

School of Occupational Therapy and Social Work

**The privatisation of the back wards: The accommodation of
people with intellectual disability and people with mental illness
in licensed boarding houses in Sydney.**

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Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Gabrielle Drake

October 2010

Dedication

For my mother and father, who inspired a belief that all people have the right to live with respect and dignity. For teaching me that all people have support needs. For teaching me that people ought not be defined or described by their disability. For inspiring a commitment to social justice and a belief that things can be different.

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Glossary

ACAT	Aged Care Assessment Team
ADHC	NSW Human Services- Ageing, Disability and Home Care
AHURI	Australian Housing and Urban Research Institute
ALI	Active Linking Initiative. ADHC funded program that provides recreation and skills based programs to residents of licensed boarding houses.
BHRP	Boarding House Reform Program
CASA	Coalition of Appropriate Supported Accommodation
CRPD	United Nations Convention on the Rights of Persons with Disabilities
CSTDA	Commonwealth State/Territory Disability Agreement
DADHC	Department of Ageing, Disability and Home Care (now ADHC)
DSA (Cth)	<i>Disability Services Act 1986 (Cth)</i>
DSA (NSW)	<i>Disability Services Act 1993 (NSW)</i>
HASI	Housing and Accommodation Support Initiative. A joint initiative between NSW Health and NSW Housing which ensures stable housing linked with specialist support for people with mental illness.

HREC	Curtin University's Human Research Ethics Committee
NAHA	National Affordable Housing Agreement
NDA	National Disability Agreement
NDS	Draft National Disability Strategy
NHMRC	National Health and Medical Research Council
PWD	People with Disability Australia is a national disability advocacy organisation.
RAC	Home Care Referral and Assessment Centre
Schedule V hospital	Schedule V hospitals refer to hospitals named under Schedule Five (V) of the <i>Public Hospitals Act 1929</i> (NSW). These hospitals were large, segregated and geographically isolated institutions for people with intellectually disability and people with mental illness.
Transinstitutionalisation	The process of moving people with intellectual disability and people with mental illness from large-scale, geographically isolated institutions without adequate support and then entering other types of institutions including nursing homes, boarding houses, homeless accommodation services and correctional facilities.
YACS	<i>Youth and Community Services Act 1973</i> (NSW)

Abstract

This thesis explores the use of licensed boarding houses in Inner Sydney as an accommodation option for people with intellectual disability and people with mental illness. Deinstitutionalisation, a significant social policy of the last century was introduced into Australia in the 1960's and 1970's, and involved the closure of large institutions and the integration of former residents into the community. One of the community-based accommodation options used for people leaving institutions was boarding houses. This research explores the extent to which boarding houses enact the human rights principles of deinstitutionalisation and contribute to the quality of life of residents with intellectual disability and residents with mental illness.

The research draws on an extensive literature review and policy and legislative analysis. Denzin's interpretive interactionism was used as the overarching methodological framework of the study. Informing the research are forty interviews with a range of participants including current and former licensed boarding house residents, proprietors, and staff of community organisations and government agencies.

The results of this research provide evidence that licensed boarding houses are a form of transinstitutionalisation and do not serve to enact the human rights principles articulated in current policy and legislation. This thesis argues for the staged deinstitutionalisation of licensed boarding houses in New South Wales.

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To my husband Michael. For telling me sixteen years ago that I would make a great social worker and I could create change. For your unwavering love and commitment. For your belief in what we have made possible over the past three years.

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Introduction

This thesis explores the use of licensed boarding houses in Sydney as an accommodation option for people with intellectual disability and people with mental illness. The central research question examines how licensed boarding houses in Inner Sydney operate within the policy framework of deinstitutionalisation. The objectives in addressing this question are to:

- Document the history of deinstitutionalisation in New South Wales (NSW) and identify the outcomes for people with intellectual disability and people with mental illness.
- Consider what support and services the NSW licensed boarding house sector delivers to the target population compared with what was modelled in the enabling act and regulations around deinstitutionalisation in NSW.
- Establish to what extent licensed boarding houses enact the human rights principles of deinstitutionalisation and contribute to the quality of life of residents with intellectual disability and residents with mental illness.

This research uses the social theory lens of social construction to explore the early history of ‘madness’ and ‘idiocy’ reform in Western societies and subsequent ‘care’ and ‘treatment’ responses, including the use of institutions, described by Foucault (1965) as ‘the great confinement’. It traces the catalysts for change, which led to the implementation of deinstitutionalisation policy. Some of these catalysts included psychopharmacological developments; exposure of abuse in institutions; emerging discourses articulated by those such as Goffman, Foucault and Wolfensberger; fiscal motivations; anti-psychiatry and the consumer rights movement.

Deinstitutionalisation is one of the most significant social policies, discourses and movements of western culture during the last century (Scull 1977; Jones 1993; Warner 1989; Emerson and Hatton 1996; Richmond and Savy 2005; Bigby and Fyffe 2006; AIHW 2001). Introduced into Australia in the 1960’s and 1970’s,

deinstitutionalisation involved the closure of large institutions and the integration of people with disability and people with mental illness into the community. This thesis highlights some of the key legislative and policy developments implemented during this process. The outcomes of deinstitutionalisation are also explored including improvement in the quality of life of people with intellectual disability and people with mental illness, restoration of family relationships, significant impact on carers, transinstitutionalisation (moving to another type of institution), homelessness and a range of accommodation options. During the first wave of deinstitutionalisation, some people returned to live with family or friends or moved into independent living. However, the majority of people moved to other types of institutions such as nursing homes, hostels, large residential homes, cluster housing and boarding houses (Scull 1977; Bostock et al. 2001; HREOC 1993).

Following the implementation of deinstitutionalisation policy in Sydney, a significant number of people with intellectual disability and people with mental illness were relocated from large institutions known as ‘Schedule V’ hospitals (as defined by the Fifth (V) Schedule of the *Public Hospitals Act 1929*) to private, for-profit boarding houses in the community. This process has been referred to as ‘the privatisation of the back wards’ and locates the use of licensed boarding houses within neo-liberal discourse (Participant 23, Government Agency). This discourse advocates for the shrinking of the welfare state, the privatisation of public services and the reliance on market forces to address social issues (Henderson 2005; Argyrous and Stillwell 1996).

These boarding houses became subject to licensing requirements in the 1970’s with the introduction of the *Youth and Community Services Act 1973* and became known as licensed boarding houses or licensed residential centres (LRC’s). This Act requires boarding house proprietors to have a licence if two or more people with disability are accommodated. It also stipulates environmental and safety obligations and some health and welfare requirements. Despite ongoing attempts to regulate and monitor this sector, licensed boarding houses have been the focus of many inquiries, reports and adverse media accounts. These have included substantiated allegations about the wide use of physical and chemical restraint and confinement, regimentation and material deprivation, poor nutrition, significant fire and other safety concerns,

serious health concerns and physical and sexual assault (NSW Government 1993; NSW Ombudsman 2006; NSW Ombudsman 2008).

In many ways the licensed boarding house sector has been ‘untouched’ by the macro legislative, policy and ideological shifts that have occurred over the past fifty years. This accommodation model is an anomaly within the current legislative and policy framework, which is founded on human rights principles, that requires community integration and opposes segregated accommodation models under the *Disability Services Act 1993* (NSW). Or is it? In 1998, the NSW Government made a commitment to close all institutions by 2010. It is now 2010 and the closure of all institutions has not occurred. Indeed work has commenced to redevelop some of the sites through the use of cluster housing (DADHC 2006).

This research took place within a dynamic period, involving a review of the regulatory and monitoring framework and concerns about the sustainability of the licensed boarding house industry. It also took place at a time when policy and practice started to contravene the principles of the enabling Act and indeed the human rights principles of deinstitutionalisation.

In seeking to meet the objectives of this research, Denzin’s (2001) interpretive interactionism was used as an overarching framework. Interpretive interactionism is ‘founded on the study, expression, and interpretation of subjective human experience’ (Denzin 1989, 24). It is an ‘attempt to join traditional symbolic interactionist thought with critical forms of interpretive inquiry’ (Denzin 2001, xi). Within this, a case study method was used enabling a holistic examination of the history of deinstitutionalisation including, the consideration of current legislative and policy reviews; in-depth analysis of how licensed boarding houses operate within the policy of deinstitutionalisation; and enabling a re-presentation of the lived experience of what it means to be a boarding house resident.

This research draws on an extensive literature review and policy and legislative analysis. Informing this research are forty interviews with a range of participants including current and former residents, licensed boarding house proprietors, and staff of community organisations and government agencies.

The results of this research provide evidence that licensed boarding houses are a form of transinstitutionalisation and do not serve to enact the human rights principles articulated in current policy and legislation. This thesis argues for the staged deinstitutionalisation of licensed boarding houses in New South Wales.

Our interview had finished and we were heading toward the door. He held onto my arm to stop me leaving. Tears welled in his eyes and he pleaded with me,

“It’s not right what they did to us. Is it”?

“It’s not right what they did to us. Is it”?

“It’s not right what they did to us. Is it”?

No. And this is why.

Chapter One: The early history of ‘madness’ and ‘idiocy’ reform in Western societies

In order to contextualise deinstitutionalisation as a policy and discourse, it is important to understand how and why institutions were used as a social policy response. Chapter One explores the social construction of ‘madness’ and ‘idiocy’ and subsequent care and treatment responses, including the use of institutions in an era described by Foucault (1965) as the ‘Great Confinement’.

This chapter also considers the catalysts for change leading to a radical discourse and policy shift. Large-scale institutions were closed and people relocated to the community. Factors considered include psychopharmacological responses, exposure of abuse in institutions, emerging discourses, the anti-psychiatry and the consumer rights movement and fiscal motivations.

The dehumanising treatment of people with intellectual disability and people with mental illness has a long and protracted history. It is a history of widespread and severe abuse, neglect, discrimination, isolation and segregation (Goffman 1961; Jones 1993; Foucault 1965; Barnes et al. 1999; Coleborne and Mackinnon 2003).

The segregation of these groups of people was embedded in legislation, policy, ideology and community values and attitudes (Jones 1993; Scull 1977; Barnes et al. 1999; Bigby and Fyffe 2006). It is against this background, that the enormity of the discourse and policy shift to close large-scale institutions and locate people in the community can be appreciated. Deinstitutionalisation was ‘undoubtedly one of the leading policy and structural transformations in health and community services over the second half of the twentieth century’ (AIHW 2001, 96).

In order to understand and contextualise deinstitutionalisation as a discourse and policy framework it is vital to first explore the historical development of how

disability was understood and subsequent ‘care’ and ‘treatment’ responses. This research uses Berger and Luckmann’s (1966) social construction framing to locate these understandings. This framework asserts that the social world is constructed through human interaction and language, where such interactions become externalised, objectified and then internalised (Berger and Luckmann 1966). It also maintains that the social world is historically and culturally specific (Berger and Luckmann 1966; Gergen and Gergen 2004; Burr 1995). In this chapter, the social construction of disability will be explored from ‘madness’ and ‘idiocy’¹ to the significant ideological shift marked in language to the ‘person with mental illness’ and ‘person with intellectual disability’. The interplaying relationship between ideology and policy responses will be explored with specific reference to accommodation and housing models (Cocks and Stehlik 1996).

In describing some of the key historical developments underpinning contemporary disability ideology, policy and service provision, it is acknowledged, that disability

does not have a universal character. Indeed, in some cultures and languages, there is no term for ‘disability’, and ‘social difference’ is categorised in many different ways (Barnes et al. 1999, 14).

For the purpose of this research the focus of historical analysis will be Western capitalist societies with specific reference to England, the United States of America (USA) and France. The Australian experience will be explored in Chapter Two.

The construction of ‘madness’ and ‘idiocy’

The historical account and representation of intellectual disability and mental illness is far-reaching and varies considerably throughout time and across cultures. Those ‘possessed by demons’ of the Bible; Hieronymus Bosch’s famous painting of the ‘Ship of Fools’ and Shakespeare’s ‘fools’ have all played a role in the social construction of ‘madness’ and ‘idiocy’ (Foucault 1965; Scull 1977; Jones 1993).

¹ The use of terms such as ‘madness’ and ‘idiocy’ throughout Chapters One and Two reflect the historical relevance of how language shaped and constructed ‘care’ and ‘treatment’ responses.

Throughout time and across cultures intellectual disability and mental illness have had particular meaning attributed to them through ongoing social dynamics (Foucault 1965; Cocks and Allen 1996; Barnes et al. 1999). In seeking to understand or explain disability, many societies have attributed specific meanings and causes to different types of disability. For example, ‘the insane’ were believed to be the result of a curse or involvement with sorcery, while ‘the imbecile’ was the consequence of the sins of their parent (Wolfensberger 1975). Subsequently, these attributions had a significant impact on how people with disability were perceived and treated. ‘The mad’ were seen as wild beasts in need of taming and physical restraint. People were considered possessed and thus required purging or bleeding. Here one starts to understand the relationship between a person’s social role and value, and ‘care’ and ‘treatment’ responses (Foucault 1965). Furthermore, the central role of discourse in shaping knowledge and actions become apparent notably ‘producing different meanings for the same types of people and behaviours at different times in history’ (Cocks and Allen 1996, 285).

Notwithstanding some of the ‘mystical’ understandings of disability, Foucault attributed the inception of ‘the mockery of ‘madness’ to the end of the fifteenth century as evidenced through art and literature (1965, 15). From the Middle Ages, the ‘madman’ was portrayed as animal or beast often put on display, a spectacle chained up (Foucault 1965). Paradoxically ‘the fool’ possessed special wisdom.

‘The Great Confinement’

The use of segregation and confinement are not new concepts. They are not concepts that are the exclusive domain of intellectual disability and mental illness. The removal of individuals from mainstream society has occurred since the first peoples gathered together in groups, governed by common rules (Meadows et al. 2007). People have been ostracised, segregated and confined because they were deemed unworthy of membership. For example, historically individuals with leprosy were segregated in an attempt to control the spread of disease; a disease originally believed to be the result of a curse or punishment inflicted by a deity (Foucault 1965). The reasons for segregating people with intellectual disability and people with

mental illness influenced how the society 'constructed' or attributed meaning to deviancy (noting the modernity of this term), in an attempt to preserve its norms and values (Cocks and Stehlik 1996).

Up until the seventeenth century in the United Kingdom, 'lunatics' and 'fools' were the responsibility of their family and local parishes. The Church reigned supreme and there was little distinction afforded between 'paupers', 'lunatics', 'fools' and other 'vagrants' (Scull 1979; Jones 1993; Scull 1993). However, Foucault (1965) maintained that the confinement of 'madmen' and 'fools' occurred as early as the fifteenth century whereby people were driven out of their towns, contained and transported by ship, giving rise to the term 'ship of fools'. Jones (1993) noted the use of houses of correction in London as early as 1555. These houses were used to accommodate 'vagrants (*including 'lunatics'*) and beggars who could not be convicted of any crime save that of wandering abroad without visible means of support, or refusing to work, together with petty offenders' (Jones 1993, 11).

The seventeenth century marked significant change. From this point institutions were used as a broad social policy response to poverty and unemployment including to house the 'able-bodied' and 'impotent poor' (Jones 1955; Jones 1972; Scull 1979; Scull 1993). The introduction of the *Poor Law Act 1601* marked a significant shift in the decline of Church responsibility for the poor and the rise of secularism (Jones 1955). It aimed to establish a consistent approach across parishes and townships to the management of 'paupers', 'lunatics' and other 'vagrants' (Jones 1993). Under the Act 'the poor', including the 'able-bodied' and 'impotent poor' were confined in workhouses and poorhouses. Here they performed hard labour, often over long hours for little food, in cramped and filthy conditions. At this time workhouses accommodated a range of people with the exception of St Peters Workhouse in Bristol, established in 1696, which 'progressively' accommodated 'lunatics' on a separate ward (Donnelly 1983; Jones 1993).

In France, formal institutions were also established, Foucault describing this period as 'the Great Confinement'.

For the first time, purely negative measures of exclusion were replaced by a measure of confinement; the unemployed person was no longer driven away or punished; he was taken in charge, at the expense of the nation but at the cost of his individual liberty. Between him and society, an implicit system of obligation was established: he had the right to be fed, but he must accept the physical and moral constraint of confinement (1965, 48).

During this period the ‘Hopital Generale’ was founded in Paris under the rule of Louis XIV (Cocks and Stehlik 1996). This was not a hospital, as we understand it today, but a place where ‘the mad’ were incarcerated alongside the ‘poor’, ‘beggars’, ‘criminals’ and other ‘idle vagrants’. Certainly, in France, it was used as a strategy to prohibit people from begging, during a period of economic crisis (Foucault 1965).

‘From the beginning, the institution set itself the task of preventing mendicancy and idleness as the source of all disorders’ (Foucault 1965, 47). It was believed that ‘the idle’ were morally lax and required punishment and reform. This reformatory approach involved long hours and hard labour in an attempt to free them from their sins and restore an ethical lifestyle. Any attempts to contravene this approach were met with the reduction of rations, increase in work, wearing stakes or irons, or being confined in dungeons (Jones 1993; Foucault 1965).

The conditions of these early asylums and private madhouses were appalling. In the late eighteenth century the conditions of another ‘hospital’ La Salpetriere in Paris were described as

Madwomen seized with fits of violence are chained like dogs at their cell doors, and separated from keepers and visitors alike by a long corridor protected by an iron grille; through this grille is passed their food and the straw on which they sleep; by means of rakes, part of the filth that surrounds them is cleaned out (cited in Foucault 1965, 72).

Samuel Tuke, in his 1807 ‘Report on the Condition of the Indignant Insane’, described the conditions of one man at London’s Bethlem Asylum, who had endured such circumstances for twelve years.

He was attached by a long chain that ran over the wall and thus permitted the attendant to lead him about, to keep him on a leash, so to speak, from outside; around his neck had been placed an iron ring, which was attached by a short chain to another ring; this latter slid the length of a vertical iron bar fastened to the floor and ceiling of the cell (cited in Foucault 1965, 72).

The conditions of these early ‘hospitals’ clearly portray the image of ‘madness’ as animal. Foucault noted, that ‘madness borrowed its face from the mask of the beast’ (1965, 72). This construct of ‘madness’ facilitated acts of brutality as described above at Bethlem and La Salpetriere. Foucault asserted that it is the imagery of ‘madness’ as animal that is ‘responsible for all the practices of confinement and the strangest aspects of its savagery’ (1965, 77).

In the early eighteenth century, passion and its impact on the four humors of the body: blood, bile, choler and phlegm, were perceived as a cause or enabler of ‘madness’ (an idea first developed by Hippocrates 2000 years earlier) (Davies et al. 1991). ‘The passions necessarily cause certain movements in the humors; anger agitates bile, sadness excites melancholy (black bile)’ (Foucault 1965, 86). Increasingly from the mid- eighteenth century a physiological and scientific understanding is applied to ‘madness’ and the medical model started to emerge (Jones 1993). Treatment responses focused on the need to balance the four humors. Balance was achieved through a variety of methods, including herbal remedies, bloodletting, using hot irons to blister the skin, bathing in ice-cold water and drilling into the skull. Indeed England’s King George III, who was believed to have lived with mental illness, was exposed to some of these treatment methods (Jones 1993; Johnson 1990).

Moral treatment and the ‘birth of the Asylum’

The late eighteenth century was a time of great reform described as the Enlightenment, which saw the advent of modern sciences and rationality and the rise of political democracies (Cocks and Stehlik 1996). During this time there were

significant reforms in the approaches to ‘care’ and ‘treatment’ of ‘lunatics’ and ‘imbeciles’ referred to as ‘moral treatment’. Jones noted that

medical men began to experiment with more humane methods of care and treatment, and hospitals were set up in some cities by public subscription. However, many still practiced the standard remedies of bleeding, purging, blistering and vomits (1993, 23).

English Quaker William Tuke and French physician Philippe Pinnel championed moral treatment in the late eighteenth century (Meadows et al. 2007; Jones 1972; Scull 1977). Tuke’s York Retreat of 1792 is regarded as the first institution to treat ‘lunatics’ with dignity. The Retreat focussed on

good food, air, exercise and occupation took the place of drastic medical methods. The Tukes believed that many patients could be rational and controllable, provided that they were not aggravated by cruelty, hostility or harsh methods of restraint (Jones 1993, 27).

The York Retreat is not without its critics. Foucault, looking back more than 150 years, described the Retreat as ‘an instrument of segregation...moral and religious segregation which sought to reconstruct around ‘madness’ a milieu as much as possible like the community of Quakers’ (Jones 1993, 30). Foucault went further, ‘in fact Tuke created an asylum where he substituted for the free terror of ‘madness’, the stifling anguish of responsibility’ (1965, 247) through self-restraint. While this is accurate in so far as patients were removed from society to focus on rehabilitation and labour, the significance of this approach, however paternalistic, in treating patients with respect and dignity cannot be underestimated and must be considered within its historical context. It must be noted however, that the Retreat only accommodated about thirty patients, all able to pay for their treatment, and most were Quakers (Jones 1993; Scull 1993).

Moral treatment was heralded as the

triumph of humanism and of therapy, a recognition that kindness, reason, and tactful manipulation were more effective in dealing with the inmates of asylums than were fear, brutal coercion and restraint, and medical therapy (Scull 1981, 106).

At this time the York Retreat (and to a lesser extent some of the ‘lunatic’ hospitals, such as St Luke’s in London) gained significant public attention (Jones 1993; Scull 1993). This new approach was considered radical compared with centuries of purging, bleeding and various methods of restraint. The Retreat’s approach against increasing allegations of abuse and neglect at London’s Bethlem and York Asylum prompted a Select Committee Inquiry ‘into the state of criminal and pauper lunatics in England and Wales’ (Jones 1993, 36). This inquiry led to the development of the *County Asylums Act 1808* (also known as the ‘Wynns Act’) for ‘the better care and maintenance of lunatics, being paupers or criminals, in England’ (Jones 1972; Scull 1979). This Act required that asylums be ‘in an airy and healthy situation, with a good supply of water, and which may afford a probability of the vicinity of constant medical assistance’ (Jones 1993, 61). The Act also authorised Magistrates to certify that a person was ‘insane’ and raise a levy to pay for their accommodation in an asylum (Scull 1977). The ‘birth of the asylum’ was a momentous event as for the first time, in a systematic manner, ‘lunatics’ and ‘idiots’ were accommodated separately from ‘paupers’, ‘criminals’ and other ‘vagrants’ (Scull 1977).

In accordance with the ‘Wynns Act’, early public asylums were built on the outskirts of towns, some accommodating up to 250 residents (Jones 1993). The care and treatment models used in these early asylums focussed on basic health care and social and recreational activity (Jones 1993). ‘Medical men’ managed the asylums although they were not of the medical profession as we understand it today. They were men who practiced medicine as a hobby or pedlars ‘offering infallible remedies and miracle cures’ (Jones 1993, 6).

There are several reasons put forward for the birth of the modern asylum. One of the central arguments is that the asylum developed as a response to concerns about the

conditions and treatments of ‘lunatics’ and ‘idiots’ in workhouses and private ‘madhouses’ in England including some of the early ‘hospitals’ like Bethlem and institutions such as the Hopital Generale in Paris (Jones 1993). Additionally, the asylum was born out of new approaches encapsulated in ‘moral treatment’ and emerging shifts in discourse that distinguished ‘madness’ and ‘idiocy’ from idleness or criminal behaviour albeit still deviant (Meadows et al. 2007; Jones 1993).

Mechanic (1969, 54) suggested that the impact of industrial and technological changes heavily influenced the birth of the asylum claiming, that

industrial and technological change... coupled with increasing urbanisation brought decreasing tolerance for bizarre and disruptive behaviour and less ability to contain deviant behaviour within the existing social structure.

Sociologist Andrew Scull (1977) critiqued Mechanic’s claims regarding the impact of industrialisation claiming that many of the areas in the UK and USA that were highly industrialised were not necessarily urbanised and requiring institutions, noting that the cotton industry remained rural.

Scull (1977, 24) contended that the push for institutions

is much more attributable to the growth of capitalist market system and to its impact on economic and social relationships. The market destroyed the traditional ties between rich and poor and the reciprocal notions of paternalism, deference, and dependence which characterised the old order, producing profound shifts in the relationships between superordinate and subordinate classes, and of the upper class perceptions of their responsibilities towards the less fortunate.

A system of asylum was established in the UK under the *Lunacy Act 1845* recognising the importance of housing ‘lunatics’ and ‘idiots’ separately from ‘paupers’ and other ‘vagrants’ (Murphy 1991). This model also reflected a changing ideology. ‘Lunatics’ and ‘idiots’ were considered patients and their ‘conditions’ were now understood to be illnesses (Meadows et al. 2007).

The distinction between ‘deviants’ and the ‘poor’ occurred later in the United States. Wolfensberger stated that,

Connecticut’s first house of correction in 1722 was for rogues, vagabonds, the idle, beggars, fortune tellers, diviners, musicians, runaways, drunkards, prostitutes, pilferers, brawlers- and the mentally afflicted (1975, 3).

Indeed, up until the 1920’s ‘mental defectives’ were included with a large grouping of ‘degenerates’ such as ‘the chronic insane, the epileptic, the paralytic, the imbecile and idiot of various grades...tramps and minor criminals; many habitual paupers, especially the ignorant and irresponsible mothers of illegitimate children’ (Wolfensberger 1975, 3).

In 1847 the first ‘asylum for idiots’ was established in London, recognising the differences between the ‘lunatic’ and ‘idiot’ (Wright 2001). However, it wasn’t until the early twentieth century that the distinction between mental illness and intellectual disability and subsequent policy responses gathered any real momentum, with a Royal Commission on the Care of the Feeble-Minded in 1904 and the beginnings of the eugenics movement (Garton 2003; Jones 1993; Block 2005; Johnson and Traustadottir 2005). This movement focused on the eradication of ‘genetic defects’ or ‘unfavourable traits’ (Block 2005). This influenced the use of geographically isolated institutions for people with disability and the segregation of the sexes. It was believed that the forced sterilisation and segregation of women with disability would prevent the ‘spread’ of disability (Johnson and Traustadottir 2005; Block 2002).

From the early nineteenth to the mid-twentieth century the asylum system grew rapidly, most notably in the UK and the USA. Scull (1977, 65) observed, that in the UK in 1845, ‘when provision of asylums at public expense became compulsory’, the number of people identified as ‘insane²’ was ‘21,000 (a rate of 12.66 per 10,000) and by 1954 the number of patients had grown to 148, 000 (33.45 per 10, 000)’.

² This term included people with mental illness and people with intellectual disability.

Catalysts for change

Central to the historical account of deinstitutionalisation, are a variety of perspectives surrounding what were the catalysts for change. What enabled such a radical discourse and policy shift to close large-scale institutions and locate people in the community?

There is a variety of influences thought to be the catalyst for deinstitutionalisation. Bigby and Fyffe (2006, 567) argued, that the closure of institutions for people with intellectual disability was ‘driven by forces that include exposés of the abuses in institutions; legislative reform; normalisation theory; and the recognition of the spiraling costs associated with ‘humanising’ institutions’. The closure of ‘mental asylums’ was also driven by exposés of abuses, legislative reform, fiscal motivations, as well as the development of new psychotropic medications and emerging discourses (Mechanic 1989; Jones 1972; Jones 1993; Warner 1989; Ingleby 1983).

There is general acceptance of these influences within the literature (including Ingleby 1983; Jones 1972 and 1993; Mechanic 1969; Puckett 1993; Scull 1977; Warner 1989; Bigby and Fyffe 2006; Emerson 2004). In contrast to this agreement, the literature diverges as to what actually constitutes deinstitutionalisation and community integration and participation (O’Brien and O’Brien 1987; Bigby and Fyffe 2006; Cocks and Broaden 2010). These debates are far reaching and involve an array of contributors including people with disability and people with mental illness, carers, advocates, policy makers, legislators and academia. The substance of these contributions will be discussed in detail in Chapter Two.

Psychopharmacological Responses

Developments in psychopharmacology continue to have a profound impact on the lives of people with mental illness and to some extent people with intellectual disability, their families, carers and advocates. Such developments have played a crucial role in reducing the time people spend in institutional care by managing some of the symptoms of mental illness, including visual and auditory hallucinations

(Meadows et al. 2007). The ability to manage some of these symptoms has enabled people to live in the community. The extent to which developments in psychopharmacology motivated deinstitutionalisation is subject of much contestation within the literature (Scull 1977).

The arrival of chlorpromazine, an antipsychotic drug, in the mid-1950's was considered a breakthrough in managing the florid symptoms of psychosis (Meadows et al. 2007). Indeed, many argue that chlorpromazine instigated a 'therapeutic revolution' that brought about the shift to community care. In the *Comprehensive Textbook of Psychiatry*, Davis noted, that the 'massive reduction in the number of hospitalised schizophrenic patients following the introduction of the new drugs is the most convincing proof of the efficacy of those agents' (1980, 2257).

Scull (1977, 80) challenged the belief that psychopharmacological advances reduced 'mental hospital' populations and was the major catalyst for deinstitutionalisation. Scull attributed this widely held belief to the 'sustained, and expensive sales drive on the part of the drug companies', which reinforced the medical model of insanity and thus the justification of psychiatry (Scull 1977, 80). Scull (1977) noted, that in some English hospitals, increases in patient release occurred before the advancement of drugs, which he attributed to changes in administrative policies. He also noted the use of 'social techniques' in American hospitals that increased discharge rates prior to the advent of chlorpromazine (Scull 1977).

Scull (1977) identified some serious flaws in the research studies of the early 1950's including their design, methods and findings. These studies have been widely used to demonstrate the impact of psychopharmacological advances on the deinstitutionalisation process. Findings from Brill and Patton's study of the New York hospital system maintained that the impact of drug treatment on hospital population rates was significant. Brill and Patton asserted, that

we know of no other major change in operating conditions which took place between 1954-55 and 1955-56 which could have produced the observed fall in hospital population (1957, 512).

However, they also claimed that

no quantitative correlation could be shown between the percentage of patients receiving drug therapy in a given hospital or a given category and the amount of improvement in releases (Brill and Patton 1957, 513-514).

Scull questioned why such studies were widely used as ‘definitive evidence’ for the impact anti-psychotic drugs had on hospital populations and are responsible for the process of deinstitutionalisation. He concluded that,

the use of psychotropic drugs may have facilitated the policy of early discharge by reducing the incidence of florid symptoms among at least some of the disturbed, thus easing the problems of managing them in the community...but that their arrival can be held primarily responsible for the change is clearly highly implausible (Scull 1977, 89).

From 1954-1959, ‘the years of therapeutic flux’, several revolutions occurred including pharmacological developments, a Royal Commission in the UK which would commence the law reform process and administrative changes to asylums instigating the ‘open door movement’ (Jones 1993). Jones supported Scull’s account by stating, that ‘the fact that all three movements operated in the same time-period made it impossible to trace cause and effect to any one movement with any confidence’ (1993, 150). However Jones later noted, that

the pharmacological revolution had much greater long-term implications than the social and legislative changes of the period. Wonder drugs provided a plausible rationale for the introduction of a hard-line policy based on market economics: the run-down of the hospitals without adequate community care services to replace them (1993, 179-80).

It remains difficult to assert to what extent advancements in psychopharmacology are attributable as the primary catalyst for deinstitutionalisation. Indeed, there are no conclusive studies that illustrate a cause and effect relationship. However, for the purposes of this research it is acknowledged that the role is significant regardless of

its 'primacy' status. Perhaps it is most appropriate to view the use of drugs as an enabler rather than the catalyst for deinstitutionalisation.

Inquiries and exposure of abuse in institutions

The history of 'madness' and 'idiocy' is often a narrative of abuse, neglect and torture. Foucault cited an account of atrocious conditions at La Salpetriere, Paris at the end of the eighteenth century:

What made the place more miserable and often more fatal, was that in winter, when the waters of the Seine rose, those cells situated at the level of the sewers became not only more unhealthy, but worse still, a refuge for a swarm of huge rats, which during the night attacked the unfortunates confined there and bit them wherever they could reach them; madwomen have been found with feet, hands, and faces torn by bites which are often dangerous and from which several have died' (1965, 71).

Tom, a man with intellectual disability, recalled his experience of living in an institution in the mid-1920s in the USA.

My first years in Rome (an institution) were the most difficult of my life. I felt like no one understood me nor cared about me. I felt all alone in the world...The staff would, for example, put me on the floor in the back of the bathroom and I had to lay there all day; sometimes without getting anything to eat (Johnson and Traustadottir 2005, 41).

While one may consider these practices abhorrent by today's standards, they were deemed acceptable by some at a point in time. It is difficult to pinpoint an exact date or period when such practices became unacceptable in the Western world. Furthermore it is difficult to gauge to what extent deinstitutionalisation was motivated by humanism (noting Foucault 1965; Jones 1972; Mechanic 1969; Scull 1977).

The period of Enlightenment and the introduction of moral treatment in the late eighteenth century are generally understood to be the beginnings of the humanist approach (Meadows et al. 2007; Davies 1997; Jones 1993). It is important to note, that while the treatment of ‘lunatics’ and ‘idiots’ began to be challenged during this period, the degree to which systemic changes occurred was a process. This is evidenced by ‘Tom’s’ account provided some 200 years later.

Moral treatment introduced a new approach to the ‘care’ and ‘treatment’ of ‘lunatics’ and ‘idiots’. Fundamental to this approach was recognising ‘lunatics’ and ‘idiots’ as human beings, not wild animals or beasts, as they had been understood throughout earlier times. Moral treatment offered something different and highlighted the contrasting approaches used at Bethlem and York Asylums, as well as Bicêtre in France (Foucault 1965; Jones 1972; Johnson 1990; Meadows et al. 2007).

Following a number of inquiries and Royal Commissions into the ‘care’ and ‘treatment’ of ‘lunatics’ and ‘idiots’, the Macmillan Royal Commission in 1924 found that this phenomenon was ‘a public health problem, to be dealt with on public health lines’ (Jones 1993, 131). It was argued that services should be provided in the community with a ‘preventative element’ (Jones 1993). For the first time, it was posited that people could and indeed should live in the community. The focus needed to be about treatment and prevention rather than detention (Jones 1993). Recommendations of the Commission included ‘establishing out-patient clinics, providing observation beds in general hospitals and to financing after-care work’ (Jones 1993, 133). The Commission also made recommendations about the size of hospitals, training of staff and patient activity.

While the Macmillan Commission proposed significant and radical change, economic depression and the Second World War largely hampered the implementation of these changes (Jones 1993; Scull 1977). It is noteworthy however, that the philosophical underpinnings of deinstitutionalisation were being discussed as early as the 1920’s in England. It wasn’t until the mid-1950s that a second Royal Commission on Mental Illness and Mental Deficiency was established which led to the *Mental Health Act 1959 (UK)* and the subsequent ‘Powell Policy’ (Jones 1972). In 1961 British Health Minister Enoch Powell, without consultation, announced a

new policy to eradicate all 'mental hospitals' within fifteen years and relocate services into the community and wards of general hospitals (Jones 1993).

The exposure of abuse in institutions led to numerous inquiries, Royal Commissions and subsequent legislative reform however, the extent to which this radical policy change was rooted in humanism is questionable (Scull 1977). The political imperative to be governments of action, righting the exposed wrongs cannot be underestimated (Jones 1993). Notwithstanding its significance, there was another imperative that possibly held greater weight: the recognition that institutional care was becoming incredibly expensive and the community-based alternative would demonstrate and actualise efficient fiscal governance (Scull 1977).

Emerging discourses

Contributors to mental health and disability discourse are many including people with disability and people with mental illness, families, advocates, community workers, academics, public servants and various health professionals. However, in considering the role of emerging discourses as a catalyst for early deinstitutionalisation there are three contributors that stand out: Goffman, Foucault and Wolfensberger.

As evidenced throughout this chapter, there have been a variety of responses to the 'care' and 'treatment' of the 'lunatic' and 'idiot' over time. Fundamental to these responses has been an institutional housing or accommodation model albeit for the purposes of containment and incarceration (Scull 1977).

The modes of incarceration have been quite diverse, including the 'ship of fools', private 'madhouses', and large hospitals accommodating thousands of people. They do, however, have fundamental similarities and effects. While several inquiries and Royal Commissions exposed the abuse and negligent treatment of patients in institutions, it was sociologist Erving Goffman in 1961 who questioned the very use of the institutional model as a treatment and social policy response (Goffman 1961; Scull 1977; Jones 1993).

Goffman's Total Institution

Goffman (1961) captured the 'inmates' experience of living in an institution most famously in his ethnographic study *Asylums*. Goffman was able to conduct his research while employed as a recreation assistant at a psychiatric hospital in the late 1950's. He coined the term 'total institution' to describe

a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life (Goffman 1961, 11).

Goffman maintained, that

A basic social arrangement in modern society is that the individual tends to sleep, play, and work in different places, with different co-participants, under different authorities, and without an overall rational plan. The central feature of total institutions can be described as a breakdown of the barriers ordinarily separating these three spheres of life. First, all aspects of life are conducted in the same space and under the same authority. Second, each phase of the member's daily activity is carried on in the immediate company of a large batch of others, all of whom are treated alike and required to do the same thing together. Third, all phases of the day's activities are tightly scheduled, with one activity leading at a prearranged time into the next, the whole sequence of activities being imposed from above by a system of explicit formal rulings and a body of officials (1961, 17).

Goffman (1961) pointed out that these features were not the exclusive domain of 'mental hospitals' and were found in other places including prisons, militaries, monasteries and prisoner of war camps.

As previously identified, the treatment and conditions of institutions came into public disrepute in the late eighteenth century. Outrage focussed on the abuse and neglect of 'lunatics' and 'idiots' and the filthy living conditions. While the humanist approach

challenged the treatment of these groups and required changes such as the removal of mechanical restraints; resident 'occupation'; and improved physical conditions, it did not challenge the institutional model itself. Goffman (1961) believed that a congregate model whereby residents carried out all aspects of their life in a tightly structured manner, ostracised from the wider community had serious consequences for individuals.

Goffman described the impact of total institutions on 'inmates' including the 'curtailment of self', 'role dispossession', loss of 'physical integrity' or sense of safety, 'forced deference' to those in authority, loss of self-determination and various other indignities that lead to 'mortification' (1961, 24-31). In practical terms this is achieved using simple but effective strategies, that include sharing the same bath towel with other 'inmates'; communal clothing; responding to a bell for meals; shared sleeping quarters; and various forms of punishment and control to achieve compliance (Goffman 1961).

Central to Goffman's claims is the belief that the curtailment of self occurs regardless of the intent of the management of the institution.

The various rationales for mortifying the self are very often merely rationalizations, generated by efforts to manage the daily activity of a large number of persons in a restricted space with a small expenditure of resources. Further, curtailments of the self occur...even where the inmate is willing and the management has ideal concerns for his well-being (Goffman 1961: 50).

The impact of Goffman's study and his later works on stigma were profound (Goffman 1968; Barnes et al. 1999). For the first time, policy makers around the globe questioned the institutional model as a care and treatment response. The detrimental effects of living in an institution started to be understood

as structural and not as the product of bad intentions or the scarcity of resources; since they were an inescapable concomitant of the institutional solution, they could be eliminated only by shifting to a system of community care (Scull 1977, 104).

Madness and Civilization

Michel Foucault's *Madness and Civilization* (1965) as evidenced throughout this chapter, also had a significant impact on challenging and shaping discourse. Foucault (1965) examined the history of 'madness' from the Middle Ages to the early nineteenth century focussing on how discourse creates and impacts on role, care and treatment. Foucault 'uncovered' the socially constructed roles of 'lunatics' and 'idiots' and overtly made the connection between the construction of 'madness' and 'care' and 'treatment' responses. The documentation of this illustrated the fact that the concepts of 'madness' and 'idiocy' had changed over time; the origins of this metamorphosis were based on social perceptions of deviancy rather than something organic. 'Madness' and 'idiocy' had 'evolved' from being mystical, to 'the face of the beast' and then to people who were 'morally lax' and 'idle' (Foucault 1965). Foucault (1965) traced the construction of 'madness' and 'idiocy' with exclusionary practices, particularly focusing on institutional care and treatment responses including the 'ship of fools', workhouses and poorhouses to the birth of the asylum.

While Foucault (1965) mostly focussed on the French experience, his work brought to light the widespread cruel and barbaric practices of institutions and the inhumane conditions. Like Goffman (1961), he challenged the use of institutions as a care and treatment response, regardless of how 'moral' the treatment may be perceived by superintendents.

The significance of Foucault's connection between the construction of 'madness' and 'idiocy' and care and treatment responses is evidenced by its syncopation with Wolfensberger's Social Role Valorization and Oliver's Social Model of Disability, all of which have had profound impact on shaping discourse and service models (Annison et al. 1996; Barnes et al. 1999).

The Normalization Principle

The promulgation of the Normalization Principle had a profound impact on disability discourse and challenged, among other things, the way services were provided to people with disability including the use of institutions as the primary accommodation model (Wolfensberger 1983; Cocks and Allen 1996; Barnes et al. 1999). Originally developed in Scandinavia in the late 1950's, the Normalization Principle, as described by Nirje, is concerned with

Making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society (1969, 181).

