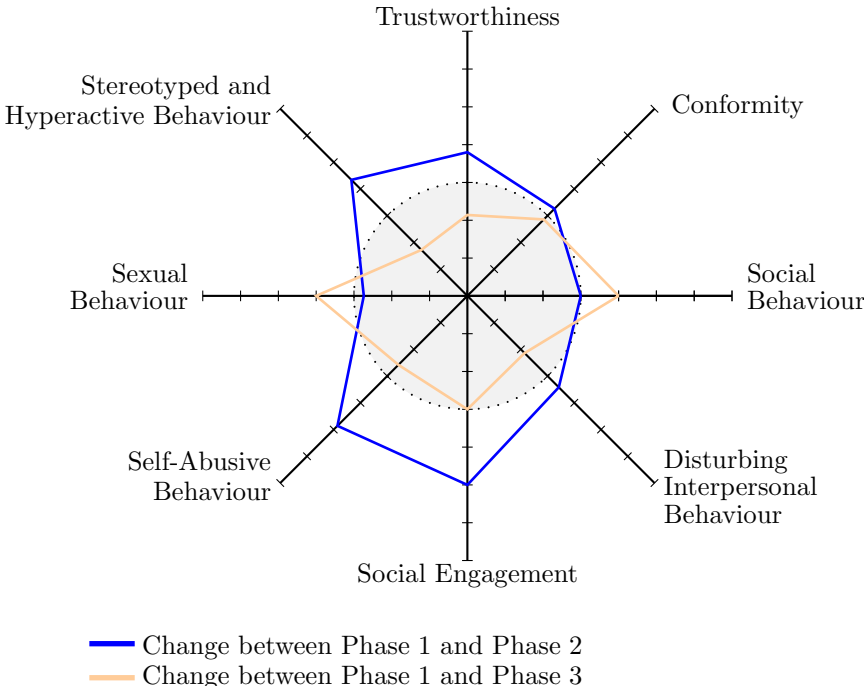
effective at improving challenging behaviour were in the areas of *Social Engagement* (-0.69, $p = 0.4$) and *Stereotyped and Hyperactive Behaviour* (-0.69, $p = 0.31$).

Table 9.4 — Mean change in Challenging Behaviour domain scores reported by Cluster Houses and Community Group Home staff one year after resettlement

Challenging Behaviour Domain	Mean ABS-RC:2 for Cluster House	Mean ABS-RC:2 for Community Group Home	Mean difference	t	p
Social Behaviour	0.25	0.68	0.43	0.59	0.56
Conformity	-0.25	0.22	0.47	0.57	0.57
Trustworthiness	-0.17	0.22	0.39	0.55	0.59
Stereotyped and Hyperactive Behaviour	0.92	0.22	-0.69	-1.04	0.31
Sexual Behaviour	0.00	0.39	0.39	0.56	0.58
Self-Abusive Behaviour	0.33	0.56	0.22	0.20	0.85
Social Engagement	1.25	0.56	-0.69	-0.86	0.40
Disturbing Interpersonal Behaviour	-0.75	0.11	0.86	1.48	0.15

Rather than reflecting any fundamental difference in service design, differences in the two populations resettled to Cluster Houses and Community Group Homes may also have contributed to this finding. The more limited inclination of residents to engage socially and the perseverance of stereotyped behaviour in Community Group Homes may represent their response to the greater likelihood of sharing a home with people who behave in challenging ways.

Whereas research that uses staff report have tended to find either no change or an increase in challenging behaviour after resettlement, comparative studies that have employed direct observation tend to report an overall reduction in challenging behaviour after residents move to community-based services.[67, 110]

A comparison between the average proportion of time residents were observed engaged in either stereotypical or self-abusive behaviour revealed a reduction in challenging behaviour that was consistent with other studies using a similar methodology (Figure 9.9 and 9.10). The observed prevalence of these two Challenging Behaviours fell after the move to either model of community-based support. Residents resettled to Cluster Houses were 1.5 times more likely to be observed engaged in stereotypical behaviour and 4 times more likely to be observed harming themselves whilst they lived at Kimberley Centre. For both measures, however, the drop in these types of challenging behaviours was more pronounced for residents supported in cluster home settings, lending further weight to the argument that the extinction of challenging behaviours is more likely when residents do not share their home with other people with complex behaviours.

Research suggests that the typical purchase arrangement of grouping people perceived as challenging together at one site and in larger services is associated with poorer behavioural outcomes.[109, 111] Mansell (2006) argues that a single model of support and lack of investment and training of direct care staff leaves people with complex behaviours exposed to "unskilled minding" in more socially demanding contexts.[111] Moving beyond aggregating the care of people with complex behaviours in 4-6 person group homes and investing in positive behaviour support training would greatly enhance the life quality of people whose behaviour challenges existing support services.

Figure 9.9 — The average proportion of time residents were observed engaged in stereotypical behaviour.
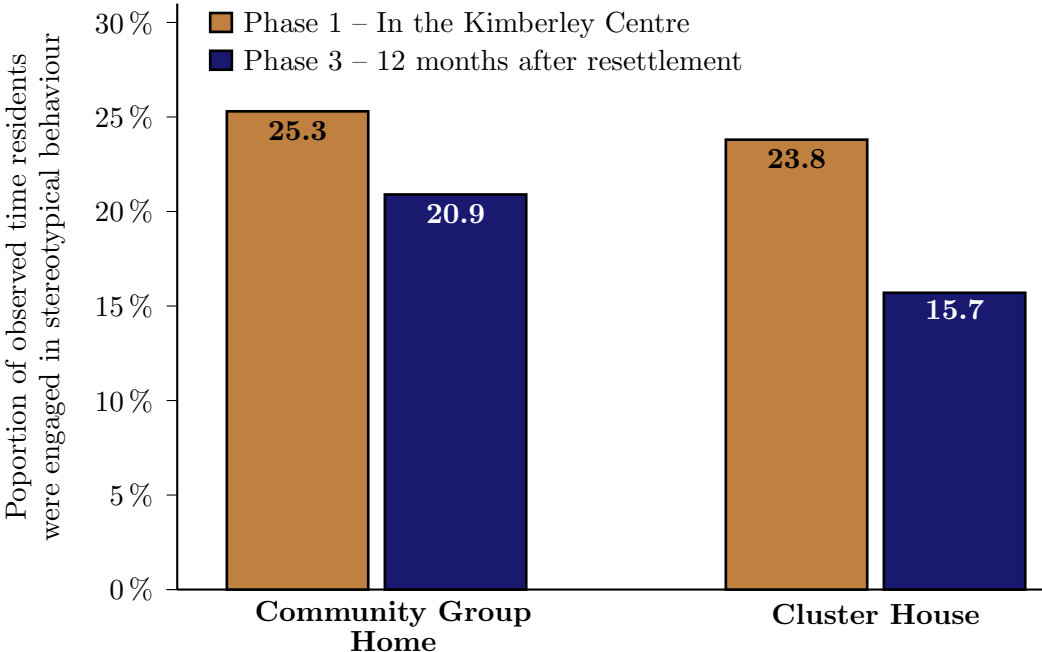
Figure 9.10 — The average proportion of time residents were observed engaged in self-abusive behaviour.
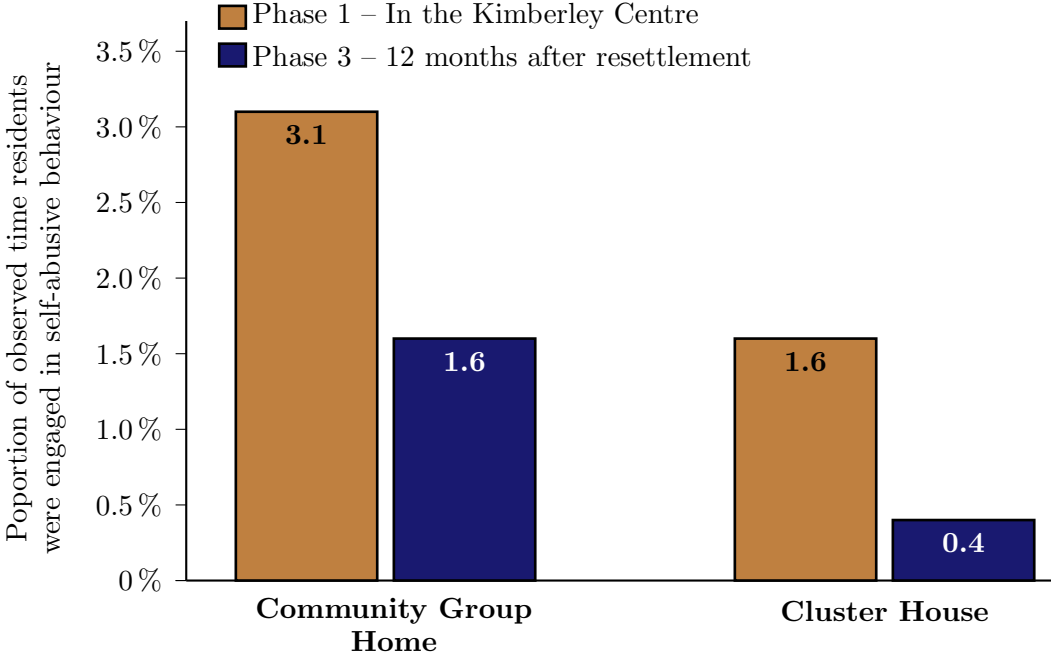
9.6 Balancing support and ordinary lives.

Widespread adoption of the principle of normalisation provided one of the most powerful impetuses to the movement of people with an intellectual disability out of institutions and into community-based service settings.[11,32] Central to the principle was a belief that the patterns and conditions of everyday life people who depend on human services should mirror

wider society as closely as possible.[27] Segregated spaces, atypical architecture and spatial proximity became totemic of the 'un-ordinariness' of service lives and public policy, in New Zealand[81] and elsewhere[87] moved towards promoting a participatory presence of marginalised populations in 'mainstream' cultural spaces as the most important indicator of progress towards a non-disabling society.[82, 86]

Although the Templeton[32, 107] and Kimberley Centre families who lobbied for Cluster Housing typically acknowledged the importance of a more normal lifestyle for their relative, they tended to prioritise the safety of segregation and congregate care as important service attributes. To critics of Cluster Housing, their potential to separate people with an intellectual disability from the normal spaces and rhythms of community life were conversely seen as disablers.

In this section we explore whether living in a Cluster House or Community Group Home influenced the spaces where former Kimberley Centre residents were present in their community, before considering whether the different models of community-based support affected what activities filled resident's days beyond Kimberley Centre.

9.7 Did living in a Cluster House or Community Group Home make any difference to where residents lived worked and played?

In Chapter 8, we observed that for Kimberley Centre residents, the move to community-based services was associated with a decrease in the proportion of time they were observed in living spaces. Residents spent less time hemmed into the day room and were instead at greater liberty to determine where they went in more homelike community residential settings. After resettlement, residents were also more likely to be present in their community, but seldom in ways that might have led to the development of ongoing social relationships.

Figure 9.11 describes the pattern to daily lives observed for residents resettled to either a Cluster Houses or Community Group Homes. The bar-graph describes the average percentage change in the total time residents were observed in a setting, 12 months after resettlement. The horizontal line represents no change, therefore the smaller the bar the more closely the geography of residents everyday lives resembled their life at Kimberley Centre. Scores above the horizontal line denote more time, and scores below less time spent in particular locations.

