



Australian Housing
and Urban Research Institute

Deinstitutionalisation and housing futures: final report

prepared by
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UNSW-UWS Research Centre**

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The seminar ended with a round table discussion on both limitations and policy implications arising from this study. The project team is indebted to the feedback provided by attendees and acknowledges their input into the development of policy implications as outlined in this Final Report.

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Abbreviations

ACT	Australian Capital Territory
ADD	Ageing and Disability Department
AHURI	Australian Housing and Urban Research Institute
AIHW	Australian Institute of Health and Welfare
CAP	Crisis Accommodation Program
CDSA	Commonwealth Disability Services Act
CDHP	Community Disability Housing Program
CSDA	Commonwealth State Disability Agreement
CSHA	Commonwealth State Housing Agreement
DSC	Disability Services Commission
DSQ	Disability Services Queensland
DOCS	Department of Community Services
DSA	Disability Services Act
EOI	Expression of Interest
FACS	Department of Family and Community Services
HMAC	Housing Ministers Advisory Committee
KRS	Kew Residential Services
MDS	Minimum Data Set
NGO	Non Government Organisation
NCID	National Council on Intellectual Disability
NIMBY	Not-In-My-Backyard
NSW	New South Wales
NT	Northern Territory
QLD	Queensland
SA	South Australia
SAAP	Supported Accommodation Assistance Program
SACHA	South Australian Community Housing Agency
SAHT	South Australian Housing Trust
SHA	State Housing Authority
TAS	Tasmania
VIC	Victoria
WA	Western Australia

Executive summary

Introduction

This paper reports research by the Australian Housing and Urban Research Institute: University of New South Wales & University of Western Sydney Research Centre. The research examines the housing futures of people with intellectual disabilities who have been, or will be, deinstitutionalised. The study documents numbers of people expected to move from residential institutions into 'community' based living arrangements in each State/Territory, focusing on the 2000-2010 timeframe.

The Final Report is intended to help policy makers, especially State/Territory housing agencies, better understand the increasingly complex and challenging links between deinstitutionalisation, community care and housing for people with disabilities.

In 1999, official figures show that throughout Australia there were 4,340 people, whose primary disability is intellectual, living in institutional accommodation. A further 630 people were living in hostels that provide supported accommodation in institutional settings (AIHW 2000a: 19). Consideration of the future housing options of this number of people poses a challenge to the policy and planning processes of disability and housing services providers in Australia.

The Australian Institute of Health and Welfare (AIHW) collect data on the use of disability services funded through the Commonwealth State Disability Agreement (CSDA). However, there is no centralised source of information on State/Territory deinstitutionalisation policy and future plans to close institutions and/or reduce bed numbers. Consequently, there is no readily available means for assessing the aggregate patterns of institutional change across Australia.

Project aims

The research directly addresses a critical policy need in human services; namely, better intelligence on current and projected patterns of deinstitutionalisation and their implications for housing and related support mechanisms. This project:

1. documents the forward plans for deinstitutionalisation in each State and Territory, focusing on the 2000-2010 time frame;
2. reviews and describes the recent housing outcomes from deinstitutionalisation in Australia, drawing upon evidence documented in Australia and other relevant policy contexts, and noting any differences between State/Territory experiences;
3. examines the broad policy implications of findings on the above and makes recommendations for policy development;
4. has involved service agencies directly in the research and in consideration of its findings and,
5. provides the basis for similar, follow up studies of other social client groups affected by residential service reform, including people using psychiatric, aged care and correctional services.

Structure of the report

Research findings are reported in two stages. Part 1 examines State/Territory deinstitutionalisation policies and programs. Part 2 examines the housing futures for people currently living in institutions.

Research findings are set within the policy context and previous research examining the housing impacts of deinstitutionalisation programs in Australia. The report concludes with policy implications emerging from the research.

Research context

A major part of this research involved the production of a Positioning Paper, which was published by AHURI in December 2000 (and is available at the following website <http://www.ahuri.edu.au/pubs/positioning/dehousfuture.pdf>). The Positioning Paper reviewed the policy context and framework for the development of disability accommodation provision and housing assistance in Australia. This revealed that:

- Analysis of aggregate data by the Australian Institution of Health and Welfare (AIHW) reveals decreasing numbers of people living in institutions. However, this is paralleled by a growth in the number of people remaining in the 'community' without ever passing into institutional care. Average deinstitutionalisation trends are mainly driven by the numbers remaining in the community, rather than by any radical change for those housed within congregate care settings.
- These trends suggest that most of the increasing demand for community care is coming from those already living in households rather than from those moving to the community from institutions. There is a high level of unmet demand for community care accommodation among people with disabilities living in the general community.