Wolfensberger 'reformulated' the Normalization Principle, later redefined as Social Role Valorization, to mean the,

creation, support, and defence of valued social roles for people who risk devaluation (1983, 234).

Wolfensberger, like Foucault, challenged the role of language in devaluing people and labelling them as deviant. Wolfensberger argued, that 'deviancy from the norm is not a function of the minds and bodies of the so-called deviants, but rather, is written onto those minds and bodies by the society in which they live' (Cocks and Allen 1996, 285).

Wolfensberger, in his book *The Origin and Nature of our Institutional Models*, maintained that 'one's image of the retarded person has definite implications on one's conceptualisation of the residential service model appropriate for persons cast as the retarded role' (1975, 2). Wolfensberger argued that institutional models are generally based on seven major role perceptions of people with disabilities including, 'sick', 'subhuman', 'menace', 'object of pity', 'burden of charity', 'holy innocent' and 'developing individual' (1975, 5-17). Not only do these role perceptions impact on the types of models of 'care' and how they are provided, they also impact on the resident's role performance and self-identity (Wolfensberger 1975).

Whilst noting that Wolfensberger's work primarily focussed on people with intellectual disability and became influential in the early 1970's after initial deinstitutionalisation processes had commenced, the impact of the Normalization Principle and Social Role Valorization is evidenced by the inclusion of its underlying principles in contemporary policy, legislation, international conventions and at times service provision (Barnes et al. 1999; Cocks and Allen 1996).

Anti-psychiatry and the consumer rights movement

The anti-psychiatry and consumer rights movement developed during the 1960's and 1970's. This was a celebrated point in history where questions started to be asked about a number of unjust and unequal practices. Social movements that emerged at this time included, the black civil rights movement, women's liberation, gay and lesbian movements as well as the disability rights movement (Meadows et al. 2007; Hazelton 2005).

Central to the anti-psychiatry movement is debate about the legitimacy of the medical model in meeting the needs of people with intellectual disability and people with mental illness (Meadows et al. 2007; Barnes et al. 1999). The work of Hungarian Psychiatrist Thomas Szasz in conjunction with British Psychiatrist Ronald David "R.D" Laing was particularly significant. In fact, Szasz's claims were quite radical asserting that 'mental illness is a myth' rejecting any physiological basis for mental illness. He argued that 'diagnoses are social constructs which vary from time to time and from culture to culture' (1994, 36). The movement considered psychiatric diagnosis as arbitrary and questioned some of the prevailing approaches to treatment. Notwithstanding Szasz's claims, the anti-psychiatry movement generally acknowledged the physiological basis for mental illness however considered that a holistic approach was required to care and treatment; one that acknowledged individual circumstances as well as social, economic and political factors (Meadows et al. 2007). The dominance of the psychiatric profession was ultimately questioned and the role of other health professionals, including social workers, became validated (Bland et al. 2009; Mechanic 1989).

The campaign for the better treatment of people with intellectual disability and people with mental illness living in institutions, specifically self-advocacy are not new concepts. As far back as the early 1600's, former patients of London's Bethlem Hospital petitioned the House of Lords for better conditions and treatment (Jones 1993). However, it wasn't until the 1960's and 1970's, in conjunction with the anti-psychiatry movement, that the lived experience of people with mental illness was heard or valued (Hazelton 2005; Richmond and Savy 2005).

People began to challenge some of the approaches to treatment, notably the use of lobotomy, electroconvulsive therapy, sterilisation of women with intellectual disability, physical and mechanical restraint and anti-psychotic medications, as debilitating side effects emerged (Meadows et al. 2007; Bigby and Frawley 2010; Richmond and Savy 2005; Barnes et al. 1999; Jones 1993; Coleborne and MacKinnon 2003). 'The key strategies used by the consumer rights movements to empower service users included questioning of professional expertise and the revaluation of service user knowledge and an increased focus on peer and mutual support processes for meeting service users' needs' (Healy 2005, 72).

There are some distinctions to be made between people with mental illness and people with intellectual disability and the advocacy and self-advocacy movements during the late 1960's and early 1970's. People with intellectual disability were largely represented by family, carers and paid staff of community organisations while people with mental illness were generally self-advocates, supported by charitable organisations (Barnes et al. 1999; Jones 1993; Richmond and Savy 2005; Bigby and Frawley 2010).

The influence of the consumer rights movement gathered greater momentum during the 1980's and 1990's with former 'patients' lobbying for further institutional closure (Bigby and Frawley 2010). The International Year of the Disabled Person in 1981 furthered the inclusion of people with intellectual disability in the self-advocacy movement. As Bigby and Frawley (2010, 39) pointed out,

Members took an active part in lobbying for institutional closure and the right to be treated equally by the community. For the first time during this period, it was acknowledged that people with an intellectual disability had a legitimate role in making decisions about their own lives as well as policy and services.

It is noteworthy however that there has been a recent rise in parents and families of people with intellectual disability and people with mental illness calling for the reinstatement of institutional based accommodation in NSW (Bostock et al. 2001a). This is generally attributed to the lack of community services available following deinstitutionalisation, which will be discussed further in Chapter Two.

Fiscal Motivations

The costs of running large institutions, especially the ongoing capital investment required to maintain decaying buildings, has been an issue of concern for most Western countries. By the end of the Second World War the financial costs of government running and maintaining institutions became untenable (Grob 1995; Jones 1972). The emergence of the welfare state and increased labour costs proved greater than state revenue sources (Scull 1977). Scull (1977, 139) illustrated this point by citing the words of an American civil servant in the 1970's who reported

Rising costs more than any other factor have made it obvious that support of state hospitals is politically unfeasible ... this is the principal factor behind the present push to get rid of state hospitals. In a sense our backs are to the wall; it's phase out before we go bankrupt.

Changes to welfare provision, specifically access to national funding for disability pensions and various other welfare payments also supported the closure of institutions (Warner 1989; Grob 1995; Dorwart and Epstein 1993). States (in the case of Australia and the USA) and local Councils (in the UK) were able to shift fiscal responsibility to the national level and ultimately back to the individual. Individuals were able to 'purchase' care with their welfare payments, which stimulated substantial growth in the private 'care' industry. It must be noted however, that

changes in welfare provision, particularly ‘social security’ income payments played a variable role in the deinstitutionalisation process cross-nationally. For example, ‘comprehensive social insurance in Norway came a decade after the onset of deinstitutionalisation’ (Warner 1989, 23).

The role of fiscal efficiency as the major catalyst for deinstitutionalisation has been argued among various contributors to disability and mental health discourse, and has gained support as the policy of deinstitutionalisation has been implemented (Scull 1977; Warner 1989; Grob 1995). Sociologist Andrew Scull (1977) was one of the first authors to write about the role of economics in his book *Decarceration*. Scull argued strongly, that the role of psychopharmacology, emerging social science research and the exposure of abuse in institutions were politically manipulated to give the policy of deinstitutionalisation a ‘humanitarian gloss’ (1977, 139).

If the programs for decarcerating (deinstitutionalising) the mentally ill were to live up to rhetorical claims about it being undertaken for the ex-patients’ welfare, these aftercare facilities would have had to be extensively present; but this would have been extremely costly, and if the program was to realise financial savings they had to be substantially absent. They are absent (Scull 1981, 142).

The implementation of deinstitutionalisation policy has occurred during a period of significant change relating to the role of the state in the provision of welfare services. From the 1980’s neo-liberal discourse has advocated the shrinking of the welfare state, the privatisation of public services, the reliance on market forces and business models to guide practice (Henderson 2005). The impact of neo-liberal discourse on the implementation of deinstitutionalisation policy is evidenced in the use of accommodation options, including licensed boarding houses that rely on the market to provide.

Conclusion

Over the past two centuries there have been considerable changes to disability and mental health (and illness) discourse and subsequent care and treatment responses. People with intellectual disability and people with mental illness have been described in various ways: ‘mad’, ‘lunatic’, ‘imbecile’, ‘fool’, ‘idiot’ and ‘retard’, to name a few. Central to these labels has been an understanding of disability based on deviancy (Foucault 1965; Wolfensberger 1983; Jones 1993).

The ‘madman’ and ‘idiot’ have morphed from ‘morally lax’ and ‘idle’, requiring occupation in workhouses, to take on the face of the ‘beast’ requiring physical and mechanical restraint (Foucault 1965). The emergence of the ‘mental patient’ required a moral approach, seeking refuge in an asylum (Jones 1993). Despite the meaning attributed to ‘madness’ or ‘idiocy’, the social policy response was institutionalisation (Goffman 1961; Foucault 1965; Barnes et al. 1999; Bigby and Frawley 2010). Against this background, the enormity of the policy and discourse shift to close large-scale institutions and locate people in the community is appreciated. The motivations for such a shift, continues to be vigorously debated.

Authors such as Scull (1977) have argued strongly that the main reason for closing large-scale institutions and relocating people back into the community was financially motivated and other reasons put forward were largely politically constructed. Scull’s arguments are passionate and convincing. He points out that deinstitutionalisation in some parts of England and America had commenced prior to the ‘drug revolution’ (Scull 1977). Scull’s (1977) arguments about the lack of services available in the community following deinstitutionalisation raise significant doubts that humanitarian principles alone underpin deinstitutionalisation.

This chapter has identified the clear themes that emerge from the literature. Developments in psychopharmacology, fiscal motivations, emerging discourses and the exposure of abuse in institutions are attributed as the primary reasons for early deinstitutionalisation (Jones 1993; Scull 1977; Bigby and Fyffe 2006; Richmond and Savy 2005). The various rights-based and advocacy movements and the emergence

of the community care model became more significant as deinstitutionalisation was actualised (Bigby and Frawley 2010; Johnson 1998). As will be explored further in Chapter Two, deinstitutionalisation is a process and has been subject to various interplaying influences as the policy has been implemented in practice.

As Korman and Glennerster (1990, 11) succinctly claimed

Just as the history of institutions is an interplay between the medical profession, public morality and hard political economy, so too is the story of deinstitutionalisation. Once again, different authors emphasise different aspects of the story, but all the same elements are there in mirror image. Professional and public attitudes, scandal and the growing cost of maintaining these institutions began to produce a change in political perceptions.

Chapter Two: Deinstitutionalisation

This chapter builds upon the historic layering of deinstitutionalisation introduced in Chapter One. It discusses some aspects of the implementation of deinstitutionalisation policy, particularly focusing on the New South Wales experience. It also explores some of the outcomes associated with deinstitutionalisation including improvement in quality of life; restoration of relationships; transinstitutionalisation; homelessness and fiscal efficiencies.

What is deinstitutionalisation?

Since the 1960's and 1970's the principles of deinstitutionalisation have underpinned mental health and disability policy in most industrialised countries (Kozma et al. 2009; Richmond and Savy 2005). Over time they have also been applied to other population groups including children and young people in out-of-home care and older people (Gordon 1988; Browning and Kendig 2003).

Central to deinstitutionalisation policy and discourse is a belief that 'total institutions' (Goffman 1961) are an inappropriate service type for ongoing and unreviewed accommodation, support and 'treatment' for people with intellectual disability and people with mental illness. Within deinstitutionalisation discourse people with intellectual disability and people with mental illness live, participate and receive services in the community (Richmond and Savy 2005; Bigby and Fyffe 2005; Emerson 2004).

While there are several examples of literature that focuses on deinstitutionalisation as a construct, overwhelmingly the literature tends to discuss deinstitutionalisation within population groups and this presents some slight definitional differences (Scull 1977; Jones 1993; Bigby and Fyffe 2006; Johnson and Traustadottir 2005). As the policy of deinstitutionalisation has been realised and implemented, its meaning has also altered. The impact of the legal, medical, human rights and management

discourses has been significant, as too, have government interpretations and ascriptions (Scull 1977; Jones 1993; Bigby and Fyffe 2006; Johnson and Traustadottir 2005). These definitional nuances, however slight, have had considerable impact on how the policy of deinstitutionalisation has been implemented and the subsequent influence on the lives of people with intellectual disability and people with mental illness, their families and carers.

Bachrach (1996, 4) focussing on people with mental illness, defined deinstitutionalisation as a

complex series of interrelated events and policy decisions, involving the replacement of long-stay psychiatric hospitals with smaller, less isolated community-based service alternatives for the care of the mentally ill.

Bachrach (1996, 4) identified the three main processes of deinstitutionalisation as being,

the release of patients residing in psychiatric hospitals to alternative facilities in the community; the diversion of potential new admissions to the alternative facilities; and the development of special community-based programmes, combining psychiatric and support services; for the care of a non-institutionalised patient population.

Johnson (1998), in her ethnographic study of the closure of a large institution for people with intellectual disability in Australia, distinguished the differences between a rights-based and a management approach in defining deinstitutionalisation. The management approach concentrates on the

reduction in the number of admissions to public institutions, the development of alternative community methods of care, the return to the community of those individuals capable of functioning in a less restrictive environment and the reform of public institutions to improve the quality of care provided (Willer and Intagliata 1984, 3).

Within a rights-based approach Booth et al. (1990, 70) stated that deinstitutionalisation recognised

the variety of needs among people with learning difficulties, their right to individual treatment, their value as individuals, their rights as citizens and the importance of integration as a guiding principle in the planning of services.

Within human rights discourse all types of ‘total institutions’ (Goffman 1961) are considered to be an inappropriate accommodation option for people with intellectual disability and people with mental illness, especially when the option involves little, if any choice, and is ongoing and unreviewed. A rights framework asserts that people with intellectual disability and people with mental illness have the same citizenship and human rights as people without disability or mental illness (Booth et al. 1990; Johnson 1998; French 2009). These include the rights enshrined in the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights and specifically relating to people with disability and people with mental illness, the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2010).

These Declarations and Covenants underpin disability and mental health legislation and policy in most industrialised countries, including Australia and outline the right to:

- freedom from exploitation, violence and abuse;
- freedom from cruel, inhumane or degrading treatment;
- live in the community;
- health;
- an adequate standard of living including food, clothing and housing;
- participate in political and public life;
- participate in cultural life, and
- freedom of movement and choice of residence (Hauritz et al. 1998; French 2009).

Notwithstanding the different perspectives raised, deinstitutionalisation is generally understood to involve the closure or downsizing of institutions sometimes described as the ‘back door policy’; the relocation and integration of ‘patients’ or ‘residents’ into the community; the diversion of new admissions and re-admissions known as the ‘front door policy’ or ‘non-institutionalisation’; and the provision of services in the community (Bachrach 1996; Richmond and Savy 2005; Doessel 2009).

Accordingly, through a human rights lens, deinstitutionalisation is about much more than the closure of institutions. It is the recognition that people with intellectual disability and people with mental illness have the right to live and participate in the community in the least restrictive environment, with appropriate and accessible support services (Johnson 1998; French 2009). Deinstitutionalisation is not about precluding access to acute hospital based services for people who are unwell or experiencing an ‘episode’ of illness (Richmond and Savy 2005). However, within deinstitutionalisation discourse, hospital-based service types or models of care are to be used as a ‘model of last resort’ and individual circumstances need to be monitored and reviewed regularly.

While general agreement can be found as to the basic principles of deinstitutionalisation, the implementation of the policy cross-nationally can be described as diverse, as are the outcomes for people with intellectual disability and people with mental illness (Bigby and Fyffe 2006; Richmond and Savy 2005).

Cross-national deinstitutionalisation

Comparing and contrasting deinstitutionalisation policy cross-nationally involves analysis across different welfare and government structures as well as significant definitional anomalies (Jones 1993; Colebatch 2002). For example, what constitutes an institution in terms of bed or ‘resident’ numbers varies considerably. Institutions in Australia are defined as ‘a congregated setting of more than 20 people’ (AIHW 2009). However, in the United States of America an institution for people with intellectual disability is defined as more than 16 residents (Stancliffe et al. 2001, 9). The ‘inclusion and non-inclusion of institution types’, for example nursing homes and boarding or rooming houses, also varies cross-nationally (Stancliffe et al. 2001, 11). This presents obvious limitations in comparing international rates of institutional

closure or downsizing. There are also a variety of terms used to describe deinstitutionalisation including devolution, redevelopment, institutional reform and community integration (Bostock et al. 2001). Definitions of intellectual disability and mental illness have also impacted data sets, especially prior to the use of the American Psychiatric Association's Diagnostic and Statistical Manual (2000). In some cases, figures for 'mental hospitals' also included people with intellectual disability (Jones 1993; Grob 1994).

In light of this, a level of caution must be applied to the analysis of data relating to deinstitutionalisation. Most accounts of deinstitutionalisation focus on quantitative data and describe the reduction of the 'resident population' of institutions (Warner 1989; Grob 1995). While this is obviously an important indicator, other factors such as discharge rates, length of stay, admission and re-admission rates, waiting lists and population growth also need to be considered (Grob 1995). Unfortunately, few studies have collected or presented such information (Scull 1977; Bachrach 1996; Warner 1989). Qualitative data such as quality of life indicators including health, accommodation, community participation and relationships while significant in evaluating or assessing the impact of deinstitutionalisation are also rarely collected nor presented systematically in the research (Noonan Walsh et al. 2008; Bigby and Fyffe 2006; Newton et al. 2001).

As might be expected of a socially constructed artefact deinstitutionalisation has been implemented differently around the globe (Emerson 2004). Some European countries including Germany, Spain and the Netherlands are beginning to develop community-based services however institutions are still the predominant model of service provision (Kozma et al. 2009). Institutions remain prevalent for people with intellectual disability in the former 'Soviet bloc' including the use of 'cage beds' for people with intellectual disability (Mansell 2004).

Deinstitutionalisation has also varied between population groups. For example, people with intellectual disability who are assessed as having 'high support needs' or 'challenging behaviours' are the last to move into the community and indeed many people still remain in large institutions, as is the case in New South Wales (NSW Ombudsman 2010).

USA

In 1955 the resident population in 'State and County Mental Hospitals' in the USA peaked at 558,900 (Scull 1977). From this point the resident numbers in institutions continued to decline, initially attributed to the implementation of new anti-psychotic medications, a fact strongly contested by Scull (1977). In 1963, President Kennedy

called for a bold new approach in mental health service delivery. In response, the federal government undertook to replace the country's psychiatric hospitals, which were largely administered by state governments, with some 1500 community mental health centres. About half of these were eventually funded and built before the federal initiative ended in the early 1980's (Bachrach 1996, 4).

Following Kennedy's announcement there continued to be a dramatic decline in the number of people living in institutions. In 1974 there were 215,000 residents and this number declined further to 100,000 by 1996 (Scull 1977; Knudsen and Thornicroft 1996). According to the US Census Bureau (2007) there were approximately 82,000 'psychiatric beds' in 2005. Grob (1991) cautioned readers on the interpretation of numerical data relating to deinstitutionalisation. He noted that there may be discrepancies between patient and bed numbers, readmission and length of stay and some figures may not include people in private hospitals. Nevertheless evidence suggests a marked decline in the number of people with mental illness in psychiatric hospitals in the USA (Mechanic 1989; Grob 1994; Warner 1989).

The deinstitutionalisation of people with intellectual disability occurred later in the USA, as is the case cross-nationally. In 1967 there were 228,581 people with intellectual disability living in institutions (90.4% of people with intellectual disability) in the USA (Stancliffe et al. 2001). This number declined considerably over three decades and in 1999 there were 49,105 people with intellectual disability living in institutions (Stancliffe et al. 2001, 9). It is noted that this figure includes 1,012 people with intellectual disability living in 'mental hospitals'.

Overall, deinstitutionalisation in the USA was considered rapid and generally ill prepared and uncoordinated (Warner 1989; Talbott 1979; Mechanic and Rochefort 1992). The lack of universal health care in the USA compounded these issues and a large number of people became homeless (Warner 1989). Current programs such as the 'Housing First' initiative goes some way to addressing this issue. This program concentrates on 'rapid re-housing' of people experiencing homelessness into accommodation and then providing health and other related support services (Tsemberis and Nakae 2004).

United Kingdom

Similar to the USA experience, there were some examples of the move to community-based care in the UK in the mid-1950's. Indeed, as early as the 1920's the 'Macmillan Commission' recommended that services for 'the mentally ill' be provided in people's homes (Jones 1993). Notwithstanding some early examples of community care models, these recommendations were largely overlooked during the Second World War and the subsequent period of economic and social instability (Jones 1993; Scull 1993).

It wasn't until 1961, following Health Minister Enoch Powell's announcement that the UK had an articulated policy about deinstitutionalisation. The Powell policy aimed to reduce 'mental hospitals' by half over fifteen years (Jones 1993). At the time of this announcement there were 135,400 residents in 'mental hospitals' in England and Wales (Jones 1993; Scull 1977). This figure 'had fallen to 36,000 by 2000' (Morall and Hazelton 2004, 5). While the number of people living in 'mental hospitals' declined significantly, the development of community services and the provision of appropriate resources did not keep pace (Jones 1993). The downsizing and closure of large-scale psychiatric hospitals in the UK has also been associated with a lack of planning and inadequate resourcing (Morall and Hazelton 2004).

In 1976 there were 51,000 National Health Service (NHS) long-stay beds for people with intellectual disability and this figure had reduced by 93% to 3,638 in 2002 (Emerson 2004). While this figure demonstrates a significant commitment to the reduction of NHS long-stay beds for people with intellectual disability, some of the

alternative community-based accommodation options have arguably not fulfilled the human-rights principles of deinstitutionalisation (Emerson 2004(b); Johnson 1998; Barnes et al. 1999). From the 1980's group homes were used as the predominant accommodation model for people with intellectual disability, which has been questioned by advocates of supported living (Bigby and Frawley 2009). Deinstitutionalisation was also achieved in some localities through the use of large residential centres and cluster housing (Emerson 2004; Mansell 2004). Emerson (2004, 80) commented that

while such living arrangements are clearly less institutional in nature than traditional NHS hospitals, they are also significantly more institutionalised in character than more 'inclusive' approaches to community living.

Furthermore, Emerson (2004, 83) asserted that the 'failure' of UK policy has been a preoccupation with the 'mechanics of deinstitutionalisation' rather than being concerned with the deficiencies of service provision.

Australia

The use of institutions as a 'care' and 'treatment' response for people with intellectual disability and people with mental illness in Australia reaches back to 1811 with the establishment of the first 'lunatic asylum' in Castle Hill, New South Wales (Meadows et al. 2007). This first asylum initially had 35 patients. By 1825 the asylum was found to be 'altogether unfit' and it was recommended that 'these afflicted and unfortunate persons should be secured in a proper hospital more directly situated in the vicinity of the town' (NSW Government State Records, n.d). These patients were moved to the Liverpool Court House, which was soon found to be unsatisfactory, and finally Tarban Park was opened, later known as the Gladesville Hospital (Meadows et al. 2007). Tarban Park was a grand Victorian building built on vast grounds with a stone wall to 'protect residents'. It was built near the river, like other early stand-alone institutions, for access to a water supply, but later to transport patients by boat in order to avoid accessing the 'Kings land' as was stipulated under Australian lunacy law (Krowsky et al. 1991).

By the 1860's, however, conditions in Tarban Park had deteriorated immensely. James Barnet, a colonial Architect, documented the conditions as follows:

Such sights as he hoped never to see again, and they affected him so much that he was unable to sleep for three nights afterwards. The rats were running over the patients, the gutters were stinking, the water closets overflowing and everything in a fearful condition (Garton 1988, 161).

Barnet's observations of Tarban Park parallel Foucault's (1965) description of the La Salpetriere in Paris and London's Bethlem asylum.

By the mid-1800's all states in Australia had institutions for people with intellectual disability and people with mental illness, many of which co-located both population groups (Neilson 1990; Bostock et al. 2001; Cocks and Stehlik 1996). The institutions were geographically isolated, set on large sites that had stone walls around their perimeter (Meadows et al. 2007). The conditions in Australian institutions worsened in the late 1800's with overcrowding, typhoid and dysentery prevalent. During this time, the numbers of people in institutions increased considerably following the introduction of various Lunacy Acts (Doessel 2009).

From the opening of the first asylum in 1811 there have been numerous Inquiries, Royal Commissions and Committees relating to the 'care' and 'treatment' of people with intellectual disability and people with mental illness in institutions in Australia (such as the Royal Commission on Lunacy Law and Administration 1923; Stoller Report 1955; Richmond Report 1983; Barclay Committee 1988, Burdekin Report 1993; Select Committee on Mental Health (NSW) 2002).

The Commonwealth Government commissioned the Stoller Inquiry in 1955 and subsequent report *Mental Health Facilities and Needs of Australia* (Lewis 1988; Coleborne and MacKinnon 2003). This Report found the conditions in Australian institutions to be of a low standard and lagging behind the USA and England in 'care' and 'treatment' advancements (Lewis 1988).

From the early 1960's, deinstitutionalisation in Australia concentrated on the downsizing of institutions through the closure of wards primarily for people with

'low support needs' or the reduction of patient numbers (Neilson 1990). During the early 1970's some community-based organisations were being established under the *Handicapped Persons Assistance Act 1974* such as sheltered workshops (Cocks and Stehlik 1996). From the mid-1980's deinstitutionalisation was accelerated and institutions started to be closed such as St Nicholas Hospital in Melbourne where 115 people with intellectual disability lived (Cummins and Dunt 1988). This was a notable event as internationally and domestically institutions for people with intellectual disability have generally closed later than 'hospitals' for people with mental illness (Scull 1977; Jones 1993; Neilson 1990).

The expansion of deinstitutionalisation policy in the mid-1980's in Australia is largely associated with the International Year of Disabled Persons in 1981, serving to lift the profile of people with disability onto the political agenda, followed by the passing of the *Disability Services Act 1986* (Cth) (Bigby and Frawley 2010). This Act was the first piece of legislation in Australia to articulate the principles of deinstitutionalisation (Bigby and Frawley 2010). The Objects of the Act, among others, are

- (b) to assist persons with disabilities to receive services necessary to enable them to work towards full participation as members of the community;
- (c) to promote services provided to persons with disabilities that:
 - (i) assist persons with disabilities to integrate in the community, and complement services available generally to persons in the community;
 - (ii) assist persons with disabilities to achieve positive outcomes, such as increased independence, employment opportunities and integration in the community; and
 - (iii) are provided in ways that promote in the community a positive image of persons with disabilities and enhance their self-esteem.

The *Disability Services Act 1986* (Cth) articulated the requirements for funded disability services. These requirements focused on supporting people to live and participate in the community. A number of new programs were also implemented including the 'Attendant Care' and '325 schemes' to prevent people from being institutionalized (Neilson 1990).

In the late 1980's a national study was conducted into the *Housing Impacts of Deinstitutionalisation* (Neilson 1990). With regard to people with intellectual disability, the study found that in 1988,

- 7,500 people lived in large, geographically isolated institutions;
- 1,300 people lived in hostels of 12-30 people;
- 3,500 people lived in non-profit nursing homes;
- 1000 younger people lived in nursing homes; and
- 450 in hostels for older people.

The study also reported that there were 4,800 people with mental illness (this only included people in NSW, Victoria and South Australia) still living in psychiatric hospitals (Neilson 1990, 9).

In 1992 all States endorsed a National Mental Health Strategy, which was largely influenced by the principles of deinstitutionalisation as stipulated by the *Disability Services Act 1986* (Cth). From this Strategy, the First National Mental Health Plan (1993-98) was developed. This plan focused on mainstreaming,

defined as moving psychiatric services from specialist to mainstream (or general) hospitals, and integration, which referred to the coordination of clinical services delivered through hospital-based and community-based services (Carter et al. 2008,9).

In 1993, the Human Rights and Equal Opportunity Commission (HREOC) released the findings of the '*National Inquiry into the Human Rights of People with Mental Illness*', now known as the Burdekin Inquiry (Brian Burdekin was the Human Rights

and Equal Opportunity Commissioner and Chairman of the Committee of Inquiry) (HREOC 1993). The Burdekin Inquiry was scathing of the treatment of people with mental illness.

One of the biggest problems for people with a mental illness is the absence of adequate, affordable and secure accommodation. Access to appropriate accommodation is often the most important single factor in the success or failure of those with chronic mental illness living in the community.

The inquiry established that the policy of deinstitutionalisation has largely failed -and that it will not succeed until it is accompanied by appropriate policies on housing - and an adequate allocation of resources.

It is also appalling that homeless shelters, refuges and boarding houses are now functioning, de facto, as a major component of the 'accommodation' provided by our society for thousands of Australians affected by mental illness. The living conditions in many of these establishments are disgraceful. Few have trained mental health workers on staff, and there are rarely any decent opportunities for rehabilitation.

In general, the savings resulting from deinstitutionalisation have not been redirected to mental health services in the community. These remain seriously under funded, as do the non-government organisations which struggle to support consumers and their carers. Poor inter-sectoral links, the ambivalent stance of the private sector and a reluctance on the part of government agencies to co-operate in the delivery of services to people with mental illness have contributed to the alarming situation described in this report. While the Inquiry welcomes the initiative recently taken by governments in endorsing a National Mental Health Policy and Plan, a major injection of resources will be needed before we are in a position to comply with our international obligations under the UN Principles for the Protection of Persons with Mental Illness (HREOC 1993, 908).

Since the first National Mental Health Plan there have been an additional three plans, with the Fourth National Mental Health Plan released in late 2009.

While there have been national agreements regarding the funding and monitoring of disability services, namely the Commonwealth State and Territory Disability Agreements (CSTDA) (now known as the National Disability Agreement) since 1992, ‘there is no national framework for the closure of large residential institutions (for people with intellectual disability) in Australia’ (Bostock et al. 2004, 3). Despite the absence of a national framework the principles of the DSA (Cth) and NDA (formerly the CSTDA) reflect the tenets of deinstitutionalisation (Bostock et al. 2001). Furthermore, the Commonwealth Government is currently developing a National Disability Strategy, which aims to

increase the social, economic and cultural participation of people with disability, to eliminate the discrimination experienced by them and to improve disability support services for them, their families and carers. For those living with profound disability and complex needs, we must ensure support and living arrangements meet the same standards of dignity and choice as all Australians expect (Australian Government 2008a, 2);

Within the proposed National Disability Strategy there is a particular focus on ‘supporting people with disabilities to live as independently as possible...and ensuring accommodation options meet the individual and changing needs of people with disabilities (and where relevant, their carers), and for the duration of need (Tually and Beer 2010, 29-30).

Following the election of the Rudd Labor Government in 2007, there have also been significant changes to broader public and social policy including the Social Inclusion Agenda and various strategies targeting homelessness and housing such as the National Affordable Housing Agreement (Tually and Beer 2010). People with disability or mental illness and people at risk of homelessness are some of the priority groups targeted within the Social Inclusion Agenda and the National Affordable Housing Agreement (Australian Government 2010; FaHCSIA 2009).

New South Wales

Prior to the implementation of deinstitutionalisation policy in New South Wales there were approximately 13,200 people with intellectual disability and people with mental illness in state-provided institutions (Neilson 1990). The nature of these institutions was defined under the Fifth Schedule of the *Public Hospitals Act 1929* (NSW). Prior to deinstitutionalisation there were 18 hospitals under the Fifth Schedule of the Act (known as ‘Schedule (V) Five’ hospitals). Five of these catered for people with mental illness, ten for people with intellectual disability and three institutions that catered for both client groups (Neilson 1990, 24).

In 1983, the NSW Government commissioned ‘an inquiry into health services for the psychiatrically ill and developmentally disabled’ and its findings and recommendations were outlined in what is now renowned as ‘The Richmond Report’ (David Richmond being the Chair of the Inquiry). The Richmond Report is often associated with the beginning of deinstitutionalisation in New South Wales (Gerrand 2005). Notwithstanding the impact of the report and subsequent recommendations for funding, administrative and program changes, deinstitutionalisation in New South Wales had commenced some two decades earlier (Neilson 1990). However, it is clear that the Richmond Report hastened this implementation and articulated the policy direction.

The Richmond Report (1983, 5-8) recommended

1. *Services be delivered primarily on the basis of a system of integrated community based networks, backed up by specialist hospital or other services as required.*
2. *That the two prime operational objectives be to:*
 - *fund and/or provide services which maintain clients in their normal community environment; and*

- *progressively reduce the size and the number of existing Fifth Schedule hospitals by decentralising the services they provide.*
3. *That services for the developmentally disabled, as far as possible, be funded separately and services delivered under separate management from mental health services.*
 16. *That a specific budget...be allocated to fund community non-profit organisations to provide supportive accommodation and innovative services.*
 17. *That as savings are achieved from the rationalisation and reduction of existing hospitals, these savings be committed to the development of community services.*

Under the Richmond Program, 163 people with mental illness left ‘Schedule Five’ hospitals and moved into the community (Neilson 1990). In 1985 there were approximately 4,800 people living in ‘Schedule Five’ hospitals (Neilson 1990, 24). The plans for additional reduction in patient numbers and the disposal of the capital assets held in institutions, many of which were located on Sydney’s waterfront, were halted in a change of State Government in 1988 (Neilson 1990).

From the early 1990’s, under the National Mental Health Strategy’s ‘mainstreaming policy’, as well as concerted and unrelenting advocacy, several of the large psychiatric hospitals in NSW were closed including Australia’s first ‘asylum’ Gladesville Hospital (formerly Tarban Park) in 1993, and Callan Park, Rozelle in 2009. Ironically, several sites of former institutions are now used as University campuses such as the University of Western Sydney at Rydalmere and Sydney University’s College of the Arts is located in Kirkbride on the grounds of the former Rozelle Hospital.

Following the passing of the Commonwealth *Disability Services Act 1986*, each state was required to legislate around its own disability services. In NSW, legislation was passed namely the *Disability Services Act 1993* (NSW). The Principles of this Act stipulated that

(a) persons with disabilities are individuals who have the inherent right to respect for their human worth and dignity,

(b) persons with disabilities have the right to live in and be part of the community,

(c) persons with disabilities have the right to realise their individual capacities for physical, social, emotional and intellectual development,

(d) persons with disabilities have the same rights as other members of Australian society to services which will support their attaining a reasonable quality of life,

(e) persons with disabilities have the right to choose their own lifestyle and to have access to information, provided in a manner appropriate to their disability and cultural background, necessary to allow informed choice,

(f) persons with disabilities have the same right as other members of Australian society to participate in the decisions which affect their lives,

(g) persons with disabilities receiving services have the same right as other members of Australian society to receive those services in a manner which results in the least restriction of their rights and opportunities,

(h) persons with disabilities have the right to pursue any grievance in relation to services without fear of the services being discontinued or recrimination from service providers, and

(i) persons with disabilities have the right to protection from neglect, abuse and exploitation.

Following the passing of the *Disability Services Act 1993* (NSW) all funded services in NSW were required to conform to the above stated principles (Cocks and Stehlik 1996; Nicholls 1998).

In 1998 the NSW Audit Office and former Community Services Commission (now part of the NSW Ombudsman) conducted a review of all 'Large Residential Centres for people with disability in NSW' and recommended that all institutions be closed.

There are other factors which are inherent to institutional models of care that are difficult to remedy. These include the whole of life umbrella approach to the delivery of services, the custodial and impersonal nature of care, their segregation from the community, their inability to provide a homelike environment and their increased difficulty in meeting the physical, emotional, social and skill development needs of residents.

These features of institutional care mean that even if centres met the requirement of basic safety and rights, institutions could never meet the individual needs of people with a disability or provide the quality of life envisaged by the Disability Services Act 1993 (NSW Audit Office and Community Services Commission 1998, ix).

Following the release of this audit report, the NSW Government announced that all institutions for people with intellectual disability would be closed by 2010 (NSW Ombudsman 2010).

Despite the assurances of successive Ministers for Disability Services, and public policy commitments to deinstitutionalise and devolve institutions for people with intellectual disability, the majority of these institutions remain open and in fact under current NSW Government policy, some of them are being redeveloped as cluster houses (ADHC 2010; PWD 2009).

Implementation of deinstitutionalisation policy

Deinstitutionalisation is a subject that attracts few ‘fence sitters’. It has been and remains the subject of passionate debate. As a professional social worker, the researcher has been exposed to some of the differently positioned perspectives throughout practice³. “They should have never been let out,” exclaimed one community member, complaining about the noise and smells from his neighbour’s house. “It was a good idea but it is so hard on us. There is no help when he gets sick”, said a mother of a 45 year old man with mental illness. “People have the right to live in the community, but we need the resources to do our jobs and support people effectively”, said a community worker.

Central to any discussion about deinstitutionalisation is significant criticism about how the policy has been implemented (Scull 1977; Warner 1989; Gerrand 2005; Grob 1995; Emerson 2004a; Lamb and Bachrach 2001). Fundamentally, criticism is attributed to a lack of planning and preparedness for relocation into the community at both the individual and systemic level (Scull 1977; Warner 1989; Gerrand 2005; Grob 1995; Emerson 2004a; Lamb and Bachrach 2001). For people with intellectual disability, the opportunity to meet future housemates and visit their new home on several occasions before leaving the institution is often important to make meaning of such significant change (Johnson 1998; Mansell 2006; Bigby and Fyffe 2006). The provision of information about individual support needs is essential. Unfortunately, this does not always happen (Johnson 1998; Clement and Bigby 2009). For people with mental illness it can be important to provide support to access community based mental health services, apply for public housing or provide information about local support groups (Newton et al. 2000). Such strategies enable people to transition to the community and aim to minimise any negative impacts associated with such significant change, especially for people who have been living in an institution for an extended period of time (Bland et al. 2009; Richmond and Savy 2005).

³ Names have not been used to uphold confidentiality.

At the systemic level, the implementation of deinstitutionalisation policy in the USA, UK and Australia has also been heavily criticised. Central to these arguments is a belief that the service system was unprepared and certainly under-resourced for deinstitutionalisation (Warner 1989; Scull 1977; Bachrach 1996; Neilson 1990; Hudson 1991; Johnson 1990; Lerman 1982). There were significant delays in moving many of the resources and assets attached to institutions into the community and indeed some of them were never realised for their population groups (Warner 1989; Meadows et al. 2007). In order to adequately support a person's move into the community it requires an understanding of that person's support needs and, at a minimum, a replacement of the service types once provided in the institution (Neilson 1990). As institutions were closed or downsized and the residents moved into the community, many of the services they once received were disregarded or overlooked. While accommodation is an obvious service type provided by institutions, many residents were and continue to be 'discharged' without an appropriate accommodation option or place to call home (Neilson 1990).

For people with mental illness, the move from a psychiatric hospital into the community rarely involved a coordinated mental health plan or referral to appropriate community-based mental health services (Newton et al. 2000). Often people were required to rely on General Practitioners to monitor and manage the symptoms of their illness (Richmond and Savy 2005). The lack of appropriate and coordinated community-based mental health care services significantly compromised people's ability to remain in the community. This has contributed to re-admissions into institutions (Richmond and Savy 2005).

Within most institutions, physical health checks were conducted, at least annually, and some provided allied health services including physiotherapy, podiatry and speech pathology (Bailey and Sheehy 2009). Once in the community, the coordination of such services and health checks fell largely with the former resident or their family (Richmond and Savy 2005). The accessibility of these service types was further compromised by the subsequent decline in the number of specialist services for people with intellectual disability and people with mental illness (Bigby and Frawley 2010). The use of mainstream health services was challenging for people with intellectual disability and people with mental illness, their family and

carers and indeed health care workers who are untrained and unskilled in providing truly accessible services to these population groups (Richmond and Savy 2005; Bigby and Frawley 2010).

A significant systemic issue that was overlooked during the early phases of deinstitutionalisation was ‘awareness raising’ or the provision of information to community-based health and welfare professionals as well as the general community about intellectual disability and mental illness (Meadows et al. 2007; Richmond and Savy 2005). Given the long history of institutionalising people with intellectual disability and people with mental illness there was and remains, enormous stigma, fear and misinformation about what it means to live with these labels. The low-levels of

mental health literacy among police, ambulance officers, emergency workers, hospital orderlies, correctional officers, welfare workers and others’ remains a significant barrier to ‘community integration and participation’ and places people at risk of reinstitutionalisation (Richmond and Savy 2005, 221).

As Krieg (2001, 373) noted,

attitudes that the mentally ill confront in the community affect the extent to which deinstitutionalisation promotes freedom and liberty. In order for deinstitutionalisation to be successful, it must have community support.

Outcomes of deinstitutionalisation policy

The implementation of deinstitutionalisation policy in the USA, UK and Australia is associated with a range of outcomes for people with intellectual disability and people with mental illness. There have also been far-reaching effects on families, carers, advocates, health, welfare and housing providers, as well as the general community. For some people with intellectual disability and people with mental illness, the policy shift has resulted in the restoration of family relationships, a supported accommodation placement in the community, independence and skill development

(Kozma et al. 2009; Newton et al. 2000; Emerson 2004; Richmond and Savy 2005; Mansell 2006). For these people deinstitutionalisation has significantly improved their quality of life.

There has also been a range of outcomes that have adversely affected people with intellectual disability and people with mental illness, their families and carers. Some outcomes include homelessness, poverty, isolation, abuse, neglect, discrimination (e.g. not in my backyard- NIMBYism), high levels of representation in the criminal justice system and increase in carers' responsibilities (Robinson 2003; Warner 1989; Richmond and Savy 2005; Ellem and Wilson 2010).