Amongst the reasons cited by families who described preferring cluster homes was that they provided a closer approximation of the type of support they had come to trust at Kimberley Centre. Comparing the average percentage change in observed time in particular locations reveals that life in Cluster Houses did, in fact, tend to unfold in similar locations. Most of the changes to geography of resident's lives noted in Chapter 6 can be accounted for by changes in the life-spaces of resident's resettled to Community Group Homes. People in Community Group Homes spent less time living in spaces like the lounge or dining room compared to the percentage change recorded for their peers resettled to Cluster Houses. Whilst the home was still at the epicentre of residents' lives, residents resettled to Community Group Homes were much more likely to be observed in domestic spaces like the kitchen and laundry. They were also more advantaged in respect to being present in their community. Relative to their lives at Kimberley Centre, residents in Community Group Homes experienced a greater change

Figure 9.11 — Mean percentage change in the time residents were observed in settings 12 months after re-settled from Kimberley Centre into Cluster House or Community Group Homes.
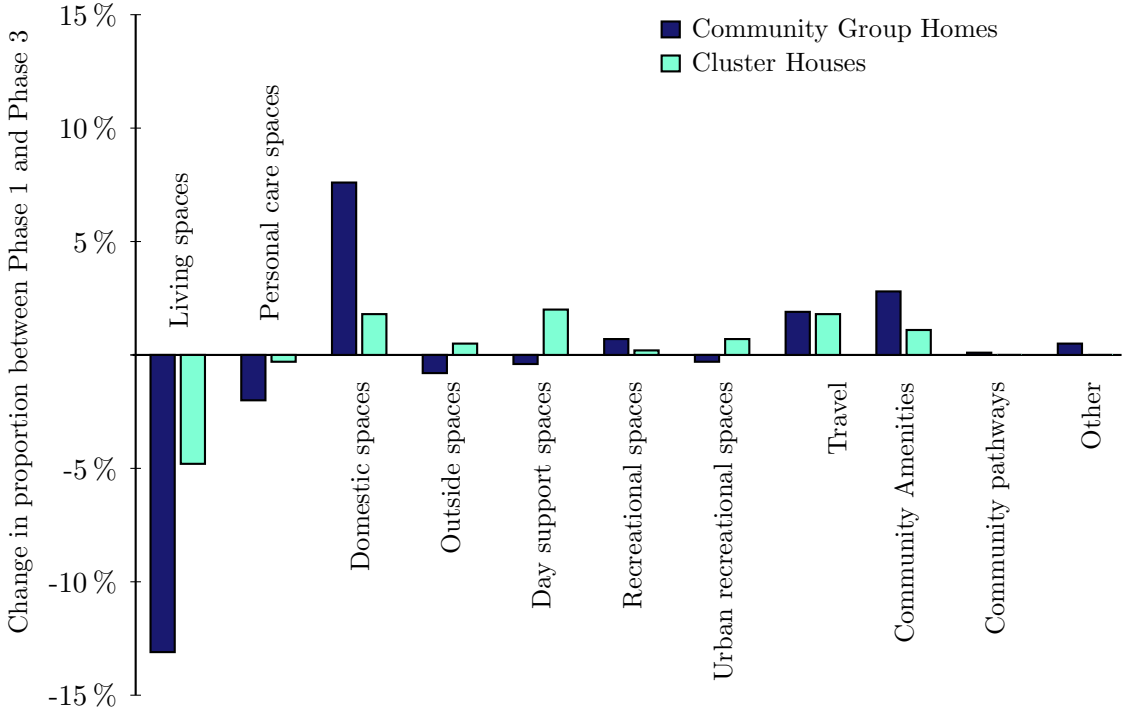
in the frequency with which they were observed visiting civic amenities like the community hall, swimming pool, health-clinic or bowling lane.

As noted previously, residents resettled to the two types of community-based services differed little in all but changing behaviours. Residents resettled to Cluster Houses and Community Group Homes were similar in age, sex, adaptive behaviour, the distance to their welfare guardian after moving and length of time they had lived at Kimberley Centre. Because challenging behaviour is generally accepted to limit, rather than enhance the ability people with an intellectual disability have to participate in community and domestic activity, it is unlikely that resident characteristics account for the more dramatic change in the life-spaces of people resettled to community group homes.

In addition to an expectation that Cluster Houses more closely replicate institutional care, a number of other factors may have influenced the culture of support in cluster sites in ways that account for the closer approximation of an institutional lifestyle. Anecdotal evidence suggests that the proportion of former Kimberley Centre staff working in the two Cluster House sites was greater than in Community Group Homes. It is possible that staff transposed the support priorities they were orientated to at Kimberley Centre, including similar patterns to support practice and a traditional understanding of the roles of staff and resident. Clustering service settings within close geographic proximity may also have made it more difficult to confront an understanding that residents were living in a service setting with the alternative that staff were supporting residents to live in their own home. During staff interviews it also emerged that in Cluster Houses there was a tendency for the community to come to residents rather than residents go out to the community. Doctors, podiatrists and even family members were

more likely to visit residents in their homes, whereas engaging the community in dispersed sites tended to require an act of migration beyond the home.

9.8 Did living in a Cluster House or Community Group Home make any difference to what activities filled residents days?

One of the more important consequences of resettlement for Kimberley Centre residents was the significant decline in disengaged activity they experienced in the first flush of deinstitutionalisation. In the first six months of resettlement, the listlessness and sedentarism of villa lives was replaced by a concomitant increase in the proportion of time residents were observed in indoor active and social activities in their new homes. A small but statistically significant decrease in *Wandering* was found and residents were significantly more likely to be observed in transit. Free of the unbending institutional rhythm residents were at greater liberty to exercise choice about where they wanted to be in their home. They were also more often recorded as in transit during the course of their travels to or from vocational centres during the week and parks and beaches on the weekend.

Figure 9.12 describes the average percentage change in the time residents resettled to Cluster Houses or Community Group Homes were observed in different activities 12 months after moving from Kimberley Centre. Comparing the percentage change between the two models of community-based support reveals that residents resettled to Community Group Homes tended to experience the greatest reduction in disengaged activity by the end of the first year beyond Kimberley Centre. Twelve months after moving from Kimberley, residents living in community group homes exhibited a much larger reduction in the proportion of time they were observed *Wandering* or engaged in *Sedentary* or *Indoor passive* activity than residents resettled to Cluster Houses. This finding is consistent with an earlier observation that they were also less likely to be observed in living spaces like the lounge or dining room (Figure 9.11).

Conversely, residents who moved to Community Group Homes tended to experience the largest percentage increase in the time they were observed engaged in social and outdoor activities. *Social Activities* included being a passenger on trips taken for pleasure, visiting friends and participating in day trips or organised activities and *Outdoor Activities* included walking for pleasure, mowing the lawns or participating in sporting or cultural events. Residents resettled to Community Group Homes experienced a greater percentage change in the amount of time they engaged in these types of activities. Again, this finding is consistent with an earlier observation that residents resettled to community group homes experienced a greater shift in the frequency with which they were observed out and about in community spaces.

Residents resettled to Cluster Houses did, however, record the largest percentage increase in the proportion of time they were observed engaged in *Indoor Activity*. *Indoor Activity* included chatting as well as being engaged in activities like playing an instrument, reading a magazine or playing indoor games. We noted in sections 9.2 and 9.3 a trend for staff to report a more marked improvement in the adaptive domain of socialisation and a similar decrease in the prevalence of withdrawn and socially unresponsive behaviours in Cluster Houses. We speculated that this might be explained by differences in the attributes of residents resettled to Cluster Houses and Community Group Homes. If the increase in this type of activity was reflective of the greater amount of time residents were observed interacting with others, the

Figure 9.12 — Mean percentage change in the time residents resettled to Cluster Houses and Community Group Homes were observed in different activity types 12 months after moving from Kimberley Centre.
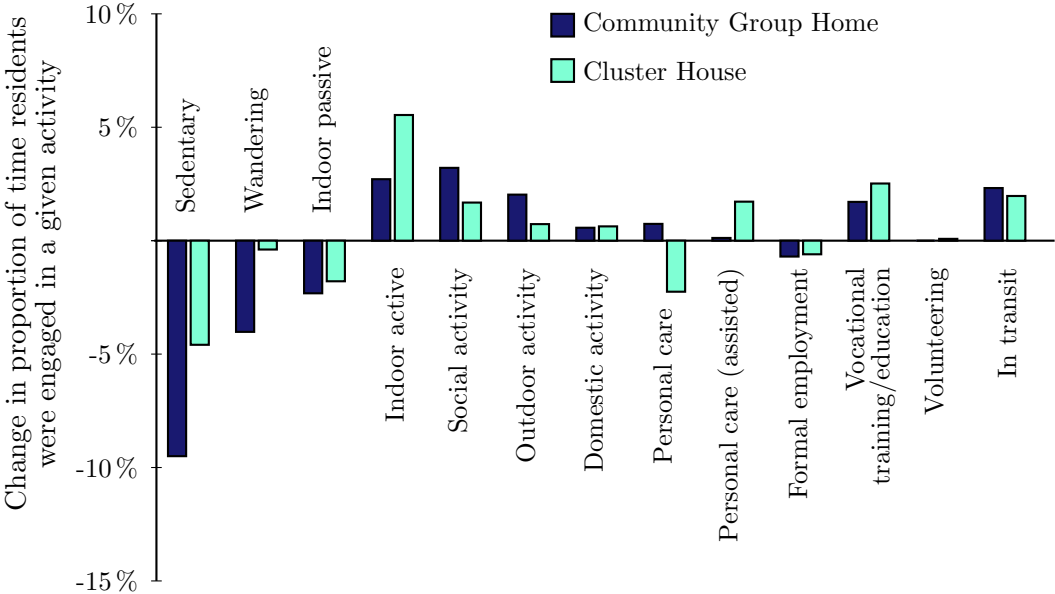
more circumscribed change in the proportion of time residents in Community Group Homes were observed engaged in *Indoor Activity* would add further weight to the argument that the inhibition of social expressiveness may be one of the consequences of living with people who are more likely to challenge services.

Unfortunately, however, analysis of the differences between the proportion of time residents resettled to Cluster Houses and Community Group Homes were engaged in a communication event undermines any simple explanation.

Figure 9.13 plots the proportion of one-minute intervals that residents resettled to Cluster Houses and Community Group Homes were recorded as having been engaged in a communication event while they lived at and then beyond Kimberley Centre.

While residents lived at Kimberley Centre, there was little difference in the pattern of communication experienced by residents who were later to move to Cluster Houses or Community Group Homes. Residents who moved to Community Group Homes (18 percent of observed one minute intervals) were engaged in slightly more communicative exchanges than residents who moved to Cluster Houses (14 percent of observed one-minute intervals). For both cohorts, support staff were overwhelmingly their most frequent communication partner. A few participants who tended to live in challenging behaviour villas regularly sought out other residents for company, but on the whole, Kimberley Centre residents directed almost all of their communication towards staff. Participants were only recorded as interacting with other people who lived at Kimberley Centre in one percent of the one-minute intervals that participant observations were broken down into.

Twelve months after resettlement, little had changed for residents resettled to Cluster Houses. In precisely the same way that Cluster Houses were found to approximate the geography and activity patterns of Kimberley Centre, the profile of resident communication also deviated little from that residents had previously experienced at Kimberley Centre. In previous

Figure 9.13 — The proportion of one-minute intervals that residents resettled to Cluster House and Community Group Homes were recorded as having been engaged as a communication partner.
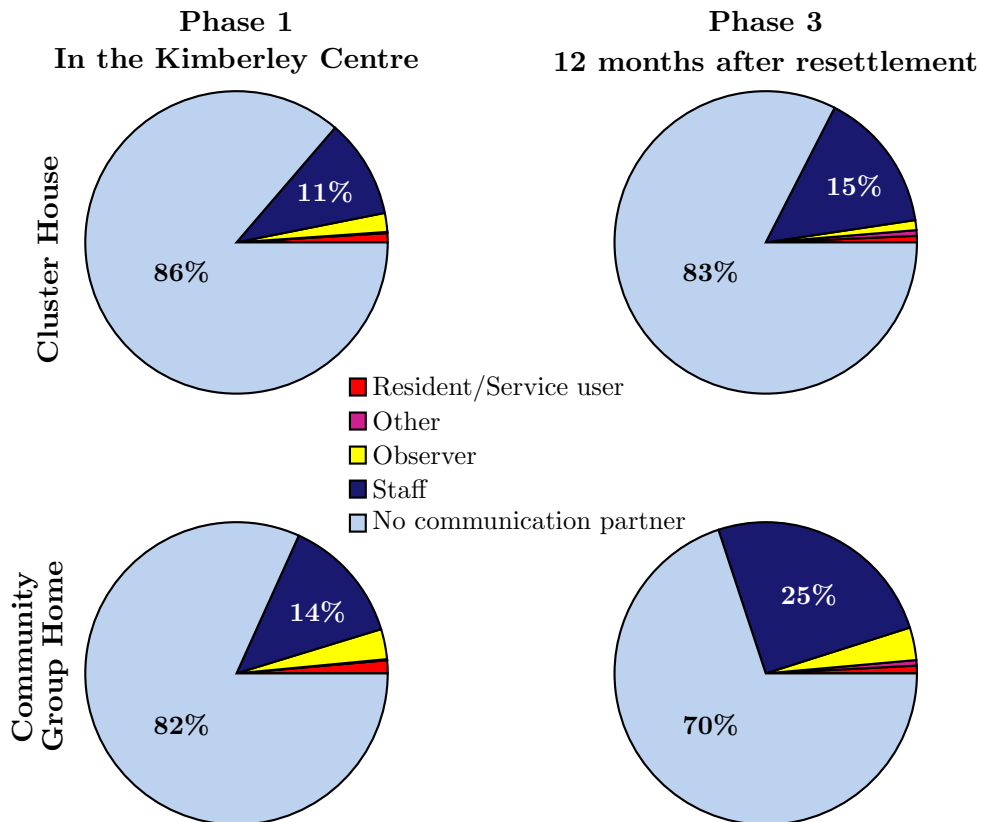
sections we speculated that an expectation of little change and the translocation of similar support practices from Kimberley Centre to the new Cluster Houses might have contributed to the similarity in some aspects of resident's lifestyle. The finding of a similar patterns of communication following residents to Cluster Houses further suggests that their move from Kimberley was not accompanied by an equivalent change in staff's understanding of their role.