Policy context

The last 15 years have seen a number of significant reforms that have reshaped social and housing policy frameworks in Australia, including a strategic emphasis on deinstitutionalisation and the restructuring of housing assistance.

- However, the development of separate Commonwealth and State/Territory policy programs on disability and housing appears to undermine effective program linkages. The 1991 CSDA was designed to be prescriptive and emphasised collaboration between different Commonwealth/State programs with particular reference to consultation with State Housing Authorities (SHAs).
- The second CSDA released in 1998 aimed to be more enabling and to facilitate variations in service delivery within each State/Territory. Consultation mechanisms included in the 1991 CSDA were not replicated in the second CSDA. An unintended consequence of this decision is that the second CSDA no longer explicitly requires consultation between disability and housing agencies.
- The 1999 Commonwealth/State Housing Agreement (CSHA), on the other hand, explicitly states the importance of developing links with specialist programs, which include the CSDA, in order to improve housing outcomes for those in need.
- Lack of coordination between these two major national policy frameworks may undermine the development of effective programs aimed at achieving stable accommodation for people with complex needs.

Research findings are presented in two parts.

Part 1. Disability and accommodation support services

Part 1 of the report examines disability and accommodation support services in Australia. This describes both deinstitutionalisation policy and the factors that impinge on program development. A summary of chapters follows.

Chapter 2. Review of State/Territory deinstitutionalisation policy and programs

The history of deinstitutionalisation varies between each State and Territory. This is reflected in current deinstitutionalisation policy and the differences in numbers of people expected to move into community accommodation.

- Data from State/Territory disability service agencies suggest that there are 6,000 people with intellectual disabilities living in institutions in Australia. This is a very approximate figure. It is based on self-reported definitions of institutions. These definitions vary in each State/Territory.
- New South Wales houses almost half (2,500) of all those people with intellectual disability living in institutions in Australia. It plans to close all of its large-scale government and non-government institutions by 2010.
- Victoria houses 822 people in four government-run institutions. In May 2001, Victoria announced plans to redevelop its largest institution, Kew Residential Services, over the next six to ten years. Some 50-100 people will live in new homes on the present Kew site. The remaining residents will be relocated to community-based accommodation throughout Victoria.
- Queensland adopted a definition of 'institution' that covers people living in hospitals, hostels as well as large-scale residential care. Queensland houses almost 1,284 people with a combination of intellectual disabilities, multiple disabilities including intellectual disability and people with dual diagnoses (intellectual disability and psychiatric disability) in institutional care. It is expected that 125 people will move to community living by 2003.
- South Australia houses over 650 people in two large-scale institutions: one government, one non-government operated. It is expected that 75 people will move from the government-run institution by 2002.
- Western Australia closed all its large-scale institutions between 1987 and 1998. Reform focuses on the hostel sector and 261 people are anticipated to move from hostels into community based options by 2003.
- Tasmania closed its only large-scale institution for people with intellectual disabilities in November 2000. Plans to assess the future housing and support needs of people with intellectual disabilities currently living in hostels are to be developed.
- The Australian Capital Territory and Northern Territory do not have large-scale institutions.

Chapter 3. Disability service evolution: debates and issues

There are a variety of factors that impact on deinstitutionalisation policies in Australia. Managing the delivery of accommodation services within the context of these often-competing factors is fraught with difficulties.

- The changing nature of disability service provision is in part dependent upon the ideology of governments and can determine changing policy priorities.
- Government inquiries concerning abuse in institutions have been conducted in New South Wales, Victoria, Tasmania, Western Australia and Queensland. These inquiries have contributed toward processes of deinstitutionalisation and institutional reform in these States. There have been no government inquiries concerning institutional care in South Australia.
- Social pressure by various interest groups, such as relatives and advocates has contributed to both closure programs and systematic reform of current institutions.
- Other voices of opposition to deinstitutionalisation have included organised labour. Deinstitutionalisation has potentially profound consequences for such workers, including job losses, redeployment, erosion of working conditions, reskilling, adaptation to new work practices, and deunionisation.
- All States/Territories report a reduction in the impact of NIMBYism in recent years. The relevant agencies in each State/Territory have adopted different strategies to reduce the impact of NIMBYism. These include decisions to locate group homes in areas where people are less likely to object to community care developments.