Improvement in quality of life

For some people, deinstitutionalisation has enabled profound positive change and significant improvement in their quality of life (Emerson and Hatton 1996; Mansell 2006; Noonan Walsh 2008; Newton et al. 2000; Young et al. 1998). These people are generally those who have left institutions and returned to live in the community with family or in an alternate accommodation option with access to adequate support and health services (Kozma et al. 2009; Newton et al. 2000). Noting this, however, the lived experience of people with intellectual disability and people with mental illness must be respected. Indeed quality of life can be a subjective construct. Some people report improvements in their quality of life, 'a sense of freedom', 'choice', even though their circumstances do not indicate any positive change as recorded by various quality of life indicators or surveys such as the Lifestyle Satisfaction Scale (Heal and Chadsey-Rusch 1985) (Horan et al. 2001).

Whilst acknowledging the continuum of lived experiences, there are several areas whereby deinstitutionalisation has been associated with positive change. For example, Emerson (2004, 79) noted, that deinstitutionalisation

has been shown to be associated with a range of benefits for people with intellectual disabilities, including increases in satisfaction, social inclusion, engagement and support (although it appears to have little impact on levels of challenging behaviour).

Young et al. (1998, 166) reviewed several Australian studies of people with intellectual disability who experienced deinstitutionalisation and reported that the majority of studies demonstrated positive effects and that overall ‘community-based service models achieve better results for the people they serve than institutions’. These findings have been supported by other studies (including Kozma et al. 2009; Mansell and Beadle-Brown 2009; Kim et al. 2001; Larson and Lakin 1989; Emerson and Hatton 1996). These positive effects have included areas such as adaptive behaviour, community participation, client satisfaction and contact with family and friends. Further, the single most important determinant in terms of achieving positive outcomes for people following deinstitutionalisation is ‘the way staff provide support to the people they serve’ (Mansell 2006, 70; see also Emerson and Hatton 1996).

Newton et al.’s (2001) ethnographic study focussed on 40 people with mental illness that left an institution in Sydney and moved into the community. The study spanned two and a half years. The study showed, that

for those who remained in the community there was a significant improvement in psychiatric symptoms over two years, there was no significant change in neuroleptic medications and there was an increase in life satisfaction. There was no significant change in living skills, depressive symptoms, or social behavioural problems (Newton et al. 2001, 153).

Restoration of relationships

Living in an institution made it extremely difficult for many people with intellectual disability and people with mental illness to maintain relationships with family and friends (Johnson 1998). Even if the institution was accessible to family and friends, the physical environment, lack of privacy or space to entertain guests, as well as rigid routines did not always encourage ‘visitors’. For some people, the process of deinstitutionalisation has resulted in the restoration of significant relationships with family, friends, work colleagues and intimate partners. Many people who are now living in the community identified these relationships as a significant factor in the improvement of their quality of life following deinstitutionalisation (Newton 2001; Emerson 2004; Kozma et al. 2009; Noonan Walsh 2008).

Impact on carers

Notwithstanding the positive impact of deinstitutionalisation on the restoration of relationships, the impact on family and carers is marked yet has not always been accommodated in the design of policy (Browne and Bramston 1998; Cummins 2001; Marsh et al. 1996). During the first wave of deinstitutionalisation many people returned to live with their families (Bigby and Fyffe 2006; Richmond and Savy 2005). In some cases older parents have been caring for adult children with intellectual disability and mental illness for more than forty years (Jeon et al. 2006). The impact of caring responsibilities has been articulated through numerous inquiries, media stories and research (such as Groom et al. 2003; MHCA 2000). Being the primary caregiver for a person with intellectual disability or person with mental illness can have far-reaching effects. For some carers the experience includes isolation, considerable stress, physical and psychological exhaustion, violence and poverty as it can be extremely difficult to maintain paid work when providing full-time care (Brown and Brumstom 1998; Jeon et al. 2006; Marsh et al. 1996). As Torrey (2006, 156) commented,

family members, especially mothers, are often expected to simultaneously be the person's case manager, psychotherapist, nurse, landlord, banker, janitor, cook, disciplinarians and best friend.

Increasingly, carers of people with intellectual disability and people with mental illness express ongoing frustration about their inability to access and navigate the service system in order to 'get any help' (MHCA 2000; Jeon 2006; Richmond and Savy 2005; NSW Ombudsman 2010). Has the 'front door policy' or commitment to 'non-institutionalisation' gone too far? Parents, who visit their children in prison following numerous attempts to secure mental health care and intervention, might reasonably form this view (Butler and Allnutt 2003). Older parents who are unable to secure supported accommodation for their adult child with intellectual disability may also agree (NSW Ombudsman 2010).

Re-institutionalisation and transinstitutionalisation

Central to deinstitutionalisation policy and discourse is a belief that ‘total institutions’ (Goffman 1961) are an inappropriate accommodation, support and long-term option for people with intellectual disability and people with mental illness. An obvious and important part of implementing this policy has been the closure and downsizing of large, congregate, geographically isolated institutions (Richmond and Savy 2005; Emerson 2004; Grob 1995; Warner 1989; Jones 1993; Scull 1977). There has been a dramatic decline in such institutions globally. However, as Johnson and Marriott (2009, 285) outlined

the question of what constitutes a ‘public institution’ remains a contested one, with some people arguing that institutions are frames of reference, attitudes and values and practices which can be present in community living, while others define an institution more concretely as an establishment in which more than 30 people lived, of whom at least 80% were mentally or physically disabled.

The first wave of deinstitutionalisation in the 1960’s and 1970’s (Bigby and Fyffe 2006) tended to focus on the second part of Johnson and Marriott’s (2009) definition of an institution. While there were certainly examples of people returning to live with family, independent accommodation options through government housing and some supported accommodation provided by community organisations, the overwhelming majority of people leaving institutions during the first wave of deinstitutionalisation moved into boarding houses, nursing homes, large residential homes or cluster-housing (Greenhalgh et al. 2004; Bostock et al. 2001; Bigby and Fyffe 2006; Emerson 2004; Warner 1989; Scull 1977). Even though these accommodation models were generally located in the community, the practices and cultures of large institutions were present including congregate care, regimentation and material deprivation. While noting that these accommodation options were cultivated almost half a century ago during the first wave of deinstitutionalisation, they remain both an existing and emerging model of ‘supported accommodation’, almost untouched by the radical ideological, legislative and policy changes that have occurred over the past fifty years (Harris 2007).

These accommodation options constitute transinstitutionalisation which is the process of moving people with intellectual disability and people with mental illness from large-scale, geographically isolated institutions without adequate support and then entering other types of institutions including nursing homes, boarding houses, homeless accommodation services and correctional facilities (Bostock et al. 2001; Kelly and McKenna 2004; Hudson 1991; Chenoweth 2000). The use of licensed boarding houses as a form of transinstitutionalisation will be discussed in detail in the following chapters.

The second wave of deinstitutionalisation in the 1980's and 1990's (Bigby and Fyffe 2006) was heavily influenced by normalisation theory and largely enabled by legislative and administrative change including the provision of funding for community organisations to provide accommodation support (Cocks and Stehlik 1996; Bigby and Frawley 2010). The dominant model was the group home whereby a small group of between three and seven people with disability lived together in a residential home in suburban neighbourhoods (Emerson 2004).

The third wave of deinstitutionalisation focused on 'rights, citizenship and increased control for people with disabilities over their own life' (Bigby and Fyffe 2006, 568). Individualised payments and accommodation options based on supported living such as the HASI model in NSW are indicative of this wave (NSW Health 2007).

Cluster-housing

The use of 'cluster-housing' or 'campus-style facilities' is a re-emerging model that has brought about significant debate especially among people with intellectual disability, parents, advocacy organisations and disability administrators (Mansell and Beadle-Brown 2009; Emerson 2004; DADHC 2009; PWD 2009). These types of accommodation options often involve the refurbishment of institutions or new developments on the institution's existing site. This means that some redevelopments remain geographically isolated and segregated. For example, residents move from the main institution to smaller 'units' of about twenty people on the existing site. As noted by Emerson, 'a number of commentators have suggested that deinstitutionalisation has proven a failure and argued instead for the creation of

cluster or campus-type living arrangements for adults with intellectual disabilities' (2004, 118). These claims tend to focus around quality of life issues including choice, social relationships and some health indicators (Emerson 2004).

In Emerson's (2004, 192-195) study 'Cluster housing for adults with intellectual disability' he found, that

people supported in cluster housing were more likely to live in larger settings, be supported by fewer staff, be exposed to greater changes or inconsistencies in 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.

Some of the strongest advocates for 'cluster housing' or 'campus-style' models are parents of people with intellectual disability (Bostock et al. 2001). Parents have formed such beliefs after witnessing some of the negative outcomes of deinstitutionalisation. A parent whose adult child remains in institutional care is likely to experience great anxiety about what might happen following institutional closure or relocation to the community. Some families have long-standing relationships with staff and residents of institutions and others have also made significant financial contributions (NSW Ombudsman 2010). Their connection is strong, and for some families, they have been involved with the institution for more than fifty years. The long waiting lists for supported accommodation placements, considerable levels of unmet need are of particular concern, especially for older parents who are usually required to 'fill the gaps' in care services (NSW Ombudsman 2010).

In NSW, the Human Services Agency Ageing Disability and Home Care (ADHC) is progressing plans to redevelop institutions as well as developing cluster-houses on existing sites. These developments contradict earlier commitments made by successive NSW Ministers for Disability Services who committed to the closure of these institutions. In 2009, People with Disability Australia (PWD), a national

advocacy organisation, mounted a legal challenge about the development of cluster-housing and the redevelopment of institutions in NSW. PWD maintained, that

these and other related developments represent the most regressive disability policy to emerge in Australia in 30 years... (They) represent a violation of the human rights of persons with disability, and they are contrary to the requirements of the Disability Services Act 1993 (NSW) (PWD 2009, 2).

Furthermore, PWD argued, that such accommodation models did not uphold the ‘United Nations Convention on the Rights of Persons with Disabilities (CRPD), which was signed by the Australian Government in 2007’ (PWD 2007, 3).

Specifically, the CRPD Article 19, ‘living independently and being included in the community’, states:

Parties to this Convention recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a. persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.*
- b. persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.*
- c. community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

The matter commenced in the NSW Administrative Decisions Tribunal (ADT) in 2010 and the outcome is unknown at the time of thesis submission. PWD's application to the ADT

formally seek(s) a review of the Minister's decision to continue to operate the Grosvenor, Lachlan and Peat Island Centres (large, geographically isolated institutions for people with intellectual disability) contrary to the requirements of the DSA (NSW) (PWD 2009, 2).

Group homes

The second wave of deinstitutionalisation concentrated on the use of dispersed housing options, predominantly group homes, and is still largely the 'blueprint for housing provision' especially for people with intellectual disability (Bostock et al. 2004). This model is based on 'small residential homes located in suburban neighbourhoods' (Bostock et al. 2004, 5) or 'ordinary domestic living' (Emerson 2004, 80). Group homes generally accommodate between three and seven people with disability and are supported by staff (Emerson and Hatton 1996). While group homes are located in the community and have significantly fewer people living together compared with segregated institutions, the appropriateness of the model has been questioned.

Bostock et al. (2004, 9) noted, that

the group home has been categorised by some critics-including disability advocates- as a 'mini institution' that has transported institutional practices and structures to community settings.

The description of group homes as mini-institutions challenges the belief that deinstitutionalisation is simply about being located in the community and the number of people living together. In some group homes staff dictate the time residents wake up and go to bed, what and when residents will eat and the activities of the day (NSW Ombudsman 2004; NSW Audit Office and Community Services Commission

1998). Not surprisingly, these activities coincide with staff rosters, which upholds Goffman's belief about total institutions running for the convenience of staff (1961). The lack of autonomy, regimentation and deprivation in these group homes certainly replicates the practices and structures of large, segregated institutions (Emerson 2004).

Emerson and Hatton's (1996, 69) study of people with intellectual disability accessing various accommodation options showed, that

staffed housing achieves better results than small institutions, which in turn achieves better results than large institutions. However, the considerable overlap in the ranges of scores indicates that better large institutions can produce outcomes as good as weaker smaller settings; and that better smaller institutions can achieve outcomes as good as weaker staffed housing.

From Emerson and Hatton's (1996) study one can assert that while the number of people living together is significant, the values and attitudes of staff working in supported accommodation certainly influences the outcomes for people with intellectual disability.

Others have argued, that the group home model is based on formulaic budgetary processes, assessment and classification and 'vacancy matching' (Bostock et al. 2004). This means that people with intellectual disability and people with mental illness infrequently exercise choice about where they live and whom they live with. Focussing on people with intellectual disability, Bostock et al. (2004, 5) maintained, that

most people with learning disabilities have not had the chance to choose the kind of house they live in, the people they live with, how they are supported or whom they are supported by. If people do have a choice, then it is...between different residential care homes that happen to have a vacancy.

Mainstreaming in general hospitals

Following the closure or downsizing of stand-alone, geographically isolated psychiatric hospitals, 'acute' services for people with mental illness were relocated to wards in general hospitals, referred to as mainstreaming (Carter et al. 2008). Some have argued that these wards operate as 'mini institutions' replicating the regimentation and routine of former institutions and often employ the use of 'chemical restraint' (Richmond and Savy 2005; Cook and Wright 1995).

Criminal Justice System

The high percentage of people with intellectual disability and people with mental illness in the criminal justice system is often attributed to deinstitutionalisation and inadequate resourcing (White and Whiteford 2006; Butler and Allnutt 2003; Priebe and Turner 2003; Riches et al. 2006; Ellem and Wilson 2010). It is believed that the closure of institutions and the lack of appropriate and coordinated community-based support has resulted in a process of transinstitutionalisation whereby a significant number of people with intellectual disability and people with mental illness are now detained in 'forensic beds' and prisons. According to White and Whiteford (2006, 302)

Australian and New Zealand studies have shown that many people involved with the criminal justice system have had psychiatric contact before entering the system. Prevalence rates for all psychiatric morbidities in the prison population are markedly higher than rates in community samples.

Riches et al. (2006, 388) focussed on people with intellectual disability in the NSW criminal justice system and noted, that of the prevalence studies conducted in Australia between 3.6 and 20 percent of inmates were assessed as

functioning either within the intellectual disability or borderline disability range...Given that the prevalence of intellectual disability in the Australian general community has been estimated at approximately 1.85%, collectively,

these data do point to a significant over-representation of people with intellectual disabilities in correctional facilities, particularly in NSW.

There are many reasons for the over-representation of people with intellectual disability and people with mental illness involved with the criminal justice system. Some of these include, the high representation of these groups of people among the homeless community where people are highly visible and therefore more closely scrutinised. The low level of understanding about disability and mental illness among police and other law enforcers compounds these issues further (Richmond and Savy 2005).

Despite general acceptance of the over-representation of people with intellectual disability and people with mental illness involved with the criminal justice system, the role of deinstitutionalisation, especially a causal relationship, has been questioned. Henderson (2005, 9) maintained, that

deinstitutionalisation is considered by some people within the mental health lobby to be responsible for the high prevalence of people with mental illness in prison... However, ...this perspective overlooks an alternative explanation, that people with mental illness present other risk factors of higher risk for imprisonment, such as substance abuse, unemployment, poor education and low income. The confounding role of such evidence was recently demonstrated in an Australian study that showed increased rates of inmates with schizophrenia since deinstitutionalisation paralleled by increased rates of imprisonment across the general population.

Homelessness

One of the main outcomes attributed to deinstitutionalisation is an increase in the representation of people with intellectual disability and people with mental illness among the homeless population. This research applies the three-tiered 'cultural definition of homelessness' as described by Chamberlain and MacKenzie (1992, 8).

Primary homelessness: people without conventional accommodation: living on the streets, in deserted buildings, in cars, under bridges and in improvised dwellings.

Secondary homelessness: people moving between various forms of temporary shelter, including friends, relatives, emergency accommodation and boarding houses.

Tertiary homelessness: people living in single rooms in private boarding houses on a long-term basis: without their own bedroom, kitchen or security of tenure.

The over-representation of people with mental illness among homeless people has occurred cross-nationally and is subject of numerous studies, reports and media stories (Meadows et al. 2007; Warner 1989; Grob 1995; Mechanic 1989). It is argued, that inadequate planning and lack of community-based accommodation, health and support services has resulted in many people, particularly people with mental illness, becoming homeless (Grob 1995; Warner 1989). The trajectories in and out of homelessness are varied (Robinson 2003). Some people are homeless after they are exited from accommodation services due to ‘challenging behaviours’. Some are unable to maintain their tenancy due to an episode of illness or poverty. For others, family and friends have exhausted their ability to provide ongoing care and support. Increasingly, there are compounding barriers to stable accommodation for people with mental illness who also have substance use issues (Robinson 2003).

There is general agreement within the literature regarding this over-representation, however ‘there is considerable debate as to the extent of the problem’ (Johnson and Chamberlain 2009, 2). A recent Australian study conducted by Johnson and Chamberlain (2009), ‘Are the Homeless Mentally Ill?’ considered to what extent people had a ‘mental health issue’ prior to becoming homeless and what proportion of the homeless population developed a ‘mental health issue’ following homelessness. Johnson and Chamberlain noted that previous studies indicated up to 82% of the homeless population had a mental illness. They argued, that the figure of 82% was probably inflated due to definitions of what constituted a mental health

issue such as defining substance abuse as the consumption of ‘more than 12 standard alcoholic drinks in any one year’ (Johnson and Chamberlain 2009, 4). Johnson and Chamberlain’s (2009) study found that the number of people with mental illness as a proportion of the homeless population was closer to 30%. Whilst noting the significance of these findings and the divergent figures of studies in this area ranging from 30-80%, the fact that one in five Australians live with mental illness (Australian Bureau of Statistics 2008) upholds the claim that people with mental illness are over-represented in the homeless population.

Homelessness has gathered increased attention in Australia following the election of the Labor Government in 2007. Honouring an election commitment to reduce homelessness, the former Prime Minister Kevin Rudd released a white paper ‘The Road Home’ in 2008. This paper outlined a strategy to halve homelessness by 2020 (Australian Government 2008). Within this paper the over-representation of people with mental illness within the homeless population is acknowledged (Australian Government 2008). In order to achieve the goal of halving homelessness additional funding and programs will be established to prevent people becoming homeless including a ‘no exit into homelessness’ strategy for people with mental illness (Australian Government 2008).

Fiscal efficiencies

One of the main catalysts for deinstitutionalisation was the rising costs of hospital-based care. Newton et al. (2001, 152) maintained that

reactions against institutionalisation arose out of a recurrent lack of funds to provide adequate and humane care for an increasing inpatient population, along with a growing awareness of decaying facilities in need of upgrading, repair, and replacement.

It was believed that through the closure of stand-alone institutions and relocation of people and services to the community, significant cost savings could be realised (Scull 1977; Meadows et al. 2007; Mechanic 1969). This assumption gained momentum over the staged implementation of deinstitutionalisation policy. Cost

savings and cost containment became the rhetoric of the 1980's with the shrinking of the welfare state and government intervention under the banner of neo-liberalism (Henderson 2005).

It is now half a century since the beginnings of deinstitutionalisation. The questions concerning cost savings and provision of cheap community-based services remain difficult to answer with any certainty. Lapsley et al.'s (2001, 153) study of 40 people with mental illness leaving an institution and relocating to the community concluded that 'community care was found to be half to a third more cost effective than institutional care'. Noting these findings, Lapsley et al. (2001) acknowledged that some costs are not always visible in the community. For example, some service costs in the community are absorbed by Medicare or other universal healthcare schemes and the participants in Lapsley et al.'s (2001, 494) study did 'not necessarily accurately reflect the total population of (the) hospital's patients, as the most chronic patients were less likely to be discharged'. Similarly, Bachrach and Lamb (2002, 8) noted that

we have also begun to understand that if all the hidden costs associated with responsible programming are considered, it is generally not accurate to conclude that community services will result in substantial savings over hospital care.

Conclusion

Chapter Two has considered the impact of deinstitutionalisation discourse in shaping mental health and intellectual disability legislation, policy and practice. It has provided an overview of some of the factors that influenced the implementation of deinstitutionalisation policy in New South Wales including the Richmond Report, Burdekin Inquiry, the introduction of the *Disability Services Act 1986* (Cth) and subsequent *Disability Services Act 1993* (NSW). While there has never been a national deinstitutionalisation framework, the National Mental Health Plans and National Disability Agreements (formerly the CSTDA), have all been underpinned by the principles of deinstitutionalisation.

The implementation of deinstitutionalisation is associated with a range of outcomes for people with intellectual disability and people with mental illness. Some of these included significant improvements in quality of life domains, impact on carers, mainstreaming of acute hospital services, homelessness and a range of options described as transinstitutionalisation (Emerson 2004; Newton et al. 2000; Ellem and Wilson 2010; Bostock et al. 2004).

Chapters One and Two have provided the context for this research in locating the accommodation of people with intellectual disability and people with mental illness in licensed boarding houses in Inner Sydney as a form of transinstitutionalisation.

Chapter Three: Licensed boarding houses in NSW

This chapter explores the use of licensed boarding houses (known as licensed residential centres or LRC's in NSW) as an accommodation option for people with intellectual disability and people with mental illness. It considers the role of LRC's in the provision of low-cost accommodation and the sustainability and viability of this sector. It also details the licensing and oversight framework that operates in NSW.

For the long-term hospitalised patient, the move is usually into a boarding home facility...where little effort is directed towards social and vocational rehabilitation. In practice it is only an illusion that patients who are placed in boarding or family-care homes are "in the community"... These facilities are for the most part like small long-term state hospital wards isolated from the community. One is overcome by the depressing atmosphere, not because of the physical appearance of the boarding home, but because of the passivity, isolation and inactivity of the residents (Scull 1977, 102).

Boarding houses as an accommodation option for people leaving institutions

The resident profile of boarding houses has witnessed a marked shift since the 1960's. Historically, boarding houses were used by 'country folk' for the purpose of 'a temporary but nonetheless respectable form of housing for people visiting the city for work or on holiday' (HREOC 1993, 386). However, during the initial phase of deinstitutionalisation in the 1960's and 1970's there were significant changes in the role of boarding houses. Boarding house proprietors responding to 'market forces' identified the need for low-cost, community-based accommodation for people leaving institutions. The use of boarding houses as an accommodation option for people with intellectual disability and people with mental illness has occurred around

the globe, notably in England, the USA and Australia (Greenhalgh et al. 2004; Scull 1977; Jones 1993; Mechanic 1992). The most significant use of boarding houses as an accommodation option following deinstitutionalisation occurred in the USA. This is mainly attributed to the large numbers of former residents of institutions, as well as the rapid and unplanned nature of deinstitutionalisation in the USA (Warner 1989; Mechanic 1992; Grob 1991). Scull (1977, 102) was scathing about the use of boarding houses for people leaving psychiatric institutions.

Overall, there has been no adequate licensing supervision or inspection of board and care facilities for released mental patients; and no effort has been made to avoid their “ghettoization” in the poorest, least desirable of neighbourhoods. And in the absence of adequate after-care and rehabilitation services, the term community care remained merely an inflated catch-phrase which concealed morbidity in the patients and distress in the relatives. As a natural consequence, one form of confinement has replaced another, and the former patients are just as insulated from community attention and care as they were in the state hospital.

Scull (1977) highlighted the fundamental criticisms of deinstitutionalisation policy including the lack of resources, planning and preparedness for relocation into the community. This lack of foresight and coordination resulted in many people having limited or no choice about the type of accommodation they moved to; seemingly policy makers had overlooked the role of accommodation that institutions once played (Neilson 1990; Scull 1977; Johnson 1990; Warner 1989; Stroman 1993; Grob 1991). Wards were closed down and many ‘patients’ were transported by the hospital authorities to boarding houses where institutionalised routines and practices were reproduced in the community.

What is a boarding house?

The definition of what constitutes a boarding house differs significantly within Australia as well as internationally. These variations are found across jurisdictions, in legislation and policy. Boarding houses can be referred to as rooming houses,

hostels, a boarding home facility or lodging house. This has obvious limitations for cross-national and national policy analysis (Greenhalgh et al. 2004).

Beyond definitional variations of what constitutes a boarding house are some commonalities. Greenhalgh et al. (2004, 3) established the following 'key attributes' of a boarding house. It is the principal place of residence for the resident; the resident has the right to occupy a room but not the whole premises; and shared facilities, such as bathroom, kitchen and laundry.

Further to Greenhalgh et al.'s (2004) key attributes, boarding houses are fundamentally private-for-profit businesses that provide low-cost accommodation. This accommodation option is characterised by congregate living, which can include dormitory style rooms. Boarding houses are often run-down buildings, which require significant repair and refurbishment (Greenhalgh et al. 2004; Davidson et al. 1997). They can also provide additional services including meals, general cleaning and a laundry service. Depending on the type of boarding house and whether or not it is subject to licence conditions, there may also be an onsite manager or proprietor.

Under NSW legislation boarding house residents do not have security of tenure or tenancy rights (Harris 2007). This means that residents can be evicted without notice, their rent increased at any time and they have no avenue for raising or resolving disputes. The NSW Department of Fair Trading is currently reviewing the exclusion of boarders and lodgers from the *Residential Tenancies Act 1987* (NSW) at October 2010.

Within the Australian context, many commentators have described boarding houses as a type of homelessness. Tertiary homelessness is defined as people living in 'private boarding houses, without their own bathroom, kitchen or security of tenure' (Chamberlain and MacKenzie 1992, 291).

Who lives in boarding houses?

The profile of boarding house residents changed significantly following the implementation of deinstitutionalisation policy in the early 1960's and 1970's

(Greenhalgh et al. 2004). From this time boarding houses emerged as an accommodation option for people with intellectual disability and people with mental illness who had previously lived in psychiatric hospitals or institutions for ‘the mentally retarded’ (HREOC 1993; Neilson 1990).

In 2006 (the latest census data available) there were 21,596 people living in boarding houses in Australia (Chamberlain and MacKenzie 2009, 247). Of these, 7,626 people lived in NSW representing 28% (a reduction of 1% from 2001 census data) of the homeless population for the state (compared with 20% nationally) (Chamberlain and MacKenzie 2009, 28). According to Chamberlain and MacKenzie (2008) 70% of boarding house residents live in capital cities.

Increasingly, the resident profile of boarding houses also includes people who are unable to access alternative low-cost housing and experience ‘multiple disadvantages’ (NSW Ombudsman 2006; Greenhalgh et al. 2004). This can be due to a number of factors including poverty, substance use, a criminal record or a lack of alternative low cost housing availability. The intersection of such factors compounds people’s experience of social exclusion.

Overwhelmingly, the majority of boarding house residents are male (Chamberlain and MacKenzie 2009). In NSW, 72% of boarding house residents are male and this is consistent with national figures (Chamberlain and MacKenzie 2009, 31). Most boarding house residents are single and the median age is 45 years (Horan et al. 2001, Davidson et al. 1997). However, the number of younger people including younger women is increasing (ADHC 2010). This is attributed to the squeeze on other sectors including services funded under the National Affordable Housing Agreement (formerly the Supported Accommodation Assistance Program) and increased demand for social housing (Australian Government 2008; Greenhalgh et al. 2004).

Most boarding house residents have a low income with many receiving unemployment benefits or a disability support pension (Davidson et al. 1999). Some boarding houses, in particular boarding houses where meals and laundering services may be provided, are able to charge up to one hundred percent of a person’s pension

(Harris 2007). This impacts significantly on a person's ability to leave the boarding house or access other services (Edwards and Fisher 2010).

The boarding house population is often described as transient (Davidson et al. 1997). This can be attributed to factors such as lack of security of tenure, costs associated with substance use and subsequent inability to pay fees, as well as reasons associated with mental illness including hospitalisation (Greenhalgh et al. 2004; Davidson et al. 1997; Merton et al. 2007).

The health status of long-term residents of boarding houses is generally poor (NSW Ombudsman 2006; Bailey and Sheehy 2009). There are many reasons why this is the case. Some residents are older people who experience an increased risk of illness such as diabetes. Poor health outcomes are also associated with the co-morbidity of mental illness and drug or alcohol use (Bailey and Sheehy 2009). People living in boarding houses are generally not involved with preventative or screening programs such as cervical, breast or prostate screening checks.

Boarding houses as a low-cost accommodation option

Boarding houses play a significant role in the provision of private low-cost accommodation nationally and internationally, even though boarding houses are often described as an option of last resort (Greenhalgh et al. 2004). The role of boarding houses is significant as it interfaces and interacts with (and arguably often replaces) disability and mental health service systems, homeless services including services funded under the National Affordable Housing Agreement and the public and private housing rental markets (HREOC 1993; Greenhalgh et al. 2004; Bostock et al. 2004).

The Australian Housing and Urban Research Institute (AHURI) conducted a study in 2004 into *Boarding Houses and Government Supply Side Intervention* (Greenhalgh et al. 2004). The study focussed on unlicensed boarding houses and found that 'there have been substantial declines in the numbers of boarding houses in some Australian states' (Greenhalgh et al. 2004, 2). This study found that there were a number of factors that contributed to boarding house decline including gentrification,

'increasing number of residents with complex needs, the introduction of the Goods and Services Tax (GST), insurance, viability, compliance with new regulations, and awareness of rebates and grants' (Greenhalgh et al. 2004, 12). Furthermore, many boarding houses have historically been family-run businesses and a significant number of proprietors are ageing.

The decline of boarding house stock in NSW has been substantial over the last twenty years, most notably in Inner Sydney (Davidson et al. 1997; Greenhalgh et al. 2004). The gentrification of Inner Sydney has meant that selling or converting boarding houses into alternative accommodation types has proved more profitable for many proprietors. Davidson et al. (1997, 15) found that

of the stock loss of 521 dwellings in Inner Sydney, the majority were converted to flats (51 per cent) or private residences (23 per cent). The remainder were converted to short-term tourist accommodation and some to student accommodation.

Against this background, it is apparent that the maintenance of the boarding house sector is an important policy issue for all levels of government. The role of low-cost housing is increasingly crucial as the rate of home ownership has decreased and the cost of private housing rental has risen (Australian Government 2008). These factors have a trickle down effect and impact upon the availability of public and social housing. This means that the demand for low-cost housing has increased at a time when this type of stock is decreasing (Australian Government 2008).

The decline of boarding house stock has far reaching effects at the individual and systemic level. For individuals who require access to low-cost accommodation, the decline in boarding house stock may lead to secondary or primary homelessness (Greenhalgh et al. 2004; Chamberlain and MacKenzie 2009). At the systemic level ongoing boarding house decline will require considerable government investment in social housing as well as various health and welfare services. The impact is also felt by the crisis accommodation sector.

The loss of boarding houses creates two problems for the crisis sector. First, there are fewer options available for crisis housing. Second, the decline of boarding houses creates further demand for crisis accommodation (Greenhalgh et al. 2004, 4).

Various levels of government have introduced targeted strategies to reduce the decline of boarding house stock (Greenhalgh et al. 2004). In NSW the State Government has introduced Land Tax Exemptions, financial assistance to comply with fire safety regulations and planning mechanisms (for example, SEPP 10) to retain low cost rental accommodation (Davidson et al. 1999). Such strategies have achieved varying success. Davidson et al. (1999) noted that proprietor's awareness of schemes such as tax exemptions and financial assistance to comply with fire safety regulations was generally low.

Compounding the issue of boarding house decline is the lack of new investment into the sector (Greenhalgh et al. 2004). The profitability of boarding houses is a problematic issue hotly contested by differently positioned proprietors, residents, government agencies and advocates. Profit is obviously influenced by the service type provided, occupancy rates, resident numbers and the requirements of specific regulations such as whether the boarding house requires licensing. The majority of boarding houses are old, run-down buildings requiring capital investment to meet even the most basic building, planning and fire safety standards (Greenhalgh et al. 2004; Allen Consulting Group 2003; Davidson 1999). The costs associated with meeting these requirements can be unattractive to new investors seeking profit in boarding houses.

What are the differences between licensed and unlicensed boarding houses?

Within some jurisdictions boarding houses can be subject to specific regulation, legislation and licensing requirements (Greenhalgh et al. 2004). While there is no national policy framework relating to the role of boarding houses in providing low-cost accommodation for people with intellectual disability or people with mental illness, several states have introduced such measures. For example NSW has 'Licensed Residential Centres', Queensland has 'Supported Accommodation', South

Australia has ‘Supported Residential Facilities’, and Victoria has ‘Supported Residential Services’.

These various licensing regimes were introduced in response to numerous reports, inquiries, Royal Commissions and media accounts identifying serious concerns regarding the practices and treatment of boarding house residents (NSW Ombudsman 2006; NSW Government 1993). Some of the concerns reported included financial exploitation, malnutrition, neglect, abuse and physical and sexual assault (HREOC 1993; NSW Government 1993; NSW Ombudsman 2006). The various licensing regimes require boarding house proprietors to provide additional services that may not be provided in unlicensed premises. These services generally include the provision of meals, laundering, personal care and medication management (Greenhalgh et al. 2004). Licences can also stipulate physical requirements of the building, determine how many people can share a room and outline other issues relating to residents’ health and welfare (ADHC 2010). There is usually an eligibility screening process for service entry.

Overwhelmingly the majority of people living in licensed boarding houses are people with mental illness (Chamberlain and MacKenzie 2009; Australian Bureau of Statistics 2008; Edwards and Fisher 2010). While a number of people with mental illness moved to their current licensed boarding house during the first wave of deinstitutionalisation, LRC’s are not an artefact of the 1970’s. Licensed boarding houses remain an active referral agent for people with mental illness leaving hospital, people leaving crisis accommodation and people who have been exited from other accommodation such as group homes because of ‘challenging behaviour’. There are many reasons that preclude people with mental illness accessing alternate accommodation including poverty, episodes of illness that disrupt tenancy and a lack of low-cost housing availability (Merton et al. 2007). While there are some programs such as HASI in NSW that seek to address these issues, people living in licensed boarding houses are currently ineligible for the HASI program as they are not considered to be living in an institution, homeless or at risk of homelessness (NSW Health 2007).

The other significant population group of licensed boarding houses is people with intellectual disability (The Allen Consulting Group 2003; Edwards and Fisher 2010). People with intellectual disability living in licensed boarding houses tend to be people who are labelled as having mild or borderline intellectual disability. Living with the label of mild or borderline intellectual disability precludes access to 24-hour accommodation support, which is targeted at people who are labelled as having moderate to high support needs (ADHC 2009). The ambiguity of ‘handicapped person’ as defined by the YACS Act and the inadequate monitoring of residents’ changing support needs means that some people with intellectual disability living in LRC’s are indeed eligible for 24-hour accommodation support (NSW Ombudsman 2006).

The population of LRC’s is largely male with men comprising 72% of licensed boarding house residents in New South Wales, which is consistent with national figures for the unlicensed sector (Edwards and Fisher 2010; Chamberlain and MacKenzie 2009). The average age of licensed boarding house residents is 55 years, which is significantly older than the unlicensed sector, which is 45 years (Edwards and Fisher 2010; Horan et al. 2001; Davidson et al. 1997). However, there are some data limitations concerning the number of residents with intellectual disability and mental illness within the boarding house sector. These limitations relate to the inability or unwillingness of unlicensed boarding house proprietors to identify residents with disability or mental illness (NSW Ombudsman 2006). In jurisdictions that require licences to accommodate people with disability (for example, the YACS Act in NSW requires a proprietor to have a licence if the boarding house accommodates more than two people with ‘handicap’ and that persons requires social habilitation) the proprietor may deliberately misrepresent their resident profile. A person with disability or mental illness may also choose not to disclose their disability or illness for reporting purposes (Edwards and Fisher 2010).

Residents of licensed boarding houses are generally less transient than unlicensed boarding houses, with many people residing in the boarding house for several decades following deinstitutionalisation (Allen Consulting Group 2003; Edwards and Fisher 2010; Harris 2007). However, this trend is starting to shift with younger people accessing this service type and high mortality rates among the ageing

population of many licensed boarding house residents (NSW Ombudsman 2008; Edwards and Fisher 2010). This is compounded by the lack of alternative low-cost housing available (Yates and Milligan 2007).

The NSW licensed boarding house sector

The NSW licensed boarding house sector developed from the 1970's following the implementation of deinstitutionalisation policy in the 1960's (Harris 2007; Allen Consulting Group 2003). This sector derived most of its initial clientele from 'Schedule V' hospitals. Following the closure or downsizing of wards, many former patients were moved to private, for-profit boarding houses 'in the community'.

Several of the boarding house proprietors (especially in Inner Sydney) are psychiatric nurses who previously worked in the 'Schedule V' hospitals (Harris 2007). These 'entrepreneurial psychiatric nurses' were well informed about the implementation of deinstitutionalisation and identified a niche market to populate their for-profit boarding house (Harris 2007). Charging residents up to one hundred percent of their pension meant a steady and reliable income (Harris 2007). Noting the skills and experience of the proprietors who are psychiatric nurses there are concerns about the currency of their knowledge and practices (NSW Ombudsman 2006). It is clear from many of the licensed boarding houses in Inner Sydney that proprietors have not updated their skills and that practices which were used forty years ago in the 'Schedule V' hospitals have been transported with the former patients to the boarding house (Harris 1997).

Sustainability and viability of the licensed boarding house sector

There has been a significant decline in licensed boarding houses since 1994 (ADHC 2010). Several boarding houses were closed under the Ageing and Disability Department's licensing team of the 1990's (Allen Consulting Group 2003). The proprietors of these boarding houses had consistently breached licence conditions and subsequently their licences were revoked (Harris 2007). Some boarding house proprietors withdrew from the market at this time as their business was no longer viable and they considered the new requirements and standards expected by the

department to be unreasonable and unworkable without government funding (Allen Consulting Group 2003). Many of the proprietors of licensed boarding houses in NSW are older people who will look to retire over the next decade and reap the rewards of Inner Sydney's gentrification and booming house prices (Greenhalgh et al. 2004). In some cases the requirements of certain licence types prevent proprietors from selling their businesses with a licence (NSW Ombudsman 2006; ADHC 2010). New proprietors would need to apply for their own licence, which would require physical changes and upgrades to meet new licence conditions. The decline in licensed boarding houses is also related to an increase in illegal operators (NSW Ombudsman 2006; Allen Consulting Group 2003; Alt Beatty Consulting 2001; Greenhalgh et al. 2004). Many unlicensed boarding houses accommodate more than two people with intellectual disability or people with mental illness (Newtown Neighbourhood Centre 2003). This may be because the proprietor is unaware of the requirements of the YACS Act or knowingly evades the licensing regime. The absence of a coordinated monitoring system exacerbates and enables this problem (NSW Ombudsman 2006).

According to the ADHC (2010), there were 194 licensed boarding houses in New South Wales in 1994, which provided approximately 3,336 beds (Figures 1 and 2). Some fifteen years later the licensed boarding house sector had declined to 39 boarding houses providing 781 beds (ADHC 2010). The licensed boarding house sector currently comprises 21 licensees. There has only been one new application for a licence since 2005 (ADHC 2010).