Residents resettled to Community Group Homes, however, experienced an almost two-fold increase in the frequency with which they were observed engaged in a communication event. Staff continued to be the dominant communication partner, but in Community Group Homes they spoke to residents 44 percent more often.

A number of potential explanations for this finding suggest themselves. It is probable that the more active lifestyles of residents resettled to community group homes generated greater opportunities for residents and staff to contemplate or affirm shared activity through shared communication. It may also be that the experience of working in a Community Group Home was a qualitatively different experience for staff. Annison (2000) argues a 'home' has a symbolic function, conveying messages of self-identity, status, refuge and personality to occupants and the community beyond.[73] She and O'Brien (1994) believe that people with intellectual disabilities could be understood as having arrived at a home of their own when they experienced a sense of place and the socially valued roles of neighbour and owner, time and household routines reflected their personal preferences and residents had a sense of control

over the comings and goings of the people who lived and worked there.[73, 112] Being in an ordinary street away from the infrastructure of disability support may have made it easier for staff to reach an understanding of 'home' and the support role that obligated greater communication.

And finally, the very differences in the disposition of residents that made resident interaction and the acquisition of pro-social adaptive skills less likely in Community Group Homes may also have contributed to the increase in communication with staff. At Kimberley, residents in challenging behaviour villas were observed to initiate more communication events than other residents. It is possible that in the smaller, more homelike community-based settings, residents understood as challenging continued to seek but found it easier to achieve the interaction with staff they had always sought. Supportive evidence was found when we explored whether any differences emerged in the frequency with which residents initiated communication (Figure 9.14 and 9.15).

Figure 9.14 — The number of times each partner to a communication event initiated interaction 12 months after residents moved to a Cluster House.
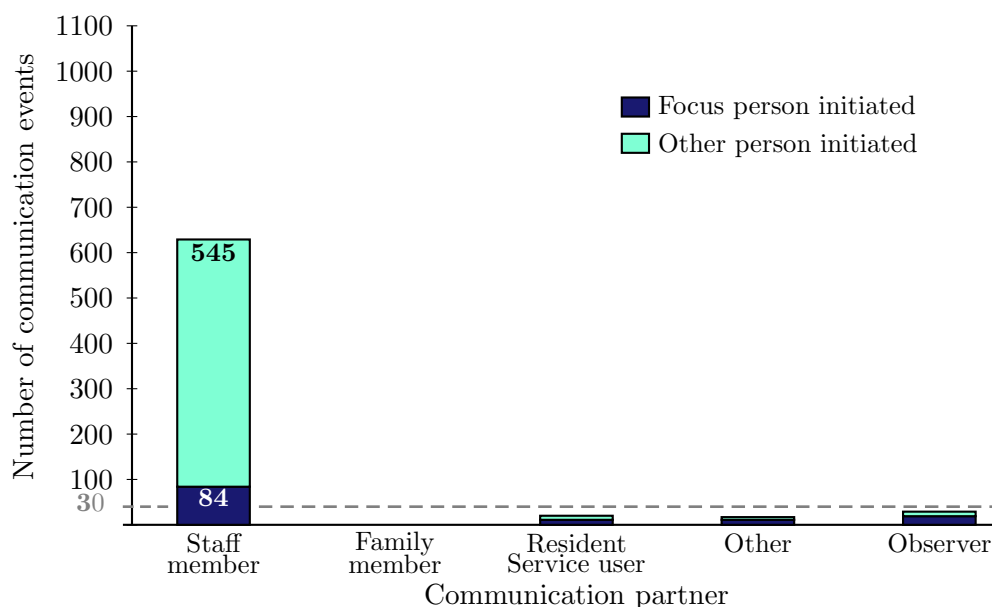
A year after resettlement residents who moved to Cluster Houses only initiated 15 percent of their interactions with staff, whereas in Community Group Homes, residents initiated 23 percent of the interactions they had with the staff who worked there.

Twelve months after resettlement, however most residents in both Cluster Houses and Community Group Homes continued not to engage the people with whom they shared their home.

Figure 9.15 — The number of times each partner to a communication event initiated interaction 12 months after residents moved to a Community Group Home.

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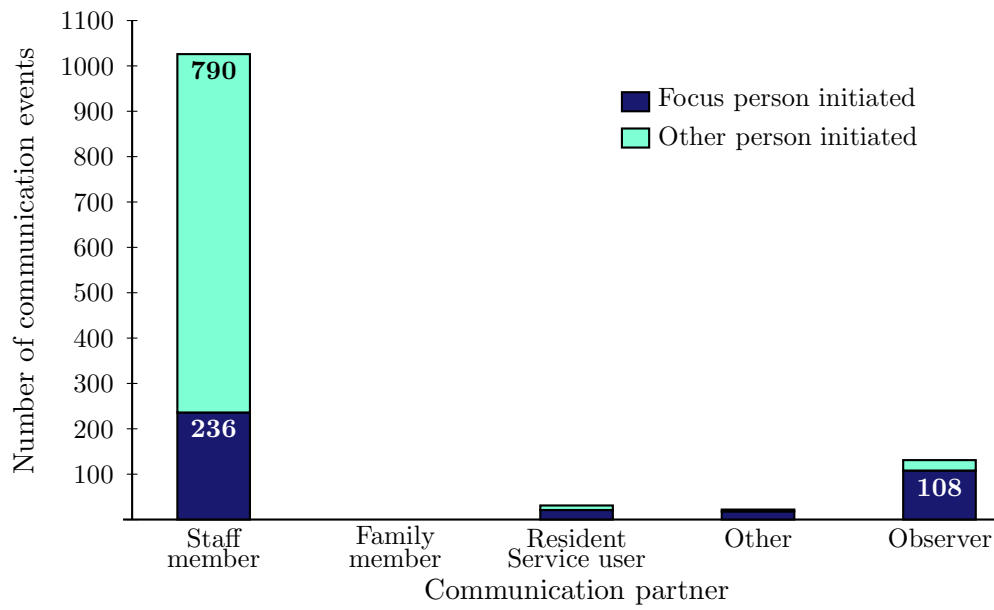
The last ones out?
Assessing what remains to be done

10.1 What did the measures say? Describing the overall pattern of life change for Kimberley Centre residents

The first New Zealand asylum was built in Karori, Wellington in 1854. Although it is unlikely that any person with an intellectual disability was amongst it's resident population, the institution represented an inauspicious beginning to congregate care. Less than twenty years later the asylum would be forced to shut after accusations of cruelty and ill-treatment surfaced during a parliamentary inquiry into patient care.

One hundred years later, exposure of some of the darker corridors of more contemporary congregate care by writers like Goffman[30] (1961) and the images of Blatt and Kaplin[31] (1974) contributed to the process of moving people out of institutions, generally referred to as deinstitutionalisation.[3] The closing of Kimberley Centre would bring to an end the era of large-scale institutional care for people with intellectual disabilities here in New Zealand.

Little is known about the lived experiences of the thousands of New Zealand men and women who passed quietly through New Zealand institutions, as their experiences are largely absent from this countries' research literature. International research attributes the policy and practice of deinstitutionalisation as leading to dramatic changes in the life circumstances of people with intellectual disabilities.[4,65,67,83] As the last specialist institution to remain open, observing Kimberley Centre's closure, therefore, represented a last opportunity to capture this moment of major social change for people with intellectual disabilities in New Zealand.

To meet the studies overall aim of examining what outcomes the closure of Kimberley Centre had for residents, the Kimberley Centre Research Project employed a prospective research design. Prior to resettlement, a picture of resident's day to day lives was built using an array of measures that were later repeated 3-6 and 12 months after their eventual move to a community based service site. Incorporated within the data were the often *silenced and deligitimised stories*[54] of the staff, families and residents making the journey.

The project was enormous in scope. During the four and a half years data was collected, 46 families shared their experiences by contributing 276 hours of transcribed interviews. Key staff volunteered 232 hours of transcribed interviews, capturing their reflections and insight into the life quality of each resident in and then out of Kimberley Centre. Four residents also described their lives in their words, yielding 24 hours of transcribed interviews. One hundred and thirteen adaptive behaviour (ABS-RC:2), 114 Comprehensive Quality of Life (ComQOL-ID) scales and 116 Choice Questionnaires were administered during the three project phases. Support information from residents' Kimberley Centre and community Individual Support Plans were also transposed and compared and 20,010 discrete moments of observation were recorded and post-coded for analysis.

To assess the overall impact of institutional closure on the life quality of the people for whom Kimberley Centre had been a home, a degree of aggregation was required. Each and every person's story of deinstitutionalisation was different, reflective both of the heterogeneity of Kimberley Centre residents and variability in the attributes of the services to which they were resettled. Whilst the findings in this report will not be true to any one individual's experience, we have attempted to present themes that were broadly representative of the process and impact of resettlement as well as something of the diversity of resident's lives in and out of Kimberley Centre.

For many residents, there was much to celebrate about the closure of Kimberley Centre. Amongst the most important was the opportunity deinstitutionalisation afforded many families to relocate Kimberley Centre residents back within the frame of their family. Institutionalisation typically dislocated Kimberley Centre residents from their families. Most participants had first entered Kimberley Centre as children and by the time the research team met them, male residents had, on average, spent 80 percent and female residents 87 percent of their lives living at the Centre. Physical separation compounded the loss of familial identity as families adjusted to the painful loss of loved sons or daughters, brothers or sisters. One of the consequences of the 1992 family court decision to place Kimberley Centre residents under the Personal and Welfare Guardianship orders was that many families could begin the process of relocation by making a decision that reflected a love for their relative that had withstood many assaults. Deinstitutionalisation changed the geography of relationship as almost every family closed the physical distance that separated them from their family member. Fifty percent of residents lived less than 40 kilometres from their welfare guardian after resettlement. For families it meant seeing their relative more often. For residents it represented an opportunity to personalise the trickle of photos families had sent, by meeting nieces nephews and cousins, as an uncle or aunt. For some families, relocation began as an act of reclamation that incorporated the hope that they could, in partnership with services, continue the love and care a lack of support had forced them to surrender.

Families contributed much to the success of resettlement. Locating Kimberley Centre residents within family lore enabled many services to re-vision the people they supported and in the first flush of deinstitutionalisation families provided both the continuous narrative to residents lives and cues to their preferences, aspirations and capacity. Being close to a family member also appeared to be a powerful determinant of residents' ability to convert opportunities for learning into adaptive behaviour. When all of the factors that had the potential to influence adaptive behaviour were modelled, being close to a family member was the only variable to emerge as having a decisive role in influencing overall adaptive behaviour. The authors speculate that the advocacy, nurture and pleasure in personal growth borne of family love underscored this finding.

By the end of the first year beyond Kimberley Centre, most families were happy with their service provider and positive about the impact Kimberley Centre's closing had had on the life quality of their relative. A few had, however, tempered initial enthusiasm, suggesting that their vision of collaborating with services as part of a community of care about their relative had not been realised. Within this group, some families spoke of feeling re-marginalised from their relative as time went on. Unwilling to be cast as negative or ungrateful, families frequently felt unable to express fresh aspiration or criticism as support practice became more entrenched. They also often felt dispirited by the continual ebb and flow of staff and their continual need to renegotiate their place in the lives of their relative. Families are typically the one continuous relationship in the lives of people with intellectual disabilities.[75, 113] Families also permit people with an intellectual disability the chance to step beyond the narrow role of service user into the roles and responsibilities of familial relationship. Families tend also to be the most effective conduit to social relationships beyond service lives.[79] For all of these reasons, finding ways to more effectively incorporate families within a community of support about resident is strongly recommended as a way to further improve the quality of Kimberley Centre residents' lives.

The move from Kimberley Centre was associated with an initial flourishing in the adaptive competence of all residents, independent of their level of impairment or the type of service they were resettled to. Twelve months after moving to a community-based service a statistically significant increase in overall adaptive behaviour was observed together with statistically significant improvements in the domains of *Economic Activity*, *Language Development*, *Numbers & Time*, *Domestic Activity* and *Responsibility* (Figure 5.2).

Figure 10.1 — Mean standardised Adaptive Behaviour domain scores (ABS-RC:2) for each phase of the Kimberley Centre Research Project.