Figure 1: Number of Licensed Residential Centres in NSW

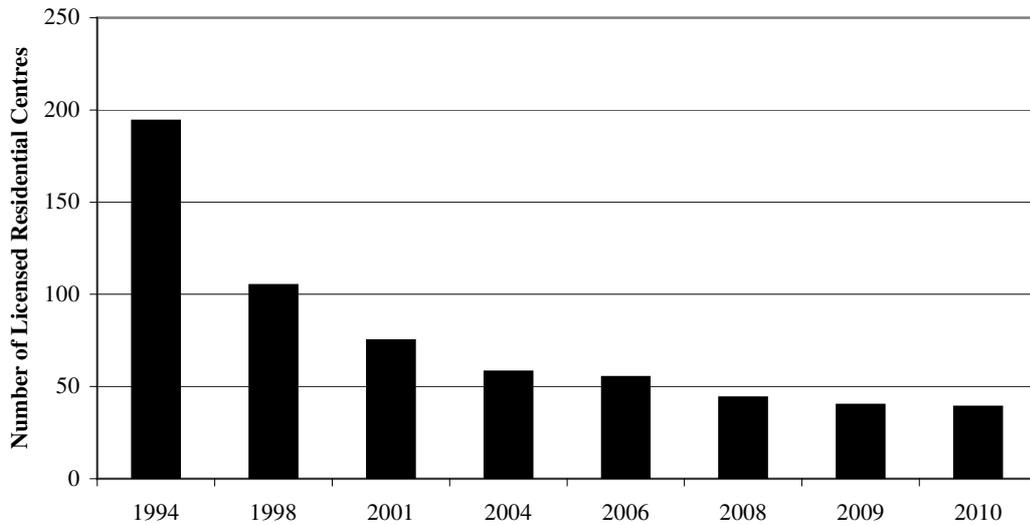
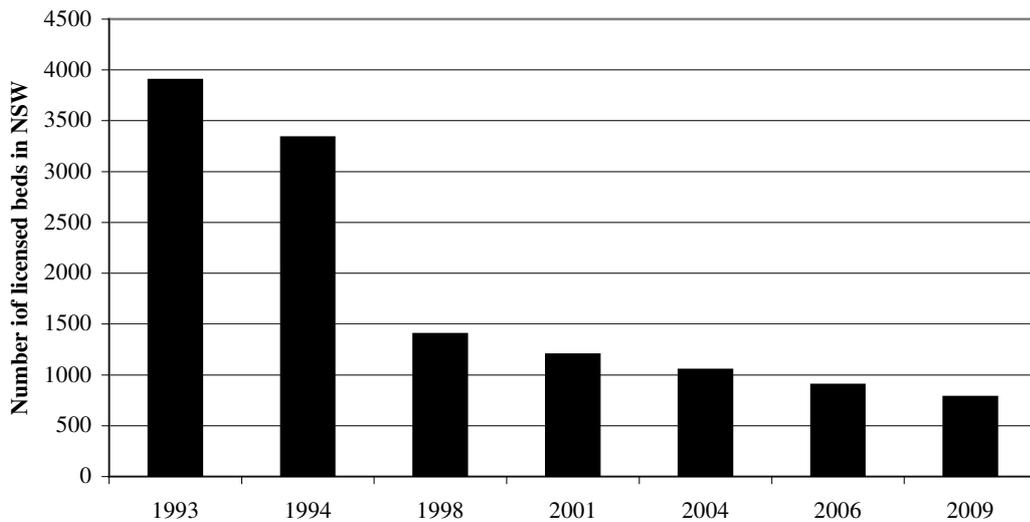


Figure 2: Capacity of Licensed Residential Centres in NSW



The decline of the licensed boarding house sector is apparent (ADHC 2010; Allen Consulting Group 2003; NSW Ombudsman 2006). Following a rapid decline in the mid-late 1990's the number of licensed boarding houses in NSW has steadily declined. There are a number of factors that indicate further decline including ageing proprietors, new regulations that will require an increase in both capital and on-costs and rising property values (Greenhalgh et al. 2004; NSW Ombudsman 2006;

Davidson et al. 1999). Despite this, there remain 781 people in 2010 who live in licensed boarding houses in NSW (ADHC 2010).

The decline of this sector presents a complex and significant policy issue. It has been established that both licensed and unlicensed boarding houses play an important role in the provision of low-cost accommodation (Greenhalgh et al. 2004). This sector intersects with and impacts upon the public and private housing, health, disability and homeless service sectors, to name a few. Notwithstanding these concerns, the maintenance of this sector contradicts government policy, legislation and contemporary discourses regarding the rights of people with intellectual disability and people with mental illness (PWD 2009; ADHC 2009; Bigby and Frawley 2010; Richmond and Savy 2005).

Licensing and oversight framework

Department of Human Services Ageing, Disability and Home Care (ADHC)

The ADHC is responsible for the licensing and monitoring of Licensed Residential Centres (LRC's or licensed boarding houses) under the YACS Act. This includes issuing licences and monitoring compliance with licence conditions. A boarding house requires a licence under the YACS Act if

Two or more handicapped persons reside:

(i) subject to the payment of a fee or the giving of some other consideration (such as working for board), and

(ii) otherwise than with a person who is a relative of each of those persons, is of or above the age of 18 years and is not a handicapped person...

Noting the outdated and inappropriate language used within the YACS Act, 'handicapped person'

means a person who is senile, temporarily or permanently incapacitated for work, mentally ill, intellectually handicapped, physically handicapped, sensorily handicapped, chronically ill, of advanced age or suffering from any medical condition prescribed by the regulations, or any combination of those disabilities, and who requires supervision or social habilitation.

This definition is broad and ambiguous, and is often a point of contention for proprietors, assessment teams (who administer service access through a screening tool) and licensing officers.

The YACS Act was developed in response to concerns about the initial phase of deinstitutionalisation in NSW, particularly the large numbers of people leaving psychiatric hospitals and moving into private, for-profit boarding houses (NSW Government 1993). While the YACS Act established a licensing regime there was little if any monitoring of licences. Myree Harris RSJ (1997, 6), an unyielding advocate with people living in licensed boarding houses, recalled the words of a boarding house proprietor:

When I got my licence back in 1973, they nearly kissed me. I could go away and do as I liked. No one came near me for twenty years. Now they want to set standards.

Despite amendments to the legislation in 1979 and several inquiries that identified significant concerns about the treatment and practices in boarding houses, notably the Henderson Report on Poverty in 1977 and the Report of the Royal Commission into Deep Sleep Therapy ('Chelmsford') in 1990, the conditions in boarding houses went largely unchanged (NSW Government 1993).

In 1993 the NSW Government formed 'The Taskforce on Private "For Profit" Hostels'. This Taskforce was established following 'allegations of abuse, exploitation and sub-standard conditions at a large licensed hostel for people with disabilities' (NSW Government 1993) and subsequent media attention including the front page of the Sun Herald 'Hostel of Horror' (Sun Herald March 28, 1993).

The Taskforce found wide use of physical and chemical restraint and confinement, regimentation and material deprivation, poor nutrition, significant fire and other safety concerns, serious health concerns, high incidence of sexual assault and numerous systemic issues including the need for an effective licensing and monitoring framework (NSW Government 1993).

The Taskforce ‘saw the principles in the *Disability Services Act 1993* (NSW) as the appropriate philosophical base for the licensing system...however, accepted that, boarding houses could not in the short term be required to fully conform with the principles’ (NSW Government 1993, ii). It recommended a new set of licensing standards to

conform as closely as possible with the DSA, changes to complaints, appeals and monitoring legislation to improve accountability, day programs for residents, restriction on size and location of boarding houses, improved referral and admission procedures, training for boarding house managers and proprietors and various committees to improve the provision and coordination of services to residents (NSW Government 1993, iii).

The Taskforce also investigated the viability of licensed boarding houses. The Taskforce found that ‘there is profit to be made and profit is being made through boarding house businesses’ (1993, 8). Indeed the Taskforce found that ‘there are some services focused on the needs of residents and still operating profitably’ (1993, 8).

At the same time as the Taskforce was conducting its inquiries, the National Mental Illness Inquiry (the Burdekin Inquiry) was publicly discussing its findings and later that year released the Burdekin Report (HREOC 1993). The findings of the Burdekin Inquiry argued against the use of boarding houses as an accommodation option for people with mental illness.

The accommodation in the majority of boarding houses is substandard and boarding houses in Australia are a national disgrace...The evidence presented to the Inquiry in all States indicated that the physical conditions in

many boarding houses are depersonalising, depressing and completely uncondusive to any dignified, normal life (HREOC 1993, 388).

In reference to the NSW licensing regime the Inquiry maintained that

These principles are excellent on paper, however it is obvious that in practice they may as well not exist at all. The prevailing conditions in boarding houses demonstrated that these standards are routinely breached or ignored. One major difficulty is the short staffing of licensing and monitoring agencies... While it is rarely stated publicly, this 'evolution' in the role of boarding houses means they have become a de facto part of the mental health system, housing a large number of that system's clients. The advantage of this situation for boarding house owners is that it provides a generally docile clientele who are easily controlled and prepared to accept minimal standards; it also guarantees a reliable regular income generated by pensions and benefits. But the evidence indicates that boarding houses have failed to fulfil the accompanying expectation that they would contribute in some way to community care (HREOC 1993, 387).

Following numerous inquiries, reports and ongoing media attention the incoming Labor Government announced a series of changes in 1995 (Allen Consulting Group 2003). These included the establishment of the Ageing and Disability Department with a dedicated Licensing, Support and Development Unit and the creation of a Boarding House Team, under the NSW Health department, 'comprising specialist nurses, a psychiatrist and a variety of allied health professionals to help residents access support services and health care' (Bailey and Sheehy 2009, 140). The new Licensing, Support and Development unit instigated significant change with some boarding houses being closed, licences revoked and others prosecuted for breaches of licence conditions (Harris 2007; Allen Consulting Group 2003). Classifications were introduced for licence types. 'Category A' licences were issued before 1995 and 'Category B' after 1995. 'Category B' licences 'are more stringent...in relation to communal and personal space requirements, and in requiring staff to undergo a criminal record check' (NSW Ombudsman 2006, 1). During the mid-1990's all licensed boarding houses were subject to close monitoring and licence requirements

were enforced (Harris 2007). A number of residents were identified as requiring an alternative accommodation placement as their support needs were greater than what was on offer in a licensed boarding house (Allen Consulting Group 2003).

Following concerted advocacy by the Coalition for Appropriate Supported Accommodation for people with disabilities (CASA), media and political ‘interest’ the NSW Government announced a reform package of \$66 million and established the Boarding House Reform Program (BHRP) in 1998 including a Ministerial Task Force (Robinson 2001). This program focused on the relocation of people with high support needs (classified as ‘high high’) into an alternative community-based accommodation option (ADHC 2010). A screening tool was also developed to prevent the inappropriate placement of people into licensed boarding houses. A range of support services were also provided to people living in licensed boarding houses including

personal care, community integration activities comprising skills development, social and recreational activities, primary and secondary health care, and escorted medical and dental transport (Robinson 2005, 9).

The program also aimed at supporting boarding house proprietors and sought to address some of the viability concerns by reducing managers’ and proprietors’ workload through the provision of personal care and community based activities (Allen Consulting Group 2003). Training was also provided to boarding house proprietors and managers about contemporary disability practices, policies and legislation (Allen Consulting Group 2003).

Under the BHRP more than five hundred residents of licensed boarding houses were provided with alternative community-based accommodation and support (NSW Ombudsman 2006).

In 2001 the Department of Ageing, Disability and Home Care (now ADHC) was formed and many of the functions relating to the licensing, monitoring and support of licensed boarding houses were gradually regionalised (NSW Ombudsman 2006). Over time this has resulted in a significant loss of corporate knowledge, skill and

expertise (NSW Ombudsman 2006). Despite a policy being introduced in 2003 *Licensed Residential Centres: Licensing, Monitoring, and Closure Policy*, the standard of monitoring and support differs across regions and overall there remains serious concern about the current licensing framework and ADHC's ability to meet its requirements.

NSW Ombudsman

In 2002, the NSW Ombudsman amalgamated with the Community Services Commission, which expanded the Ombudsman's role in relation to licensed boarding houses (NSW Ombudsman 2006). At this time, the NSW Ombudsman assumed responsibility for the provisions relating to licensed boarding houses under the *Community Services (Complaints, Reviews and Monitoring) Act 1993* (NSW) as well as the *Ombudsman Act 1974* (NSW).

The NSW Ombudsman now has a number of functions in relation to licensed boarding houses. These include the coordination of Official Community Visitors who visit LRC's, reviewing 'the circumstances surrounding the deaths of people who are residents of licensed boarding houses', handling complaints in relation to LRC's, 'reviewing the situation of a person, or group of people, with disabilities' in LRC's and monitoring and oversight of the Human Services Agency- Ageing, Disability and Home Care' (NSW Ombudsman 2004, 1-2).

Since assuming responsibilities for these expanded functions, the NSW Ombudsman has released a number of reports relating to licensed boarding houses. Notably, in 2006, the NSW Ombudsman released a report *DADHC: Monitoring standards in boarding houses*. This report found

serious problems with the way boarding houses are licensed and monitored in NSW. Some of these problems relate to a failure by particular regions within DADHC to properly carry out their monitoring responsibilities. However, even where monitoring has occurred in accordance with DADHC's requirements, we have found limitations in the monitoring system because of uncertainty as to whether certain standards can be legally enforced. We have

also found inadequate safeguards for protecting people with a disability who live in unlicensed boarding houses (2006, xi).

Despite numerous inquiries, investigations and commitments by DADHC to improve its monitoring of licensed boarding houses, the NSW Ombudsman reported in its 2008-2009 Annual Report the following circumstances of the death of a man living in a licensed boarding house.

The death of a resident in 2008 raised questions about living conditions at a licensed boarding house and the adequacy of monitoring by DADHC. Our review of the man's death found that hospital staff had raised concerns about his hygiene and nutrition during an admission to hospital for pneumonia three months before. At that time, hospital staff noted that the man was at high risk of malnutrition and they had to use a peroxide solution to remove dirt from his skin and nails. The man was found in his room by a staff member at the boarding house. He had been dead for at least 12 hours and had blood stains on his fingers, head and clothes. There was also evidence of bloodstains on the walls and body tissue was found on two exposed nails on the back of the door to the room. The police officers who attended the scene reported that the man's bedclothes were covered with cobwebs and dust, and faeces and used toilet paper were strewn around the room. There were also several unopened sandwich packages in the room.

At the same time as our review of the man's death, Official Community Visitors complained to us about the failure of the licensed boarding house manager to address concerns they had identified. These included domestic duties not being attended to, smoking by residents indoors, the selling of cigarettes on the premises, broken windows, limited access to bathrooms and the dining room, and unsecured medication left on a shelf in the kitchen.

We met with DADHC to discuss these concerns. They told us about initiatives in place to improve the support provided to residents at the boarding house and to monitor compliance with the licence conditions. They also advised us that they were seeking legal advice in relation to the boarding house's

ongoing failure to comply with many of the conditions of their licence. DADHC subsequently told us they received legal advice that they did not have the power to enforce the licence conditions that apply to the health, well-being and cleanliness of residents and the facility. They said they were considering their options including prosecution and/or revocation of the licence in relation to the licensee's failure to comply with a fire safety order issued by the local council.

This year a decision was made to close the boarding house and DADHC are now in the process of finding alternative accommodation for the residents (NSW Ombudsman 2009).

It is alarming to consider that the conditions and treatment in this boarding house, the health and well-being of this man and presumably other residents have been subject to continued monitoring by hospital staff, DADHC licensing officers and Official Community Visitors (coordinated by the NSW Ombudsman). It is hard to believe that the physical condition of this man and his environment could go unnoticed for so long. It raises serious concerns about the current monitoring framework relating to licensed boarding houses.

Illegal operators

Boarding or rooming house proprietors who accommodate more than two people with 'a handicap' (as defined by the YACS Act) without a licence are considered to be operating illegally and are liable to fines and prosecution (ADHC 2010). The number of 'illegal operators' in NSW, particularly Inner Sydney, is unknown. As noted in a report about unlicensed boarding houses in Sydney (Newtown Neighbourhood Centre 2003, 6).

There is no central register of them and some may be operating without Council consent... At the same time others have opened, without going through planning and building approval processes.

During the mid-late 1990's the former Ageing and Disability Department (now ADHC) worked closely with local Councils to actively monitor unlicensed premises (NSW Ombudsman 2006). However, the current ADHC policy relating to unlicensed premises is to respond to complaints about boarding houses where it is alleged that more than two people with 'handicap' reside there (NSW Ombudsman 2006). ADHC has also raised concerns about its capacity to monitor and investigate 'illegal operators' citing *ultra vires*, meaning that it is beyond the power of the department to enforce. ADHC's current policy in relation to unlicensed boarding houses stipulates that

- *An officer may enter unlicensed premises if invited by a person with the authority to issue the invitation.*
- *An officer could accept from a boarder or lodger to enter but only for the purpose of conversing in the privacy of their room or space set aside to receive visitors.*
- *In the performance of duties authorised by the YACS Act, an officer may only enter an unlicensed premises for the purpose of making an inquiry following an application for a licence or under the authority of a warrant (Section 25 (5) of the YACS Act) (NSW Ombudsman 2006, 11).*

Noting ADHC's interpretation of the YACS Act, the current policy has serious limitations relating to the identification, investigation and monitoring of illegal operators. Furthermore, there is a lack of communication and coordination between ADHC, NSW Health, NSW Housing, local Councils, community organisations and the general community in facilitating the identification of unlicensed premises where two or more people with 'handicap' are residing (NSW Ombudsman 2006). People with disability living in unlicensed premises are generally perceived to be at greater risk of abuse and exploitation (Harris 2007).

Screening Tool

In order for a person with intellectual disability or person with mental illness to be considered eligible for entry into a licensed boarding house, they must be assessed as meeting the requirements of a screening tool (ADHC 2010). The screening tool focuses on a person's functional, behavioural and communication abilities such as whether the person is able to 'mobilise independently', feed themselves, toilet independently and manage their own health needs (ADHC 2010).

The screening tool was initially developed in 1999 and administered by NSW Health's Aged Care Assessment Teams (ACAT) (Bailey and Sheehy 2009). The screening tool aimed to 'ensure people with high or complex needs were screened to prevent inappropriate admission' into a licensed boarding house (ADHC 2010). It has gone some way in reducing the inappropriate placement of people in licensed boarding houses however, there were a number of concerns identified with the administration of the tool including a lack of review; a low rate of screening for residents with intellectual disability; and pressure experienced by members of the ACAT to place people in licensed boarding houses (Bailey and Sheehy 2009; NSW Ombudsman 2006).

In response to some of these concerns, ADHC facilitated a review of the screening tool in 2009 (ADHC 2010). From this review, ADHC made some amendments and changed the service provider responsible for administering the screening tool.

The revised screening tool requires reassessment of existing residents when

a resident's physical health or psychiatric condition significantly deteriorates; an admission to hospital occurs; or a resident is absent from the licensed residential centre for more than two months (ADHC 2010, 2).

As discussed earlier, many residents moved to their current licensed boarding house during the first wave of deinstitutionalisation and have never been a part of a screening process (Allen Consulting Group 2003). Many residents will have experienced deterioration in their skills and abilities due to their disability or illness

as well as health related issues that may be associated with ageing (Bailey and Sheehy 2009). This new requirement to reassess and re-screen residents goes some way in addressing some of these concerns (DADHC 2010). However, the responsibility to identify the need for and request a new screening falls largely with proprietors or licensed managers. While noting that some proprietors and managers advocate for residents to be reassessed, many do not recognise this need or are unresponsive to the deterioration of a resident's health and functioning (NSW Ombudsman 2006; NSW Ombudsman 2008).

The Home Care Service of NSW's Referral and Assessment Centre (RAC) replaced the ACAT's in administering the tool in April 2010 (ADHC 2010). While the Home Care Service of NSW is a separate authority it remains part of the ADHC. This means that ADHC is responsible for funding community support services that work with LRC's, licensing and monitoring licensed boarding houses and now assessing eligibility and entry. Given the gate-keeping role of the screening tool there remains perceived or actual conflict of interest for ADHC.

Review of the YACS Act- ultra vires

It has been identified for some time that the YACS Act is an outdated piece of legislation including inappropriate language (for example, 'handicapped person') and lack of clarity about what licence conditions are enforceable (NSW Ombudsman 2006; Allen Consulting Group 2003). In 1999, the then Ageing and Disability Department, sought legal advice about what licence conditions could be imposed by the department (NSW Ombudsman 2006). The department was advised that 'many of the licence conditions imposed by the department on boarding house licensees may be *ultra vires*, that is, beyond the power of the department to enforce (NSW Ombudsman 2006, 2). Since this time there have been several reviews and inquiries relating to the YACS Act and the issue of *ultra vires* including the Allen Report 2003, various NSW Ombudsman Reports to Parliament and ADHC's review of the YACS Act that commenced in 2002. Some eight years after the initial review of the YACS Act significant changes were made through the introduction of the *Youth and Community Services (YACS) Regulation 2010*. This Regulation outlined conditions that relate to some aspects of health and welfare such as nutrition, clothing,

medication and record management (ADHC 2010). It also required that staff of licensed boarding houses possess appropriate qualifications and experience including a current first aid certificate (ADHC 2010). These regulatory changes will require proprietors or licensees to meet the new conditions of licence. Notwithstanding the importance of such changes, the Regulation will only prove effective through enforcement and monitoring by the ADHC.

Support services provided to licensed boarding houses

Licensed boarding houses in NSW do not receive government funding for the services they provide to residents. Residents pay fees, usually between 85-100 percent of their pension (Harris 2007; Edwards and Fisher 2010). However, there are various tax exemptions, as well as grants available to proprietors relating to capital upgrades to comply with fire regulations (NSW Housing 2009). As part of the BHRP released in 1998, a variety of services were funded to provide support to residents of licensed boarding houses (Allen Consulting Group 2003).

The Active Linking Initiative (ALI) began in 2000 as part of the BHRP (Edwards and Fisher 2010). ALI aims to link people who live in licensed boarding houses into the community through ‘skills development; community based recreational/leisure opportunities; and education and vocational training opportunities’ (Edwards and Fisher 2010, 6). A recent review of the ALI found

increased community based activities, linkages and participation for the person; improved personal well-being; and increased social contact...The evaluation did not show evidence of impact on participation in employment and education (Edwards and Fisher 2010, 4).

The review also found that ALI providers were least likely ‘to engage with people with unmanaged mental health problems or a long history of isolation due to prior institutionalisation’ (Edwards and Fisher 2010, 4). Unfortunately, this describes a significant number of residents, especially those residing in licensed boarding houses in Inner Sydney (Edwards and Fisher 2010; Harris 2007; Allen Consulting Group 2003). Furthermore, some managers of licensed boarding houses treat ALI as a

recreation service, preferring group and in-home activities (Edwards and Fisher 2010).

The BHRP has also provided funding for the provision of personal care services in licensed boarding houses provided by the Home Care Service of NSW. Additionally, a range of allied health services has also been provided (Robinson et al. 2005; Edwards and Fisher 2010).

There are currently 8.5 case workers employed by ADHC that provide case management services to residents of licensed boarding houses. ADHC caseworkers have facilitated positive changes for residents of some licensed boarding houses including the introduction of a health record management system as well as requiring separate laundering of resident clothing (Edwards and Fisher 2010). Notwithstanding the importance of such change, there remains significant disparity regarding the role and impact of caseworkers between regions (NSW Ombudsman 2006).

Additionally, People With Disability Australia (PWD) provides individual advocacy services to residents of licensed boarding houses. PWD also undertakes various project and systemic advocacy work in relation to LRC's such as the provision of sexual health awareness training to residents (PWD 2009).

Conclusion

Following the implementation of deinstitutionalisation policy in the 1960's, boarding houses have played a significant role in the provision of low-cost accommodation for people with intellectual disability and people with mental illness. The use of this accommodation option has been subject of numerous reports, inquiries, Royal Commissions and media accounts, which have influenced the use of regulatory and licensing frameworks in some jurisdictions (NSW Government 1993; HREOC 1993; NSW Ombudsman 2006; NSW Ombudsman 2008).

This chapter has detailed the licensing framework in NSW and the roles of various agencies in licensing and monitoring boarding houses. A number of concerns have

been identified about the sustainability and viability of the licensed boarding house sector including the ageing population of proprietors, gentrification and recent changes to the regulatory framework (NSW Ombudsman 2006; NSW Ombudsman 2008; Greenhalgh et al. 2004; PWD 2010). Moreover, this chapter has identified ideological concerns about the suitability of this accommodation option within current discourse, policy and the principles of the *Disability Services Act 1993* (NSW). These concerns form the basis of this research, which is to establish to what extent licensed boarding houses achieve the value-based aims of deinstitutionalisation and contribute to the quality of life of people with intellectual disability and people with mental illness.

Chapter Four: Methodology and Method

This chapter describes the overarching methodological framework used to shape and guide this research. The research used Denzin's interpretive interactionism and within this a case study method enabling a holistic examination of the research question. The chapter also describes the process of conducting the research including the methods of data collection and various ethical and practical considerations and challenges.

Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape enquiry. Such researchers emphasise the value-laden nature of inquiry...in contrast, quantitative studies emphasise the measurement and analysis of causal relationships between variables, not processes (Denzin and Lincoln 2005, 13).

The research question

How do licensed boarding houses operate as an accommodation option within the policy of deinstitutionalisation?

This research started long before my application for admittance into the doctoral program or my application for candidacy. It started with a social worker's ponderings about how such an accommodation option existed within current discourses including deinstitutionalisation, integration, participation and social inclusion. It emerged from a place of disquiet about how such an anomaly existed within current legislative and policy frameworks. This research question was born out of fourteen years practice experience working with people with intellectual disability and people with mental illness. My practice experience spans across a number of different areas including direct practice, community development, policy, research, teaching and investigation. The settings within which this practice has taken place have also been

diverse. They include community-based organisations (recreation, health promotion and accommodation support services); government human service agencies (including program management and policy development roles); universities (teaching in undergraduate social work programs, including the provision of social work clinical supervision) and oversight bodies (systemic and individual investigations and monitoring).

The research question is also born out of a deeply personal belief that people with intellectual disability and people with mental illness, have the right to live and participate in the community with support.

The overall aim of this research is to establish how licensed boarding houses operate as an accommodation option within the policy of deinstitutionalisation? The objectives in addressing this question are to:

- Document the history of deinstitutionalisation in NSW and identify the outcomes for people with intellectual disability and people with mental illness.
- Consider what support and services the NSW licensed boarding house sector delivers to the target population as compared with what was modelled in the enabling act and regulations around deinstitutionalisation in NSW.
- Establish to what extent licensed boarding houses enact the human rights principles of deinstitutionalisation and contribute to the quality of life of residents with intellectual disability and residents with mental illness?

The research focuses on licensed boarding houses in Inner Sydney licensed under the YACS Act. The research was conducted in a dynamic environment, which involved a review of the regulatory and monitoring framework and concerns about the sustainability of the licensed boarding house industry.

Social work practitioner research

“So I suppose as a social worker you will be using a qualitative approach”, queried a colleague.

Social work research has ‘witnessed polarised debates about the relative value of quantitative versus qualitative methods’ (Riessman 1994, vii). At one end of the continuum is a belief that qualitative research is ‘soft’ and lacks scientific rigour. At the other, quantitative research values scientism, maintaining that knowledge gained through scientific methods is always superior. Although qualitative approaches have gained wide acceptance since the 1990’s, especially in the social and applied sciences, quantitative approaches remain dominant (Denzin and Lincoln 2005). This is evidenced in many practice areas such as social work education, direct practice and practitioner research (Riessman 1994; Fook 2001). I have experienced multi-disciplinary case conferences where research was used to guide decision-making. Quantitative methods were valued over qualitative. I have participated in tender panels where submissions for funding were assessed. Projects that demonstrated causal relationships were ‘highly regarded’.

In light of this, my colleague’s assumption that I would use an interpretive approach seems surprising. Perhaps social work is perceived as ‘soft’ and therefore associated with qualitative approaches. Or is it that my colleague identified social workers communication skills as being congruent with qualitative methods such as in-depth interviews?

The researcher acknowledges the value, strengths and limitations of both approaches in seeking knowledge, and joins with Ann Hartmann in her claims that there are ‘many ways of knowing’ (1990). Notwithstanding this, an interpretive approach was selected for this research as it enabled the researcher to gain insight and ‘thicken’ understanding about the use of licensed boarding houses as an accommodation option for people with intellectual disability and people with mental illness. Most importantly, this approach provided for residents of licensed boarding houses to ‘tell their story’ in their own words. This would not have been possible using quantitative methods exclusively.

Interpretive interactionism

Interpretive interactionism is a term coined by Denzin in an applied response to Mills' sociological imagination. It is 'founded on the study, expression, and interpretation of subjective human experience' (Denzin 1989, 24). It is an 'attempt to join traditional symbolic interactionist thought with critical forms of interpretive inquiry' (Denzin 2001, xi).

Denzin advocates for this mode of critical research when a researcher wants to

examine the relationships between personal troubles... and the public policies and public institutions that have been created to address those troubles. Interpretive interactionism speaks to this interrelationship between private lives and public responses to personal troubles. It works outward from the biography (2001, 2).

In order to establish how licensed boarding houses in Inner Sydney operate within the policy of deinstitutionalisation, Interpretive Interactionism was used as the overarching methodological framing. Interpretive Interactionism was selected based on its strengths in researching with a range of interacting players in a particular setting (Denzin 2001). The research was designed to enable consultation and dialogue with a range of differently positioned stakeholders about licensed boarding houses in Inner Sydney. This included the lived experience of current and former residents of licensed boarding houses and the views and opinions of licensed boarding house proprietors and staff of community organisations and government agencies. This enabled the perspectives of different stakeholders to be mapped, compared and contrasted.

Case study method

Within the overarching framework of Interpretive Interactionism, a case study method was used to address the objectives of the research. This method was selected for three main reasons. Firstly, case study methods provide for the holistic examination of phenomenon. Stake noted that

A case study is expected to catch the complexity of a single case...Case study is the study of the particular and complexity of a single case, coming to understand its activity within important circumstances (2005, xi).

Stake's comments are often interpreted as meaning an individual case, an individual client or consumer. The concept of 'case' can also be applied to broader constructs including groups. This research applies case study to the case of licensed boarding house residents in Inner Sydney.

Case study methods enabled the holistic examination of the history of deinstitutionalisation including, the consideration of current legislative and policy reviews; in-depth analysis of how licensed boarding houses operate within the policy of deinstitutionalisation; and the ability to re-present the lived experience of what it means to be a boarding house resident.

Secondly, case study methods provides for 'experiential knowledge of the case and close attention to the influence of its social, political and other contexts' (Stake 2005, 345). This approach utilised the researcher's practice experience as a social worker and knowledge of the licensed boarding house sector. The case study approach values the practitioner lens and the tacit knowledge developed through practice experience (Fook 2001). As Denzin noted (2001, 3),

The qualitative researcher is not an objective, politically neutral observer who stands outside and above the study of the social world. Rather, the researcher is historically and locally situated within the very process being studied.

Finally, this method 'is richly descriptive, because it is grounded in deep and varied sources of information...and brings to life the complexity of the many variables inherent in the phenomenon (Hancock 2006, 16). 'It also has the potential to be a force in public policy settings and to provide a reflection of human experience' (Macpherson et al. 2000, 52).

Case study method is sometimes criticised from within a positivist research positioning for a lack of scientific rigour, reliability (or dependability), validity (or trustworthiness) and low generalisability (Yin 2003; Patton 2001; Lincoln and Guba 1985). Many of these criticisms are also levelled at other types of qualitative research methods. Fook (2001, 125), a social worker, maintained that

Probably the most embedded way in which the culture of positivism prevails is in determining the criteria against which soundness of research is judged. The issues of reliability, validity and objectivity raise constant problems for qualitative researchers, as they are concepts which arise from a positivist frame of reference.

A decade later, Fook's observations remain pertinent. While qualitative research has developed its own traditions and claimed a place in the broad research community, the 'soundness of research' is often determined against quantitative measures (Silverman 2000). This can be reflected in research grant applications and ethics approval processes highlighting the politics of research.

Some of these concerns are addressed through the triangulation of methods, which is an inherent process of the case study approach (Stake 2005). Triangulation is a strategy that involves the application of mixed methods, which 'adds rigor, breadth, complexity, richness and depth to any inquiry' (Stake 2005, 5).

The ability to generalise findings remains a contentious issue for case study methods. Positivists argue that in the absence of a representative sample, derived from a random sample, research findings are unable to be generalised to the 'population'. Denzin claimed, that 'the interpretist rejects generalisation as a goal' (1989, 26). Yin (1989, 21) argued that while the findings are not 'scientifically representative', findings from case study research are 'in principle generalisable to theoretical propositions'. Yin (1989) also encouraged the use of more than one unit of analysis and clearly demonstrating how interpretations were made.

Mason goes further, and argued that

Qualitative researchers should not be satisfied with producing explanations which are idiosyncratic to the limited empirical parameters of their study...Qualitative research should therefore produce explanations which are generalisable in some way, or which have a wider resonance (1996, 6).

In light of Yin and Mason's comments, the researcher applied a number of strategies with the view to 'have wider resonance'. As discussed earlier, triangulation of methods was used to address some of the limitations as to representativeness and generalisability, which are inherent in the method. The use of reflexive practice, a focus group to test data coding and regular supervision were other strategies that the researcher employed.

Mixed methods within Case Study

In accordance with the case study approach a variety of data collection methods were used including semi-structured and unstructured interviews, literature reviews, and policy and legislative analysis. These methods provided triangulation of information that increased both depth and breadth of understanding as to the research question and highlighted contradictions and anomalies (Wadsworth 1997; Stake 2005).

Primary Sources

Semi-structured interviews

Semi-structured individual interviews were conducted with staff of community organisations, government agencies and licensed boarding house proprietors. This method was selected as it provides enough structure to enable useful coding and comparison as well as a deeper understanding of the issue (Shaw and Gould 2001). The majority of interviews were held face-to-face with the exception of two interviews that were conducted by phone due to distance (Minichiello 1998).

Participants were provided with a copy of the participation information sheet, which was discussed prior to establishing and obtaining informed consent. Participants were reminded that their participation was voluntary and that they were able to withdraw at any time.

Participants were asked to respond to eight open-ended questions (Bryman 2008) relating to deinstitutionalisation and licensed boarding houses in Inner Sydney (Appendix One).

The duration of each interview was generally one hour. The majority (35) of participants agreed to have their interview digitally recorded. All participants were provided with a copy of their transcript or researchers interview notes for endorsement.

Unstructured interviews

The active involvement of people with intellectual disability and people with mental illness in research, especially research that endeavours to uncover the lived experience of disability and illness, is critical and arguably a citizen's right. The motto 'nothing about us, without us' needs to ring out loud and clear to the research community. Indeed, the researcher acknowledges some of the weaknesses of this study's methodology and methods in not involving or sharing power with people with intellectual disability and people with mental illness at every stage of the research process, which might be found in an emancipatory action research methodology (Oliver 1992; Brown and Strega 2005).

Unstructured individual interviews were held with current and former residents of licensed boarding houses. This method was selected for several reasons. As Robinson noted (2003, 9), a 'qualitative approach is more respectful and inclusive' when discussing personal and potentially traumatic subjects. The unstructured nature of the interview enabled participants to 'tell their story' with minimal interruptions. Alternative or complementary data collection methods such as surveys were

considered inappropriate as the literacy competency of boarding house residents is generally quite low (Swan 2001).

All unstructured interviews were conducted face-to-face. It was essential that the interviews take place in an environment that maintained the participants' anonymity in order to minimise the potential for retribution. Most interviews were held in cafes or the offices of community organisations. Participants were able to have a support person attend the interview and one resident participant requested a support person. Prior to the interview, participants were provided with a copy of the participation information sheet and consent form. The researcher discussed the participation information sheet and applied set criteria to establish whether or not a person was able to provide informed consent. If and when informed consent was provided, the researcher reinforced that participation was voluntary and that the participant was able to withdraw at any stage.

Although the interviews were unstructured, the researcher provided participants with information about the types of questions or issues that might be discussed throughout the interview. These included what support and services licensed boarding houses provide; participants' accommodation history; community access and participation; and other support services received. The duration of most interviews was 45 minutes.

Field Notes

Field notes were made following individual interviews. Often the researcher would digitally record observations, reflections and interpretations and transcribe these. These field notes provided supplementary information to the individual interviews. For example, field notes included observations of body language, environmental factors that may have impacted on the participant and interview process. Field notes were used to reflect on 'tours' of licensed boarding houses conducted by proprietors. One field note captured the following observations:

*The proprietor commented to one man who was smoking on the fire stairs
"Don't worry, she's not from the Department"!*

The proprietor commented, “We give them fruit” as he took a bite of an apple that had clearly been there for a while. I turned around to see him spitting it out.

Personal medical notes and medication schedules are visible to anyone who enters the office.

Secondary Sources

Literature review

An extensive literature search was conducted across numerous databases, electronic resources and library catalogue searches. Some of the electronic databases searched included PsychInfo, ProQuest, APA-FT, Social Work Abstracts, Social Welfare Abstracts, Sociological Abstracts, Web of Science, Factiva. Other electronic resources were sourced through searches of websites such as the Ageing, Disability and Home Care Department, the NSW Ombudsman, Australian Bureau of Statistics, the Australian Institute of Health and Welfare, Austlii and Parlinfo.

Data searches were conducted using several keywords including, deinstitutionalisation, deinstitutional*, institution, institutional*, licensed boarding house, boarding house, rooming house, lodging house, hostel, community participation, community integration, social inclusion, social exclusion, mental illness, mental health, intellectual disability, mental retardation, case study methodology, social research methods, qualitative research, social construction and supported accommodation. These keyword searches highlighted some of the definitional constraints inherent in this research. The definition of boarding house varies nationally and internationally (Greenhalgh et al. 2004). Some variations included rooming house, lodging house, hostel and boarding house facility.

Legislation

The researcher was aware of the main pieces of legislation that direct practice in the area of licensed boarding houses in NSW, including the *Youth and Community*

Services Act 1973, Disability Services Act 1986 (Cth) and Disability Services Act 1993 (NSW). The researcher accessed the legislation via the search engine available on the Austlii website. First and second reading speeches were obtained from Parliamentary Hansard to ascertain the principles and political context of the introduction of the legislation.

Policy and document analysis

Through practice experience, I was also aware of the main policies and documents that related to the research question. Some of these documents included various Reports to Parliament by the NSW Ombudsman (NSW Ombudsman 2006; NSW Ombudsman 2008), reviews conducted on behalf of ADHC such as the National Competition Review of the regulation of boarding houses (Allen Consulting Group 2003) and the boarding house screening tool (ADHC 2010).

Sampling

Two non-probability sampling methods were used for the identification and recruitment of participants, including purposive and snowball sampling.

Purposive sampling ‘uses the judgement of an expert in selecting cases or it selects cases with a specific purpose in mind’ (Neuman 2000, 198). This sampling method enabled the researcher to select unique cases that are especially informative and provide in-depth information. The researcher was able to utilise practice knowledge as a social worker to identify ‘information-rich’ cases. Purposive sampling was used to recruit participants from community organisations and government agencies.

The second strategy, snowball sampling is described by Sarantakos (1999, 15).

Researchers begin the research with the few respondents who are available to them. They subsequently ask these respondents to recommend any other persons who meet the criteria of the research and who might be willing to participate in the project. If and when such respondents are recommended, the investigator approaches them, collects the information required and asks

them to recommend other persons who might fit the research design and be willing to be studied.

The researcher used snowball sampling to identify current and former residents of licensed boarding houses and boarding house proprietors. During interviews with staff of community organisations and some government agencies, the researcher was provided with names and contact details of people who were identified as potential participants.

These strategies were selected as they provided the best safeguards for anonymity, which was a significant concern for many participants and is discussed further throughout this chapter. These sampling methods also provided rich information and the ability to recruit participants who may not have been accessible by other means.

Recruitment of participants

Recruiting residents of licensed boarding houses

While the researcher had access to the location of all licensed boarding houses in Inner Sydney, the researcher chose not to recruit resident participants directly through their residential address. Firstly, the potential for retribution against residents who chose to participate in this study meant that such a recruitment strategy placed residents at risk. Secondly, the researcher considered that this approach failed to respect resident's privacy.

Two community organisations that provide services to people living in licensed boarding houses were approached to provide advice and support in the identification and recruitment of resident participants. Both organisations agreed to assist with the recruitment and support of residents and provided written confirmation of the same to Curtin University's Human Research Ethics Committee (HREC). Both organisations were provided with copies of this study's research proposal, participation information sheet and consent form. Staff from the two community organisations provided this information to their members and discussed the contents.

They explicitly communicated to their members, that receipt of support services was not dependent upon participation in the research.

Both organisations invited the researcher to meet with members who had expressed interest in the research. During these initial meetings the researcher discussed the purpose of the research and the interview process including how long interviews would go for, what types of questions would be asked and how the participant's information would be used. Participants were asked to nominate a preferred location for the interview. It was important to reassure people that their anonymity would be maintained, emphasising that boarding house proprietors would not be informed about their participation in this research. Copies of the participation information sheet and consent form were provided. Potential participants were advised that they were able to bring a support person to the interview. During the initial stages of these meetings, further reassurances were made that a person's support services would not be impacted by a decision not to participate in the research. I also reiterated that participation was voluntary and participants were able to withdraw from the research process at any stage.

Access was a central feature of the research process. Some of the strategies the researcher applied included:

- Residents were able to nominate their preferred location for interviews and where possible this was accommodated.
- Written and verbal information was provided in 'Easy English'.
- Additional or reduced time for interviews was made available to participants.

Recruiting community organisations and government agencies

Participants were identified through my previous work experience and knowledge of the licensed boarding house sector. Participants were selected based on their role or position within a particular agency and experience in providing services, oversight,

advocacy and/or policy direction for people with intellectual disability or people with mental illness.

Using a purposive sampling approach, letters were sent (via email) to heads of agencies inviting them to nominate a representative to participate in a semi-structured interview. The letter included information about the purpose of the research, the researchers professional background, ethical considerations and interview questions. Attached were copies of the participation information sheet and consent form (Appendix Two and Three).

Recruiting Licensed Boarding House Proprietors

Three Licensed Boarding House Proprietors were also contacted by letter with a follow-up phone call and invited to participate in the study. These proprietors were recruited by snowball sampling method and all had been involved with licensed boarding houses for several decades.

Response rate

Licensed boarding house residents

The use of snowball sampling facilitated by the community support organisations meant that most resident participants were able to self-nominate. Nine current residents and three former residents of licensed boarding houses self-nominated to participate in the research. One licensed boarding house resident actively declined the invitation to participate in the research stating, “I love where I live. I don’t want to move”!