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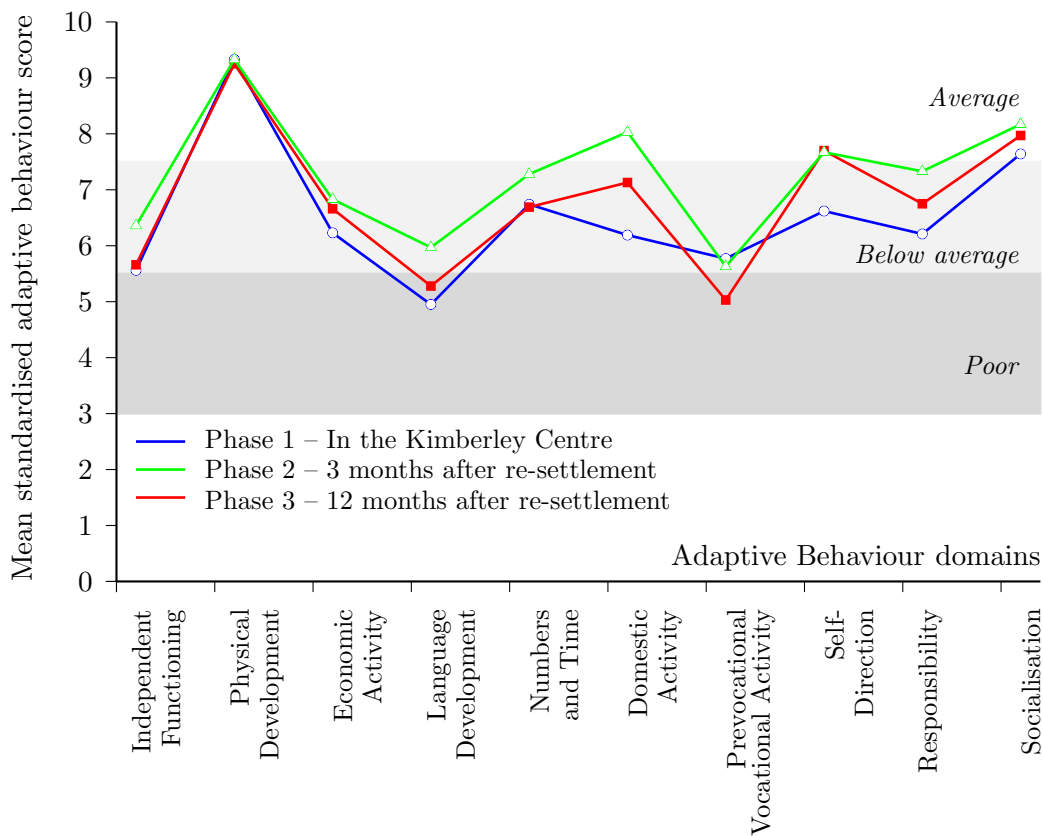
Although important in its own right, the improvement in adaptive behaviour reflected a number of key changes in residents' lives that were harder to quantify but which added greatly to life quality post-resettlement. The more homelike and architecturally typical community dwellings permitted resident's greater opportunities to demonstrate and rehearse latent skill. At Kimberley Centre everything tended to happen beyond the space of the dayroom and residents were escorted to activities in orchestrated, and anticipated, exits and entrances. In the more intimate and informal community-homes, ordinary activity unfolded with residents' lounges and dining rooms, kitchens and laundries, supporting vicarious as well as actual participation in the ordinary routines of daily living. Fewer people and lower staff ratios allowed greater opportunities for people to notice and support preference and competence and staff were at liberty to broaden their role from surveillance and attention to biomedical support needs, reducing the bright line of social distance between residents and staff.

The flourishing of competence that occurred in the first months of resettlement also contributed to a wider humanising of residents beyond Kimberley Centre. Families that had been told their relative lacked development potential or alternatively had witnessed competence wain at Kimberley Centre were confronted with an alternative reading of their family member and staff were energised by the process of unearthing and extending the limits of resident competence. The discovery of spoken language and other forms of communication that had sometimes been silenced over time at Kimberley Centre was the most potent reinforcer and staff often worked hard to expand vocabularies of expression.

Free of the repetitious cadence of villa life, staff spent more time speaking to residents. Both the frequency and duration of communication events increased at every phase of the project. More important however was the time staff and residents 'wasted' in each other's company, building rapport and relationship through non-task orientated conversation and touch. At Kimberley Centre, communication with residents was typically brief as busy staff acknowledged residents on their way to somewhere else or rationed their attention to preserve villa homeostasis. In community service, the same pressure did not exist and the greater number of staff roles obligated wider discourse.

Staff and residents also did more together allowing for the vocabulary of shared experience to punctuate conversation. At Kimberley Centre, many residents seldom ventured beyond Kimberley Centre's grounds. After moving to a community-based service, Kimberley Centre residents had a much greater presence in their community. Residents spent statistically less time hemmed into the residential service settings and significantly more time in community settings. Rather than the community coming to people, consistent with the understanding of the institution as self-sufficient community, people went out to ordinary public spaces to get their hair-cut, have a coffee or recreate. In spite of their fleeting and chaperoned presence in most community contexts, residents appeared to value a greater ability to share ordinary civic spaces, many appearing to equate a presence beyond segregated service settings as a freedom gained.

Beyond Kimberley Centre, residents also had greater liberty to author their presence within the spaces of their own homes. More flexible daily routines and greater freedom to negotiate one's engagement with the day-to-day rhythm of domestic life meant residents could come and go as they pleased. Equally importantly, many were able to assist to blur sharp boundaries between staff and residents by contributing to the maintenance of their own homes or through acts of thoughtfulness, add value to the lives of those they shared their home with.

Small but statistically significant increases in resident's ability to exercise autonomy in key life domains was indicative of resident's greater ability to shape the pattern of their own days in community-based settings. The increase in residents' *Self-Determination* was but one of the ways community service settings approached a more recognisable phenomenological meaning of 'home.' Despres, cited in Annison (2000), suggests that 'homes' serve symbolic as well as material functions.[73] The well appointed, spacious houses residents moved to were a source of pride to many, perhaps because they declared a shared humanity to those who supported them and to the community beyond. The quality of residents' houses was a potent indicator of service quality to most families and it is tempting to speculate that seeing their relative in beautiful homes confronted the bio-medical emphasis reinforced in visits to hospital dorms and villa dayrooms. It certainly appeared to make it easier to visit, as most families closed the social as well as physical distance to their family member post-resettlement.

STAFF   Definitely, [Resident's mum] has made sure everything that happens for him is right for him and I think the [Flatmate 1's family] are the same, the [Flatmate 2's family], the [Flatmate 3's family] they have come back and they are being involved. They are closer to them now than they were at Kimberley. Visits were maybe a bit sterile. [Resident] was the only one who used to go home for weeks on end. A lot of them didn't have that. A lot of them had a fleeting visit in a day room or else they took them out to the church or for a walk around to the bird aviary or something like that whereas now they can actually come and stay in the house, see what's happening, they never had those opportunities and they never had the opportunity to actually look through the files and see what's been written. See what's been done, see that everything is in place. We've got nothing to hide and that's the way it should be.

RESEARCHER   One of the families that I have been speaking to, they said to me whenever we went to Kimberley we went as visitors and we took our cakes for the staff. We take our cakes for [Resident] [now] to share with everyone in his home.

STAFF   Yes because the [Flatmate 2's] family came down and we were making pancakes so they all sat down and we all had pancakes. I mean that wouldn't happen back then.

Residents' bedrooms were most often interpreted to be the most sacred of all home spaces. Although a degree of personalisation had occurred as part of wider institutional reforms at Kimberley Centre, few residents had their own bedrooms. In community-based settings residents had a space that was uniquely and privately their own and into which they were able to declare individuality. Similarly, whereas most Kimberley Centre residents had few material possessions to call their own, their bedrooms publicly and unequivocally displayed a greater material wellbeing that the authors suggest may also have contributed to a greater sense of permanence and ownership.

When staff responses to the objective scale of Cummins' (1991) ComQOL-ID were compared prior to and 12 months after resettlement a 2.29 point improvement in the average assessment of residents' Material Wellbeing emerged as the strongest statistically significant difference associated with the move from Kimberley Centre (95% CI [2.11 − 3.48]; $p < 0.01$).

An improvement of 1.27 points in indicators of social intimacy post-resettlement was also statistically significant (95% CI [0.17 − 2.76]; $p = 0.03$). Smaller more intimate social spaces, more personally referenced activity, and a statistically significant increase in the frequency

Figure 10.2 — Mean staff ratings of residents' objective quality of life domains for each phase of the Kimberley Centre Research Project.
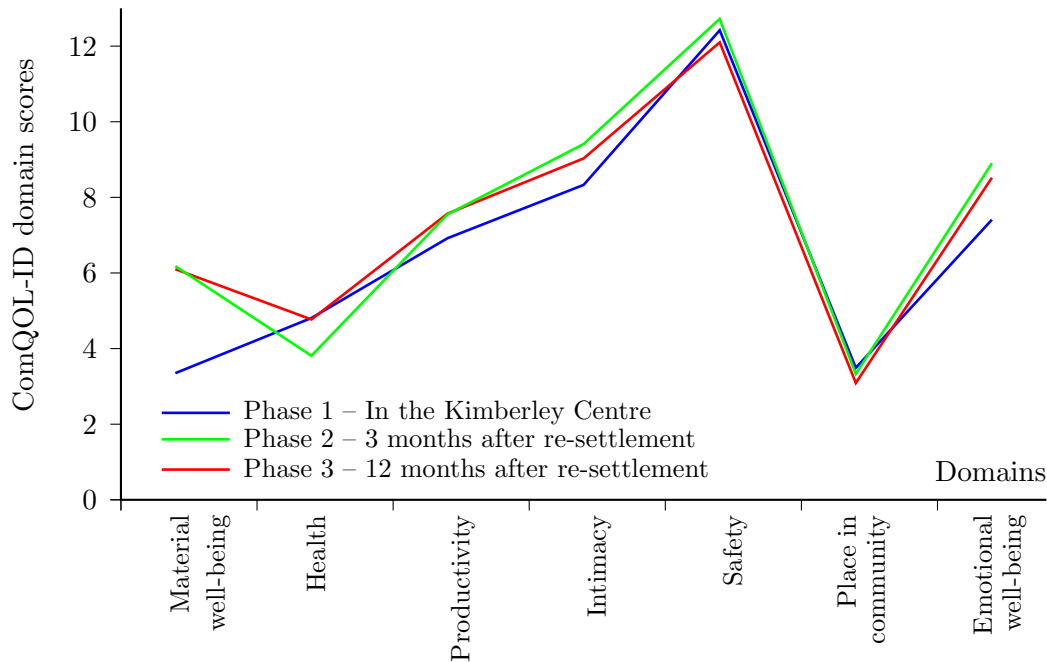
with which residents were observed in socially orientated activity, closed interpersonal distance. It also opened opportunities for community-based staff to acknowledge intimacy by bending their support to suit known preferences. The greater ability staff had to 'waste' time constructing deeper relationship and insight by being alongside residents also appeared to make empathy and action more likely in community settings.

Although no statistical difference emerged in the indicators of *Productivity* post-resettlement, residents' greater presence in vocational centres represented a significant change in many lives, especially those previously supported in Challenging or Multiple Disability villas at Kimberley Centre. As day support at Kimberley Centre withered, people understood either as challenging or frail were typically excluded from vocational activity in the years residents were observed. A narrow understanding of the support role of villa staff also meant that the environments in which most resident's lives unfolded tended to be extremely unstimulating. Attending community Day-Bases added structure, purpose and momentum to residents' lives as well as the opportunity to be in the company of other people with intellectual disabilities. Although the authors express grave reservations about the capacity of existing vocational day programmes to nurture authentic community participation or ongoing learning, attending day bases did represent a significant departure from unstimulating and circumscribed villa lives. Furthermore, during the first year beyond Kimberley Centre a decrease in observed and reported stereotypical behaviour was coincident with more interesting community-based support milieu.

10.2 The physical wellbeing of residents at and beyond Kimberley Centre

Between Phase 1 and Phase 3 there was a statistically significant decrease in staff's assessment of resident health status (95% CI [-1.92 – -0.17]; $p = 0.03$).

As noted in Chapter 1, in the consultation rounds that preceded the decision to close Kimberley Centre, families tended to emphasise the vulnerability of their relative, with fears related to the potential for more limited access to specialist care and psychopaedically trained nursing contributing to an overwhelming preference for preserving the status quo. Similar to other New Zealand[32] and Australian[114,115] research into the impact of deinstitutionalisation, Kimberley Centre families echoed their earlier concerns in Phase One of this project by identifying the ability of community-based services to provide access to specialist care, surveillance and trained, committed and caring staff as axiomatic to the life quality of their family member beyond Kimberley Centre*.

Within the disability literature, concern has been expressed that as a consequence of the emphasis placed on social markers of the success or otherwise of deinstitutionalisation we may have minimised the impact of bodily difference, including the importance of acknowledging the health care of people with complex bio-medical conditions. During the era of institutionalised care, institutions like Kimberley Centre defined and captured specialist care. Residents who lived in institutions had access to psychopaedically trained nurses and training offices. The psychopaedic assistant tended to be mentored by staff with years of experience. Residents also had access to a range of on-site ancillary professional services that had had greater exposure to the associated and secondary health conditions more prevalent in people with an intellectual disability. In stark contrast, the move to community-based services has been associated with the dismantling of specialist training and an elevation in the importance of generic and typically primary health care as the appropriate providers to meet the health needs of people with an intellectual disability.[116]

Early meta-analysis found little evidence for differences in health related outcomes between institutional and community-based settings[83] and equivocated about the impact of deinstitutionalisation on resident mortality.[68,117]

Community based population studies, on the other hand, have tended to find that relative to other citizens, people with intellectual disabilities experience a higher incidence of untreated simple medical conditions, untreated specific health issues related to their individual disability, have a poorer uptake of generic health promotion and significantly higher use of psycho-active medication.[9,116]

Following their consultation with adults who used disability support services in New Zealand, the National Health Committee's (2003) reported unrecognised ongoing and complex health needs and inappropriate medical care and management for people with intellectual disabilities. They attributed poorer health outcomes to the challenge of diagnosis and treatment faced by generic services struggling to accommodate formally institutionalised populations and recommend 'the systemic neglect of the health of adults with an intellectual disability be urgently addressed'.[9]

Not valuing all health outcomes for people who often depend on others to make their health related needs known is a potential barrier within this important domain of wellbeing. Staff recognition of common and treatable conditions as well as the specific and associated

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*See sections 5.2 and 5.3 in *The Impact of Deinstitutionalisation on the Families of the Kimberley Centre Residents*, p. 47-49.

biomedical support needs of people with an intellectual disability are an equally important determinant of good health outcomes.[116] Webb and Rogers (1999) recent finding that 73 percent of 1311 people who used a major New Zealand disability support service required a health related action following the administration of a standardised health screening tool[118] lends weight to the argument that the level of health related competency for direct care staff is critical to the physical wellbeing of people with an intellectual disability.

Within community-based services, the training and experience of support staff varied greatly. All sites had access to someone with health related training, but whereas some services had actively recruited psychopaedically trained direct care staff from Kimberley Centre prior to its closing, at other sites the pool of direct care staff had no formal training and limited experience assisting people with significant health related support needs. Well-intentioned staff, therefore, sometimes reported feeling exposed by their lack of training and apprehensive in the face of the complex health care needs of many Kimberley Centre residents.

STAFF   No one ever taught me what to do for [Flatmate 1] if he aspirates and he did, didn't he! He vomited up bile, well his bowel was twisted and he had pneumonia and it was a quarter of a bucket full of bile came out and he breathed it back. His eye balls rolled back in his head and I am like [Flatmate! Flatmate], I am blowing on his face you know, oh please, and I was shaking him to try and get it up and patting his back so he will breathe. It hurts because if that was my kid, like if there was something wrong with my son, I would learn how to deal with it. There was something wrong with [Flatmate 1] and I didn't know how to deal with it. There was something wrong with [Flatmate 2]. I asked a lot of questions to try and get something out of people. The doctor, I rang the doctor, I asked people to tell me stuff but they don't sit you down and they don't say well this [Flatmate 2], this is what is wrong with [Flatmate 1], this is what could happen and this is how you fix it up. No none of that and even that bit of training would be good when you come in to the house and they explained about these people but no, you get chucked in and you have got to do it yourself. It is shocking and yet what happens when you have got a whole lot of different care givers coming and going, in the end nobody knows what is wrong with the people. And I kid you not, that's how it is.

Except for service protocols around administration, direct care staff at Kimberley and in community settings also tended to have limited knowledge of resident medication and the specific conditions for which it had been proscribed. At Kimberley, registered nurses were responsible for dispensing medication. In community-based services it was the responsibility of direct care staff to dispense, monitor and report behavioural side effects.

STAFF   This is a clinical house, where the sickest people are. We should be taught what medications are for. They are not doing that. They tell you give it at the right time, – the five r's but what have the five r's got to do with it. We don't know what medications they are on. I don't understand anything about medicines. We should be trained in that, what the different medications are for, what you are not allowed to give people. and why do they take the medication.

Although analysis is ongoing, a preliminary examination of resident Special Incident Reports suggests that at many sites, errors in the dispensing of medication were reasonably frequent. Staff were generally aware of the protocols, including that dispensing was double checked, but mistakes were often made as dispensing typically occurred at busy moments in the day (morning and evening) by staff with multiple roles.

STAFF   I think there is a lot of responsibility on staff in these houses. Even just administering medications which has always been an RNs responsibility and now it is ours and mistakes can and do get made probably so it is stressful I suppose and there was a few incidents where things weren't being done right and people were SIR'ed and then people were saying I don't want to do the medication, I would rather not. Everything is supposed to be co-signed but to actually physically do that in the way that it probably should have been set out is impossible because you are asking for two people to be there at all times while you are making it up, drawing it up, and administering it to make sure it is given correctly. Well it doesn't happen that way because in theory you have three people that are busy.

Staff with onsite supervision by a registered nurse tended to report their appreciation of being relieved of some responsibilities and were more confident in their practice as a consequence of ready access to advice and mentoring. All staff reported a desire for greater health related competency training.

Although the move to community-based settings was associated with a statistically significant decrease in staff's assessment of the health status of Kimberley Centre residents, anecdotal evidence suggests that a more benign explanation may also underscore this finding. Most of the difference in this domain is accounted for by the increased frequency with which community-based staff reported that residents saw their doctor or named other impairments. In previous chapters we asserted that in the first flush of deinstitutionalisation, an ethic of 'discovery' was evident in many community-based service sites. Seeking assurances about the nature of impairment and scope for remediation were included within a more general process of unearthing the resident competence. The ethic of discovery appeared to generalise to a more comprehensive 'knowing' of the health status of the residents staff met in community settings. During the course of the first year beyond Kimberley Centre, residents were taken to eye specialists, had their hearing retested and medical conditions of concern were checked out, increasing the number of doctors and specialist visits and elevating service knowledge about other disabilities and medical conditions.

STAFF   They worry about the smallest things and they do it with a passion. [Resident] has had his eyes tested and is getting fitted for glasses. He came out not being tested for diabetes. He has regular blood tests now. The eczema he had is gone. They are the most consistent team I know.

Smaller settings and staff's participatory presence across all aspects of daily living could enable the type of intimate knowing required to detect subtle changes in resident wellbeing.

STAFF   Yes well see that's the same, when you are giving them a shower you are always checking all their skin and her stoma site and all sorts of bits of pieces and all that and that gives you a good each day you can do a whole head to toe assessment of that sort of thing and by knowing from

our experience of her we can look at her and know - I think there is something wrong, I can't put my finger on it, she has got a sore ear sort of thing, just by knowing her and knowing changes in her and in her mood and in her look. You can sort of pick it up.

And sometimes curiosity had unwelcome consequences.

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Fieldnotes (abridged)

[Resident] died at her new home on [date]. She was 61 years old
but her doctor described her as having the body of an eighty year
old. [Resident] died of cerosis of the liver after a lifetime of
Hepatitis and anticonvulsants. She was not a well woman at Kimberley
and on telling staff of her death they would remark ''she was dying
at Kimberley you know.'' Despite being part of the villa lore,
[resident's] cerosis was only diagnosed beyond Kimberley. Her liver,
her sister said, had shrunk to the size of a heart. When asked what
[Resident] liked about her new home, she replied, ''it gave her a
reason to live.''
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Evidence of a culture shift towards an antithetical ethic of knowing, anticipating and predicting resident behaviour by the end of the first year after resettlement was also presented. Knowing whether the frequency of medical visits, sensitivity to indicators of physical wellbeing and advocacy for residents persisted in community-based services beyond an ethic of discovery is an important area for future research.

The feeling that *having a reason to live* and other advantages to living in the community influenced resident health and wellbeing was another common theme within community staff narratives. More physical activity, stimulating lifestyles and nutritious food were all attributed as occasioning improvements in some resident's mood, weight, resilience and related conditions like hypothermia.

RESEARCHER And in terms of improvement in his quality of life?

STAFF Yes, he has put on lots more weight since he has been out. He was a lot smaller at Kimberley and he is a lot happier, smiling a lot. He is eating and drinking. He was quite anorexic. He was anorexic for a while. He had a gastro tube in to give him his drink and now he is doing it himself.

People with intellectual disabilities have higher rates of obesity, visual and auditory impairment, endocrine and skin diseases, psychiatric disorders as well as specific disability related conditions like hypertension and hypothyroidism associated with Down's syndrome.[116] With the move towards more generic, community-based primary and secondary health care, the ability of physicians and other health services to recognise and respond appropriately to the health and associated morbidities of people with an intellectual disability will be an increasingly important determinant of the health status of this cohort. One of the unfortunate legacies of institutionalisation has been the denial of more profoundly disabled men and women from their community. In the context of deinstitutionalisation, primary health practitioners more limited exposure to people with intellectual disabilities and specialist knowledge related to associated morbidities may present a challenge to the generalist community-based health practitioners who have become increasingly pivotal to good health outcomes for people with an intellectual disability.

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An analysis of community-based staff interviews revealed that on the whole, most staff reported residents were experiencing good primary health care and that resident's general practitioner in particular appeared to them to be responsive to the health care needs of former Kimberley Centre residents. Some staff suggested the speed of resettlement and aggregation of residents in smaller towns had overwhelmed primary health services who were themselves struggling to acculturate to the health care needs of residents.

STAFF   Maybe it was all done too quick. That final closure date just had to happen and I think they fired ahead and everything was done too fast and probably because Levin had a high proportion of elderly care homes and everything like that, we are, and Shannon and Foxton didn't have doctors either, they have got themselves in quite a predicament by just fast tracking everything. And even for a doctor some of these people, even for them they are quite a mystery. They have diverse health needs and so many things wrong with them that your normal GP is just – yeah.

The picture was more variable if residents required hospital care.

STAFF   When [Resident] went in to hospital. It is just quite horrible. They were just going to put him in an ambulance and send him with no one with him. We decided not to send him because he was so anxious but he actually really needed to go so the next night when his temperature was getting too high we did send him but we got a sanction for myself and for [staff person] to be up with him for that week which is not the actual policy. They are used to that support from Kimberley, we would have had a 'special,' one of the staff would have 'specialed' him. From what I saw when I was up there, the nurses were quite apprehensive of even touching him and doing anything with him because [Resident] was really unsettled.

A lack of confidence in the ability of the hospital to meet the total "care" needs of this resident compromised his health status because the service delayed sending an unwell person for the medical attention he required.

Unfamiliarity with the health related needs of people with profound impairments, difficulty in communicating and interpreting resident behaviour and a general sense of unease were commonly reported by support staff reflecting on resident's experience of hospitalisation. As is evident in the narrative above, staff were also concerned that a lack of funding meant they no longer had the capacity to remain with residents in hospital to act as social interpreters, provide reassurance and a continuity to their care. As was the case outlined in the field-notes below, in such circumstances staff often volunteered their time to support hospitalised residents.

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Fieldnotes (abridged)

[Resident's sister] contrasted [Resident's] love of her home with
her hatred of the hospital she spent long hours in, in the months
before she died. In particular she highlighted differences in the
way [Resident] was cared for. She believed discomfort and
unfamiliarity with intellectual disability meant hospital staff
failed to 'look for' [Resident] in the same way as her community-based
staff did. [Resident's] sister characterised the reaction of many of
the hospital nursing staff as being 'terrified of [Resident] and
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'repulsed' by moments when she 'kissed or cuddled her.'

[Residents sister] said the nursing staff were at first 'scathing
of her support staff,' but quickly re-visioned them. What impressed
hospital staff was their exemplary documentation and record-keeping.
Hospital staff, she suggested also quickly realised that her
community-based staff 'could do a better job'. For example,
[Resident's sister] reported that when hospital nurses tried to feed
[Resident}, she would frequently choke or 'not do what she was told.'
Community based support staff were also able to give hospital nursing
staff a comprehensive support plan but remained unmoved by
[Resident's sister's] humanising of her with hugs and kisses. Support
staff said they 'took control of Resident's] care.' 'You do you're
your bits' a staff person reported "and we will do everything else
- because they were useless.'
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Community based staff also believed delays many residents experienced accessing specialist and dental care represented a failure to acknowledge the speed with which the health status of people with an intellectual disability could change or the way compromised physical wellbeing could uniquely impinge on other quality of life domains for former Kimberley Centre residents.

STAFF   With Kimberley closing people that have come out have just been dumped on the scrap heap. They have always had on the spot medical treatment when they needed and I don't feel they have got that now. They had it on site but if they needed anything per Mid-Central Health, they didn't really wait. They were done pretty quickly because of who they were and they just had all the specialist services and now there are delays. People have appointments, they wait the same time as you or I would now and sometimes I feel that people are so frail they can't afford that.