Monitoring agencies

The NSW Ombudsman was identified as a potential participant based on its legislated powers and its role in coordinating the Official Community Visitors (OCV) program where OCV’s visit licensed boarding houses; the investigation and monitoring of ADHC’s role in relation to the licensing and monitoring of LRC’s; and

the role of the Disability Death Review Team in reviewing the deaths of people with disability who die in licensed boarding houses. As discussed in Chapter Three, the NSW Ombudsman has released several Reports to Parliament in relation to these roles and the work of the Office (for example, NSW Ombudsman 2006; NSW Ombudsman 2008). In response to my request to interview a delegate, the Deputy Ombudsman (Community Services Division) advised in May 2008

Section 34 of the Ombudsman Act places conditions on what information this office can disclose. Given the privacy provisions, I believe that an interview would be problematic for us, as we would be disclosing information obtained through the course of our official work.

While work in relation to licensed boarding houses continues to be a priority within this office, with regret I advise that we will be unable to participate in your research project.

Minister for Disability Services

A letter was forwarded to Premier Kristina Keneally MP (former Minister for Ageing and Minister for Disability Service) in January 2008 inviting her, or a nominated delegate, to participate in a semi-structured interview. This request was made in order to obtain information about the NSW Government's current policy in relation to deinstitutionalisation and the role of licensed boarding houses as an accommodation option for people with intellectual disability and people with mental illness. Premier Keneally provided the following response via the then DADHC Director-General.

The Department of Ageing, Disability and Home Care (DADHC) is responsible for the licensing and monitoring of boarding houses that accommodate two or more people with a disability who also require supervision and habilitation, as required under the NSW Youth and Community Services Act 1973.

These boarding houses are known as Licensed Residential Centres and are subject to a set of Licence Conditions, which set out minimum standards for provision of the accommodation service. Licensed Residential Centres are privately-owned and operated services and provide a low cost accommodation option. As such, Licensed Residential Centres are not part of a planned policy initiative by DADHC in response to de-institutionalisation.

Stronger Together: A new direction for disability services in NSW 2006 – 2016 is DADHC's 10-year plan to provide greater assistance and long-term practical solutions for people with a disability. Stronger Together includes a commitment to the closure and/or redevelopment of Large Residential Centres in NSW over time, including relocation of people with a disability into community accommodation support services.

Unfortunately, the Minister is unable to participate in an interview for the fieldwork component of your research. Please be assured that DADHC will consider your research proposal and your request for support, in line with DADHC's Research Policy.

ADHC and 'The Research Agreement'

The ADHC was an obvious 'potential participant' for this research given its role in licensing and monitoring licensed boarding houses in accordance with the YACS Act.

The researcher initially contacted ADHC in December 2007 and invited the department to participate in the research. The invitation extended to interviews with a total of six departmental officers, including representatives from central and regional offices. The researcher was referred to the Department's Planning and Research Unit, which required the completion of a lengthy application including a research proposal and ethics clearance. Four months later the Department advised that the application had been approved subject to the signing of a 'Research Agreement'.

The 'Research Agreement' presented the researcher with several concerns. Foremost, was the inclusion of a clause that provided the Department with a power of 'veto' over certain aspects of the publication and presentation of the research findings.

If the Principal (ADHC) wishes to withhold or restrict the Researcher's use of such material, for reasonable reasons relating to the sensitivity of the material contained in the Research, he must negotiate in good faith with the Researcher a reasonable agreement for conditional, partial or restricted use of the material.

Due to the impact on the perceived and actual independence of the study the offered Agreement was rejected.

The researcher contacted the Department:

As you will appreciate, an interview with six DADHC officers represents a small component of my research. However, I am committed to presenting balanced research. I am able to provide DADHC with copies of interview transcripts and a document that reports on the information obtained from DADHC officers, my interpretations/observations on that information and invite the department's response to the same. Alternatively, I invite the department to nominate a representative to participate in a one hour face-to-face interview or alternatively provide a statement for inclusion in my study.

No response was received to this letter or several others as well as numerous phone calls. In April 2010, more than two years after the initial invitation, the researcher contacted the Department to obtain some demographical information, such as how many people were currently living in licensed boarding houses. The Department questioned whether or not the researcher intended to sign the Research Agreement and interview Departmental staff. The researcher advised that no ADHC staff had been interviewed. The researcher also advised that the Agreement compromised the integrity of the research and the ability to present its findings. The Department consented to the researcher meeting with a Departmental Manager who provided demographical information.

This experience presents several challenges for researchers including non-commissioned researchers. The first being the challenge of engaging government departments in research that may be perceived as threatening. The second being the viability of presenting balanced research given the objections of key stakeholders.

Pinkerton (1998, 33) provided some observations about similar challenges focussing on the UK experience.

The development of social research in the UK has been a political process which has been closely associated with the changing trajectory of government policy and the welfare state. It is clear that much of the funding available for research in the wider field of social work has its origins in government departments and as a result we might reasonably expect that these will have a considerable degree of influence over the research process at all levels, from agenda setting, through to the selection of researchers, to the methodology, conduct and dissemination of findings.

Pinkerton's observations can readily be applied to the Australian context and certainly to this research experience. Government's influence on the research process, particularly the use of research agreements to control the research process, is similar to the 'gag' clauses used in community organisation's funding agreements (Maddison et al. 2004). These clauses prohibited community organisations from engaging in public comment.

The sensitive nature of this research is understood and appreciated. However, the need for independent and balanced research is essential and is a fundamental tenet of democracy.

Other government departments and community organisations

All other government departments recruited for this research participated in a semi-structured interview. The majority also provided policy documents, contact officers for ongoing follow-up and displayed a genuine interest in the research and its findings.

All community organisations responded to the invitation to participate in this research. Some organisations referred the researcher to alternative organisations that represented ‘the sector’ on such issues.

Licensed boarding house proprietors

The three licensed boarding house proprietors that were invited to contribute to the study participated in a semi-structured interview. Each proprietor also escorted the researcher on a tour of his or her boarding house.

Participant Attributes

Table 1: Total Number of Participants

Participant type	Number of Participants
Licensed boarding house resident	7
Former licensed boarding house resident	3
Boarding house proprietor	3
Staff of community organisation	15
Staff of government agency	12
TOTAL	40

Current licensed boarding house residents

Seven current licensed boarding house residents participated in a semi-structured interview. Of the seven people interviewed, five had been ‘transported’ directly from a large psychiatric hospital (one of the ‘Schedule V’ hospitals in Sydney) to their current licensed boarding house during the first wave of deinstitutionalisation in the 1970’s.

One resident had lived in a number of institutions since he was twelve years old including orphanages and several licensed and unlicensed boarding houses. He had been living at his current licensed boarding house for five years.

One resident had returned to live with her family following the closure of an institution. Her parents were unable to provide the level of care she needed and she moved into a group home. The organisation managing the group home exited the resident due to ‘challenging behaviours’. This resident has been living in the same licensed boarding house for three years.

Of the current resident participants, five are people with mental illness. One participant is a person with intellectual disability. One participant is a person with intellectual disability and mental illness.

Former licensed boarding house residents

Three former licensed boarding house residents participated in an unstructured interview. All former resident participants had significant experience of living in licensed boarding houses.

One former resident had lived in a licensed boarding house for thirty years following the downsizing of a ‘Schedule V’ hospital in Sydney in the 1970’s. This boarding house was closed in 2007 and the resident is currently living in independent accommodation. This participant is a person with intellectual disability.

One former resident had lived in a number of accommodation options including independent accommodation, licensed and unlicensed boarding houses over a number of decades, dispersed with admissions to psychiatric hospitals during periods of mental illness. This former resident had lived in his last licensed boarding house for a ‘few years’ before it closed in 2007. He is now living in a flat provided by NSW Housing and receives support from a community organisation. This participant is a person with mental illness.

One former resident had lived in a number of institutions ‘for the mentally retarded’, group homes, licensed and unlicensed boarding houses as well as ‘sleeping rough’. This former resident is currently living in independent accommodation and is

supported by a community organisation. This participant is a person with intellectual disability and mental illness.

Table 2: Resident participant by disability type

Disability	Current resident	Former resident	TOTAL
Person with intellectual disability	1	1	2
Person with mental illness	5	1	6
Person with intellectual disability and mental illness	1	1	2
TOTAL	7	3	10

Proprietors of licensed boarding houses

Three proprietors of licensed boarding houses participated in this study. All of the proprietors owned licensed boarding houses in NSW and two proprietors had licensed boarding houses in Inner Sydney. Each of these participants had purchased their boarding house during the initial wave of deinstitutionalisation in the 1970's.

Staff of community organisations and government agencies

A total of 27 staff members participated in a semi-structured interview including 12 from government agencies and 15 from community organisations. These participants included representatives from a variety of professional backgrounds and roles such as chief executive officers, coordinators, policy officers, social workers, mental health nurses, advocates, a psychologist, doctor, lawyer and academic.

Three more staff representatives of community organisations participated in the study compared with staff of government agencies. This is attributed to the lack of access to staff of the ADHC as discussed in Chapter Four in relation to the Research Agreement.

Table 3: Professional identity of staff participants

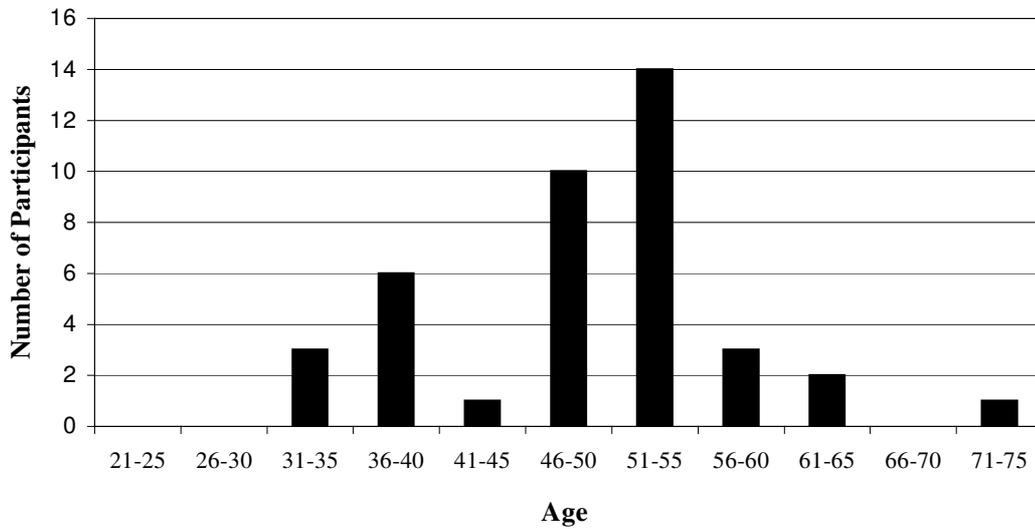
Professional identity of staff participant	Number
Social worker	2
Mental health nurse	5
Doctor	1
CEO	5
Coordinator	4
Policy officer	5
Academic	1
Psychologist	1
Lawyer	1
Advocate	2
TOTAL	27

Table 4: Participant type by gender

Participant type	Male	Female	TOTAL
Licensed Boarding house resident	5	2	7
Former Licensed boarding house resident	2	1	3
Boarding house manager/proprietor	3	0	3
Staff of community organisation	5	10	15
Officer of government agency	4	8	12
TOTAL	19	21	40

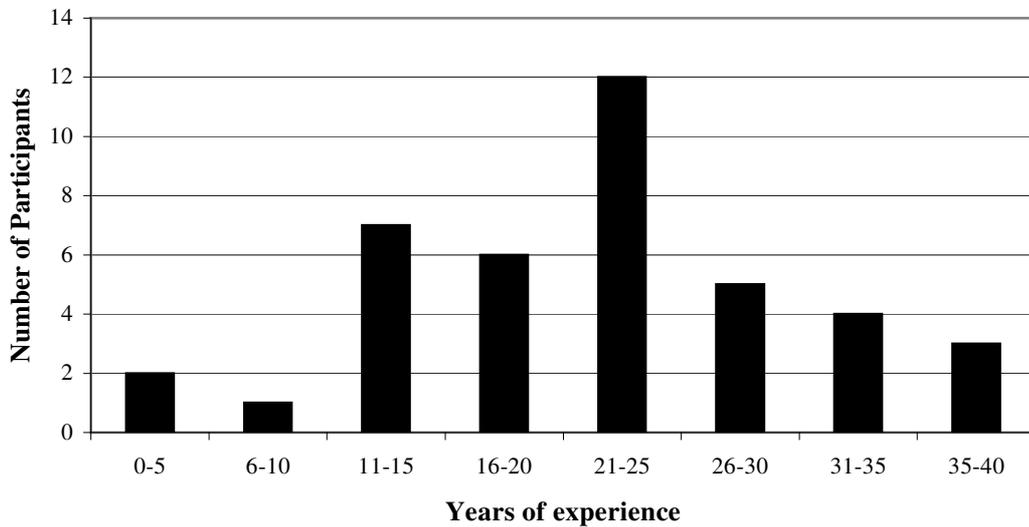
Table 4 indicates a balanced gender representation in the overall number of participants. However, males represent 70% of the resident participants, and female participants represent 66.7% of staff participants of community and government agencies. This gender breakdown is not surprising as most residents of licensed boarding houses are male. Similarly, the gender breakdown for staff participants reflects the high proportion of women working in community work.

Figure 3: Age of Participants



Most participants were aged over 46 years and had significant experience with licensed boarding houses, as demonstrated in Figure 4.

Figure 4: Participant's experience with licensed boarding houses



The majority of participants had more than eleven years experience with licensed boarding houses. Sixty percent of the participants (24) had more than 21 years of experience. Some participants were connected with licensed boarding houses as residents or proprietors during the first wave of deinstitutionalisation in the 1970's.

The collective experience of the participants spans forty years including the implementation of deinstitutionalisation policy, the introduction of boarding houses as an accommodation option, the introduction of a licensing and monitoring framework and various inquiries and investigations. Most importantly, the experience of living in a licensed boarding house has been re-presented.

Ethical Issues

This study required a formal application to Curtin University's HREC for Ethical Approval of Research Involving Humans. The application was approved subject to clarification about how the data would be analysed, how participant's anonymity would be maintained and the provision of written confirmation from support services that they would provide support to participants in 'cases of distress'. The researcher provided a detailed response to the HREC and final approval was granted in December 2007. The approval number for this study is HR 128/2007. Applications for ethics renewal were submitted annually to track if changes were made to the research proposal and whether or not any ethical issues arose since approval was granted.

This research was conducted within the requirements of Curtin University's Guiding Ethical Principles and the National Statement on Ethical Conduct in Research Involving Humans set out by the National Health and Medical Research Council (2007). As a social worker I was also guided and bound by the Australian Association of Social Workers (AASW) Code of Ethics (2002).

This research required careful consideration and management of the ethical issues identified throughout the ethics application process. Some of these included anonymity, privacy and confidentiality, voluntary participation, informed consent, duty of care and storage and security of information. The research also required 'ethical consideration specific to participants' given the study's participants included people with intellectual disability and people with mental illness, as well as people 'in dependent or unequal relationships' (NHMRC 2007). Furthermore, many of the participants were vulnerable to perceived or actual retribution for participating in the research or making adverse comments. This included residents making adverse

comment about licensed boarding houses and proprietors, community organisations funded by government as well as government employees making adverse comment about departmental policy or procedures.

Anonymity, privacy and confidentiality

This research presented significant challenges regarding anonymity, privacy and confidentiality. It was essential to provide participants with the assurance that the information they provided would be de-identified and securely stored.

The majority of interviews were digitally recorded and transcribed. Transcriptions were de-identified by removing personal information including a person's name, address or name of boarding house, phone number, job title and agency. A coding system was developed allocating each participant a number. Transcribed interviews were electronically stored under the participant's number and password protected. A spreadsheet with participant's names and allocated numbers was developed and stored electronically with a different password.

Boarding house residents identified anonymity as a major influence in their decision to participate in the research. Many discussed concerns about eviction or other forms of retribution including threats of violence if the proprietor or manager became aware of their participation. Four of the participants who were boarding house residents declined to have their interview recorded for this reason. While this presented some documentation issues for the researcher, it was heartening to hear the word "no" from people who have lived with a culture of compliance and fear for most of their lives.

Other participants expressed significant concern about retribution if they were identified as a participant of this research. Community workers expressed concern about having funding withdrawn if they were linked with adverse comment about licensed boarding houses or the licensing and monitoring framework. Government employees made similar comments relating to adverse comment and their continued employment. Several government employees from various departments contacted the researcher and requested an interview "off the record". While these interviews would

have provided valuable data, after careful consideration, the researcher declined. Policy pertaining to government employees participating in research, discussing or sharing information or opinions that they have come across in their official duties and roles is clear. Permission must be sought from a delegated officer, often the Director-General. In the absence of this approval, the researcher did not conduct interviews with departmental staff as this would constitute a breach of the Code of Conduct and the participant could be open to dismissal or disciplinary proceedings (ADHC 2010b).

The complexity of anonymity and confidentiality was further highlighted on one occasion whilst attending a boarding house to interview the proprietor. The proprietor took me on a tour of the boarding house. During the tour I was introduced to the residents of the boarding house, including participants of this research. Recognising me, residents approached to say hello while others simply nodded. Fortunately, I was able to engage with the residents in a manner that concealed familiarity.

The need for vigilance throughout all stages of the research process is essential to maintain anonymity and confidentiality. Preliminary analysis of the data identified challenges in describing and reporting information that maintained participants anonymity while balancing the methodological consideration for 'thick description' (Geertz 1986). De-identifying is more than simply removing a persons name, title, or address. A guarantee of anonymity requires the elimination of all distinguishing characteristics. This is particularly significant in a relatively specialised industry. Describing behaviours, quoting certain phrases or a description about how many people live in a room may compromise a participant. Anonymity requires the researcher to be acutely aware of the participant's world and ensure that what is reported or discussed cannot be attributed to the participant.

All participants were provided with a participant information sheet before attending an interview. One of the issues this document addressed was the limits of confidentiality. The participation information sheet stated,

Participants will be provided with information about the limits of confidentiality. For example, if a participant discloses information that breaches law or indicates harm to self or others, I will have a duty to disclose this information appropriately. This might include providing information to the NSW Ombudsman who oversees boarding houses and the ADHC who is the licensing agency (Appendix 2).

During the course of the field research, a participant disclosed information about a resident of a licensed boarding house relating to neglect and physical abuse. The researcher informed the participant of the requirement to report this information to ADHC and the NSW Ombudsman. While there was a clear duty to report this information, the researcher was not required to disclose the source of this information and therefore was able to maintain the participant's anonymity. This information was reported to ADHC and the NSW Ombudsman. A manager from ADHC investigated this complaint and informed the researcher that the department would 'continue to monitor the situation closely'. The NSW Ombudsman referred the complaint to an Official Community Visitor who attended the boarding house and spoke with the resident.

Voluntary participation and informed consent

All participants were provided with a copy of the participation information sheet and consent form prior to attending an interview. This document provided participants with full information to enable informed consent including the purpose of the research, the voluntary nature of participation, and how the data would be used and stored. Participants were provided with the researchers contact details if they required clarification or additional information.

At the beginning of each interview the researcher reviewed the participation information sheet with the participant. Participants were encouraged to ask questions or seek clarification. Once the participant was satisfied that they had full information, they were asked to sign the consent form. At this point participants were reminded of the voluntary nature of participation and that they were able to withdraw from the

interview at any stage. Current boarding house residents were reminded that participation was not linked with the receipt of support services.

As previously stated, the HREC required satisfaction of ‘ethical considerations specific to participants’ (NHMRC 2007) as the study’s participants included people with intellectual disability and people with mental illness, as well as people in dependent or unequal relationships.

In order to determine whether or not a person with intellectual disability or person with mental illness was able to provide informed consent and participate in the research, the following criteria was applied.

- Following the provision of information, in an accessible manner, the resident is able to describe what the research is about and the option of withdrawing from the study at any time. The resident should also be able to describe any risks or benefits of participation.
- Does the resident have a guardian? This includes a public or private guardian? If yes, consent will need to be obtained from the resident’s guardian.
- Consideration of information provided by staff of disability services that have experience working with the resident.
- If the resident is unable to provide informed consent or the person’s ‘guardian’ or ‘person responsible’ does not provide consent, the resident is unable to participate in the study.

The researcher has fourteen years experience working with people with intellectual disability and people with mental illness. The knowledge and skills developed over this time enabled the researcher to augment the communication style and assess whether or not a person was able to provide informed consent. For example, people who have experienced institutionalisation or service dependency can often be

compliant due to perceived retribution (Barnes et al. 1999). It was important to ask open-ended questions in neutral, Easy English.

There were two people who expressed interest in the research that were unable to provide informed consent, and did not have a 'guardian' or 'person responsible' who was able to provide consent on their behalf. Both people were unable to explain what the research was about or the risks associated with participating thus were unable to provide informed consent. The researcher was also aware of the potential for retribution if the proprietor of the boarding house became aware of the residents' involvement. Based on the consent criteria not being met, these residents were unable to participate in the research.

Duty of care

All research involving human participants carries a duty of care (NHMRC 2007). This duty requires researchers to ensure certain safeguards are put in place so that participants do not experience harm by virtue of their participation. The NHMRC's National Statement on Ethical Conduct in Human Research (2007) and the Australian Association of Social Workers (AASW) Code of Ethics (2002) informed the development of strategies to minimise the risk of harm and uphold the researchers duty of care to participants.

The NHMRC's Statement (2007,15) outlined the definition of 'risk' when conducting research with humans.

A risk is a potential for harm, discomfort or inconvenience. It involves the likelihood that a harm (or discomfort or inconvenience) will occur; and the severity of the harm, including its consequences.

The AASW's Code of Ethics defined 'duty of care' (2002, 20) as

The obligation to take reasonable care to avoid acts or omissions which one can reasonably foresee would be likely to injure another.

In addition to the general provisions provided for in the Code of Ethics, the AASW (1999, 20-21) also outlined the ethical responsibilities of social workers conducting research. Some of the responsibilities included:

c) Place the interests of research participants above the social worker's personal interests or the interests of the research project.

l) Where feasible, inform research participants or their representatives of research results that are relevant to them.

m) Bring research results that indicate or demonstrate social inequalities or injustices to the attention of the relevant bodies.

Prior to each interview all participants were informed of the researcher's need to disclose information that indicated harm to self or others, in keeping with the researchers duty of care. As discussed earlier, the disclosure of allegations surrounding the abuse and neglect of a licensed boarding house resident required notification to the NSW Ombudsman and the ADHC.

Risk

The main risk identified in this research was the potential for participants, particularly current and former residents of licensed boarding houses, to become distressed or experience discomfort by participating in individual interviews. These interviews could reasonably include discussing histories of abuse, isolation, grief and loss.

The risk of harm to participants was minimised in the following ways:

- Two community organisations that provide services to people living in licensed boarding houses were approached to provide advice, information, referral and support to resident participants. These organisations provided written confirmation of their support to Curtin University's HREC.

- Initial meetings were held with resident participants for the purpose of my introduction and to discuss the research. It was essential to develop rapport with residents prior to the interviews and demonstrate a genuine interest and respect for their lived experiences (Liamputtong 2007).
- Participants were advised of their ability to withdraw from the study at any time.
- Participants were encouraged to have a support person present at the interview if preferred.
- The researcher is a professional social worker, with fourteen years practice experience with people with intellectual disability and people with mental illness. The researcher has the essential skills and knowledge to provide immediate support and referral to participants if required.

Storage and security

The anonymity of participants was critical to this research and consequently the following multi-tiered approach to storage and security was applied.

- All paper based information including signed consent forms and diaries were stored at the researchers home in a locked filing cabinet.
- All electronic files including analytic notes, digitally recorded audio files, transcripts, data contained in NVivo8 files were password protected on the personal computer of the researcher.
- Electronic data was also stored on an external hard-drive, which was password protected, and kept in a locked filing cabinet at the researchers home.

- All participants were assigned a participant number. This number was used to store audio files, transcripts and entering data into the NVivo8 software for analysis. All identifying features including name, role and agency details were removed and replaced with the allocated number. A list of participant's numbers and corresponding names was stored separately and password protected. It was important to collect this information in the event that a person required referral to support services.

The above data storage provisions were developed in consultation with Section 2 of the Joint National Health and Medical Research Council (NHMRC 2007), Australian Vice Chancellors' Committee (AVCC) and the Australian Research Council's (ARC) Statement and Guidelines on Research Practice.

Making meaning of data

Following each interview field notes were completed including 'analytic notes' (Neuman 2000). These notes recorded initial impressions and themes that emerged from the interviews in relation to the overarching research question.

The digitally recorded interviews were transcribed and checked for accuracy by editing text as well as seeking participant's feedback and endorsement. Once transcriptions were endorsed, the researcher randomly selected three transcriptions and conducted some preliminary data analysis. Each transcript was read several times and then thematic codes allocated to words, phrases or paragraphs.

This preliminary data analysis was presented to a focus group, comprising people external to the research, representing a variety of backgrounds. The group was provided with a de-identified copy of each transcript. Using a data projector the group was asked to analyse each paragraph and code by theme. After each transcript had been analysed, the group compared their thematic analysis with the researchers coding of the same transcript.

Although this was an arduous task it was important for several reasons. The researcher came to the research with a particular lens concerning whether or not licensed boarding houses are an appropriate accommodation option for people with

intellectual disability and people with mental illness. The researcher was committed to accurately reflecting the findings of the study, not simply finding data that matched or supported the researcher's lens.

Secondly, the research was conducted in Sydney, external to Curtin University based in Perth. The researcher had ongoing access to supervision via phone, email and video teleconferencing. However, the use of the focus group to check coding verification applied an additional layer to demonstrate trustworthiness and dependability (Sarantakos 1998).

As Neuman (2000, 420) pointed out

Coding data has a different meaning and role in qualitative research. A researcher organises the raw data into conceptual categories and creates themes or concepts, which he or she then uses to analyse data. Instead of a simple clerical task, qualitative coding is an integral part of data analysis. It is guided by the research question and leads to new questions. It frees a researcher from entanglement in the details of the raw data and encourages higher-level thinking about them.

The researcher used the feedback from the focus group and analytical notes to improve the thematic coding of the text.

The next phase of data analysis involved uploading transcripts and audio recordings (the use of a digital dictaphone enabled the researcher to save audio files electronically) into a software program called NVivo8. This software is specifically designed for the analysis of qualitative data and enabled the researcher to classify, sort, arrange and perform textual searches.

Using the software, the researcher categorised participant interviews under sources. Each participant had a separate file, which contained his or her de-identified interview transcript and audio file. The researcher critically read through each transcript and identified themes from the text and allocated a theme code (known as a 'tree node' within NVivo8). For example, the following transcript excerpt was

highlighted and a node 'communal washing' was created. This node was linked to the participant's file and number. If another participant identified this theme within their interview their text was linked to the original node. The researcher then reviewed the tree nodes and collapsed them into conceptual themes. For example, the tree node 'communal washing' was collapsed into the theme 'institutionalised practices'. NVivo8 provides the ability to identify trends by theme.

Participant 2, Community Organisation

There have been boarding houses that have communal washing. They just hand out underpants. Here's a pair that will fit you. Can you imagine? I just think that that is the most degrading thing. It is just appalling. And there have been places where you didn't get your own clothes back...And towels. Wet towels. Homecare have had to do a lot of complaining because there are not enough clean towels or dry towels...What gets me is why can't they buy them for the residents?

The software also provided for the creation of 'cases', which are linked, to the participant's number and file. The researcher developed a case profile on each participant, which identified the participant's gender, age range, participant type (e.g. licensed boarding house resident), professional identity and years of experience with boarding houses.

Using the software program the researcher was able to identify patterns in the data, which are presented in Chapter Five: Findings.

Chapter Five: Findings

Chapter Five presents the findings from the fieldwork of this study. These findings have been sourced from forty interviews including ten unstructured interviews with seven current and three former residents of licensed boarding houses; three semi-structured interviews with proprietors of licensed boarding houses; and twenty-seven semi-structured interviews with staff of community organisations and government agencies in Inner Sydney.

The findings included participants' views as to the main values underpinning deinstitutionalisation and the outcomes of the implementation of this policy. This chapter includes participants' exploration of the extent to which licensed boarding houses uphold the principles of deinstitutionalisation and contribute to the quality of life of residents. It also explores what are identified as the main challenges facing the licensed boarding house sector and recommendations for change.

The findings are presented within major themes as identified through data analysis supported by the application of NVivo8 (software designed for the analysis of qualitative data).

Deinstitutionalisation

The first part of the semi-structured interviews with staff of community organisations, government agencies and licensed boarding house proprietors concentrated on deinstitutionalisation. These questions achieved two goals. Firstly, one of the objectives of this research was to document the history of deinstitutionalisation in NSW. The information provided by participants added an experiential layer and complemented information sourced from literature and policy documents. Secondly, the sequencing of the questions enabled participants to explore

the use of licensed boarding houses as an accommodation option within the policy framework of deinstitutionalisation.

The unstructured interviews with current and former residents of licensed boarding houses explored people's experiences of living in large-scale, geographically isolated institutions and their experiences of living in licensed boarding houses. Three former residents were able to discuss their experience of life after leaving a licensed boarding house.

Some participants queried why deinstitutionalisation was still being discussed and researched now in the twenty-first century. They considered the policy to be discourse of the 1960's and 1970's and didn't consider it to be a current policy. However, when these participants considered current policies such as the ADHC's 'Devolution' policy they claimed, "they've just changed the name". Other participants asserted that deinstitutionalisation is a contemporary policy and is just as pertinent as it was at the time of its inception in the 1960's and 1970's given that there remain many people living in institutions, particularly people with intellectual disability in NSW (NSW Ombudsman 2010).

Participants discussed current challenges to deinstitutionalisation policy and discourse including the NSW Government's recent cluster-housing developments and capital upgrades to institutions (ADHC 2009; PWD 2009). They also spoke of families of people with intellectual disability and people with mental illness who had expressed a desire to maintain institutional models, as they believed that deinstitutionalisation had failed them and their family member with disability or illness.

Overwhelmingly, participants considered deinstitutionalisation to be a sound policy however felt that the implementation of the policy had been unplanned and under-resourced.

What are the main values that underpin deinstitutionalisation?

Self-determination and choice

Self-determination and choice were identified as two of the main values that underpin deinstitutionalisation. Many participants had either worked or lived in large-scale, geographically isolated ‘Schedule V’ hospitals in Inner Sydney. These participants recalled the relentless routines and structures of the hospitals, which afforded no consideration for individual preferences, always focusing on ‘the groups’ and often staff’s needs. Participants believed that deinstitutionalisation was to be the antithesis of hospital and institutionalised practices, primarily focusing on people’s right to self-determination and choice.

It is about self-determination and choice and having control over the decisions that affect your life. Having individualised services as opposed to being treated as a group in a congregate setting (Participant 3, Community Organisation).

It’s about people having choice and people living in the community...It’s about people making choices about where they want to live, who they want to live with and doing the activities they want to do and generally when they want to do them. Learning to live within the community (Participant 40, Community Organisation).

Citizenship, community integration and participation

The other major values identified by participants included citizenship, community integration and participation. Participants believed that a central tenet of deinstitutionalisation was recognising people with intellectual disability and people with mental illness as citizens. This recognition afforded people the rights (and responsibilities) of other citizens including the right to live and participate in the community with access to support. Living in the community was considered to be more than being out of hospital; access to participation rather than simply having a presence was emphasised. This theme is discussed later in this chapter and Chapter Six.

I think certainly for me the central theme of deinstitutionalisation is that notion of community citizenship. So it revolves around accepting the person as a citizen and this needs to be individually defined rather than institutionally defined. There are demonstrable elements that are within institutional care that take from the individual the capacity to be able to approximate participation and integration. Deinstitutionalisation is a process of removing that institutional set of elements (Participant 23, Government Agency).

First and foremost it is about people having a right to live in and participate in the community and it is also about people having a voice and the ability to live a normal lifestyle (Participant 11, Community Organisation).

I suppose the objective was to create opportunities for people to live in mainstream communities and neighbourhoods and participate in community life in the same ways that everybody else does rather than being shut off in closed institutions (Participant 16, Government Agency).

Catalysts for deinstitutionalisation

Some participants also discussed the catalysts for change that enabled or motivated deinstitutionalisation. One participant identified new social theories including those of Goffman (1961) and Wolfensberger (1972) as important influences on the development and implementation of deinstitutionalisation policy. These accompanying discourses questioned the use of institutions as a social policy response for the 'care' and 'treatment' of people with intellectual disability and people with mental illness (Goffman 1961).

Literature started to emerge about no longer needing to have these big institutions. The culture of institutions is negative and not desirable, so therefore people should be cared for in the community... It was seeing institutions as not an appropriate place and not good for people with a range of disabilities to be living (Participant 19, Community Organisation).

Two participants (both mental health nurses) discussed the role of pharmacological advancements in enabling deinstitutionalisation.

From a clinical treatment point of view it was an advancement because of the introduction of psychotropic drugs. People embraced the concept that people who were given these drugs could be managed. They no longer had to stay in hospital. So therefore if you don't stay in hospital then you should be out in the community (Participant 8, Government Agency).

The other thing that people have forgotten is that during the 60's the pension was being given to people with disabilities and people with a mental illness, where in the past people did not get the pension. Once they got the pension and their condition could be controlled or managed by the medication, the hospital felt that they should go out, no longer be kept in hospital (Participant 19, Community Organisation).

Surprisingly, only a small number of participants identified 'fiscal motivations' as an enabler or catalyst for deinstitutionalisation. Within the literature 'fiscal motivations and efficiencies' is emphasised as a major influence for deinstitutionalisation (Scully 1977; Warner 1979; Grob 1995). Participants of this study tended to focus more on how neo-liberalism, particularly the shrinking welfare state and the privatisation of state services influenced the implementation of deinstitutionalisation and the lack of community-based resources and investment that followed (Henderson 2005).

What I think it's about is reducing the cost of health care and it's cheaper for the government (Participant 2, Government Agency).

Saving beds. Saving money. It's always about money (Participant 33, Community Organisation).

What do you consider to be some of the positive and negative outcomes of deinstitutionalisation?

Exposure of abuse

Several participants identified the exposure of abuse in institutions as a positive outcome of deinstitutionalisation. This included neglect, physical, sexual and psychological abuse. It was acknowledged that abuse continues in smaller accommodation options, such as group homes, however it was believed that the presence of group homes in the community and various monitoring frameworks provided some safeguards from institutionally sanctioned abuse and opportunities for reporting and action.

The other big positive is that all empirical and anecdotal evidence over the past 50 years has shown that institutional living takes away the choices but it also leads to abuse. Empirical evidence shows that it doesn't matter how well the institution is run, how kind hearted people are, church-based, charity-based, invariably you end up with people being abused in institutions. And that is a reality of life in institutions. So perhaps the biggest plus for deinstitutionalisation was that people stopped having their human rights abused (Participant 40, Community Organisation).

There is still abuse in group homes and other forms but because there is so much outside intervention and involvement with the community it is less likely to be reinforced internally within a contained environment (Participant 10, Community Organisation).

Personal autonomy

Another positive outcome of deinstitutionalisation was considered to be personal autonomy. Participants described this concept in relation to the opportunity for personal freedom having been 'released' from locked wards and moving beyond stone walls into the community. Participants described opportunities for some people

to make choices about how they spent their day. Deciding what time to get up; choosing whether or not to have sugar in coffee; deciding whether or not to take medication; deciding what time to have meals and with whom; deciding who to share a bedroom with. However, several participants believed that personal autonomy had been compromised by the lack of support provided to people following arrival in the community.

I think it gave them the opportunity to eat their meals when they wanted to, sleep when they wanted to, go out when they wanted to...conceptually there were opportunities to mix with more people. I think we have found that people needed support to do that (Participant 15, Government Agency).

Living in the community

Many participants believed that the ability for people to leave large-scale, geographically isolated institutions and live in the community was one of the main positive outcomes of deinstitutionalisation. One participant commented that deinstitutionalisation is often described by what it did not deliver, which the participant believed was a fair assertion. However, this participant commented that the closure of large institutions was a radical policy shift against centuries of confinement and the ability for people to live in the community should not be understated.

People were afforded their fundamental human rights to live in the community like everybody else (Participant 16, Government Agency).

One of the positives of course was the formal breaking down of large hospitals and other institutions, which meant that there was a hidden population that now became visible. And so in terms of being able to bring about reforms about normalisation they were a much more visible population. Of course a percentage of them disappeared back into institutions like boarding houses so then negated somewhat that positiveness. I think for a lot of people with a disability the movement to individualised programs such as the HASI program or other disability programs was only possible because

of the breakdown of the institutions and that was a positive shift in the consciousness (Participant 23, Government Agency).

I guess some of the positives are that people are not locked away behind big stone walls. It's actually recognised who the people are and the impact of the illnesses that they are actually living with. So it's more about them as individuals rather than being totally locked away. So I think that's probably the positive, that you haven't got them on segregated land behind walls (Participant 5, Community Organisation).

Lack of planning and resourcing

Many of the participants commented that deinstitutionalisation was a sound policy founded on human rights principles, a belief that people had the right to live and participate in the community. However, many participants found the implementation and resourcing of the policy to be severely lacking.

We are judging deinstitutionalisation as a concept and as an activity by the way in which it's been implemented and I think that's a mistake. In 1981 the International Year of the Disabled Person we were working on the Richmond Report and we were deciding that deinstitutionalisation was the way to go and the way it was implemented was by emptying institutions but not necessarily at the same time creating other options and supports for people coming out of institutions, as well as maintaining the institutions appropriately until they closed. And providing options for people who would not go into institutions but required support. In my opinion we didn't do that well and it was badly planned nor did we make the appropriate investments in those supports. So now I believe we are judging the concept and the activity of deinstitutionalisation by its poor implementation in the 80's and 90's and even the 2000's...That is the failure of implementation rather than the object (Participant 10, Community Organisation).

Almost all of the participants discussed the lack of adequate planning and resourcing of deinstitutionalisation policy, which is a consistent theme throughout the literature (Scull 1977; Jones 1993; Warner 1989). Participants described former patients leaving ‘Schedule V’ hospitals in Inner Sydney with no mental health care plan or referrals, unstable accommodation and no support services. Several participants asserted that ‘the state had failed these people’; ‘it had set them up for failure’.

The premise is that the model that they were in before was not a good model but it was better than what happened to them when they went into the community but nothing went with them (Participant 1, Government Agency).

I think from the mental health perspective it went wrong in that Richmond was only partly resourced...and so you ended up with a whole load of people losing the supports they did have in the hospital system without the replacement support (Participant 11, Community Organisation).

Nothing was set up. No one was referred to community mental health. In fact community mental health barely existed at that point in time. So everybody fell through the gaps (Participant 12, Community Organisation).

The government sold off large institutions and sent these people off into the community without any support, accommodation and no one looking after them and this is why people ended up on the streets and other places where they don’t want to live (Participant 40, Community Organisation).

I mean the tragedy is that it was driven by passion and not enough planning. And not enough forward thinking to follow it through and so that in itself is damaging to a very good cause and that’s a problem. The Richmond Program inherited a very bad name unfairly (Participant 19, Community Organisation).

I am not sure enough has been done to consider the changes for some people when they’ve been in institutions for a long time, the learned helplessness and hopelessness (Participant 5, Community Organisation).

The acute units in public hospitals are probably ok for people who only require short admissions but for anyone that needs an extended stay I don't think they are particularly well suited for that. They are too confined. Often it is just one floor on a multi-story building and people feel like they can't get off it. They are much more confined. The security requirements are such that they are locked in...For people who require a longer term rehabilitation they need slightly more specialised arrangements and they won't get that in an acute unit in a public hospital (Participant 16, Government Agency).

What I think it's about is reducing the cost of health care and it is cheaper for the government...We knew enough 20 years ago that if people were just dumped out into the streets they weren't just going to recover from their illnesses and start jobs 9-5, Monday to Friday. Where were they supposed to go? So the boarding houses provided an economic opportunity for people who had enough money to buy big houses back in the 70's and 80's. Deinstitutionalisation in theory is about getting people out of the institutions. I think they thought if people came back into the community they would be re-integrated but they haven't been because they have been socialised and institutionalised to be sick and be dependent and even now I have a client who has only recently come to X. She went into hospital when she was 14 and she is now in her late 40's and she has been out for two years. Developmental losses. You can't just integrate back into society when you've been outside of it for so long and the behaviours you pick up in hospital...When you're out on the street they increase your stigma and identify you as a person with a mental illness and yet they've often got nothing to do with the mental illness. I think in theory it was a good idea but they didn't give it enough money (Participant 21, Government Agency).

You have to threaten to hurt someone or have hurt yourself; even people who have attempted suicide are discharged that night without us knowing. They will go to hospital; somebody else calls the ambulance. We find out from the other clients that they have overdosed, stomach pumped and back home. I mean there are just no beds and you can't get people in and that's really problematic when people are unwell and that is becoming increasingly

difficult...I think the pendulum has swung too far in that we can't get people into hospital. But I do think that it is good that people are living out of the institutions in a normalised setting. I do think they are good results for people lucky enough to be in a community-based program (Participant 17, Community Organisation).