RESEARCHER   The waiting list compromises them in a way that it doesn't other people.

STAFF   Yes, I mean if you or I get sick, we might have a bit of a headache or a bit nauseous or something like that, they can't tell us those things and it seems like when they get sick it happens so fast, it is just snap and they are really ill. We found with appointments at the hospital, they just get cancelled time and time again, like [Flatmate] had to go up for his catheter thing. Five cancellations when he first came out and we have had three already. It would have been three months before it was even seen by a specialist. They haven't seen the dentist yet. [Resident's] tooth broke off and it took them two weeks to do an extraction.

RESEARCHER   So why is that, is it because they are generic services and you wait in line like everybody else?

STAFF   Well most of these people, they have to have an anaesthetic and that service is not available in Levin so that means they have gone to Palmerston Hospital and they have such a big waiting list, they have added three hundred and something people to it haven't they, so it just hasn't happened.

In a few locations, consultants had been hired to give specialist advice in generic primary and hospital care settings. An evaluation of the effectiveness of specialist advisors, standardised

health screening and barriers to improved health outcomes for people with intellectual disabilities are suggested as important areas of future research. Similarly, addressing the high rates of turnover to improve the continuity of care provided by direct care staff, improving health related support competencies by investing in greater training and improving staff access to professionals with health related training able to act as mentors are all recommended as ways to improve the physical wellbeing of people supported in community-based residential settings.

In their report *To Have an "Ordinary" Life: Kia Whia Oranga "Noa,"* the NHC (2003) expressed concern about the prescribing practices for people with an intellectual disability in New Zealand. Of a sample of more than 2500 pharmaceutical records they had access to the NHC reported 40 percent of adults who were being treated with psychotropic medicines, did so in the absence of a diagnosed psychiatric condition. Adult service users were described as tending to be over-medicated, using outdated medication or were unable to access specialist review.

Psychoactive drugs are medications that produce behavioural, emotional or cognitive change in the individual taking them.[119] In 1970, Lipman published the first prevalence study on the use of psychoactive medications for people with an intellectual disability. He reported high rates of prescribing in institutional populations, and whilst some were reported to be as high as 80 percent of residents, his and other published studies tend to report in the range of between 29 and 53 percent in institutional populations.[119, 120] These early prevalence studies raised concerns regarding the possible inappropriate use of psychoactive medication, including that some-times medications could be used to sedate or manage behaviour rather than treat a specific disorder and that too many people tended to receive multiple medications rather than managing symptoms with a single medication (polypharmacy).

Analysis of file information for Kimberley Centre residents is continuing, but initial findings suggest that most began lives in the community after prolonged use of two or more psychoactive medications. Eighty-eight percent of Kimberley Centre residents in this study were prescribed psychoactive medication and in excess of 76 percent were administered two or more psychoactive drugs on a daily basis while they lived at the centre (Figure 10.3).

Included within the group of psychoactive medications are a number of drugs not usually thought of as psychiatric medications. Although most anticonvulsant drugs have psychoactive effects and can be prescribed to alter mood, they are also used to control epileptic seizures. Figure 10.4 breaks down the psychoactive medication administered to residents at Kimberley Centre according to major clinical category. Whilst few residents received antidepressant, anxiolytic, stimulant or antimanic drugs, the prescribing profile at Kimberley Centre was dominated by the administration of antipsychotic and anticonvulsant medication. Of the 43 resident files that information could be collected from, 29 resident participants (67.5%) had been formally diagnosed as having epilepsy. It is reasonable to suggest, therefore, that the extremely high prevalence of prescribed psychoactive medication at Kimberley Centre, may be partially explained by the large proportion of residents diagnosed with epilepsy. A small number of families nonetheless voiced concern about the prescribing of psychoactive medication for their relative.

Figure 10.3 — The number of psycho-active medications administered to the Kimberley Centre residents on a daily basis. The outer labels represent the number of psycho-active medications a resident takes on a daily basis. The inner percentage shows the proportion of residents taking the given amount of medication among the total population.
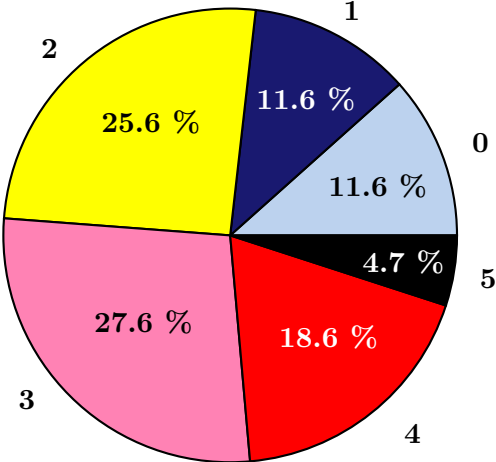
SISTER	Now she came home with all these bottles of pills and there was a Doctor from up there and all these pills and I said why does she need all these pills, these are psychotic pills, she has not got a psychiatric problem, why has she got all these pills. At this time she used to shake and her tongue, I didn't realise that was a symptom of being over medicated. I said well as far as I can see she should not have had them and could they give me an explanation why she had them and they said no, they would speak to the doctor about it.

The low rates of prescribing for antidepressants is an interesting finding in the context of recent research that suggests that the incidence of depression and depressive equivalents, including behaviours that may be medicated in other ways, like aggression, screaming and self-injurious behaviour, are much higher for people with intellectual disability.[121]

The prevalence of psychoactive medication tends to be lower and more variable for people supported in community-based settings. Aman and Singh (1995) summarised 30 prevalence surveys published up until 1988 and found rates of psychoactive drug prescription (both psychotropic and antiepileptic) to range between 29 – 48 percent of people living in community-based services.[120] In the only reported survey of adults using community-based disability support services in New Zealand reported rates of administration as low as 14 percent[122] before the sequence of major institutional closures. What is not clear, however, is whether changes in the social practices that underscore prescribing in community-based settings contribute to the lower prevalence of psychoactive medication beyond institutions or what, if any effect this has for people taking them. Work is continuing to determine whether any changes in the pattern of prescribing occurs following the resettlement of Kimberley Centre residents.

Information was also collected about the prescribing of non-psychoactive medication at Kimberley Centre and one year after resident's eventual resettlement. Comparisons are still being made between the types of medication prescribed and although the sample is small, formative

Figure 10.4 — The number of psychoactive medications dispersed on a daily basis to resident participants by clinical category.
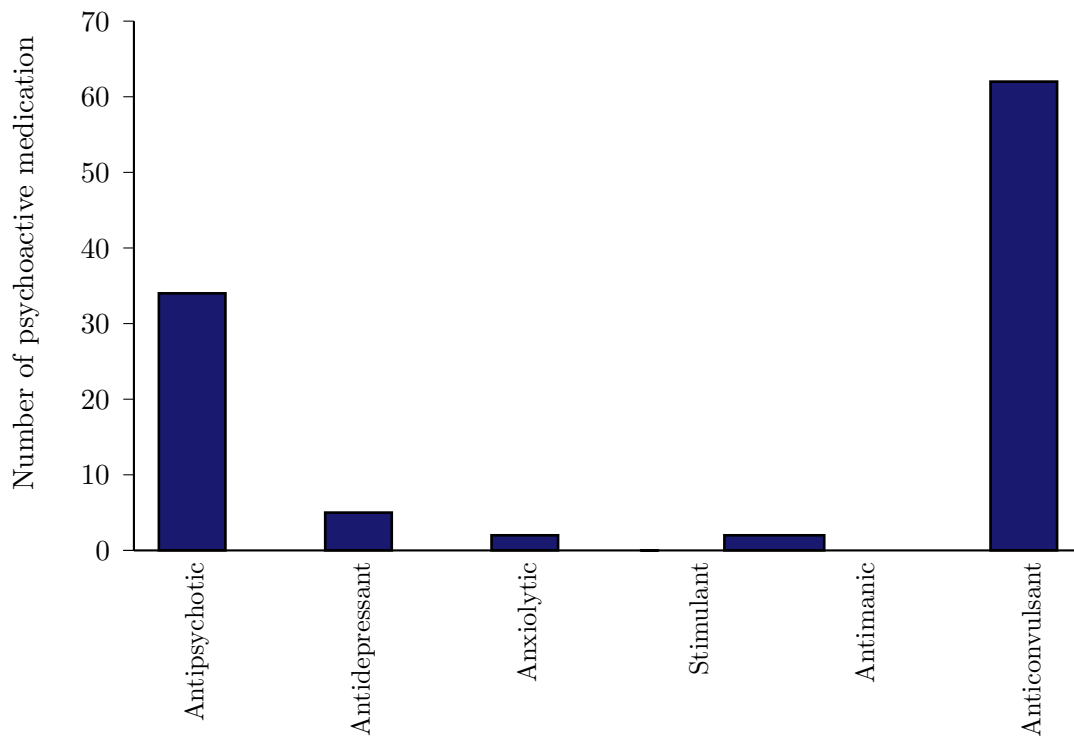
analysis indicates relatively low rates of prescribing anticholenergic (stops involuntary movement of smooth muscles in organs – including asthma), analgesic (pain relief), cardiovascular, contraceptive and antihypertensive (lowers blood pressure) medication (Figure 10.5).

The NHC described a high level of acceptance that poorer health outcomes were concomitant with intellectual impairment.[9] If the findings reported here can be generalised to the wider Kimberley Centre resident population, it is possible that this form of diagnostic overshadowing may have contributed to the relatively lower rates of prescribing of medication used to treat common, relievable conditions.

10.3   Are we there yet?

The findings of the Kimberley Centre Research Project described above add additional weight to a large body of literature that asserts the closure of institutions like Kimberley Centre are generally associated with positive quality of life outcomes for the people who move to community-based settings.

An improvement in life quality was not true for all people. While most, in the words of one mother, "took to it like a duck to water," a small number residents experienced life becoming more difficult and demanding beyond the world they were acculturated to at Kimberley Centre. Of most concern was the small number of residents that found themselves hemmed in living situations where their right to live free of abuse was compromised and those who were obliged to exchange roles and liberties that had historically supported the maintenance of subjective wellbeing at Kimberley Centre.

Figure 10.5 — The number of non-psychoactive medications dispersed on a daily basis to resident participants by clinical category.
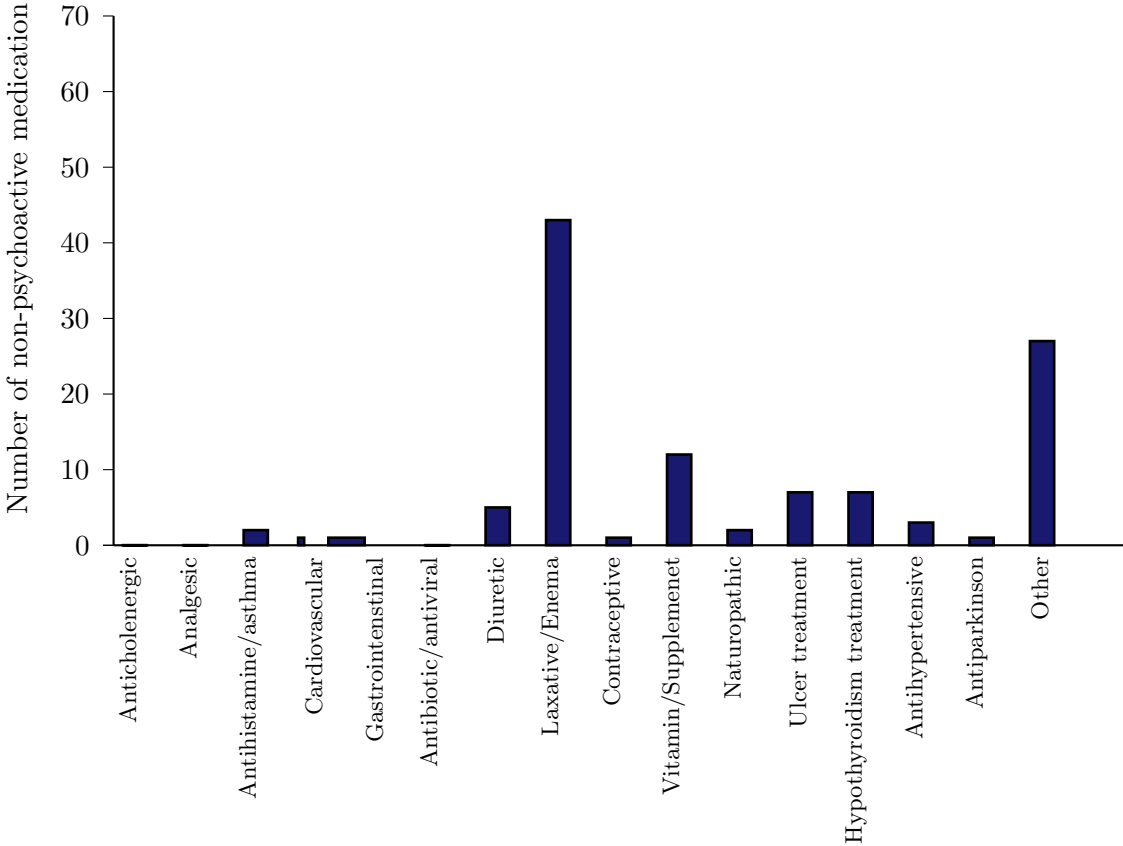
It is telling to note that, with the exception of the opportunity for residents to deepen their relationship with their family, all of the benefits outlined above related to changes that occurred in the segregated spaces of service provision. Bigby and Fyffe (2006) distinguish[5] between institutional closure and deinstitutionalisation because, whilst being present in the community is a necessary prerequisite to people with disabilities becoming valued and contributing members within society, it does not guarantee it. To give effect to the more ambitious goal of re-embedding institutional populations within the wider community, services need to support ordinary New Zealand men and women to step in to each others private social lives.

That people with intellectual disabilities continue to live segregated service lives is one of the most enduring criticisms of service delivery in and out of the institution.[79, 100] Almost all of the lives of the men and women who moved from Kimberley Centre unfolded in segregated service settings and although residents were present in community spaces more often after moving from Kimberley Centre, the timing, duration and destination of their fleeting and chaperoned visits continued to be service led. Living service lives leaves people with intellectual disabilities vulnerable to professional authorship of life quality. Not only does an entrenched dependence on professional support threaten the evolution of natural community, the danger is that service practice can come to define an ordinary life.

The most striking feature of staff's assessment of the objective quality of life of the residents who participated in the Kimberley Centre Research Project is the unanimity with which institutional and community based staff both rated the domains of *Safety* and *A Place in the Community*. *Safety* was always highly rated and *A Place in the Community* always

poorly related regardless of context (Figure 10.2). The findings have important quality of life implications for two different reasons. Exploring how safe Kimberley Centre residents were in and out of Kimberley Centre and how well they became integrated within the communities to which they moved are discussed next together with finds and recommendations that relate to the final research aim of identify any issues of service quality and service gaps within the resulting community services.

10.4   How safe were Kimberley Centre residents?

The right to bodily integrity, including the right to be free from harm or violence is one of the most basic of human rights.

Research has consistently demonstrated that people with intellectual disabilities are more likely than other citizens to experience abuse and violence with incidents typically occurring within private spheres like the home.[3] In a recent New Zealand study,[123] Bray et al. (2002) analysed the Special Incident Reports written for 255 adults living in residential support services and found 82 people had been the victim of a physical assault at least once in a calendar year. Intentional injuries accounted for 22 percent of all injuries, leading Bray et al. (2002) to conclude that a picture of unprovoked bullying and a pervasive low-level culture of violence existed in many service settings where residents had neither chosen to live with each other nor had any opportunity to escape.

For the families of Kimberley Centre residents, the vulnerability of their relative to abuse and poorer quality of care in community settings was a pre-eminent concern in the submissions made during the 2000 consultation process. Families would reiterate the same concerns during Phase 1 of the Kimberley Centre Research Project, emphasising the professionalism of Kimberley Centre staff, ever-present surveillance and the strong weighting towards meeting residents biomedical support needs as amongst the most valued attributes of Kimberley Centre.[37] When Kimberley Centre staff reported that Kimberley Centre residents were safe within institutional care, their response was consistent with the same master narrative that had contributed to the construction of the first generation institutions. Walmsley argues that the promotion of specialist institutions as a safer alternative than community support was emphasised and reinforced by symbols that communicated permanence and professionalism, including staff uniforms and the expansive architecture and walled grounds of institutional settings.

Over the years at Kimberley Centre, however, the research team were made aware of a quieter, counter narrative. During key staff interviews some staff reminisced about Kimberley Centre's past and a darker, less humane discourse emerged.

STAFF   See I have been here over ten years all up and these people were brought up in fear here and I have seen that. They were brought up in fear, when you look at things that went on in this place, it was horrific. They were cruel, they were very cruel people. We had men out in the courtyard here, do you know how they got showered? With the fire hoses. And they used to get beaten. If you rush up to one of these people quickly, they will cower and that's when they have had hidings at a very, very young age. The Kimberley Cringe. That's what they call it.

While staff typically qualified the narrative by suggesting that acts of abuse perpetrated by staff were historical, in many villas peer abuse and random acts of violence and intimidation tended to be seen as the inevitable and immutable consequence of living in an institution.

STAFF   He wasn't really Ward 7 material because Ward 7 was more the violent type and I think it was only because there was a vacancy in Ward 7 that he went to Ward 7. He was certainly struggling to cope when he arrived. Like set in his ways I suppose. When he came he was a lot noisier, he has settled down a lot and I think it is probably because he may have had to fight for what he needed.

After resettlement, entrenched behaviour and a tolerance of its impact followed many residents into their community-based settings.

Despite the rhetoric of the importance of assessing resident compatibility, the decision to prioritise location in placement decisions, preference for a single landlord and relative inflexibility regarding the preferred model of support meant that in reality any process for assessing resident compatibility was meaningless. Sometimes the serendipity that characterised placement decisions worked out and residents were reported as enjoying each other' company.

STAFF   They interact with each other, they talk with each other, they tease each other, they swear at each other, but they converse with each other and they communicate every day. They are mates, they are mates, and they are close. Once we take them away from the house they are very close to each other.

And at other times it did not.

STAFF   I remember when he arrived He and [Flatmate] just glared at each other. They remembered each other from Kimberley see. Apparently she used to whack him all the time and with him being so unsteady on his feet now.

Some of the most fraught living situations were those where men understood as challenging had been clustered together. In the more socially complex, personalised and intimate community living spaces, people diagnosed with autism or who had a low anxiety threshold struggled to keep their equilibrium and houses quickly calibrated to violence being an everyday occurrence.

STAFF   Sometimes over there it can just get too much, the noise is too much if one of the others is playing up and he gets agitated and there have been other ones hitting out at other residents and he is growling at them and yet he was the worst offender to start with. [Resident] doesn't tend to take him. [Flatmate 1] has actually got stuck in to [Resident] and punched him full on in the face, and [Flatmate 2] has attacked him. So if anything, he is set upon by the other two. He has been fair pounded by [flatmate] and that was – and the only thing we could think it was, was [Resident] went past him and flicked him and then next minute we looked [Flatmate 1] was literally pounding his head so he actually gets more beatings than what he dishes out which is nothing.

Peer abuse in community homes was inevitable. Of concern to the research team, however, was the lack of preparation of community-based services for incidents of abuse. Staff were not trained to nurture pro-social resident competencies and services were often unable to respond in effective ways in defence of residents fundamental human right to bodily integrity.

Direct care staff were not trained to provide positive behaviour support. Some staff had been taught to safely restrain residents, but the dominant model of support was consistent with Mansell's (2006) assertion[34] of "unskilled minding." Intervention tended to be reactive and uneven in application. Individual staff practice tended to be informed by personal theory about resident behaviour and intervention applied in an uncoordinated way. A strong emphasis also appeared to be placed upon maintaining household equilibrium rather than the longer-term consequences of failing to address entrenched anti-social behaviour.

STAFF   A few weeks ago I had to come over here and he was really playing up that day because he had had a run of staff who would just let him get away with anything and everything. It comes down to staff dynamics. Sometimes behaviour can be extreme but with the way some of us have done it, its fun, turned it in to a play thing so it is not extreme and it is just no, no, no, no, I am watching you and it just becomes a fun game.

The other aspect of the deinstitutionalisation of Kimberley Centre that made it difficult for some residents was that they crossed the bridge to their new community-based services alone. Staff and residents met as strangers and whereas that had advantages for many, people who struggled to readjust to new settings had no way of making their struggle transparent. Community-based staff similarly had limited knowledge either of the environment in which observed behaviours were purposeful or the things about Kimberley Centre that had previously supported resident self-esteem and subjective wellbeing. For example, the life quality of some residents at Kimberley Centre had been sustained by moments that made them feel special. Examples included the freedom to come and go from day activities, performing domestic responsibilities that conferred status, or having greatest insight into the rhythms and cultural conventions of their villa. In community-based settings these important fillips to life quality were often displaced by an egalitarian ethic and an unconscious focus upon the wellbeing of the group.

Because of the way resettlement was organised, services were denied access to Kimberley Centre staff who had worked alongside residents, sometimes for up to 30 years. The failure to take advantage of these relationships was disrespectful both to the staff who had invested in their care and to residents who had often depended upon it.

Some residential sites were able to draw upon behavioural support from inside of their own service. Others were able to access specialist assistance from the Explore transdisciplinary support service*. Involving Explore tended to the option of last recourse. Part of the problem appeared to lie in the way using an external service was experienced by support staff. Staff comments often reflected difficulties in establishing a relationship of trust and in particular a belief that the model indirectly implied a failure on their part to deliver effective support. Community staff said they were not seen as part of the therapeutic response and that interventions and behavioural outcomes designed in the absence of insight into the day-to-day reality of providing support.

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*Explore was contracted to provide specialist assistance to the community based services during the deinstitutionalisation of Kimberley Centre residents.

STAFF	I wish that they had taken in to consideration what [Resident] is like and when she was going to be coming out in to the community, she was put on a one on one staffing situation and living situation and then all the goals that are set by Explore would be easily accessible. When Explore came in to this house, everything is based around [resident], we have other clients in this house too, we have to get around the whole lot – do you know what I mean?
RESEARCHER	Can I ask, are you feeling under pressure to meet those goals.
STAFF	I am, I definitely am, and so are the girls that I work with here. I am just wondering, I am just wondering how long we are going to keep on keeping on. We have had very little intervention from Explore. And we have been doing it ourselves. And we have been following through on all their base plans and everything and nothing has worked.

Increasing the collaboration between direct support staff and specialist support services, including confidence that behaviour support specialists are attentive to the day to day realities of direct care may improve responsiveness within the sector to residents experiencing difficulty adjusting to life in community-based settings.

10.5   Responding to incompatibility and abuse

In planning for the closure of Kimberley Centre it was anticipated that in some instances, matching residents would be unsuccessful. The remedy proposed was to offer residents and their families new living options.[35]

Where instances of incompatibility and abuse were observed, the collective response within the disability sector was generally leaden footed. Although analysis of resident Special Incident Reporting is continuing, the Research Team is aware of a number of sites where in excess of 30 assaults were perpetrated in a year with only the most superficial of service responses. A number of factors appeared to contribute to the inertia.

Larger disability service providers appeared to struggle most in making timely and efficacious responses. Staff in larger services reported waiting for Special Incident Reports to pass up and back down chains of responsibility for appropriate interventions. Staff also suggested people in decision-making rules lacked the immediacy of a sense of personal knowing of residents whose lives were influenced by their decision making.

Similarly, the sector lacks capacity for ready alternatives. Against the backdrop of policy discourse that emphasises individualised service delivery, choice and person centred service delivery, Kimberley Centre residents and their families were only able to choose the 4-6 person group home. Unless residents behaviour crossed the threshold of eligibility for RIDCA funding, the Community Group Home was the only residential support model available. Where existing services were full and no respite facilities existed, residents in abusive circumstances were forced to remain or move away from families who bought them "home". Denying people with intellectual disabilities and their allies direct access to funding that would support the design of authentically individualised support arrangements confounds the ideals espoused in disability related public policy.

And finally, people living in disability services lack effective advocacy. At present, Health and Disability Consumer Advocacy denies the bodily experience of some of the most vulnerable

health and disability service users. People with intellectual disabilities are frequently disenfranchised from their Code of Health and Disability Service Consumer rights either by the failure of services to make them transparent or because they are themselves unable to lay a complaint. A significant number of people in receipt of disability support are dependent upon a proxy voice when their code rights are breached. Given the restricted social networks of people with intellectual disabilities, staff and family members tend to be their only potential allies in situations of abuse or when service falls below an acceptable standard. During the Kimberley Centre project we found both voices muted for different reasons.

Staff who work in disability services are themselves dependent upon services for their employment. Many also have confidentiality clauses written into their contracts making it difficult for support staff to advocate when service users interests are not coincident with their services.

STAFF   You tend to put management in the back of your mind and you go for the client. At the end of the day that's what you are there for isn't it? A lot of us are sick to the back teeth with what has been going on and what is happening but we go for the client and we care very much for their welfare and they are lucky because they have kind, caring staff. We did get a – it was one flyer came out that stated that we weren't to talk to the press if they ever appeared or to anybody in the public, whatever happened in the confines of the house or the property, it was to be kept confidential and we were not to talk to anybody.

Often staff themselves knew little of the rights people they loved and cared about were entitled to.