One of the major problems was psychiatric hospitals referring people into boarding house who really weren't well and their mental health issues weren't stable and that was one of the reasons we tried to set up a kind of gate keeping process because these people were literally being dumped out of psychiatric hospitals. There was this pattern emerging over a decade where people would come into a psychiatric hospital being acutely unwell and the hospitals would fill them full of drugs just to take the edge off and then turf them out again and rather than turn them out onto the street they would put them in boarding houses which to a large extent would amount to the same thing (Participant 16, Government Agency).

Stigma

Further to the lack of planning and resourcing discussed above, several participants discussed the lack of preparedness of the community. Against a background of centuries of confinement and separation from the community there is much misinformation and fear about what it means to be a person with intellectual disability or a person with mental illness (Barnes et al. 1999; Goffman 1968; Meadows et al. 2007). Many of the participants believed that the state did not prepare the community or facilitate integration by providing the community with information and support. Living with the label of 'former patient' or person with intellectual disability or mental illness carried and continues to carry great stigma (Gray 2008).

While the hospital was very keen to let people out in to the community, the community isn't very keen to have people out...The community was very ill-prepared and you are confronted by two things; the non-acceptance of the community and the under-preparedness of the community to provide support (Participant 19, Community Organisation).

People with disabilities are seen as 'other', they are not seen as 'us' and the reason for that is that in a general life course everyone expects to be old so 'they' are 'us' but at another time. Everyone can relate to being a carer of a person with a disability or an older person because they're not the older person or a person with a disability but you could find yourself with the care of someone with high support needs and you could imagine what that is like. But no one can imagine what it is like to become or to be a person with disability. It's not part of ones life plan or imaginings. And so there is still this 'otherness' about, in much the same way as racism, it's 'other' so it doesn't really count. We have made great gains in moving people with disabilities into the community because people with disabilities are known and seen. It doesn't mean they are accepted yet (Participant 10, Community Organisation).

Unfortunately, while they strive to get people out, there are people outside driving people to keep them in because of the non-acceptance and stigmatisation and lack of service. So there are conflicting forces in that process (Participant 19, Community Organisation).

Boarding houses as an accommodation option

Transinstitutionalisation

Almost all of the participants, including proprietors, considered licensed boarding houses to be an institution. However, within this accord there were a variety of positions about whether or not licensed boarding houses were preferable compared with previous types of institutions such as large psychiatric hospitals, isolated from the community behind stone walls.

Five participants believed that licensed boarding houses were an improvement compared with isolated psychiatric hospitals. These participants comprised three proprietors and two participants from community organisations who had been involved with licensed boarding houses and 'Schedule V' hospitals from the 1970's.

These participants considered that licensed boarding houses provided residents with more freedom, autonomy and independence compared with psychiatric hospitals. To this extent some participants considered that licensed boarding houses upheld the principles of deinstitutionalisation which related to being located in the community, having moved through the physical barrier of stone walls and locked wards. However, most of these participants believed that although licensed boarding houses were ‘better than being in hospital’ they did not reflect contemporary standards.

As you can imagine it was from institution to institution. I can call myself an institution because people live here for good but it is better than the hospital institution. With the hospital institution you have restrictions and you have got to do what you are told and you have the sister coming in. People here are free. You can come inside and go outside (Participant 26, Boarding House Proprietor).

They become more institutionalised than when they left. So there's been no improvement in the quality of life. At the end of the day it's just another institution in the community. The only thing is it's changed location (Participant 12, Government Agency).

Yes, people would say and I would agree that an institution is as much a building as it is a state of mind. Look, locking people up like we used to in places like Gladesville Hospital or Macquarie and Rozelle, it never was great and sure there are other problems when they moved into the community and boarding houses were not the best option for those people, but they were a better option than what they were in. They're not wonderful but they are actually a bit better. People would exercise a bit more independence. Probably their parents or some of their relatives wouldn't agree with that statement, saying that it's better for them to be in the institutions as they are very well organised and the rest of it (Participant 8, Community Organisation).

These boarding house managers and owners saw an economic opportunity... The residents are often living in squalor and crowded and even though I know that the law says, 'one metre between beds' or it used, to I always take the attitude that I wouldn't like it so why would I expect anyone else to do it and I think some of these Parliamentarians should come and live in one, not for a week, for a couple of months. Getting all your clothes washed together even though they're not supposed to. We seem to have different expectations for the mentally ill and the socially marginalised than we have of general society and yet when we talk about recovery and rehab we say that everyone is the same. Everyone can get better and adapt to their different circumstances, they should be able to live to the best of their abilities (Participant 21, Government Agency).

Well certainly boarding houses aren't the environment where you would develop independence or individuality. It's better than in a hospital where clothes are being issued to you like a concentration camp. But nonetheless there is a glimmer of individuality. Not a lot but it is slowly moving on to the modern day approach. But at least they are in the community and at least they're not locked up. At least they have the opportunity to go out and mix with the community. To go to the shops, to go to centres and do things. They might not have a lot of money left over with the boarding house proprietor taking all the pension...They can wander around the community, much to the displeasure of some community members (Participant 19, Community Organisation).

There is congregate living. There's up to five or six people living in a room in some places. Occasionally there are people having their own bedroom. There's shared bathroom facilities. Out of thirty people living in a premises there might only be two or three bathrooms, so up to 10 people sharing a bathroom. There is a communal kitchen area and eating area. There is often only one recreation area...The outside area usually consists of just seats. You could pick the boarding house if you were driving down the street. It was a place with a number of seats out the front, for people to sit around and

smoke...The other thing you will find is that they are mini-institutions, there is institutionalised behaviour (Participant 40, Community Organisation).

Yeah I always think it is an interesting thing describing a boarding house...well it is congregate. There are a number of people accommodated in the one address that are unrelated. There are some similarities in that by and large most of the people have a disability of some kind...That dynamic creates an environment that has to, by virtue of its congregation, operate to particular regimes and rules that eventually extinguishes the capacity for individuals to express themselves within that environment or interact with the outside world without reference to that environment. So when you describe it to somebody you're describing a picture of sameness, routine and an environment that increasingly becomes the central point that the person refers to in their life to define themselves in relation to their self worth and ultimately an environment that takes on almost tactile disadvantage and incapacity in relation to the individual participating in the broader community around them (Participant 11, Government Agency).

Usually you walk in and it's quiet, sterile sometimes. Faded pictures on the walls that appear to have been there for a long time. Narrow hallways and always for some reason a bit darkish. Lino. Large kitchens. Sitting around. In some boarding houses sometimes lounges. Smoking, nearly always smoking, there's nothing else to do. The TV or radio is often on in the background somewhere. There might be a courtyard with people sitting out in the full glory of the sun without a hat or sunscreen on, smoking away. People are isolated, not talking. They just sort of sit beside each other and stare at the TV. They don't look at each other. It's lonely and isolated and dark. If you go into the rooms they are always a bit stale; they are dark; small; the beds might be made but they are narrow with a very small table or bedside chest of drawers that they can put a few things in. There might be an ashtray on top, not that there is supposed to be (Participant 21, Government Agency).

We have to do better. We have to ensure there are more choices for people and more flexibility, not just slot people in because there is a space. Are boarding houses better than living in a hospital back ward? Yes. They have a bit more freedom but you can't say that it is enough. People need more than that (Participant 14, Government Agency).

One participant asserted that licensed boarding houses played a 'crucial role' in the implementation of deinstitutionalisation. This participant believed that without boarding houses many people would have remained in 'Schedule V' hospitals and would not have returned to live in the community.

Without these boarding houses I don't think deinstitutionalisation would have happened so quickly as what we have seen... I think to be very fair boarding houses played a very important part in the development and without that I don't think many people would have been discharged from hospital in the 70's and 80's (Participant 19, Community Organisation).

A significant majority of participants believed that licensed boarding houses do not uphold the principles of deinstitutionalisation. Of these participants, many emphasised that deinstitutionalisation 'was more than just being in the community'. For these participants the principles of deinstitutionalisation extended to participation in the community rather than simply a presence (O'Brien and O'Brien 1987). These principles also included non-congregate accommodation options, choice and independence.

Boarding houses and their residents, while they are located in a neighbourhood, don't experience that connection or belonging. A structure simply existing within a neighbourhood doesn't by virtue automatically mean that the people in that structure belong in the community. Boarding houses are not really any different from traditional institutions, which was the focus of deinstitutionalisation, as they are still segregated and still isolate people. They are largely congregate facilities where large numbers of people are co-located together without alternative options and the only thing that brings

them together is their disability and the fact that they have no other choice of anywhere else to live (Participant 3, Community Organisation).

Several participants believed that licensed boarding houses were an inferior accommodation option compared with isolated psychiatric hospitals. These participants considered that licensed boarding houses had less accountability mechanisms and did not provide the level of health monitoring that was provided in ‘Schedule V’ hospitals. One participant also noted that licensed boarding houses in NSW could be larger and have more residents than psychiatric wards.

The person is no longer formally institutionalised but then becomes informally institutionalised with the same effect but without the same degree of accountability that might relate to being in a state organisation (Participant 23, Government Agency).

Boarding houses of 100 people were not what the institutions were. The wards never had more than 30 people. There were never 100 people even when I started in 1970. No wards had more than 30 people (Participant 12, Government Agency).

Institutionalised practices

Almost all of the participants considered boarding houses to be institutions with some describing the use of this type of accommodation as transinstitutionalisation. Many of the participants believed that boarding house managers and proprietors continued to use ‘institutionalised practices’ in managing their licensed boarding houses. Such practices do not uphold the human rights principles of deinstitutionalisation (Bigby and Frawley 2010; French 2009; Johnson 1998; Willer and Intagliata 1984). Participants attributed these practices to three main reasons. Firstly, several of the boarding house proprietors were previously psychiatric nurses in ‘Schedule V’ hospitals and have not received additional training, with the exception of some disability awareness training, since the 1970’s. Their current practice models do not reflect current ideology and recommended practices regarding

disability or mental health and illness; rather they reflect the practices of staff and management of the 'Schedule V' hospitals. Some of these practices included responding to a bell to line up for meals or lining up for medication.

The story is that psych nurses who were already in the system, who knew how compliant these people are, decided that this was the way to make a lot of money. And they went out and bought up the big houses or rented them around Stanmore, around the Inner West, in the Blue Mountains, around Lake Macquarie; the big old guest houses in places up there and they simply got busloads of people. They emptied wards. As far as we can work out they transported them ward-by-ward and dumped them in these places and closed the doors (Participant 15, Community Organisation).

Ex-nurses were dissatisfied with the institutional setting so they branched out. They saw this opportunity...And there were even suggestions of corruption that for every- we called it human farming at the time- for every patient that goes to a boarding house certain people who were able to initiate that would get a payment (Participant 12, Community Organisation).

At one boarding house, on a number of occasions I witnessed medications being handed out and it was always at a certain time and they all queued down the hallway. At that same boarding house I have witnessed when the doctor was there and people were getting their injections for their mental health issues and they were queuing down the hallway, and they were literally dropping their pants down the hallway waiting to have their injection to save time; they're the degrading parts of institutionalisation. The trade in cigarettes, the behaviour of people sitting around doing nothing, absolutely nothing, with literally nothing to do all day. You would be there at nine o'clock and there would be people sitting around and they are sitting there three hours later. They get up and go and have their meal and come back to the same seat...Because their mental health issues aren't being addressed properly, just walking around in circles, around and around the same circle for 4-5 hours throughout the day. So they're the types of institutionalised behaviours that you would see (Participant 40, Community Organisation).

I'd be there often for breakfast or lunch or dinner and there was a bell rung. They always sat at the same seat everyday. "That's my seat". Other boarding houses there isn't enough room for them to all sit down at the same time so they have to have it in shifts. The first bell, "If I don't get fed in the first bell I will go for the second". It reminded me of Oliver. People lining up for their food, getting a pile of slop thrown on it in the spot they've always sat (Participant 13, Community Organisation).

Ticking people in and out of the dining room and I thought what am I doing this for? Horrified. You would count people in and count people out and it was not uncommon to bump people into the seclusion room, stuff like that. It was incredibly draconian. I see boarding houses as being the most vile aspects of that draconian system. I'll never forget the first time I went into one and it was lunchtime and I saw a slice of bread, white buttered bread at the bottom of a bowl with one scoop of baked beans and I looked at it and that was lunch. No fresh fruit, nothing. But that system of counting cutlery in and out, and counting people in and out and having no choice and no say, it was just like being back at Rozelle. Big pots of tea with sugar, regardless of whether you want sugar or not. Regardless of whether you want milk or not. And it's all still there and it's the most draconian aspects. I saw that regularly in the boarding houses and the licensed boarding houses. It's so disrespectful, denying you of any rights whatsoever (Participant 11, Community Organisation).

There are certainly a lot of paternalistic approaches to providing support. There is still a custodial approach, it isn't a rehabilitative approach. So therefore, and in honesty, I think a lot of them in good faith think that they are doing them a favour. They truly believe they've got to watch them. "If you don't do this they will end up back in hospital". Medication compliance is a major factor in mental illness, as you know. Boarding house proprietors would mix medication in residents orange juice to make sure they had their medication and of course it's good luck to you if you get your medication, sometimes you ended up with somebody else's medication. But there are some proprietors that will tell you, "I watch them. I make sure they take their

medication. They won't take it but what I do is I crush it and I put it in their orange juice and then make them drink it". But if you talk to them they think it is caring and the thing to do. They honestly and truly believe they are doing a good job. "You can't give them all the money. If you give them all the money they will go and smoke it away so we keep it for them so we stretch it out for them, it's all very good". But it doesn't promote a learning environment; it's not an environment where a person gets the benefit of rehabilitation and recovery. None of this (Participant 19, Community Organisation).

Secondly, participants believed that the model of accommodation also influenced the use of institutionalised practices. Participants believed that a congregate model of care whereby a large number of unrelated people are co-located together relied upon structures, routines, efficiencies and group management strategies. Participants described such practices including the communal washing of clothes, rows of seats rather than clusters that could facilitate conversation, dormitory style bedrooms, scheduled meal times and locked kitchens.

There would be communal washing. There would not be individual clothing- so people did not own their own clothes. I've seen a cupboard where the underwear is kept and people go and get underwear. Often it is males. Predominately people living in boarding houses are male. So they just pull out any underwear, so yeah it's not their own underwear. The towels would not be their towels. The sheets would not be their sheets and the pillowslip would not be theirs. It would not be their shirt. It would not be their trousers. So that still does occur in some cases (Participant 40, Community Organisation).

Some have very strict routines and I think some are a bit more flexible...One of them is very controlling. Breakfast is served at a certain time; lunch is served at a certain time. They can be quite strict. When I first went into one of them at 4:30pm they were all lined up in the hallway and I wondered what's happening here and then I realised that they were lining up for medication and dinner at 5pm. They do have quite firm structures. Some houses if you

don't turn up for any meal that will be it, you won't get anything. To be able to get a cup of tea, that varies between houses and between residents. So some people might have access to a kettle and tea or coffee or to make something. Some will be sold the tea or coffee to make it and some won't have access at all. So there doesn't seem to be much rhyme or reason to it. It does seem to vary and then you can go to another place and morning tea is always at 10am. It's percolated coffee so they don't have to have it there and then, it's put out and stays there and people can get it when they want it... The thing that is not seen is the psychological side. They can polish the places up and have them looking good. I can think of one manager that is very proud of his place, he was on the 7:30 Report and it was a couple of years ago. And the residents couldn't believe it when they saw the sandwiches coming out; they'd never seen that sort of food. He obviously knew the film crew were coming in... Stuff goes on in that house. It's the underlying stuff, the tension. It's not blatant until you get to know what's going on and very difficult to live under (Participant 16, Government Agency).

Not being able to have your own underpants, you don't exist as a person. You are just a thing. It's shocking (Participant 11, Community Organisation).

In those early days you've got to remember who ran these boarding houses and they were often run by people who had a career in institutions and so they were run not unlike the ward of an institution. They were regimented, some in particular, some were worse than others...they certainly did not uphold the values of deinstitutionalisation, it was more a case of trans-institutionalisation. The urban based, smaller boarding houses probably offered more freedom for the residents, focussed a bit more on linking people to other service agencies and opportunities for community integration but there were a lot that didn't...Boarding houses are most certainly a mini-institution there are no two ways about that (Participant 19, Community Organisation).

According to the boarding house managers it's meeting the legislative standards. They seem to get around it though. Some of the boarding house managers, I guess some of them are quite nice people in their own ways but it's that attitude that this is the best option for them when they could be improving their quality of life. One boarding house manager doesn't have lounges because the clients might lie on them. I lie on my lounge and I'm sure he lies on his lounge. And in saying that he is othering the residents. It's that transition from 19th Century to a more 21st Century type of thinking (Participant 21, Government Agency).

Finally, participants identified the 'for-profit' nature of licensed boarding houses as influencing the use of institutionalised practices. These practices are driven by a business model that relies upon efficiencies of scale at the cost of care standards, human rights and indeed even human life (O'Faircheallaigh et al. 1999). These practices included having untrained staff, paying residents with cigarettes to complete chores, cleaning or maintenance and reusing tea bags.

The better run ones are the smaller ones. To me it's common sense. If you only have eight or ten people at a place it is easier to treat people like individuals than if you have 30 plus people... I think it comes down to the fact that they're not as large as others and they also have managers, they've got onsite managers that have some training and skills and aren't 100% profit driven because they are getting a salary and they don't have to balance a budget. It's a job not their livelihood. So those two were considerably better than some of the other places. The quality of the food was better, people were generally treated a lot better (Participant 40, Community Organisation).

Boarding houses are for-profit businesses so at the end of the day they're there to make money. Some of them might have a bit of interest or a little moral obligation but in general no, they're running a business (Participant 5, Community Organisation).

In funded disability services there are frameworks about how you employ and continue to train staff but in boarding houses that framework is not there. It is a challenge in that the structure doesn't lend itself to promoting individual choice or the independence of individuals. There are few resources to provide adequate supervision and support and individualised programs for people. And that's partly because it is a for-profit industry and their main driver is the owner making money and so that is the first priority as opposed to the needs of the people with disability who live there (Participant 3, Community Organisation).

And I guess if we look at what the state was doing, essentially for a raft of reasons, but the end product was to privatise back wards of hospitals and the way they privatised it was to re-create the back ward in the community and that opportunity was seized on most vigorously by a lot of people working within the institution. They saw an opportunity to have their own business but keep the same personnel and you can see them still in the industry. People like X and some of the ones in the Inner West had a history in the psychiatric care industry, especially institutions. They bought real estate, speculated on real estate in the Inner West and then took a number of people under the guise of community care out from the institution and so primarily you had a base of financial interest informing what was supposed to be a care environment and we never recovered from that (Participant 23, Government Agency).

High rate of deaths

Several of the participants discussed the high number of residents who die in licensed boarding houses. Participants attributed the high rate of resident deaths to factors including illness associated with ageing, side effects of long-term drug and alcohol use, side effects of long-term use of antipsychotic medications, the lack of preventative health care and screening, poor nutrition, poor mental health management, unreviewed and untreated physical health issues and the need for staff to be trained in first aid. The role of the NSW Ombudsman in reviewing the deaths of

people living in licensed boarding houses was raised as a positive measure in monitoring and making recommendations for change.

An example of DADHC's incapacity, reluctance, lack of will around addressing the issue of the inadequacy of the legislation and the problems it has with enforcing what currently exists was demonstrated again in the Ombudsman's Disability Death Report which was released last week where the Ombudsman's Office recommended several years ago recommendations around first aid requirements and that one person should be on shift at all times with a first aid certificate. The Ombudsman recommended that DADHC address this in its own operated services, in funded services and in licensed boarding houses. Two years on they've addressed it in their operated services, they still haven't addressed it in their funded services and they are saying there is no enforceability even though there is a licence condition that actually stipulates this. And this is DADHC's answer to an issue that is clearly linked to the death of people in licensed boarding houses. Why should a person with a disability, simply because they live in a boarding house expect to receive a lesser service, and in fact have their needs abused and neglected, simply because of where they live? As opposed to because they deserve to have CPR and prevent their death (Participant 3, Community Organisation).

A number of participants also raised concerns about how proprietors responded to resident deaths.

You have a lot of deaths at boarding houses. That's why they get reported to the Ombudsman. How the proprietor works that, how they talk to the residents about that; allows some grieving. Allows people to actually go to a funeral, encourages that. To have a small service at the premises later if people don't want to go. I remember a death about a year ago at X (boarding house) and there was none of that. It was almost as if, the body was discovered in the morning, the person had died overnight and it was as if nothing had happened (Participant 40, Community Organisation).

We had one place that closed...A person died there and they ended up on a slab at the morgue for seven or eight months. And the proprietor did nothing about it, about providing a funeral. So it was when the closure was going ahead and it was discovered that this body was still at the morgue. It was during a head count and one was missing because it was down at the morgue...People deserve a decent send off. It is absolutely appalling that you would allow a body to lie on the slab at the morgue for months and do nothing about it. And the proprietor would just say, "It's not our responsibility" (Participant 2, Community Organisation).

A lot of the boarding house residents have known each other for 20 or more years and they are friends. To have one of your good friends die and not be able to grieve. To not have a funeral or a service. At X (boarding house) when a person died the proprietor did nothing about a service. He didn't even tell the residents. All of a sudden that person just isn't there (Participant 5, Community Organisation).

In August 2010, the NSW Health Department responded to concerns relating to the death of seven people who had died in a licensed boarding house in Inner Sydney over a three-month period, including a person who had been dead for two days, unnoticed. Health professionals attended the boarding house and three residents were taken directly to hospital for immediate medical attention. Paid support staff were put into the boarding house to provide 24-hour care for the other residents. The proprietor has given notice to the ADHC of his intention to 'hand in his licence' and the boarding house is scheduled to close in November 2010. It must be noted that this boarding house was subject to the monitoring and oversight framework discussed in Chapter Three and raises serious concerns about the legitimacy and effectiveness of this review system.

Abuse and exploitation

Several participants asserted that freedom from abuse and exploitation is a basic human right. Participants did not believe that licensed boarding houses provided for this right. There were numerous examples given to illustrate this concern. Many

residents 'work' in the boarding houses providing manual labour, cleaning and cooking and are often paid in cigarettes. One former resident told of a time when he provided maintenance services over two days and was paid five cigarettes. Another resident talked about how a proprietor would collect her pension card and use it to obtain cheaper fares. Residents talked about risks to their belongings and personal and sexual safety because they do not have a lock on their door.

Many participants identified domestic violence as an ongoing concern, which is consistent with a recent study conducted by PWD and the Department for Women in 2010 (Attard and Price-Kelly 2010).

In most of the boarding houses there are people who have different roles. Some of the roles include gopher. That person's job is to, and it doesn't matter what the weather is like, it can be bucketing down with rain. Their job is to run down the street to buy cigarettes, to buy milk, whatever else needs to be bought at the last minute. Other people's role is the enforcer. And literally their job is to thump the residents into submission and make sure they behave. And after you've been thumped a few times you will generally behave because it's not nice being beaten. At some boarding houses people play the role of dobber and their role is to report on other residents on anything that is said against the proprietor or about the general running of the boarding house (Participant 40, Community Organisation).

Stuff still goes on, yes. Some of it is consensual. I will use the expression "smoke for a poke". Residents have said that to us and that it's consensual and we've actually got people because of their poverty. I don't want to play the moral card but it is because choices are just so limited... And again if people are sharing rooms so they don't have access to their own room. You actually need a private space to have a relationship (Participant 5, Community Organisation).

I have seen men that won't go to a facility that only has men in it. They would only go to somewhere that had women because they felt vulnerable (to sexual assault) (Participant 1, Government Agency).

There's client-to-client abuse. There is staff to client abuse. In every case in my opinion where there is a contained environment of staff, the standard of service from those staff to clients deteriorates because of internal reinforcements. So there is no outside looking in and also that's particularly so when we are talking about vulnerable people who often can not be their own advocates or who cannot be their own effective advocate (Participant 10, Community Organisation).

At the end of 1994 I walked into the back of X (boarding house) and thought I had walked into Dickens era. I couldn't believe what I was seeing. At that point things were far, far worse than they are now, they have cleaned it up a lot. There were some really, really sick people. People on crutches staggering around; people trying to carry a glass of water across the yard and shaking so much it would be empty by the time they went to drink it. Some disgusting things; dried up bits of bread; rock hard sandwiches, they only used to provide day old bread. He was giving them old food. It was dreadful. The toilets were stinking and rotten floorboards. Guys took me in and showed me their rooms. Walking across rotten floorboards, it was just unbelievable. The boarding house team went in and they did an investigation and started to assess the people and that was the beginning of action. The licensing team went in and for the next 18 months there was someone on site every weekday...So that place was eventually taken to court and there is the most extraordinary evidence; there's videotapes and 100's of still photographs and then all the assessments of the people...The day it closed the boarding house team went in at nine o'clock and the owner had already moved half of the residents to one of his friends boarding houses. They had gone at seven in the morning. And then there were boarding house owners sitting on the fence saying I'll take that one, do you want that one, a little slave trade going on. The word out on the traps was that there was \$1000 bonus if you got a resident; you paid the previous owner \$1000 as you were getting access to all the pension for the next umpteen years. There was \$1000 levy on people, it's called slave trade, it's called selling people and that has been going on for so long...They work on the families and convince them it's the best thing for

them, to go to another boarding house (Participant 2, Community Organisation).

Abuse is prevalent but no one will go to the police station. "Abused by the carers", I use that term loosely. I remember we used to have community meetings with the LAC's (Local Area Commands) and I remember once talking about a person who had been assaulted and the police officer said, "of course they can come up to the police station and they can bring the manager with them". But we said, "what if it is the manager"? The police couldn't conceive that that was a possibility. They thought a carer was a carer, a person of good repute but they couldn't get their head around that one. No one will ever report it to the police. Even when you say I will move you today and you don't have to go back ever, I'll arrange for your stuff to be packed. They're community-institutionalised (Participant 10, Community Organisation).

It's not like it's a state prison with people walking around with shotguns in their hands. We have still got our freedom. Like everybody else we have rights but in some boarding houses the ones that run it don't think like that. They think they can walk around and speak to any of the people there how they like. Like they think they have every right to go around laying their hands on a person. That as far as I am concerned is not on. You don't do that type of thing in a boarding house. If you want to keep your boarders you play fair with them (Participant 29, Current Licensed Boarding House Resident).

They've been complaining about food, that they don't get enough. All of them have lost weight. X actually confronted the owner and told him that they weren't feeding them (Participant 2, Community Organisation).

When I visited the boarding houses I was shocked and appalled basically. I was appalled by the physical state of the people living in the boarding houses, they all had a mental illness, and some of them had other diagnoses, drug and alcohol issues, intellectual disability. They certainly had many other physical problems as well. The level of filth that the people were living

in...It was winter and it was freezing in the boarding houses. It was a cold winter, holes in jumpers, holes in clothes, I mean for all intents and purposes the people looked like they were homeless. The state of the boarding houses was horrific. People sharing rooms and no privacy, clearly overmedicated. People were very unwell...filth in terms of hands, filthy clothes, body lice, a whole range of health issues. I had a chance to go into the offices and the kitchens to find out how those things were running in an effort to try and figure out a person's pattern and routine so I could help with the transition and not disrupt that. I found that pensions would go straight to the proprietor, then the money was dolled out from that person. There were absolutely no rights. All your money went to the owner of the boarding house and cigarettes and food. The people living there lacked any control over their life (Participant 17, Community Organisation).

Choice

"People choose to live in boarding houses"

The concept of choice emerged as an important issue throughout the semi-structured interviews with staff of community organisations and government agencies. Many participants were incensed by the view that people choose to live in licensed boarding houses. Some passionately asserted that 'choice' had been manipulated by the State to avoid the costs associated with providing an accommodation response under the DSA (NSW). Other participants considered that it was possible that boarding house residents chose their accommodation option and a small number of participants noted residents who had actively chosen to live in a licensed boarding house.

We have a captured market in boarding houses... It's a default mechanism rather than an actual choice. People with disabilities will go into boarding houses simply because there is nothing else for them (Participant 4, Community Organisation).

Obviously that's a fallacy...I suspect that often people were given no choice at all and that of course was a problem if the ACAT member gave an approval it would potentially be the green light for someone who was disadvantaged or didn't have the insight to realise that they could say no (Participant 1, Government Agency).

Some people believe that boarding houses are an escape from the excessive regimentation of institutions or even the group homes where their whole behaviour is constantly monitored...I've seen one woman who had a mild intellectual disability and mental health issue saying, "I don't want to go to a group home where I will learn to cook and wash my clothes". There are some people who do it by choice (Participant 15, Community Organisation).

The reality is that you've got people who have been institutionalised for 20, 30, 40 years. They've never had a chance to express their opinions; they have been slammed down if they have ever tried to express anything like an opinion. Besides the overarching factor is they have no money (Participant 2, Community Organisation).

I believe that people are driven to boarding houses out of necessity not choice. I know that there is priority housing but there are a lot of people because of their own background, they've probably got no family and they wouldn't be able to cope with shopping and paying bills. Some people have no choice about living in a boarding house. One of the guys that died in the boarding house, his family didn't come near him but when it comes time to go to the funeral you've got people there that you don't even know who they are and they're his family. I believe families see boarding houses as a dumping ground for people because the family can't look after them. That's probably a generalisation but people are cut off from their own families because of violence or mental health. The majority of people in boarding houses are very lonely people that have to go there. I just think the system stinks because some of these boarding houses that exist now should have been closed down (Participant 35, Former Licensed Boarding House Resident).

You can work out who the people are in boarding houses. People with strong family support don't live in boarding houses. Largely people with intellectual disabilities who have access to quite an extensive non-government run service structure don't live in boarding houses, some do but the majority don't. And people who have obvious alternatives don't often live in boarding houses. For example, older people who have the means to go into an aged care hostel don't live in boarding houses. People that live in boarding houses are predominately people with a history of psychiatric problems who have not got family support and who have little or no advocacy and don't have the means to take advantage of other options. So they're poor, mentally ill and have little or no family support, they are the people that end up in boarding houses. The most vulnerable people in the community and most capable of being exploited. And there are some people, for example people with an acquired brain injury as a result of substance abuse, will end up in boarding houses simply because there are no other options, notwithstanding the fact that government has been made aware of this fact for a long time, there are still no other options available (Participant 16, Government Agency).

Some of the negative symptoms of schizophrenia are motivation, withdrawal and isolation. A lot of the people cannot live in this rehabilitative environment. They don't want anyone to come and make them do this and that. "If I live in a boarding house they leave me alone. Just leave me alone. I don't have anyone hassling me to come in and get me out of bed. I can do my own thing which is just fine". You know I don't want that. But some people want that. And this is the balance again. So the reality is that some people just don't want to do anything. To them that's real. That's what they want (Participant 19, Community Organisation).

I don't think if people had an array of choices they would choose to live in an LRC. The unlicensed sector, yes. I do think some people choose to live in these. The people that we work with and I suppose some of them have been living in boarding houses for almost thirty years didn't have any choices and ended up in them in a variety of ways. I don't know that people would actually choose that. When people are questioned, a lot of them are saying

they are happy to live there but they're used to it, they've learned how to live there. How appropriate is that in this day and age? I do think that we should have greater choices available. It may be about living in and sharing houses but it's actually the intent and ethos that is about supporting the individual not just fitting into a service system (Participant 5, Community Organisation).

What really annoys me is that people don't think they deserve a choice. Everyone else gets to choose where they live and who they live with and often they are put in housing with people where the only thing they have in common is that they have mental illness. In boarding houses they have to share rooms. Sometimes there are 40 year olds and they are sharing with 80 year olds. I don't understand. We are a wealthy country. How can we say that people don't deserve a choice about where they live? I think that you should have the choice of safe, secure housing with support to help you with your tenancy and be able to choose where you live and not just get bundled into something. I've seen it. There's a spot there and they just get jammed in. You've got a mental illness and you've got this level of support so that's where you go. There are not enough choices around it. You see people who have lived with mum and dad for 30, 40, 50 years and everything has gone along very happily and suddenly dad died and mum had to go to a nursing home and the person is put into a boarding house and you get put upon and people steal your stuff and you are absolutely miserable (Participant 14, Government Agency).

"It's better than being homeless"

Another issue that many participants commented on was the belief that living in a licensed boarding house was better than being homeless. This assertion seemed to polarise participants. Several participants believed that licensed boarding houses, while not ideal, were preferable to secondary or primary homelessness (Chamberlain and MacKenzie 2009). These participants tended to focus on how the current licensed sector could be improved and maintained as a low-cost accommodation option.

Other participants passionately asserted that many people have and do choose to 'sleep rough' if presented with the option of living in a licensed boarding house (Harris 2007). This included some women who considered it safer to sleep on the streets than live in a boarding house. Some participants noted that homeless accommodation services, including refuges, provided a higher standard of care as well as having enhanced accountability mechanisms in place.

You can be put out and regularly are put out on the street with an hours notice if you're lucky and with no guarantee about what's happening with your property. So I don't call that being securely housed. I call that being marginally housed if not homeless. And to be honest if you were homeless at least you might stand a chance of being one of the lucky 15% across Australia to be in a SAAP service where there were support workers, where there were accountability processes...Many of those people particularly the women would actually choose to sleep rough when things got too hot. They felt too scared, too vulnerable, too at risk of assault and so they had no where else to go, no other choice so they would say it was safer to sleep rough than stay in a boarding house (Participant 11, Community Organisation).

I don't know. The food's good for the homeless. The sheets are clean at Matthew Talbot (Men's crisis refuge). They have clinics with nurses. I think you have more human rights in Matthew Talbot than you do in a boarding house. If you read the Declaration of the Rights of the Disabled Person how many violations can you pick out of that for people living in boarding houses? Most of them (Participant 2, Community Organisation).

You can argue it from two sides. You can argue that it is better than nothing and that's the hideous argument because it is true, it is better than nothing. Well it is partly better than living on the street. If you are on the street you get picked up and taken to a hospital if you are unconscious. It is better than living in an unlicensed boarding house or a guesthouse. It is better than those because at least there is something called the screening tool to determine if you should or shouldn't go there (Participant 1, Government Agency).

People claim that it's better than being homeless as a defence argument for either not having to think about what else might need to be provided or they know the consequence of it and are seeking to re-prioritise resources by defining a group that is already housed in some way. But at the end of the day the state will not respond of its own volition in relation to disadvantage unless that disadvantage has some form of political imperative to it. And so the arguments that say they're better off because they're not homeless is paradoxical because if they were homeless the political pressure to then bring to bear a solution to the matter is more acutely available than if they remained where they are (Participant 23, Government Agency).

Quality of life of licensed boarding house residents with intellectual disability and residents with mental illness

This study applied an interpretive approach to 'quality of life' (Cummins 2001). The aim of this research was not to 'measure' resident's quality of life through the application of an instrument, such as the Lifestyle Satisfaction Scale (Heal and Chadsey-Rusch 1985) or the Client's Quality of Life Scale (Mulkern and Manderscheid 1984). Rather the study aimed to seek residents' thoughts, feelings and experiences across a number of quality of life domains. These quality of life domains included relationships, physical and mental health, self-determination and choice, financial security, participation and community access, recreation, access to support services, education and employment, security of their accommodation tenure, general feeling of well-being and other domains as identified by participants.

Relationships

Many of the resident participants interviewed had lived in their current boarding house for many years, some since the first wave of deinstitutionalisation in the 1970's. Over this time they had developed significant relationships with other residents and in some cases with the proprietors. Several of the residents had developed strong relationships with staff of community organisations including the

Active Linking Initiative (ALI) providers and staff of advocacy services. Only one of the current residents of this study had regular contact with her family.

In some boarding houses visitors are not welcome and in others there is no space to entertain family or friends compounded by no access to the kitchen to offer guests refreshment. Shared bedrooms make it inappropriate to have an intimate relationship.

Security of accommodation tenure

Generally, residents did not consider themselves to be marginally housed or believe that licensed boarding houses were a type of homelessness (Chamberlain and MacKenzie 2009). Most of the current residents considered the boarding house to be their home, although they were aware that they could be exited if they didn't 'follow the rules'. One resident participant described being exited from several boarding houses without notice and considered his current accommodation to be insecure.

They often get told, "Where else do you think you can go"? (Participant 5, Community Organisation)

Self-determination and choice

Both current and former residents described the lack of opportunities in licensed boarding houses to exercise self-determination and choice.

The tea was made in big tea pots but we were only allowed to put five bags in. It was rationed. It was like washing up water. To me the whole thing of rationing things and the meals... He served the same meal each week. We could predict today we are going to get pies. Today we are going to get sausages. He had the same menu each week. They didn't really care (Participant 36, Former Licensed Boarding House Resident).

They wouldn't let me close my door...They used to ration food. I know it sounds strange. One of my friends who lived there before each meal used to have to go along to each cup and put one spoon of sugar in the cup, that's all

they gave you...They didn't seem to care about the residents. X used to do the washing in bulk and used to get me to put all the washing on the clothesline and take it off...Breakfast was at 6.30am and people were rounded up like sheep. We were forced out of bed to go to breakfast at 6.30am and they used to use powdered milk. Everything they did in terms of food was cost cutting. They made a fortune out of us (Participant 37, Former Licensed Boarding House Resident).

Recreation

Many participants described the lack of activity, boredom and relentless routine of licensed boarding houses. Participants maintained that most residents spend the majority of their day smoking and do not leave the boarding house.

Most of them are very heavy smokers and they would spend most of their day just sitting around the backyard just smoking and not leaving the place (Participant 37, Former Licensed Boarding House Resident).

We don't understand the importance of occupation, of having something to do. People get so bloody bored and often sometimes end up sleeping all day because they can't be bothered (Participant 15, Community Organisation).

Several of the current residents interviewed accessed the ALI, which provides recreation and skills-based programs for residents of licensed boarding houses. All of the resident participants in this study accessed services provided by community organisations. This high rate of participation and access is not indicative of the majority of licensed boarding house residents but rather reflects how participants in this study were recruited.

Physical and mental health

The extent to which licensed boarding houses provide for residents' physical and mental health was generally poor. This included a lack of access to physical, mental, dental, sexual, nutritional and preventative health care. Participants did acknowledge

however that there was a continuum of quality and some boarding house proprietors did support residents to access external health care services.

There are people who have had all their teeth out and haven't had dentures for 12 months and when they got them their gums had shrunk so much they couldn't wear them...I've been told these people don't need teeth and they don't need glasses if they can't read (Participant 2, Community Organisation).

The trade in cigarettes encourages people to smoke and means that this lessens their life expectancy, especially excessively, it's not good for you (Participant 40, Community Organisation).

There is a high risk in institutional care anyway, but it is a much higher rate of early death associated with uncontrolled preventable illness. So cigarette smoking and malignancy. Heart disease. Unsupervised accidents that could be interpreted as suicidal behaviour could be alternatively confusion or accidental death (Participant 1, Government Agency).

Lack of any integrated care plan that really is monitored and followed up because of not having someone to advocate for them and take them to appointments...There isn't monitoring of the blood levels of medications that are being used as mood controllers, but are dangerous in themselves, particularly combined with major tranquillisers. The use of major tranquillisers for a person who is compliant with them increases the risk substantially of diabetes and osteoporosis (Participant 1, Government Agency).

There were people who had CT scans that showed aneurisms and nothing was done about it. Nobody followed up the outcome...And you can see that that is a hallmark of people living in boarding houses because if you compare it to hostel and nursing home care there are specific physical health assessment tools that are probably 20 or 30 pages long documenting the health care needs, the emotional health care needs of people who go to

residential care. The boarding house screening tool is ridiculous in its brevity for people who have many more disabilities than some people who go to hostels for example, and at least on par with many people who go to nursing homes...Unless people have a very motivated GP they could just sit there quite literally without any kind of screening until they die. I think that probably applies to a portion of people right now or they get a token screening that doesn't delve anywhere below 'this person has a disability of this sort and this person has a mental illness of this sort'. Rather than saying that as a result of these, this person is likely to have heart disease and should be getting an ECG and lipids done and reviewing annually glucose, and sending them to the eye specialist for review, and checking large vessel disease and all those sorts of things that happen for people (Participant 1, Government Agency).

In years gone by there was a recognition that there were GP's that were less than ethical in their approach to the ongoing care of people in licensed and unlicensed boarding houses, particularly in Inner Sydney. The Health Care Complaints Commission investigated nine or ten complaints. Of course there are two sides to the story. It is better to have a doctor go in there and do something than have no doctors there. But of course that is reliant on and dependent on the ethics of the doctor. And there are some good doctors that go in there and do good things. They check on the medication, they review the side effects but there are unscrupulous doctors and there are quite a few of them (Participant 19, Community Organisation).