STAFF   They teach us that if you don't do what the policy says, go and find another job. Because they can't talk I am their voice. They can't speak up for themselves, I can, I can, you know. I care, yeah, I care. My life has become entwined with theirs now and it will always be that way while I am working

RESEARCHER   Does [Resident's] family advocate for him?

STAFF   Not really. I try and tell them everything but they don't know what's happening

RESEARCHER   If you weren't doing it.

STAFF   No one will, no.

RESEARCHER   Have you thought about Health and Disability Advocacy?

STAFF   Who are they?

RESEARCHER   I was just thinking I need to ask [Staff] does she know (a) about the Health and Disability Advocacy Service...

STAFF   No.

RESEARCHER   And (b) about the Code of Health and Disability Rights.

STAFF   I don't know what you are talking about. We haven't been trained

Families were compromised in other ways. Effective advocacy begins with knowledge and families were sometimes given incomplete or censored information about the wellbeing of their relative. During the course of the first year beyond Kimberley Centre it came to light that one participant had been repeatedly assaulted by one of his flatmates. In spite of her status as welfare guardian, and despite making transparent her wish to be informed of incidents affecting her son, 13 Special Incident Reports would pass to and from the service setting before his mother would learn of the assaults. Frustrated at the lack of momentum, a

staff member ultimately breached confidentiality by attempting to lay a complaint of assault against one of the residents in the home and it would be from the Police that his mother would ultimately learn of the assaults. Of particular concern was that not only was her son unable to defend himself, but that he had no template for assault.

MOTHER   [My son] has never done anyone harm. He has never been hit and now he is. He is afraid and it just isn't fair. I don't know what I can do. What can I do?

As the year rolled on and little changed funding for an extra staff person was found but the assaults and intimidation continued. In the course of advocating for her son's right to live in a home free of violence this mother was required to engage with many of different agencies and services. Faced with the complexity of the disability support sector other less confident welfare guardians may have become dispirited and resigned themselves to the ordinariness of low-level assault for people with intellectual disabilities. (Figure 10.6). Exposure to violence

Figure 10.6 — The network of organisations and agencies that contribute to one person's care.
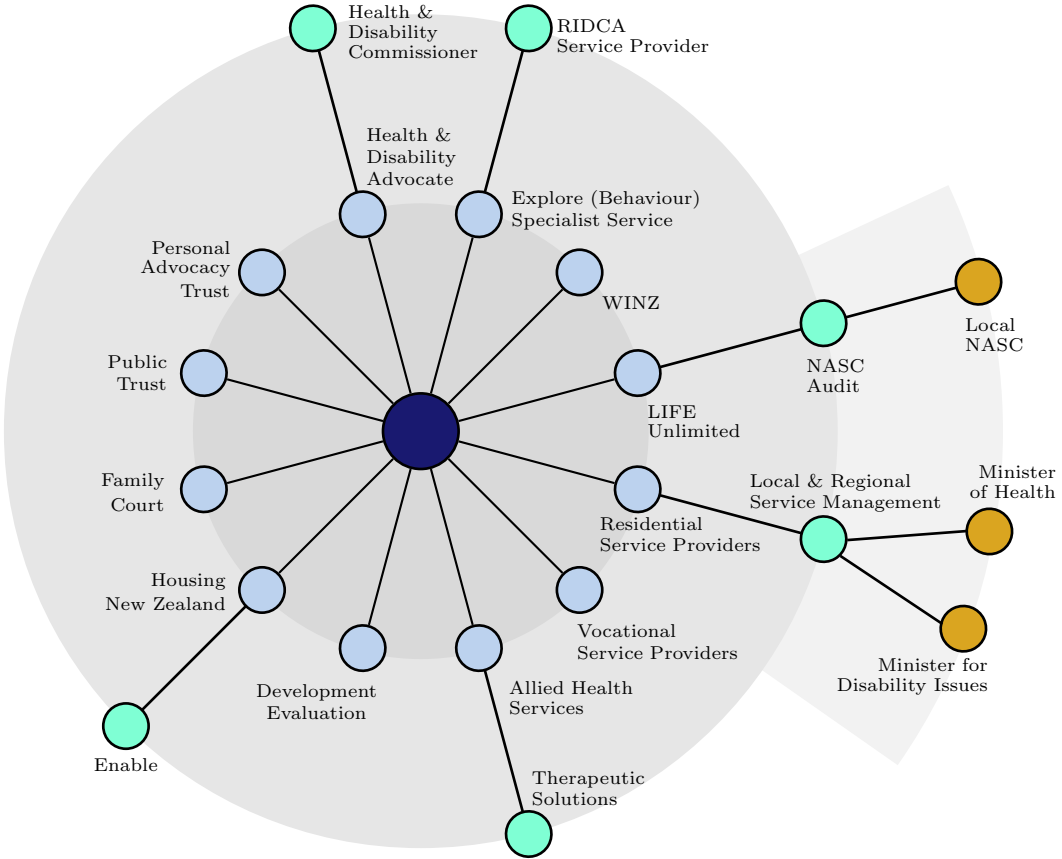
and intimidation in the sacred space of one's home represents a failure of effective support. Adjusting expectations to give effect to residents human right to bodily integrity represents an elemental way the life quality of people with an intellectual disabilities can be improved. Other ways to build safer homes and communities are discussed as final recommendations in the next two sections.

10.6   Building safer homes: Recommendations

- Residents resettled from Cherry Farm (situated near Dunedin) left for community-based services at the beginning of the 1990s with an independent advocate. The role of the advocate was to support families through the transition and subsequent service related issues. They were also available to families in an advocacy/advisory capacity. The strengths of the model included that advocacy was grounded in a more intimate knowing of the person and their aspirations. Services were also required to forward Special Incident Reports to a person's advocate, adding an additional layer of transparency. Decisions about support or service change were made by a person and their chosen allies, including their independent advocate. Given the way service users and their family can be marginalised from their Code rights, a similar form of advocacy ought to be available to service users and their families. The role of advocates could be extended to helping service users and their families navigate the forest of disability service provision described in Figure 10.6.

- Address the lack of staff training in positive behaviour support and resolve the friction of distance between specialist behaviour support services by incorporating an educative, hands on role for behaviour support providers.

- Find ways to give effect to support arrangements beyond the standard Community Group Home. Carefully managed, direct funding has the potential to build community as well as create a broader range of person centred support options.

10.7   Building a place in the community: Recommendations

Staff ratings of how well residents were embedded into their local community were uniformly poor. Even though the residential reform that closed institutions was predicated upon an imperative to relocate people back within their local community, living in community settings made little difference to residents' capacity to build community relationships. The findings presented in this report are consistent with previous research, but also hint at possible remedies.

- Kimberley Centre residents experienced their community in fleeting and chaperoned visits to the quietest cafés, far end of beaches or stops along a circuit of civic amenities. They tended to be public spaces that presented few opportunities for people to develop ongoing relationship or for the public to gain confidence and affect. A few residents had begun to develop community relationship by having a continuous presence inside of places that matched their participatory aspirations and in which they could contribute to the wellbeing of the community. However well intentioned, programmatic and collective vocational service practice fails the test of mainstream reference and is inconsistent with the way people with and without intellectual disabilities find and nurture social relationship. Small services that mentored residential staff to a holistic vision of a person's total support needs appeared to be the most effective at forging community and this model could inform a wider re-visioning of vocational service provision.

- The physical location of most service settings distanced Kimberley Centre residents from natural community. Residential sites close to the heart of communities permitted a frequent and spontaneous community presence. Many Kimberley Centre residents had been resettled to houses in commuting zones on the outskirts of town, some without neighbours. Acknowledging the physical limitations of people by locating them close to

shops and other amenities would elevate activity and the potential for people to become incorporated in their local community townscape.

- A significant number of families came to embrace deinstitutionalisation as an opportunity to relocate their relative back within the body of their family. The hope for many was that they could collaborate as partners with services as part of a community of support around their family member. By the end of the first year beyond Kimberley Centre, some families expressed a view that their vision had not been realised. Families tend to be the one continuous relationship in the lives of people with intellectual disabilities. They also offer a conduit to other community relationships and we found being close to family supported the acquisition of ongoing learning. A community development approach is possible provided services were able to alter the focus of their support to assisting natural supports to take an active role in improving life quality rather than restricting their gaze to service users. Using service skills and expertise to support families would be a logical first step.

- Many services appeared overwhelmed by the logistics of moving so many people safely into community service settings. It wasn't until the end of the first year and audits loomed that services contemplated lifestyle planning and many staff remained unsure about the process and it's purpose. Lifestyle planning also typically happened beyond the authorship of the people whose hopes and dreams was supposed to capture. Transforming lifestyle planning into a process that is owned by residents and their families or advocates would be an important way for service users to authentically hold services accountable to personally valued support outcomes. We will know we have accomplished this when the process is as heterogeneous as the people who services support and lifestyle plans are liberated from their filing cabinets to become the property of the people who own the goals.

- In the first flush of deinstitutionalisation staff worked hard to 'discover' Kimberley Centre residents. Improving language competence was amongst the most potent reinforcers. In spite of the commitment to crossing the communicative divide, residents needed to make themselves understood without communication aids or technology. Staff were similarly not given the opportunity to improve their communicative skills in a systematic way. No sign or choice boards or other inexpensive communication tools were evident throughout the project. Acknowledging the importance of self-expression by improving access to communication technology and up-skilling support staff in effective communication strategies with support the wider visibility of people with intellectual disability.

- When we first visited residents in their community-based services, they lived more active and less sedentary lives than we observed at Kimberley Centre. When we returned six months later, their activity pattern was not dissimilar to the pattern we first observed in the institution with a concomitant plateauing in the acquisition of adaptive skills. A number of factors appeared to contribute to this trend including the steady loss of staff who took their skills, an ethic of discovery and the original vision of making a difference. New staff were orientated new markers of competence including the procedural and technocratic dimensions of support, recreating the institutional resident-staff role division in community-based settings. Residents were infrequently observed in domestic activity nor were they able to take responsibility for other activities likely to blur the boundary or convey a sense of home ownership. Encouraging a wider contemplation of the role of support may also improve the life quality of people with an intellectual disability.

- The life quality of Kimberley Centre residents appeared inextricably linked to the quality of their relationships. The most dramatic changes in the life and disposition of Kimberley Centre residents occurred within unashamedly loving relationships. Where families and staff communicated their respect for the men and women who had stepped into their lives, residents flourished. The nurture and advocacy suggested themselves as important enablers of life quality. Given the centrality of the qualitative attributes of relationship to subjective wellbeing and the accessibility of community rights and resources, including qualitative indicators of life quality ought to be fundamental to future assessment of service quality. Furthermore, though not risk free, cross-cultural precedents exist for service delivery modelled on the strengths of familial support. It is the research team's conviction that it is timely for a more honest discussion about the costs and benefits of accommodating the vocabulary of affect and care into the discourse of human service delivery.

10.8   Concluding remarks

Each and every journey beyond New Zealand's last total institution was different. Together their stories sum to suggest a brighter future beyond Kimberley Centre's gates. In this respect the Kimberley Centre Research Project evaluation aligns itself with the majority of deinstitutionalisation research.

We also found the variability of service quality that Mansell and Emerson & Hatton argued[34, 67] had the potential to undermine the consensus in support of community living.

There were moments that shocked the research team including the leaden and intractable response to incidents of abuse, the continual loss of motivated community staff and a failure to train staff adequately in positive behaviour support, the goals and objectives of lifestyle planning, and even elemental requirements like first aid and medication dispensing.

And there were moments of elation as the research team got to see the men and women they had got to know and respect at Kimberley Centre reconnect with families that had held fast to their love despite the assaults open it. We saw people sew the first seeds of valued community relationships, including changing the lives of staff with whom they shared their homes. And we saw people brush off old horizons and declare themselves and their capacity for learning and re-creation in the first flush of resettlement.

We also found for the resiliency and grace of people who had lived very different lives to most New Zealanders.

> "He has never been crushed by this place, no matter what he had done or what anybody had done to him, he would still be [Resident]."

And a few residents we got to see truly find a *home*.

RESEARCHER   When I first met [Resident] three and a half years ago, he would say to me in a quiet moment, 'going home, I am going home' The staff interpreted that as a sign that [Resident] was beginning to elevate. They saw it as a sign he was becoming unwell. I like to think now [Resident] had it right all along. Do you think [Resident] is home?

STAFF   I think yeah, we had a powhiri like you saw today but it was at the whare and his sister was there and all our other whares and he came in to the house and he got to meet the staff, he got to meet the other mokopuna

and he wasn't even with us for an hour and he was telling his workers to go home. It is almost like when he got that powhiri he knew he was home. He knew, it in himself and it is not something that you put there because it was our first time meeting him you could feel it, almost feel it, you could feel it, it was like somebody who was lost and came home.

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