X had been in a boarding house where doctors had seen him and they had missed a tumour on his eye and it was seeping and bleeding. Real difficult to miss! We went and spoke with the GP, the one who had missed it, and asked him for a referral to a specialist. He had been seeing him (the GP) for months and he had missed it. The specialist couldn't believe it and sent him straight away to a surgeon and within two weeks he had an operation on his eye because it was that serious. We also found a number of other health concerns, which his GP had again just said it was old age (Participant 2, Community Organisation).

The licensed boarding houses all have doctors that come to them and some of them are the same doctors that were going there when I was on the crisis team in the late 80's. It's an economic niche for them, they have strong ties with the boarding house owners and they all work in together. They've got a good little business going. Say hello to someone and get them to sign a form. Sometimes when people first come into the boarding house or they come from another area and they don't know me...as soon as I walk in and I talk to them they say, "Do you want me to sign something"? Well they're just so used to it. Anybody that comes and talks to you, you sign a form. We need to do it better (Participant 21, Government Agency).

Financial security

All of the residents commented about the high costs associated with living in a licensed boarding house. Residents paid 85-100 percent of their Disability Support or Age Pensions. Many of the resident participants were smokers and the increased cost of cigarettes left residents with little, if any money to purchase clothes, medication or food. The poverty experienced by residents of licensed boarding houses significantly impacts on their ability to leave the boarding house and to access services.

One boarding house I know of collects most of the pension. Some of these places are immoral. They really use the tenants and they are fundamentally profit making. They prey on the poorest of the poor. I think it is disgusting. I really don't think boarding houses should be allowed. Group homes- sure. I have been in a group home and you have staff coming in everyday and they care. But not boarding houses, you are just a number (Participant 30, Current Licensed Boarding House Resident).

I think the poverty of the people is one of the things that is the most scandalous. And it really prevents them from integrating. In the early days around 95/96 I took some people shopping for clothes...The whole shop would turn around and stare at them because they looked so weird. Their clothes second hand, ill fitting and unmatched... The clothing was awful and there were people there that only had slippers to wear, filthy slippers and so

you can't integrate into the community if your clothes are so horrible...you are a laughing stock. That's why ALI has been so successful and I also think Home Care doing the showering and dressing people (Participant 2, Community Organisation).

I think it's money that stops people integrating into society because they don't have the money to do the sorts of things that will make them friends and give them opportunities, because so much social networking happens over the coffee table (Participant 21, Government Agency).

Participation and community access

The poverty experienced by residents and the institutionalised practices and routines of licensed boarding houses impact significantly on residents' ability to participate in and access the community. For example, in most licensed boarding houses if residents are not present during meal times they will not have access to food at other times. After paying for their cigarettes and 'rent' many residents do not have enough money for a bus fare to be able to access the community.

If you are not there for your meals then you get nothing. They generally lock the kitchen up around 6pm (Participant 27, Current Licensed Boarding House Resident).

They have no money. They have no cigarettes. Their food is there. They might come and go but they can't leave there because where else are they going to go? Even when they go for a couple of days they need to go back because that's where their ciggies are. It's like that domestic violence issue where I don't have access to my money, food or shelter so I just go back there. There are many ways to control a person. One is a physical barrier, like doors and big grounds and fences but that's not the only way you can imprison someone (Participant 17, Community Organisation).

People living in licensed boarding houses typically live unfulfilled lives where they have very few opportunities; their lives are often empty. They sit around a lot. They don't always get out of bed during the day and aren't particularly motivated to participate in life, which is a very typical scenario for people who are institutionalised. They have very little vision or dreams for themselves as they don't have the opportunity to make those things real for themselves. And even with the ALI program being introduced it certainly has opened doors for some people but the reality is that that program is so poorly funded, the money to hours ratio is so small that people are spending the majority of their lives in a boarding house without support to access the community and now that the ALI program is in place it has taken the onus off proprietors to provide those services (Participant 3, Community Organisation).

I was aware of one man in a boarding house that hadn't left the property for about four or five years (Participant 40, Community Organisation).

Access to support services

All of the licensed boarding houses have visiting General Medical Practitioners and most also have a psychiatrist. The Home Care Service of New South Wales now provides personal care services to residents. Residents also have access to the ALI and some advocacy services.

We had a doctor, a GP who came in regularly. At that stage I was on an injection and the GP used to come every week and I also used to have a psychiatrist that used to come every week but the manager didn't seem to care. It seemed to me he was in it for the money. They very rarely asked you how you were going (Participant 36, Former Licensed Boarding House Resident).

We've got people from Home Care who come to shower people. The chemist girl comes every Monday with our medication for the full week. Once a month she will bring over her chemist bill. So we have to pay for our

medication: it's not included in the rent (Participant 29, Current Licensed Boarding House Resident).

Education and employment

None of the current and former residents interviewed were participating in employment or formal education. This is consistent with the findings of the Social Policy Research Centre's (a research centre at the University of New South Wales) review of the Active Linking Initiative (Edwards and Fisher 2010). This review found that

Employment and formal education did not increase because of disability, stigma and availability of suitable opportunities (Edwards and Fisher 2010, 20).

Life after licensed boarding houses

All of the former licensed boarding house residents stated that their quality of life and skill development had improved markedly after leaving the boarding house. One man talked about his experiences when he left a licensed boarding house, following its closure, and moved to independent accommodation where he receives 'drop-in' support from a community organisation.

We had priority housing. They advocated for us with the Department of Housing. I have a two bedroom flat. It has fresh carpet and floorboards. The living conditions are much, much better. I have my own bedroom. I have my own privacy, I am very lucky because I can play my music at night-time in the lounge room without disturbing my flatmate because there are two doors between the rooms...The privacy factor is a big thing and the standard of food. I can cook good food. My quality of life now is so much better. My support worker visits me everyday to check that we are taking our tablets and that sort of stuff. Our medication is in a blister pack. Having that extra contact, that person to come in and see you and they really do care for you and the standard of care is a very high standard. They help us with shopping;

we catch public transport to shopping. What's most noticeable is the care of the support workers. I just find the standard of care to be very good
(Participant 37, Former Licensed Boarding House Resident).

I saw the difference straight away...They became more confident. They didn't just sit outside and smoke...At the beginning people used to get the fruit and put it in their room. They didn't steal things, they just weren't sure if it would be there tomorrow. But then they started to trust...At our first meeting he said to me, "It's just so fantastic to do my own washing, I am so excited". So straight away we saw skills coming in..."I'm going to the bank by myself every week, I've never done that". Before in the boarding house the owner used to co-sign all the bank books so there was never an opportunity to go to the bank for some of them...People started to become more confident
(Participant 6, Community Organisation).

Some of the best things were people's pride in themselves. There were a couple of guys and they really looked like they had been living on the streets, absolutely filthy, and drinking a lot and just wouldn't speak. Some of them just wouldn't speak during my interviews with them. Head down. When we moved them in we bought brand new everything and we made sure we made everything really nice and it was about meeting some of those basic needs. Initially they were really overwhelmed and there was no comment but three months down the track, six months down the track, a year down the track, just better and better. Communicating, a sense of pride, dressing, wanting to be really well dressed (Participant 17, Community Organisation).

Challenges facing the licensed boarding house sector

Participants identified a number of challenges facing the licensed boarding house sector including financial viability and sustainability due to ideological, regulatory and licensing requirements and the emergence of illegal operators. Against a background of significant decline, participants considered whether or not licensed

boarding houses had a future as an accommodation option for people with intellectual disability and people with mental illness.

Sustainability and viability of the licensed boarding house sector

As discussed in Chapter Three, the licensed boarding house sector has witnessed marked decline from the mid-1990's. In 1994, there were 194 licensed boarding houses, which provided 3,336 beds. In 2010, there are 39 licensed boarding houses in NSW that provide for 781 residents. A staff member of a government agency claimed, "Look at the figures. The sector is only going one way". Based on historical data and trends, the staff member's inference that the sector would decline completely may have merit. However, the most significant decline in the sector occurred during the 1990's at a time where the former Ageing and Disability Department had a dedicated licensing team and more importantly a political imprimatur to prosecute and close boarding houses that breached their licence conditions.

Significant part of low-cost accommodation sector

Many of the participants believed that licensed boarding houses would continue to play a role in the provision of low-cost accommodation, despite the obvious decline in the sector from the 1990's. The majority of participants believed that this would be the case in the absence of government providing appropriate accommodation options or funding community based services under the DSA (NSW).

They are dying out but I think they do have a future for the short to medium term. I think they do. My problem is that I look at it from the housing perspective because if they are not there people will have nothing.

(Participant 13, Government Agency).

No they won't disappear. There will be a need for some semi-structured facility because there will be a population of people refused nursing home or hostel care (Participant 1, Government Agency).

The way that things are set up no, they are always going to be in business because there is not enough supported accommodation out there...As the current proprietors start to die out other people with an entrepreneurial view will see a niche market...There are always going to be people looking to make maximum dollar from a marginalised people because they need a house and they need a roof over their heads...The reality is that there will be a government imperative to keep licensed boarding houses going because as bad as they are they are cheaper than funded services (Participant 11, Community Organisation).

I think people are quite naïve when they say that there will be no need for boarding houses in 20 or 30 years. We still have a core group of people with a chronic mental illness who are in and out of hospital and who need significant support to live in the community. So unless we provide that, boarding houses will stay around (Participant 14, Government Agency).

I don't know. There has been one new place open in this past year out at Miller. No one's lining up to open them and if you look at the figures then yes it is declining. And perhaps when it is to a small enough number...perhaps the state will finally take some responsibility (Participant 5, Community Organisation).

I've been concerned about it for some time. The whole situation is completely hopeless really. The only good news is the industry is slowly closing up and the numbers of people in places is disappearing. It was 2100 when I started and it's gone down to about 990 and it is falling and it will never be resurrected again as it's a feature of the old days; it's a left over of history really. No one would sit down today and say "oh wouldn't it be a good idea to run something like that". It is just a left over...No reputable NGO would run places like the places that are run in the Inner West of Sydney; that's the way people acted once...There are also a number of people with disabilities living in unlicensed boarding house. We know about that, and of course the law is that if there is more than two people with disability it's supposed to be

licensed and the department say that they follow that up but it is questionable what happens to these people (Participant 8, Community Organisation).

Ideological sustainability

Many participants believed that licensed boarding houses were no longer 'ideologically sustainable'. They described this accommodation option as an 'anomaly' within systemic accommodation responses as licensed boarding houses do not comply with the principles of the DSA (NSW). One participant refused to comment on changes that could support the maintenance of this accommodation option 'as a matter of principle'.

Why and where does this sit in the whole range of accommodation services for people with disabilities? The major challenge on the human rights side is why are they there in the first place? (Participant 5, Community Organisation).

Viability

Several participants identified viability as an ongoing concern in relation to the sustainability of the licensed boarding house sector. All of the proprietors expressed concern about how they could 'stay afloat' if the government introduced regulations that required them to 'do more than what they were already doing'. The proprietors were referring to the introduction of regulation that required minimum standards relating to health and welfare provisions (ADHC 2010). Other participants stated that licensed boarding house proprietors could continue to make a profit, albeit reduced, even if adequate health and welfare provisions were upheld.

I think there will be commercial consideration. In other words will it make commercially viable sense to remain in business for people with disabilities because people with disabilities provide viable business enterprise? From a social justice viewpoint while they do provide basic support services, in other words shelter, and sometimes that's questionable, do they provide real

supports or do they provide real opportunities for real support? And the answer is not always (Participant 10, Community Organisation).

And because they are business people and it is their investment and in some ways the licensing regime applied pressure, because the margin of profit is small and they don't receive funding, they take all of the pension or 90 percent but they are servicing people with moderate to high support needs. That isn't a lot to do that so they save money on food, unskilled staff, but the margin is not huge. A lot of them work on capital appreciation. Some of them are dedicated, some of them are just straight out businessmen and some of them are just crooks (Participant 15, Community Organisations).

Ageing proprietors and gentrification

Many of the proprietors of licensed boarding houses in NSW established their boarding houses in the 1970's and 1980's and have operated their boarding house for almost four decades. These proprietors are approaching or have reached retirement age. A significant number of licensed boarding houses are family businesses and it remains uncertain whether or not younger generations will choose to carry on the business. In some cases there are concerns about whether or not boarding house licences can be passed on within families without upgrading the licence category, which would involve capital upgrades. The sustainability of the licensed sector has gained great attention throughout the research period 2007-2010. During this time two proprietors died, including one proprietor who had acquired a significant proportion of the sector. Another proprietor is closing his boarding house in November 2010, which is the boarding house referred to earlier where seven people died over a three month period.

Another factor that influences the sustainability of the licensed boarding house sector is the gentrification of Inner Sydney. Sydney's real estate market continues to boom and for proprietors who originally purchased boarding houses in the Inner West including suburbs such as Rozelle, Marrickville and Summer Hill, their capital investment if realised would reach several million dollars.

Those people are getting old and their children don't want to take over the business and they're being told they can't sell it on. It's so tempting with the prices you get for these big places in Sydney now. They're sitting on a fortune (Participant 12, Government Agency).

Increasing prices of Sydney real estate will drive people out of the market. I would make a business decision on a block of land probably worth a million dollars (Participant 40, Community Organisation).

In Sydney they'll keep decreasing. In the past few years we have seen a large number go. Yes, there are some new admissions. I also know that there are some vacancies in boarding houses. But I do know that there are still people leaving hospitals so I'm concerned and I've raised this with ADHC in the past. I'd like to know if they're going to the unlicensed sector...Generally I think that the ones in Sydney will decline but the rural ones will hang around longer (Participant 40, Community Organisation).

I think there are two views and I don't know which is right. I do know of the view that boarding houses are a dying breed. There are those amongst us who would be very pleased about that as long as there was something else because the object is not boarding houses and then homelessness. The option should be more appropriate service provision rather than boarding houses or homelessness...From a commercial viewpoint people could potentially make more money by selling off the land...The other issue that you would know is the retirement of families...They are not being able to sell them to other proprietors so they're closing down...It's not an attractive option as a commercial enterprise (Participant 10, Community Organisation).

Illegal operators

Several participants believed that the licensed boarding house sector would continue to decline, while the unlicensed sector would develop outside of the requirements of the YACS Act. The YACS Act requires a boarding house to be licensed if there are

two or more people with ‘handicap’ accommodated who require ‘social habilitation’. Participants considered that there were many ‘illegal operators’ amongst the unlicensed sector and ADHC’s current policy was inadequate in monitoring unlicensed boarding houses. ADHC’s current policy states that unlicensed premises will be investigated should a complainant allege that there are two or more people with disability accommodated. Several participants discussed the importance of establishing an inter-departmental committee and strong relationships across levels of government to effectively monitor the unlicensed sector.

Honestly, I am surprised that the licensed sector is still continuing in a formal sense. And the reason I say that is that if you are an astute reader of bureaucratic process you would have to say that there are moments when the state is loathed to regulate. And at the moment it’s one of them. So why wouldn’t you diversify and start five unlicensed boarding houses and just give up the battle with ADHC and give up this pretence with having a licensed boarding house (Participant 23, Government Agency)?

The entire Eastern suburbs for instance has no licensed boarding houses in it, yet all those large homeless persons services who in many cases support people with a mental illness and people with disability who are homeless place people in boarding houses as a way of securing them ongoing accommodation, yet none of those services are licensed...In the days of the Ageing and Disability Department it was actually a routine practice of the department to monitor unlicensed premises. The department then had a relationship with local government to identify low-cost accommodation and boarding houses, and licensing officers would routinely visit those premises to ensure there weren’t two or more people with disability, that providers understood their obligations under the YACS Act (Participant 3, Community Organisation).

In what ways does the service system need to change to improve the services provided by licensed boarding houses?

Funding licensed boarding houses

There were diverse and passionate views expressed in relation to whether or not the licensed boarding house sector should receive funding by the state government.

Most participants did not believe that the current proprietors would pass on funding to residents, as they were not focussed on the needs or rights of residents.

Furthermore, it was believed that the current proprietors did not have the knowledge or skills to provide a service that upheld the principles and standards of the DSA (NSW). Some participants believed that the state had a responsibility to support residents and the provision of funding would enable greater accountability mechanisms.

Not on your sweet life. It wouldn't go anywhere near the people...If they had to comply with the DSA they would close because it would reduce their profit margin so markedly (Participant 2, Community Organisation).

Well that would solve the problems in lots of ways because then they must be accountable. They must meet standards (Participant 10, Community Organisation).

No I don't think you can give them money. I think that's almost giving in. I think many others are happy for our taxes to support the people. We know it happens, we have tunnels that are being bailed out by state governments (Participant 5, Community Organisation).

I would be completely against the current batch of owners getting any government money. I think that is completely the wrong way to go because I just think it would end up in the owner's pockets. I have always opposed the

owners getting any sort of money. I just think they are an unsuitable bunch (Participant 8, Community Organisation).

And by helping the proprietors you help the boarders. So I think government has a role to play... You can't expect to shut down one part of the healthcare system and rely on someone else to provide it and then not provide any resources (Participant 19, Community Organisation).

If I was to take the hard line and I have taken the hard line for a long time that human services should not be in the profit-making sector because while there is a profit-making mentality it is very difficult to deliver a good service. But then on the other hand when government are inept to provide adequate services then this is not a bad way to fill in the gaps. Providing there are good standards and a good monitoring system, good policing... Nursing homes are private, but I trust that there are adequate safeguards and regulations. Then to me it's a good measure (to fund) to fill in the gaps if government are not going to provide the services (Participant 19, Community Organisation).

If you were going to fund private boarding houses why wouldn't you move people into more adequate facilities, funded by the government, provided by reputable non-government providers? Why would you give it to a private operator who is going to take some of that money at least for profit and they will try and exercise the same economic imperatives quite rightly because that's their business to cut all overheads to the bare minimum to give the prominence to making profits. Why would you do that? There is no internal logic other than if you are a part of that sector and say that is my right to make a profit out of that asset and I wish to do that by using people with a disability (Participant 23, Government Agency).

Compliance with the *Disability Services Act 1993* (NSW)

Many participants asserted that all services provided to people with intellectual disability and people with mental illness should comply with the DSA (NSW). Participants described licensed boarding houses as an anomaly and considered that the YACS Act (NSW) was inadequate in meeting contemporary service standards.

We believe that any supported residential service must meet the principles and objectives of the NSW Disability Services Act. However, how that translates into applications of standards and minimum requirements is a movable feat. The types of accommodation that should be available to people with disabilities regardless of their support needs should be as varied as other people of the same age that don't have disabilities. So some people should be able to live alone if that's their choice with whatever supports are needed; shared care, joint tenancies, supported living arrangements, individualised packages and small group disbursed living (Participant 10, Community Organisation).

Certainly things have improved for people since the boarding house reform program has been implemented but that was implemented because it recognised that boarding houses were unable to or unwilling to provide the services that are now funded to go into boarding houses to supplement the basic services provided. That has improved people's lives but it has taken the onus away from the proprietor to do these things so there's been an improvement in that respect. I think if there's an acknowledgement that there needs to be a for-profit sector as an alternative to funded services, this needs to be within a framework that provides contemporary standards...to ensure peoples rights are the same regardless of where they happen to live. The anomaly that exists at the moment is that people who are in licensed boarding houses are afforded the rights provided by the DSA so long as they are with the service that is funded to provide that service. So when a person is with the ALI program they are afforded all the rights and standards that the Disability Services Act provides and all associated policies and so on. And as soon as the person leaves that program and returns to the boarding house they no

longer have those rights and protections in place and that seems a ridiculous anomaly that shouldn't exist (Participant 3, Community Organisation).

It's about being more personalised and having more choice...less focussed on making a profit and more focused on giving quality service (Participant 11, Community Organisation).

The accommodation should not be 6, 7, 8 people per room. The ground floor should be available for people with mobility restrictions and should not be putting people with high risk to falls upstairs. The ability to choose whether you have a single or shared room should always be available...Better bathroom facilities with appropriate alarm services for people who have an injury or are on their own and need help...Fire training, first aid training (Participant 1, Government Agency).

I think it would actually help if they were run by the not-profit sector so the profit motive wasn't the highest. It would help if you had a maximum size on them and they were set in locations where there is infrastructure of community services (Participant 15, Government Agency).

Provide disability awareness training to managers and proprietors

The provision of training to licensed boarding house managers and proprietors was seen as a potential area for change. Participants believed that managers and proprietors should receive disability awareness training. This training would focus on the development of knowledge and skills founded upon contemporary practice, underpinned by the Disability Service Standards and the DSA (NSW). Many participants discussed concerns about the lack of basic first aid knowledge of managers and proprietors, which has been identified in several annual reports on reviewable deaths by the NSW Ombudsman (for example, NSW Ombudsman 2007).

The government should simply train and establish that at least two staff in any facility should be first aid trained and that should be funded by

government not by the service providing it (Participant 1, Government Agency).

They need to have their knowledge updated and upgraded and some assistance to support them (Participant 19, Community Organisation).

They've developed expertise you might say loosely, simply because they have run these places for such a long time but it's not expertise of a contemporary nature and it's certainly not developing as it would be in equivalent sectors where it's constantly being reviewed and updated and improved upon. It's very much the status quo that existed in 1973 and it hasn't moved much beyond that (Participant 3, Community Organisation).

I think some disability awareness training but they have all done this. You talk to people in the sector who have been around for years and years and they did a course, proprietors all did a course ten years ago. They all got certificates. Did it make any real difference? No! So I think you could try but I don't think it will make any difference in the end (Participant 40, Community Organisation).

Monitoring and reviewing resident's physical and mental health

Participants identified significant gaps in the monitoring and review of resident's physical and mental health care. Some participants believed that these gaps were due to the siloing and mainstreaming of primary and allied health care services for people living in licensed boarding houses. One participant described the NSW Health Department's former boarding house team.

The Boarding House Team consisted of a variety of allied health services including primary and mental health nurses, a dietician, physiotherapist, speech pathologists, doctors, and psychiatrists. It was a huge team because everything was neglected for residents in boarding houses. Very few were mainstreamed into anything. They had no mental health follow up. Almost no one was involved with community mental health. So they were running under

the radar and no one was servicing them...Now all that they receive is mental health services (Participant 12, Government Agency).

One participant outlined the changes required.

A model of care that is appropriate for their needs with appropriate ongoing assessment of nutritional support, dental state, all the things that are ancillary, so general preventative health care strategies. So mammograms and pap smears for an older woman and prostate checks for a man. Screening tests for malignancy as appropriate within the family. Getting to appointments, getting an advocate to go with them to ensure that they get there and whatever is recommended is implemented with appropriate follow up and strategies to see the outcomes...Medication review with a licensed pharmacist coming in to advise on what needs to be changed and what is unsafe. That would cut out a significant number of deaths from my experience or admissions to hospital...Medical records and documentation need to be held on site as well as in the GP's rooms of both blood results, overall care plan, case management resources, timing of follow up, appropriate referrals with whatever specialists that are involved with care (Participant 1, Government Agency).

Several participants commented about changes introduced in 2008 by ADHC's Metropolitan South Region, which caters for Inner Sydney. These changes included mandatory health audits.

I think the mandatory health checks have had a good outcome because somebody's been charged with the responsibility of doing regular health checks. And that's important because you could say that we have systems that already do that but if people with disabilities who live in boarding houses are not facilitated to exercise their rights then it doesn't happen. So it doesn't matter what's in legislation if those rights can't be exercised then they're not actual (Participant 10, Community Organisation).

Met South have set up a committee and there has been a health audit of the residents in Central Sydney... They have health cards and electronic information on every boarding house resident...Before this people moved from one boarding house to the other and no one knew anything about them. Now they have a medical history and there have been referrals to GP's and specialists and urgent things followed up straight away (Participant 2, Community Organisation).

However it must be acknowledged that, this region was responsible for monitoring and 'auditing' the licensed boarding house where seven people died over a three-month period and several people were taken to hospital for immediate medical attention. This raises concerns about the effectiveness of the health audit process.

Monitoring of the unlicensed sector

ADHC's current policy in relation to monitoring unlicensed boarding houses that accommodate two or more people with 'handicap' was considered inadequate. Participants asserted that ADHC should develop an active monitoring strategy in conjunction with Local Council, Community Organisations, NSW Housing, NSW Health and other state government departments.

Boarding houses that have people with disabilities must be licensed... the law must be enforced. If there are two or more people with disabilities living in a boarding house, the boarding house must be licensed. So someone needs to go and do periodic reviews to check that (Participant 10, Government Agency).

Legislative and regulatory reform

A key area for change that participants identified was the need for legislative and regulatory reform. Many participants discussed their frustrations with the YACS Act describing it as an outdated piece of legislation. So too, participants outlined their frustrations with 'legislative reviews' that had spanned more than a decade. During the research period 2007-2010 the NSW Parliament introduced changes to the *Youth*

and Community Services (YACS) Regulation 2010, which are discussed in Chapters Three and Six.

My understanding is that the YACS Act came about because people were concerned about the standards of the boarding houses that these people lived in and foolishly what they did was set up physical standards that already existed under the Local Government Act for fire standards and so forth. They focussed on those and did nothing about the welfare of the individuals who lived in the boarding houses (Participant 13, Government Agency).

The term 'handicap' and 'requires habilitation' needs defining and updating (Participant 5, Community Organisation).

If you look at it in some detail it's quite limited but it's broad within its theatre of operation. But the problem is that you have to have a bureaucratic imprimatur in order to interpret the Act and move within the other less detailed parts of the Act to bring about positive action, especially in relation to unlicensed premises (Participant 23, Government Agency).

Any attempt to regulate them was always going to be limited by the resources available to these boarding house operators and the amount of resources was essentially pensions times the number of residents and unless you were warehousing really large numbers of people then the income was strained, particularly if people were trying to take a profit out of it and pay wages and so forth (Participant 16, Government Agency).

It's going to require a profit focussed business owner to think differently and have pressure put on them in terms of quality. The industry needs to be well regulated. There needs to be good systems and good support and education (Participant 11, Government Agency).

There is no actual assessment process to determine if someone is actually handicapped and therefore fitting the definition of handicapped persons. It is an extremely broad definition. The Screening Tool looks at support needs not

whether or not the person fits the definition of handicapped persons. So I don't think it is very well understood at all and certainly there isn't and never has been an education campaign to properly inform people who might operate businesses of this nature that there are any requirements on them to not accommodate more than two people with disability (Participant 3, Community Organisation).

The word 'handicap' and 'requires habilitation', what does that actually mean? For most people, it is about being on the disability support pension, that is generally used to show if someone has a disability. But of course not everyone on a disability pension needs habilitation. So the level of supports can be varied. The other term that is really difficult is 'boarding house' or 'rooming house'. What is a boarding house? In many senses it has been thought of as someone not having any tenancy rights but that doesn't make a great deal of difference to the level of support. But you do have unlicensed boarding houses that require a bond and a key deposit and will give you a three- month lease. Talk about living in the grey area (Participant 5, Community Organisation).

We've been campaigning for ten years at least to have a new Act, a new licensing regime but it hasn't happened. It was strongly recommended in 1993 when Jim Longley was the Minister and he set up a special task group and their first recommendation was we need a new Act of Parliament. And here we are 14 years later and nothing has happened...The Allen Report was to look at how the government could go and they made a number of recommendations and nothing has ever happened...The NSW Ombudsman's report was more fruitful and last August or July the then Minister Della Bosca issued a press release saying that a whole new strategy will be developed. Although that's all it was, a press release and there was no action. In fact, DADHC didn't know anything about the press release. I think the fact that the industry is dying, there's a sense that it's all disappearing anyway so why put ourselves through the grief of a new Act of Parliament (Participant 8, Community Organisation).

I think sometimes when we go in day after day and week after week you think this can never change or when you look at how much money has been spent under the boarding house reform you question what has changed, as people's lives don't look much different. Well not significantly different for that amount of money. Certainly some people have had some gloss into their lives but when we haven't got legislation that supports the food that they eat or the amount of people in a room and some of their basic human rights I think that's pretty sad (Participant 5, Community Organisation).

Deinstitutionalisation of boarding houses

Almost all participants considered licensed boarding houses to be an institution. Many believed that this accommodation option should be 'devolved' under the policy of deinstitutionalisation. Some participants believed that a moratorium should be placed on new admissions to licensed boarding houses and 'potential residents' provided with accommodation options based on the human rights principles of deinstitutionalisation such as those provided under the Housing and Accommodation Support Initiative (HASI). The HASI model ensures stable housing linked with specialist support for people with mental illness (NSW Health 2006). These participants considered licensed boarding houses to be an inappropriate structural option within the disability and mental health sectors.

If we are to transfer away from a boarding house as a structural option we need to give safeguards to the current residents. And that needs to be accompanied by a 'no admissions' policy. There needs to be options for the types of people who get streamlined into boarding houses (Participant 10, Community Organisation).

Conclusion

This chapter has presented the findings of this study sourced from forty interviews with current and former residents and proprietors of licensed boarding houses, and staff of community organisations and government agencies.

Participants of this study identified self-determination and choice; and citizenship, community integration and participation as the main values that underpin deinstitutionalisation.

In considering the outcomes of deinstitutionalisation, this study found the exposure of abuse in institutions, personal autonomy and living in the community to be positive outcomes. Participants identified the lack of resources in the community and stigma as the most significant negative outcomes of deinstitutionalisation.

Overall, the study found that licensed boarding houses do not uphold the human rights principles of deinstitutionalisation and constitute a form of transinstitutionalisation. Within this, some participants considered that licensed boarding houses were an improvement compared with 'Schedule V' hospitals. Others believed that licensed boarding houses were an inferior option with fewer accountability mechanisms that existed in the 'Schedule V' hospitals.

Participants identified three factors that contributed to the use of institutionalised practices that prevented licensed boarding houses upholding the human rights principles of deinstitutionalisation. These included the outdated knowledge, skills and practices of managers and proprietors; the congregate model; and the for-profit nature of licensed boarding houses.

The extent to which licensed boarding houses contribute to the quality of life of people with intellectual disability and people with mental illness was generally very poor. Of particular concern were the areas of physical and mental health, self-determination and choice, privacy and safety, community access and poverty experienced by residents of licensed boarding houses.

Participants identified several factors influencing the sustainability of the licensed boarding house sector including viability and ideological sustainability, gentrification and ageing proprietors. A number of recommendations for change were considered including funding licensed boarding houses, an improved monitoring and legislative framework and the deinstitutionalisation of licensed boarding houses.

The findings of this study are considered within deinstitutionalisation and human rights discourse in the following chapter: Discussion.

Chapter Six: Discussion

Chapter Six explores the findings of this study within the context of deinstitutionalisation and human rights discourses. It explores to what extent licensed boarding houses constitutes transinstitutionalisation. The outdated knowledge and practices of proprietors; the congregate model; and the for-profit nature of licensed boarding houses are identified as key impediments to boarding houses meeting the human rights principles of deinstitutionalisation. The quality of life of residents of licensed boarding houses is discussed across a number of domains.

The use of institutional models as a social policy response

Chapter One explored the social construction of ‘madness’ and ‘idiocy’ and the use of institutional models as a social policy response to the ‘care’ and ‘treatment’ of people with intellectual disability and people with mental illness. These models reach back to the Middle Ages and have been diverse in size, location and purpose (Jones 1993). Some of these models included the ‘ship of fools’, workhouses and poorhouses, the use of large-scale hospitals, described by Foucault as ‘the Great Confinement’, and geographically isolated asylums located on the outskirts of towns under ‘moral treatment’ (Foucault 1965; Jones 1993; Scull 1977). Institutional models have been used as a social policy response for a variety of reasons.

Workhouses and poorhouses were used as a response to poverty and unemployment confining ‘paupers’, ‘lunatics’, ‘fools’ and ‘other vagrants’ (Jones 1993; Scull 1977; Foucault 1965; Rogers and Pilgrim 2001; Johnson 1990). Asylums aimed to provide ‘care’ and ‘moral treatment’ to patients through the provision of basic health care and social and recreational activities (Jones 1993; Scull 1977; Foucault 1965).

Institutions for ‘retarded’ women aimed to protect the community from deviant behaviour and contain the ‘spread’ of disability evidenced through the eugenics movement (Barnes et al. 1999; Block 2005; Johnson and Traustadottir 2005; Brady 1997).

In many cases institutional models have achieved their purpose as a social policy response. Women with intellectual disability were segregated and sterilised (Barnes et al. 1999; Brady 1997). Workhouses ensured that the 'poor' and 'other vagrants' were off the streets and not idle (Jones 1993; Foucault 1965). However, little consideration was afforded to the impact of institutions on individuals.

From the late eighteenth century there have been numerous inquiries surrounding the abuse and negligent treatment of people in institutions, however it was Goffman (1961) who questioned the use of institutionalised models as a social policy response (Jones 1993; Scull 1977). As identified in Chapter One, Goffman described the impact of 'total institutions' including the 'curtailment of self', 'role dispossession', loss of 'physical integrity' or sense of safety, 'forced deference' to those in authority, loss of self-determination and various other indignities that lead to 'mortification' (1961, 24-31). Goffman maintained, that the curtailment of self occurs regardless of the purpose of the institution; even when management are concerned with residents' well-being (1961). He asserted, that there was something inherent and fundamental to the model that would lead to mortification.

Richmond and Savy (2005, 217) noted, that Goffman's

critique was not primarily directed at physical or even the painful and frightening nature of the many fashionable psychiatric treatments of the time. Rather, his main concern was the damage done to the mental patient's sense of self.

Goffman's assertions resonated with numerous authors including Scull (1977), Foucault (1965), Nirje (1969) and Wolfensberger (1983). Their contributions to the deinstitutionalisation and rights discourse have been profound and influenced current legislation and policy (Bigby and Fyffe 2006; Richmond and Savy 2005). Within these discourses, institutions are considered to be an inappropriate accommodation and support model for people with intellectual disability and people with mental illness. Institutions are understood to be places where people's human rights cannot be realised (Goffman 1961).

The congregate nature of institutions means that individual wants, needs and rights are always secondary to that of the groups, especially management's need for compliance and efficiency (Goffman 1961). Institutions disconnect people from their family, society and indeed their sense of self. They are known for their culture of fear and retribution (Goffman 1961; Scull 1977; Barnes et al. 1999). Within institutions, days become nothing more than a series of activities, whereby residents generally have little choice about involvement unless they are prepared to accept a harsh consequence such as the withdrawal of food or access to visitors. Personal belongings are kept to a minimum. Everything is structured to maximise efficiency. Plastic tablecloths are used, as they are easy to wipe down. Coffee is pre-made with sugar and milk, despite personal taste, to reduce waiting times in queues and restrict consumption. Individual thoughts, desires and needs are eradicated and replaced with the doctrine of the institution and its functional requirements.

Deinstitutionalisation

Since the 1960's and 1970's the principles of deinstitutionalisation have underpinned disability and mental health policy in most industrialised countries (Richmond and Savy 2005; Meadows et al. 2007; Bigby and Fyffe 2006; Emerson 2004; Kozma et al. 2009). For example, current legislation and policy in the UK, USA and Australia focuses on the use of non-congregate accommodation options that are located in the community (Bigby and Fyffe 2006; Richmond and Savy 2005; Emerson 2004; Bachrach 1996; Meadows et al. 2007).

This thesis has identified a number of catalysts that led to the radical discourse and policy shift to close large, geographically isolated institutions and relocate people with intellectual disability and people with mental illness into the community. Some of these included psychopharmacological developments, exposure of abuse in institutions, emerging discourses, the anti-psychiatry and consumer rights movement, and fiscal motivations (Bigby and Fyffe 2006; Richmond and Savy 2005; Jones 1993; Scull 1977; Barnes et al. 1999).

Although the principles of deinstitutionalisation have underpinned policy and legislation across the Western world, how these principles have been realised has differed cross-nationally and across population groups (Emerson 2004; Warner 1989; Jones 1993). For example, the closure of psychiatric institutions in the USA was rapid and the pace of institutional closure did not provide for adequate planning and coordination. The process was grossly under-resourced and, in the absence of a national health scheme, many people with mental illness became homeless (Warner 1989; Grob 1995; Dear and Wolch 1987; Bhugra 1996; Lamb 1984). Within the Australian context deinstitutionalisation has been a staged process and is arguably at a standstill in several jurisdictions including NSW (Neilson 1990; PWD 2009). Despite a staged approach, the implementation of deinstitutionalisation policy in Australia has also been criticised for inadequate resourcing and planning (Richmond and Savy 2005; Meadows et al. 2007; Bigby and Fyffe 2006). The closure of institutions for people with intellectual disability has generally happened later than the closure of psychiatric institutions globally (Emerson 2004; Scull 1977; Neilsen 1990; Jones 1993). For example, more than 1600 people with intellectual disability remain in large, geographically isolated institutions in NSW (NSW Ombudsman 2010).

There have also been a number of outcomes associated with the implementation of deinstitutionalisation policy. Numerous studies have indicated the improvements in people's quality of life after leaving an institution (Kozma et al. 2009; Young et al. 1998; Emerson and Hatton 1996; Newton et al. 2001). These studies have highlighted the positive changes for people with intellectual disability and people with mental illness who are living in the community with access to appropriate support (Kim et al. 2001; Larson and Larkin 1989; Emerson and Hatton 1996; Young et al. 1998; Newton et al. 2001). Improvements have mostly been in the areas of adaptive behaviour, community participation, client satisfaction and contact with family and friends (Kim et al. 2001, Larson and Larkin 1989, Emerson and Hatton 1996, Young et al. 1998, Newton et al. 2001).

There has also been widespread legislative reform including Australia, USA, UK and Scandinavia (Jones 1993; Warner 1989; Katy and Richmond 2005; Mansell 2006; Bigby and Frawley 2010). These legislative reforms have focused on the rights of

people with intellectual disability and people with mental illness, specifically the right to live and participate in the community. Within the Australian context, the introduction of the DSA (Cth) and subsequent state Acts, articulated the requirements of funded services to promote community participation and integration and that these services are not provided via congregate models (Bigby and Frawley 2010).

There have also been a number of negative outcomes associated with deinstitutionalisation including transinstitutionalisation, homelessness and the impact on families and carers (Richmond and Savy 2005; Ellem and Wilson 2010; Warner 1989; Groom et al. 2003; Torrey 2006; Emerson 2004). These outcomes are often attributed to inadequate resourcing and planning at both the individual and systemic levels.

Is deinstitutionalisation a contemporary policy?

A senior policy officer of a NSW Government Agency commented

I was looking at your (interview) questions with the Director General and we thought, deinstitutionalisation, wow! Why look at that now? That is from years ago. I don't even know that we have a policy on deinstitutionalisation anymore.

Several participants of this study considered deinstitutionalisation to be a process that occurred 'years ago'. These participants tended to be people who worked in the 'mental health sector' who commented that most of the geographically isolated 'Schedule V' hospitals had been closed in NSW (NSW Health 2007). This belief reflects the global trend of institutional closure occurring more rapidly for people with mental illness (Emerson 2004; Neilson 1990; Jones 1993; Scull 1977).

The majority of participants asserted that deinstitutionalisation was a contemporary policy as many people with intellectual disability and people with mental illness remain in institutions provided by government, community and for-profit organisations. Many participants commented that deinstitutionalisation was an

ongoing policy as ‘former patients’ who had been relocated to the community were still waiting for various service types such as supported accommodation to be transferred from ‘Schedule V’ hospitals.

Within the broader public and social policy context there are numerous contemporary policy examples that reflect the principles of deinstitutionalisation in Australia. The election of the Rudd Labor Government in 2007 witnessed significant policy changes including the Social Inclusion Agenda, the Taskforce on Homelessness and the National Affordable Housing Agreement (Australian Government 2008; Australian Government 2008a; Australian Government 2010; FaCHSIA 2009). As a signatory to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) the Australian Government has publicly supported the rights enshrined in the Convention, including Article 19 of the CRPD, ‘living independently and being included in the community’ (Australian Government 2009). Another example is the implementation of the Younger People in Residential Aged Care (YPRAC) program, which is a joint state and federal program implemented in 2006 to reduce the number of younger people with disability living in nursing homes (ADHC 2010c). A further example is the HASI program, which is a partnership between NSW Health and NSW Housing, which provides stable housing with specialist support for people with mental illness (NSW Health 2007).

The NSW Government has closed many of its former psychiatric institutions, which were large, geographically isolated psychiatric hospitals such as ‘Callan Park’ in Rozelle and Gladesville Hospital. Acute services are increasingly provided within mainstream hospitals (NSW Health 2007).

As discussed in earlier chapters, the NSW Government made a public commitment in 1998 to close all institutions for people with intellectual disability by 2010 (NSW Ombudsman 2010). This commitment was based on the belief that institutional models were an inappropriate social policy response to meeting the accommodation and support needs of people with intellectual disability (NSW Audit Office 1998). At the time of this announcement, there were more than 2000 people with intellectual disability living in large residential centres in NSW (NSW Ombudsman 2010). The NSW Government commenced a staged ‘devolution’ program whereby people living

in institutions would move into the community and would receive appropriate support (ADHC 2009).

Against this background of policy and legislative commitments to the human rights principles of deinstitutionalisation, there are emerging anomalies that highlight a disconnect between human rights discourse, current policy and the legislative framework that relates to the use of institutions as a social policy response for people with intellectual disability and people with mental illness (Emerson 2004; Mansell and Beadle-Brown 2009). Cluster housing, as an accommodation option for people with intellectual disability, is one such anomaly that is emerging globally including the UK, Scandinavia and Australia (Emerson 2004; ADHC 2009; PWD 2009; Mansell and Beadle-Brown 2009).

In 2006, the NSW Government released its disability services strategic policy 'Stronger Together 2006-2016' (ADHC 2006) and subsequent 'Allocation of Places in Supported Accommodation' Policy (2009). These policies maintained, that 'one size doesn't fit all' and announced a number of accommodation models that the government would provide and fund (ADHC 2009). These included institutionalised models such as cluster-housing and the redevelopment of existing institutions. As previously mentioned, PWD, a national advocacy organisation, has taken this matter before the NSW Administrative Decisions and Appeals Tribunal claiming, that such models are in breach of the DSA (NSW) (PWD 2009). The outcome of this matter is unknown at October 2010.

The NSW Ombudsman facilitated a forum about deinstitutionalisation and moving into the community in August 2010. More than 300 participants including people with disability, families, carers, support services and representatives from the ADHC attended the forum (NSW Ombudsman 2010). The Ombudsman's Report noted, that 1,600 people with intellectual disability remain in large residential centres in NSW. This figure included 400 people who live in the one institution, geographically isolated from the community (NSW Ombudsman 2010).

The NSW Ombudsman called on the ADHC to uphold its previous commitments and deliver on devolution by progressing closures of Large Residential Centres (NSW Ombudsman 2010).

What are the main values that underpin deinstitutionalisation?

Within this study, participants identified what they considered to be the main values that underpin deinstitutionalisation. Two key themes that emerged from the research were self-determination and choice; and citizenship, community integration and participation.

It is about self-determination and choice and having control over the decisions that affect your life (Participant 3, Community Organisation).

Opportunities to exercise choice and personal autonomy were also identified as positive outcomes of the implementation of deinstitutionalisation policy.

Citizenship, community integration and participation are complex concepts and can be interpreted from a variety of positions (Cocks and Boaden 2010; Clement and Bigby 2009; Bigby and Frawley 2010; O'Brien and O'Brien 1987). The majority of participants of this study identified with a rights-based approach to deinstitutionalisation (Booth et al. 1990, 70; Johnson 1998; French 2009).

Within human rights discourse deinstitutionalisation is much more than the closure of institutions. It is more than physical relocation to the community. It is the recognition that people with intellectual disability and people with mental illness are entitled to the same citizenship and human rights as people without disability and mental illness (Hazelton 2005; Booth et al. 1990; Johnson 1998; French 2009). Hazelton (2005, 231) noted, that

The concept of citizenship is usually approached as a combination of social rights and obligations that determine legal identity, access to scarce resources and social membership.

These citizenship rights included the right to an adequate standard of living including food, clothing, housing and access to health care; freedom from exploitation, violence, abuse and degrading treatment; and full access to participation in the community (UN Documents n.d.; Hauritz 1998; French 2009).

Participant 3 (Community Organisation) described deinstitutionalisation as

the opportunity to live in and be part of the community; integrated and included like anybody else regardless of your disability or support needs...It is the opportunity to be in and of the community... Being connected with the community, belonging to it, sharing its common values, experiences and opportunities.

But what does it mean to live in and participate in the community? Does it mean going bowling and getting McDonald's after 'the outing'? What about a group of residents sitting in a row of plastic chairs on the footpath outside the boarding house? Surely, they are 'in' the community. O'Brien and O'Brien (1987) first described the tension between community presence and participation. Many people with intellectual disability and people with mental illness may be physically located in the community however few experience meaningful relationships and connections outside of paid staff, other people with disability or close family members (O'Brien and O'Brien 1987; Bigby and Fyffe 2010; Noonan Walsh et al. 2008; Newton et al. 2001).

Most participants in this research believed that the ability to integrate and participate in the community had not been fully realised because the implementation of deinstitutionalisation policy was unplanned and under-resourced. These claims find widespread support throughout the literature (Warner 1989; Scull 1977; Bachrach 1996; Jones 1993; Savy 2005). Participants identified stigma, lack of discharge planning and lack of resources in the community as fundamental barriers to integration and participation.

The use of licensed boarding houses as an accommodation option for people with intellectual disability and people with mental illness.

Central to deinstitutionalisation discourse is the view that institutions are an inappropriate social policy response to meeting the accommodation and support needs of people with intellectual disability and people with mental illness (Scull 1977; Jones 1993; Emerson 2004; Bigby and Fyffe 2006; Richmond and Savy 2005). Within this discourse are differently positioned perspectives. From a neo-liberal perspective institutions are considered to be inefficient and an expensive and unsustainable option for the state (Henderson 2005; Argyrous and Stillwell 1996; Scull 1977; Warner 1989). From a rights perspective institutions do not enable people with intellectual disability and people with mental illness to access their human and citizenship rights (Willer and Intagliata 1984; Johnson 1998).

Chapter Two identified some of the main outcomes of deinstitutionalisation including transinstitutionalisation. This phenomena is described as the process of moving people with intellectual disability and people with mental illness from large-scale, geographically isolated institutions without adequate support and then entering other types of institutions including nursing homes, boarding houses, homeless accommodation services and correctional facilities (Bostock et al. 2001; Kelly and McKenna 2004; Hudson 1991; Chenoweth 2000).

During the first wave of deinstitutionalisation in the 1960's and 1970's many people with intellectual disability and people with mental illness left large-scale, geographically isolated institutions and were relocated to the community (Bigby and Fyffe 2006). Some people moved into independent accommodation options and others returned to live with family. Overwhelmingly, the majority of people with intellectual disability and people with mental illness moved to boarding houses, nursing homes, large residential homes and cluster-housing (Bigby and Fyffe 2006; Emerson 2004; Warner 1989; Scull 1977; Horan et al. 2001; Greenhalgh 2004).

Several participants of this study described the use of licensed boarding houses as 'the privatisation of the back wards'. In this context, a back ward was described as a hospital ward for non-acute, long-term chronic patients of psychiatric hospitals. It was asserted that the 'back wards' had been privatised; services once provided by the state in 'Schedule V' hospitals had been replaced by private, for-profit licensed boarding houses in the community. Some participants believed that the state used the human rights tenets of deinstitutionalisation to hasten the realisation of neo-liberal motivations that focused on reducing the state's responsibilities and costs, a view which finds resonance with Scull (1977). In this study the role of 'entrepreneurial psychiatric nurses' in facilitating this process was emphasised. Participants described how psychiatric nurses of the 'Schedule V' hospitals aware of the state's commitment to deinstitutionalise, purchased old nursing homes and grand old homes to be used as boarding houses. Patients were transported directly from the 'back wards' to these boarding houses.

In considering whether or not the use of licensed boarding houses constitutes transinstitutionalisation, Goffman's (1961) concept of 'total institution' was applied to LRC's in Inner Sydney.

For many residents of licensed boarding houses all aspects of their lives are conducted within the LRC. This included sleeping in dormitory-style bedrooms, eating in the same seat, at the same time each day with a predictable menu. For many people it also meant sitting around in rows of plastic chairs smoking all day.

Most of them are very heavy smokers and they would spend most of their day just sitting around the backyard, just smoking and not leaving the place
(Participant 37, Former Licensed Boarding House Resident).

Most participants believed that licensed boarding houses were institutions, including a proprietor who stated, 'It was from institution to institution'. As Johnson and Marriott (2009, 285) pointed out, the definition of what constitutes an institution 'remains a contested one'. Are institutions defined by a congregate model; a certain number of beds? Does the population group influence the definition? Does an institution have to be geographically isolated from the community? Are they defined

by institutionalised practices? Within the Australian context, the NDA (formerly the CSTDA) Minimum Data Set (MDS) defines an institution in the following ways.

Small residential/institutions are usually located on large parcels of land and provide 24 hour residential support in a congregate or cluster setting of 7 to 20 beds.

Large residential/institutions are usually located on large parcels of land and provide 24 hour residential support in a congregate setting of more than 20 beds (AIHW 2009, 178).

Based on the NDA MDS definitions of an institution, all licensed boarding houses in NSW would meet these criteria. Size, number of people living in a congregate setting and location remain important features in determining whether or not an accommodation model is described as an institution (AIHW 2009). Within a rights-based approach institutions are defined more broadly, not just in relation to size or congregate model but the institutionalised practices that lead to mortification (Johnson and Traustadottir 2005; Booth et al. 1990; Goffman 1961). Through the lens of Goffman's (1961) 'total institution', it is apparent that licensed boarding houses are an institution. Furthermore, relocating people to such an accommodation option constitutes transinstitutionalisation (Bostock et al. 2001).

Do boarding houses uphold the human rights principles of deinstitutionalisation?

Within a rights-based approach, deinstitutionalisation is more than the closure of geographically isolated institutions and the relocation of people with intellectual disability and people with mental illness into the community (Johnson and Traustadottir 2005; Booth et al. 1990). The human rights principles of deinstitutionalisation recognises that people with intellectual disability and people with mental illness have the right to live and participate in the community in the least restrictive environment, with appropriate and accessible support services. In considering whether or not licensed boarding houses uphold the human rights

principles of deinstitutionalisation, participants provided a variety of perspectives (Johnson and Traustadottir 2005; Booth et al. 1990; Bigby and Fyffe 2006; Richmond and Savy 2005; Emerson 2004).

The majority of participants of this study believed that institutional models were an inappropriate social policy response to meeting the accommodation and support needs of people with intellectual disability and people with mental illness. However, it was argued by a few participants that licensed boarding houses, 'while not ideal' were an improvement compared with isolated 'Schedule V' hospitals. These claims related to a sense of freedom, autonomy and independence. For these participants, licensed boarding houses had achieved some of the human-rights principles of deinstitutionalisation as compared with the former geographically isolated psychiatric institutions.

Conversely, it was argued that licensed boarding houses were an inferior model compared with the 'Schedule V' hospitals as they had less accountability mechanisms and provided less health care and monitoring.

Participants of this study identified three main reasons why boarding houses do not uphold the human rights principles of deinstitutionalisation. These included the outdated knowledge and skills of managers and proprietors; the congregate model; and the for-profit nature of licensed boarding houses that influenced the use of institutionalised practices.

Several of the proprietors and managers of licensed boarding houses in NSW were psychiatric nurses from 'Schedule V' hospitals and have not updated their knowledge or skills since the 1970's. The management and treatment practices used in the boarding houses reflect the practices of the 'Schedule V' hospitals.

And then if you've got people who are not trained or wouldn't have a clue about the DSA they can't fathom the way that you might support someone develop skills or get a different outcome. It's the language you use, how you do things and the respect you have for people. It's the underlying values

rather than blowing a whistle to get everyone to be quiet (Participant 5, Community Organisation).

The values, knowledge and skills of most proprietors and managers of licensed boarding houses do not reflect a contemporary understanding of disability or mental health and illness, for example, the principles of the DSA (NSW). This is particularly concerning as numerous studies have demonstrated that it is the way staff provide support that is the most important determinant in achieving positive outcomes for people with intellectual disability and people with mental illness (Mansell 2006, 70; see also Emerson and Hatton 1996). Notwithstanding concerns relating to outdated skills and knowledge, it became clear throughout the study that there was a spectrum of quality amongst the boarding houses; ‘some licensed boarding houses are better than others’ (Participant 10, Community Organisation). The better licensed boarding houses tended to have managers that were responsible for the day-to-day running of the LRC. Resident participants believed that managers were less profit-driven compared with proprietors. They believed that some of the managers prepared better quality food and demonstrated care and interest in the residents. ‘She asks us how we are going’ (Participant 37, Former Licensed Boarding House Resident). ‘You feel like you can ask them for help if you need it’ (Participant 35, Former Licensed Boarding House Resident).

The congregate nature of licensed boarding houses whereby a large number of unrelated people are co-located together was considered contrary to the human rights principles of deinstitutionalisation (Johnson and Traustadottir 2005; Booth et al. 1990; Richmond and Savy 2005; French et al. 2009). Participants considered that the model relied upon routines, efficiencies and group management strategies that did not promote residents’ human or citizenship rights. Such practices included the communal washing of clothes, dormitory style bedrooms, the use of bells and whistles to manage behaviour, food only accessible at scheduled meal times and locked kitchens.

I think it is shadowed by their expectations of who the clients are and what they are supposed to be doing. And what they’re supposed to be doing is providing housing and basic food and medication supervision for the clients

and do it in a really efficient way. It's that Ford style of economics, get everybody in a line and go down the line sort of thing. It doesn't work with people, they are not machines (Participant 21, Government Agency).

The for-profit nature of licensed boarding houses was also considered as a major barrier to enabling the human rights principles of deinstitutionalisation. Participants believed that proprietor's primary focus was achieving a profit. This was achieved by adopting a business model that relied upon efficiencies of scale at the cost of quality of care (O'Faircheallaigh et al. 1999).

Boarding houses are for-profit businesses so at the end of the day they're there to make money (Participant 5, Community Organisation).

I felt like saying to the manager, "Why do you have a boarding house? You don't seem to care for the people there". I can't understand what their motivation is, except to make money (Participant 37, Former Licensed Boarding House Resident).

The use of for-profit organisations in the provision of human services remains a contested one (O'Faircheallaigh et al. 1999). Under the banner of neo-liberalism many public services have been privatised from the 1980's based on the belief that the market will ensure greater efficiencies (Henderson 2005). The use of privatisation as both a social and public policy response has some fundamental difficulties. O'Faircheallaigh et al. (1999, 167) maintained, that

In theory, private firms have an incentive to provide quality services in order to maintain their market share and their profits, and market forces could thus act both as a means of maintaining quality and an accountability mechanism.

The reliance on market forces to achieve quality services may be appropriate for public transport or electricity services however, O'Faircheallaigh et al. maintained, that the incentive to achieve quality services can be compromised in the human services where the 'tendency for profit-maximising outweighs equity, effectiveness, service quality and accountability' (1999, 166-7). Market forces have not achieved

quality and accountability for residents of licensed boarding houses, following the 'privatisation of the back wards' (Harris 2007, NSW Ombudsman 2006). Proprietors of licensed boarding houses have a captured market. Indeed, some of the former psychiatric nurses of 'Schedule V' hospitals transported wards of people directly to their boarding houses. The findings of this study indicated that residents of licensed boarding houses live within a culture of compliance, fear and retribution. They do not have tenancy rights or security of tenure and have very little knowledge of, or access to, complaints processes. For some people the nature of their disability or mental illness, compounded with poverty, diminishes their ability to access alternative options (Harris 2007; Edwards and Fisher 2010; Greenhalgh et al. 2004).

Henderson (2005, 243) commented, that neo-liberalism had influenced conceptions of citizenship

toward active citizenship involving independent decision-making and a willingness to act in one's own best interests. Where citizenship was previously understood in terms of welfare, it is increasingly understood as access to the potential to exercise free choice.

Most participants believed that licensed boarding house residents were not provided with a choice about their accommodation option. Many residents moved to their current boarding house from a 'Schedule V' hospital in the 1970's and 1980's. Other residents had been approved by an administrator of a screening tool whilst in hospital and were unaware that they could refuse entry into a licensed boarding house. For some residents their choice was between the licensed boarding house and sleeping rough. Some of the participants of this study asserted that choice had been manipulated by the State to avoid the costs associated with providing an accommodation response under the DSA (NSW).

Do licensed boarding houses contribute to the quality of life of residents with intellectual disability and residents with mental illness?

As identified in Chapter Five, this study applied an interpretive approach to ‘quality of life’. In keeping with this approach, residents’ thoughts, feelings and experiences as well as other participant’s perspectives were considered across a number of quality of life domains. These quality of life domains included relationships, physical and mental health, self-determination and choice, financial security, participation and community access, recreation, access to support services, education and employment, security of their accommodation tenure, general feeling of well-being and other domains identified by participants.

Many of the residents that participated in this study had lived in a licensed boarding house for many years, some since the first wave of deinstitutionalisation in the 1970’s and 1980’s. Of these residents some had previously lived together in ‘Schedule V’ hospitals, which meant in some cases, residents had known each other for more than half a century. Residents identified these relationships as significant describing them as ‘close friends’. A few residents considered that they had a ‘good’ relationship with their boarding house proprietor. Most of the residents interviewed accessed an ALI program and had developed significant relationships with ALI workers. Only one of the residents had regular contact with family. With the exception of this resident, all other significant relationships were with paid staff or people living in the licensed boarding house. This is consistent with some studies of people with intellectual disability who have left institutions and relocated to the community (Cummins and Dunt 1990; Clement and Bigby 2009, Barber et al. 1994; Noonan Walsh et al. 2008).

Most of the residents described the licensed boarding house as their ‘home’, with some participants having lived in their current boarding house for several decades. ‘Home’ tended to focus on where they lived, a place of residence, rather than other connotations that may be associated with home such as security, somewhere to relax, feelings of belonging or the ability to exercise choice. While residents of licensed

boarding houses do not have tenancy rights and security of tenure, most of the resident participants were unaware of this or did not consider it to be an issue of concern. One participant considered his current accommodation to be insecure.

Residents of licensed boarding houses are generally less transient than residents of unlicensed premises (Davidson et al. 1997; Greenhalgh et al. 2004). The resident participants of this study tended to have long-term accommodation placements in their boarding houses.

Although most of the residents described the licensed boarding house as their 'home', the majority of residents expressed concerns associated with the accommodation model and its institutionalised practices. This extended to many quality of life domains including privacy, self-determination and choice, financial security, recreation and participation in the community.

All of the residents commented about the poor quality of food provided in licensed boarding houses. Residents described proprietors purchasing cheap food and in some cases food at reduced prices because it was out of date. The rationing of food and amenities is considered general practice in licensed boarding houses. Residents believed that they should receive a better quality of service based on the fees they paid. Many described feeling 'used' and believed that the proprietors were only focused on making a profit.

They used to ration food...Everything they did in terms of food was cost cutting. They made a fortune out of us (Participant 35, Former Licensed Boarding House Resident).

All of the residents paid 85-100 percent of their pension. Any remaining income was used to purchase medication and cigarettes as the majority of participants smoked. The poverty of licensed boarding house residents, coupled with restrictive practices was a barrier to leaving the boarding house and accessing the community.

If you are not there for your meals then you get nothing (Participant 27, Current Licensed Boarding House Resident).

The BHRP has gone some way in addressing the impact of the ‘total institution’ (Alt Beating Consulting 2001; Goffman 1961). As one advocate noted,

The Boarding House Reform Strategy made the government assume responsibility for the people they had abandoned during deinstitutionalisation (Participant 5, Community Organisation).

The BHRP has provided funding for recreational activities, personal care, and health and advocacy services for residents of licensed boarding houses (ADHC 2009). The ALI, which is an initiative of the BHRP, provides funding to community organisations to provide recreation and skills-based programs for residents of licensed boarding houses (Edwards and Fisher 2010). These programs are mostly provided external to the boarding house. A review of the ALI, conducted by the NSW Social Policy Research Centre in 2010, found that residents’

Participation in community based activities increased...such as recreation in community clubs and going to a café...but had done little formal skills development...ALI providers were least likely to engage with people with unmanaged mental health problems or a long history of isolation due to prior institutionalisation. Investment in time to build rapport was necessary to help these people to develop trust so that they can benefit from ALI support. Poverty prevents some people from participating in ALI support because of the cost of the activity, transport and clothing suitable for going out (Edwards and Fisher 2010, iii-iv).

Residents identified privacy and safety as quality of life domains that were not being adequately addressed. Many of the residents shared their bedrooms with people they did not choose. Access to privacy whilst showering or using the toilet was often compromised. The researcher observed this when a licensed proprietor was conducting a tour of the boarding house and opened a toilet door exposing a woman using the toilet. Many of the residents had had personal items taken, as they do not have a lock on their door or a safe storage facility. All of the female residents discussed occasions when they had felt unsafe because they do not have locks on their doors and the licensed boarding house generally remained unlocked. Other

participants stated that many women have chosen to sleep rough as they consider it safer than living in a licensed boarding house.

I've got no lock on my door. People just come in and take what they like. I've got no privacy or security (Participant 28, Current Licensed Boarding House Resident).

Self-determination and choice were identified as quality of life domains that were not met in licensed boarding houses. This included a lack of choice about the duration of a shower, when to eat meals, how tea or coffee was taken, and who shared a bedroom.

Fundamental to any measure of quality of life is health and well-being (for example, Heal and Chadsey-Rusch 1985). The majority of residents described both physical and mental health concerns. For most residents the only health care service they accessed was the 'two minute reviews' conducted by the GP or psychiatrist who had visiting rights at the boarding house. The extent to which proprietors of licensed boarding houses meet the physical, mental, dental, sexual, nutritional and preventative health care needs of residents is extremely poor. These concerns are not new. They are concerns that have been noted on monitoring, investigation and Parliamentary reports since the beginnings of the licensing regime. They are concerns that have been expressed by advocates, community organisations, ADHC, police, various health professionals, Official Community Visitors and the NSW Ombudsman (for example, NSW Ombudsman 2006; NSW Ombudsman 2008; PWD 2009). The introduction of health audits of boarding house residents in the Metropolitan South Region of the ADHC have provided some improvements in residents' health and access to primary, allied and preventative health care (NSW Ombudsman 2006). Despite these health audits, seven people died over a three-month period at one boarding house in 2010, including a person that had been dead for two days; unnoticed. Following the attendance of the NSW Health Department at the licensed boarding house, three other residents were taken directly to hospital to seek immediate medical attention and paid support staff were put into the boarding house to provide 24-hour care for the other residents. This raises significant concerns about the effectiveness of the monitoring framework.

This study included interviews with three former residents of licensed boarding houses. All of the former residents stated that their quality of life and skill development had improved markedly after leaving the boarding house. A community worker commented on the changes for people with intellectual disability and people with mental illness who had left a licensed boarding house.

I saw the difference straight away...They became more confident. They didn't just sit outside and smoke (Participant 6, Community Organisation).

Residents described having the opportunity to develop and practice skills such as cooking, washing or catching a bus to meet their partner for coffee. Two of the residents had more contact with their family after leaving the boarding house. Privacy and autonomy were also described as significant domains that had improved. All of the former residents described their current support workers as caring. This in turn fostered a feeling of being valued and worthwhile. The changes in these people's lives were profound. The experiences of these former residents is consistent with studies of people who have experienced deinstitutionalisation and moved to group homes or independent living options with access to appropriate support (including Kozma et al. 2009; Emerson and Hatton 1996; Young et al. 1998; Newton et al. 2001). Bigby and Frawley (2010, 81) observed that

three decades of research has unequivocally demonstrated the improved quality of life outcomes for people with intellectual disabilities who move out of institutional environments and live in small-scale group homes in terms of more choice and self-determination; more frequent contact with people in their social networks; and more participation in community based activities.

Sustainability of the licensed boarding house sector

Following the implementation of deinstitutionalisation in the 1960's and 1970's, boarding houses were used as a low-cost accommodation option for people with intellectual disability and people with mental illness leaving institutions (Greenhalgh et al. 2004). Increasingly, people who cannot access alternative accommodation and may experience multiple disadvantages use boarding houses (Davidson et al. 1997;

Edwards and Fisher 2010; Greenhalgh et al. 2004; Harris 2007). These disadvantages include poverty, substance use, a criminal history or lack of alternative low-cost housing availability. Although boarding houses are often considered as an option of last resort, they play a significant role as a provider of low-cost accommodation. This role is important because it interacts with public and private housing markets and arguably replaces disability, mental health and homeless services (Greenhalgh et al. 2004).

There has been a substantial decline in boarding house stock in NSW, as well as other Australian states over the past two decades (Greenhalgh et al. 2004; Davidson et al. 1997; Davidson et al. 1999; NSW Ombudsman 2006). The AHURI attributed this decline to factors including the gentrification of Inner Sydney, compliance with new regulations, viability, insurance and the introduction of the Goods and Services Tax (2004). The decline of the licensed boarding house sector in NSW has been substantial. In 1994 this sector provided 3,336 beds in 194 boarding houses. In 2010, there are 39 licensed boarding houses that provide for 781 residents (ADHC 2010). This decline has been particularly influenced by gentrification and the enforcement of licensing conditions during the 1990's, which led to numerous closures (NSW Ombudsman 2006; Harris 2007).

In considering the sustainability of the licensed boarding house sector, many participants believed that licensed boarding houses would continue to play an important role in the provision of low-cost accommodation for people with intellectual disability and people with mental illness. These participants asserted that although there had been a marked decline in the licensed boarding house sector and they were considered 'ideologically unsustainable' in so far as they do not meet the principles of the DSA (NSW), participants did not believe that the government would provide or fund alternative accommodation options.

Many participants believed that the licensed boarding house sector would experience further decline due to the gentrification of Inner Sydney and ageing proprietors. The viability of licensed boarding houses was also identified, as an issue of concern and several participants believed that the regulatory changes introduced in September 2010 would exacerbate these concerns. The *Youth and Community Services (YACS)*

Regulation 2010 introduced some minimum standards in relation to health and safety (ADHC 2010). It is unclear at October 2010 how these regulatory changes will impact the viability of the licensed sector.

Several participants maintained that although the licensed sector would experience further decline, unlicensed boarding houses would continue to operate in breach of the YACS Act. Participants considered ADHC's current policy in relation to 'illegal operators' to be inadequate. ADHC responds to complaints that allege that there are two or more people with disability who require social habilitation residing in an unlicensed boarding house (NSW Ombudsman 2006). Participants believed that a more assertive monitoring approach was required that was informed by strong inter-departmental committees and communication between the NSW Human Services Agencies and local Councils. Local Councils were identified as an important source of information in relation to dwelling types.

There were clear themes that emerged from the study in relation to recommendations for change including whether or not licensed boarding houses should receive government funding; deinstitutionalisation of the licensed boarding house sector; and an enhanced monitoring system. These themes and conclusions are discussed in Chapter Seven.

Chapter Seven: Conclusion

Chapter Seven presents the conclusions of this study. It is argued that licensed boarding houses are a form of transinstitutionalisation that are maintained under neo-liberalism. The social construction of intellectual disability and mental illness and the use of institutional models as a social policy response are considered. This chapter identifies what needs to change to enact the human rights principles articulated in current policy and legislation including the deinstitutionalisation of licensed boarding houses in NSW and improvements to the current monitoring framework.

I have reacted with disbelief and bewilderment to what I saw. I found it difficult to understand how a society which is built on such noble principles, and which has the resources to make these principles a reality, can and will tolerate the dehumanisation of a large number of its citizens (Nirje 1969, 53).

Do licensed boarding houses uphold the human rights principles of deinstitutionalisation?

This study found that licensed boarding houses do not uphold the human rights principles of deinstitutionalisation. Specifically, participants considered that such an accommodation option did not provide residents with opportunities for self-determination and choice or the realisation of their citizenship rights. A key theme that emerged throughout the study was that licensed boarding houses do not promote community integration and participation.

Participants identified three main reasons why licensed boarding houses do not uphold the human rights principles of deinstitutionalisation. The outdated knowledge and skills of licensed boarding house proprietors and managers; the congregate model; and the for-profit nature of licensed boarding houses contributed to the use of institutionalised practices. Some examples of these institutionalised practices included rationing food, using bells and whistles to manage behaviour, time-limited

showers, dormitory-style bedrooms, communal laundering, queuing for medication, and structured meal and bed times. These practices devalued residents and did not uphold their human or citizenship rights.

Do licensed boarding houses contribute to the quality of life of residents with intellectual disability and residents with mental illness?

The extent to which licensed boarding houses contribute to the quality of life of residents with intellectual disability and residents with mental illness was generally very poor. Some residents identified significant relationships with other licensed boarding house residents particularly those that had previously lived together in 'Schedule V' hospitals. Most residents did not have regular contact with family and many commented that their main contact outside of the boarding house was ALI workers. This finding is consistent with a recent study conducted by Edwards and Fisher (2010).

The ability to participate in and access the community was compromised by the structures, routines and financial costs of living in a licensed boarding house. Residents pay 85-100 percent of their pension, which leaves very little money to purchase clothes, medication, food, services and other personal items (Harris 2007; Edwards and Fisher 2010). The poverty experienced by residents of licensed boarding houses prevents active participation in activities and services external to the boarding house. Lack of access to food outside scheduled meal times is a significant barrier to people leaving the boarding house. The Boarding House Reform Program has gone some way to addressing this issue through the ALI and the provision of advocacy and primary and secondary health services (Robinson et al. 2005; Edwards and Fisher 2010; ADHC 2009). The provision of personal care services by the Home Care Service of New South Wales has also positively influenced the quality of life of licensed boarding house residents.

Residents described concerns surrounding personal safety and access to privacy. This included experiences of domestic violence and concerns surrounding physical and sexual safety (Attard and Price-Kelly 2010). Dormitory-style bedrooms without locks and shared toilets and bathrooms were identified as barriers to privacy and safety. Licensed boarding houses are often unsecured and residents do not have access to locked storage facilities.

This study found that licensed boarding houses do not promote self-determination and choice. Residents' meals are structured at the same time everyday based on a set menu that is the same each week. Tea and coffee are generally pre-made. There is limited choice about who shares a bedroom.

The health and well-being of licensed boarding house residents is of particular concern. Residents can experience higher risks of some diseases and illness for a variety of reasons including their age and side effects from long-term use of antipsychotic drugs (Bailey and Sheehy 2009). Most residents do not access mainstream or health services external to the boarding house. Health care services are generally provided by short reviews conducted by a GP or psychiatrist who visit the boarding house. The extent to which licensed boarding house proprietors promote or address the physical, mental, dental, sexual, nutritional and preventative health care needs of residents is extremely poor. Participants of this study identified the health audits conducted by ADHC's Metropolitan South Region as a positive step in addressing residents' health care needs. The effectiveness of these audits was questioned in 2010 following a review of a licensed boarding house in ADHC's Metropolitan South Region conducted by the New South Wales Health Department. This review identified the death of seven residents over a three-month period and the immediate health concerns of several other residents. Regulatory changes introduced in September 2010 now require proprietors and managers of licensed boarding houses to have a first aid certificate (ADHC 2010). The impact of these changes is unknown at October 2010.

Legislative and monitoring framework

This study identified significant concerns relating to the current legislative and monitoring framework. Participants of this study identified concerns with the administration of the screening tool that authorises entry into licensed boarding houses. These concerns included long-term residents not having their support needs reassessed following entry into the licensed boarding house. This has been addressed in part by changes to the screening tool introduced in April 2010 which requires the administration of a new screening tool when

a resident's physical health or psychiatric condition significantly deteriorates; an admission to hospital occurs; or a resident is absent from the licensed residential centre for more than two months (ADHC 2010, 1).

The responsibility to identify these concerns and request a revised screening tool falls largely with proprietors or managers of licensed boarding houses. Whilst noting that some proprietors and managers advocate for residents to be reassessed, this study found that many do not recognise this need or are unresponsive to the deterioration of a resident's health and functioning. The Home Care Service of NSW's Referral and Assessment Centre (RAC) replaced the Aged Care Assessment Teams (ACAT) in administering the screening tool in April 2010. ADHC is now responsible for funding community organisations that provide services to licensed boarding houses, licensing, monitoring and now assessing eligibility and entry through the RAC. Based on the gate-keeping role of the screening tool, there exists a perceived or actual conflict of interest for ADHC.

The YACS Act has been subject of numerous reviews and is considered an outdated piece of legislation including inappropriate language and ambiguities surrounding what licence conditions are enforceable (NSW Ombudsman 2006; Harris 2007; PWD 2010). This included contention about the extent to which proprietors were required to provide for the health and welfare of residents. The ADHC have maintained that such licence conditions are *ultra vires*, that is, beyond the power of the department to enforce (NSW Ombudsman 2006). Regulatory changes were introduced in September 2010, namely the *Youth and Community Services (YACS)*

Regulation 2010, which focused on some aspects of residents' health and welfare and provide for ADHC to enforce these licence conditions (ADHC 2010).

Notwithstanding the importance of such changes, the Regulation will only prove effective through enforcement and monitoring by ADHC.

The standard of monitoring and support differs across ADHC Regions and overall there remain serious concerns about the current licensing framework and ADHC's ability to meet its requirements (NSW Ombudsman 2006). The situation previously described, whereby seven residents died over a three-month period and other residents required immediate medical attention, is an obvious example. This licensed boarding house was subject to 'regular' monitoring visits by ADHC and part of a regional health audit process.

The research also identified concerns relating to the monitoring of the unlicensed boarding house sector. Participants discussed numerous unlicensed boarding houses where more than two people with disability were accommodated. The current ADHC policy relating to unlicensed premises is to respond to complaints about boarding houses where it is alleged that more than two people with 'handicap' reside (NSW Ombudsman 2006). This policy was considered inadequate in monitoring the unlicensed sector. Participants believed that ADHC needed to take a more active role in monitoring proprietors who are operating in breach of the YACS Act.

Role as a provider of low-cost accommodation

This study acknowledges the role of licensed boarding houses as a provider of low-cost accommodation for people with intellectual disability and people with mental illness (Greenhalgh et al. 2004). The licensed boarding house sector has experienced marked decline from the mid-1990's (NSW Ombudsman 2006). The sustainability of this sector is uncertain given the ongoing gentrification of Inner Sydney and ageing proprietors (Greenhalgh et al. 2004; Davidson et al. 1997; Allen Consulting Group 2003). The impact of the new Regulation introduced in September 2010 relating to health and welfare minimum standards is unknown.

The funding of licensed boarding houses is not supported by the findings of this study as they are a congregate model of care and do not reflect the principles of the DSA (NSW).

Conclusion

This thesis has explored the use of institutions as a social policy response for the 'care' and 'treatment' of people with intellectual disability and people with mental illness. Some of the institutions included the 'ship of fools', 'workhouses' and 'poorhouses', asylums and large-scale, geographically isolated hospitals (Jones 1993; Scull 1977). The use of institutions as a social policy response have reflected the social construction of disability and mental illness over time and highlighted the central role of discourse in shaping knowledge and actions (Berger and Luckmann 1966; Foucault 1965; Cocks and Allen 1996).

This study has found that the accommodation of people with intellectual disability and people with mental illness in licensed boarding houses in Inner Sydney constitutes transinstitutionalisation and does not serve to enact the human rights principles articulated in current policy and legislation (Johnson and Traustadottir 2005; Booth et al. 1990; French 2009). The extent to which licensed boarding houses contribute to the quality of life of residents with intellectual disability and residents with mental illness was found to be generally very poor. While licensed boarding houses are located within the community, their congregate model and institutionalised practices reflect Goffman's (1961) 'total institution'.

In considering the relationship between a person's social role and value and social policy response, one reasonably concludes that people living in licensed boarding houses remain some of the most devalued members of our community. Against this background it becomes clear why this service type is considered appropriate for residents with intellectual disability and residents with mental illness.

I don't understand why we are comparing boarding houses to worse things and saying thank goodness. Why aren't we comparing them to better things and saying why not (Participant 10, Community Organisation)?

Through the lens of neo-liberalism licensed boarding houses have found meaning as a legitimate structural response to meeting the needs of people with intellectual disability and people with mental illness (Hazelton 2005). Services previously provided by the 'back wards' of 'Schedule V' hospitals were privatised and replaced by licensed boarding houses in the community. Market forces would ensure quality of care, as people with intellectual disability and people with mental illness are viewed as active citizens who make choices about where they live (Hazelton 2005). But this is not what happened. This is not the reality of living in a licensed boarding house in Inner Sydney. Despite attempts to regulate and monitor the licensed boarding house sector, the state has failed to provide for the human rights of people living in LRC's. This study has highlighted the contradictions inherent in achieving the human rights principles of deinstitutionalisation through neo-liberal strategies.

Based on the findings of this study, it is argued that licensed boarding houses are an unacceptable social policy response to meeting the accommodation and support needs of people with intellectual disability and people with mental illness. Licensed boarding houses do not uphold the human rights principles of deinstitutionalisation.

There remain 781 people with intellectual disability and people with mental illness living in licensed boarding houses in NSW (ADHC 2010). In considering how the human rights principles of deinstitutionalisation might be enacted for these people and 'potential residents', this study argues for the staged deinstitutionalisation of licensed boarding houses in NSW and the resourcing of accommodation and support models that uphold the principles of the DSA (NSW).

While this study focused on licensed boarding houses in Inner Sydney, it has reinforced the impact of the 'total institution' (Goffman 1961) and challenged the ability of congregate accommodation models to enact the human rights principles of deinstitutionalisation articulated in current policy and legislation (Emerson 2004; Bigby and Fyffe 2006; Richmond and Savy 2005; Johnson and Traustadottir 2005; French 2009). This study has also highlighted the need for appropriate planning and resourcing of the deinstitutionalisation process (Scull 1977; Warner 1989; Emerson 2004; Richmond and Savy 2005). These assertions remain important given that thousands of people with intellectual disability and people with mental illness remain

in institutions in NSW, and the NSW Government is investing in the redevelopment of existing institutions (NSW Ombudsman 2006; PWD 2009; ADHC 2009).

Dissemination of findings

The Australian Association of Social Workers (AASW) Code of Ethics (2002, 20-21) requires that social workers conducting practice research disseminate findings. The Code states, that

l) Where feasible, inform research participants or their representatives of research results that are relevant to them.

(m) Bring research results that indicate or demonstrate social inequalities or injustices to the attention of the relevant bodies.

Accordingly, the findings of this study will be provided to research participants, the Ministers for Disability Services, Health and Housing and peak advocacy organisations in NSW.

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Appendix 1: Semi-structured interview questions

Interviewer: Gabrielle Drake (PhD candidate)

Participant's Name:

Participant's Job Title:

Participants Agency:

Date:

Time:

Location:

Information for participants

- Outline purpose of research.
- Voluntary participation. Ability to withdraw from interview at any time.
- Confidentiality. Limits of confidentiality.
- Informed consent.
- Anonymity: de-identified.

Consent form

Participants are required to sign consent form prior to the interview. Participants are provided with the opportunity to discuss the research before signing the consent form.

INTERVIEW QUESTIONS:

Question one:

Please provide details of your current role and responsibilities within your agency.

Question two:

Please provide a brief outline of your knowledge and experience of and/or involvement with licensed boarding houses in Sydney.

Question three:

This research locates licensed boarding houses as an accommodation option within the policy framework of deinstitutionalisation. What do you consider to be the main values that underpin deinstitutionalisation?

Question four:

What do you consider to be some of the positive and negative outcomes of deinstitutionalisation?

Question five:

Do you consider boarding houses uphold the values of deinstitutionalisation?

Question six:

What do you consider to be the major challenges facing the licensed boarding house sector?

Question seven:

How could licensed boarding houses improve the services they provide to people with intellectual disability and people with mental illness?

Question eight:

In what ways does the service system need to change to improve the services provided by licensed boarding houses as an accommodation option for people with intellectual disability and people with mental illness?

Appendix 2: Participation Information Sheet



Participant Information Sheet

The use of licensed boarding houses in Sydney as an accommodation option for people with intellectual disability and people with mental illness.

My name is Gabrielle Drake and I am conducting this research for the degree of Doctor of Philosophy- Social Work & Social Policy at Curtin University of Technology (Western Australia).

Purpose of research

The purpose of the research is to explore the use of licensed boarding houses as an accommodation option for people with intellectual disability and people with mental illness. The research will focus on inner Sydney.

Your role

The interview process will take approximately 45 minutes. The interview will be recorded and notes from the interview are available upon request.

Why participate in this research?

By participating in this research you are able to discuss your opinions and experiences about the use of licensed boarding houses as an accommodation option for people with intellectual disability and people with mental illness. Your views will contribute to the research findings and assist with considering recommendations for change.

Voluntary participation

Your participation in this research is strictly voluntary. You are able to withdraw from participation at any time. Non-participation in this study will not impact on the services or support you receive.

Confidentiality

The information you provide during the interview process will be kept confidential. It will be kept separate from your personal details, and only I will have access to it. Tapes and notes from your interview will be securely stored for five years, before being destroyed.

However, if you disclose information that breaches a law or indicates harm to yourself or someone else, I will have a duty to disclose this information. This might include providing information about your living conditions to the NSW Ombudsman or the Department of Ageing, Disability and Homecare.

Use of information:

The information collected from interviews will be documented and findings reported in a doctoral thesis. Participants will not be identified in published data.

Thank you very much for your involvement in this research, your participation is appreciated.

Appendix 3: Consent Form

Consent Form

Participant's name: _____

Please select a category that best describes you:

- Boarding house resident
- Staff of community organisation
- Staff of advocacy organisation
- Boarding house proprietor
- Departmental officer
- Other _____

Participant's agency (optional): _____

- I have been provided with a copy of the *Participation Information Sheet*.
- I understand the purpose of this research.
- The information has been discussed and I have had the opportunity to ask questions.
- I understand that my participation is voluntary and I can withdraw at any time.
- I understand that no personal information will be used and the information will be securely stored.
- I agree to participate in this research.

Signature of participant

Date

Signature of support person/guardian
(if applicable)

Date

Gabrielle Drake (PhD Candidate)

Date