Part 2. Housing and support policies for people with disabilities

Part 2 of the report looks at the links between housing and support policies for people with disabilities. First, it examines the housing futures for people with intellectual disability living in institutions.

Second, it suggests that successful housing outcomes for deinstitutionalised people are dependent on links between housing and disability service agencies. The chapters are summarised as follows.

Chapter 4. Deinstitutionalisation and housing futures

Evidence from this study suggests that at least in the short to medium term, institutions remain a significant housing future for many people who are currently living in congregate care facilities in Australia.

- The housing futures for people leaving institutions across Australia have tended to be driven by support requirements. This has led to the predominance of the group home model, whereby several people can share their support packages.
- A range of housing has been designed, modified and built to maximise the potential to pool support packages. These include duplex, triplex, quadruplex and cluster developments.
- The development of cluster housing is a source of debate. Western Australia aims to downsize existing developments. Queensland has built two new cluster

developments in order to provide centre-based care as an accommodation option. Victoria provides cluster housing but in the form of a congregated setting.

- An array of arrangements exists between housing and disability service agencies. Housing outcomes have been delivered via both public and community housing.
- Philosophical as well as practical considerations impact on the delivery of housing solutions. Disability and housing agencies in both Western Australia and Queensland have worked together to improve understandings about the roles and responsibilities of each respective agency.
- The over-reliance on group models of accommodation is recognised by all States/Territories as problematic. New South Wales aims to provide individualised packages of support to people leaving its institutions over the next decade. This should promote a wider range of housing futures. However, for many people living in congregate care, housing choice remains constrained.

Chapter 5. Successful housing solutions: debates and issues

The success of housing solutions for people with complex support needs is framed by the development of working relationships between disability and housing agencies.

- The development of different models of accommodation support (a package of care and accommodation services) is dependent on which agency is the primary policy driver — housing or disability. This means that if the focus is on meeting individual housing needs then support packages can be designed to take account of accommodation requirements. On the other hand, if support services are the policy driver then it becomes logical to suggest that people share support packages by living together in group homes.
- The predominance of the group home model suggests that in many States/Territories in Australia support agencies are the primary policy driver. There are notable exceptions. In Queensland, housing is recognised as the principal policy driver. However, it is recognised that addressing the person's housing needs first can increase accommodation support costs.
- Each State and Territory is reviewing the strategic development of disability services. There is an emphasis on providing services that are flexible and responsive to the changing needs of individuals across the whole of their lives. This focus emphasises the need to tailor services to individuals rather than services imposing 'one-size-fits-all' models of accommodation support.
- The development of new funding frameworks that 'tie' funding to individuals and are portable between service providers will help facilitate control, choice and flexibility in terms of housing and support.
- Housing agencies, like disability services agencies are faced with the challenge of providing housing assistance that is responsive to the complexity of client need. This reflects the recognition that growing numbers of social housing tenants require extra support and that this support may be crucial to their ability to maintain their tenancy.
- Diversity within the community of people with disabilities may mean that different groups have additional housing and support needs. These groups include

disabled women and children; people living in rural and remote areas; people from a non-English speaking background; as well as Aboriginal and Torres Strait Islander people with disabilities.

- People with disabilities represent almost 40 per cent of people receiving housing assistance (AIHW 1999: 134). There is increased targeting of social housing programs and specialised support programs toward this population group.
- There is also the tendency to site new community care homes in 'places of least resistance'. This may serve to compound the concentration of people who require additional support in particular places.

Chapter 6. Policy implications

At the beginning of this study it had been anticipated that deinstitutionalisation significantly impacts upon local housing markets and that people moving from institutions lead relatively diverse housing careers. However, data from this study show that relatively small numbers of people with intellectual disabilities can expect to move from institutions to community living in the near future.

The study also reveals that the client relocation process tends to be closely managed in disability services and that the group home remains the major community housing model. It therefore appears that deinstitutionalisation of people with intellectual disabilities has a minor direct impact on housing markets.

Information sharing

In order to improve the understanding and anticipation of deinstitutionalisation trends and wider housing and disability support provision, there is a need for greater information sharing between key State/Territory and Commonwealth agencies. This project has contributed to the aim of greater information sharing, both through its reports, contribution to the Housing Ministers Advisory Committee and its early findings seminar.

Data collection

- The AIHW provide an excellent service for planners and providers of housing and support services through collation and coordination of sources on CSDA funded programs in Australia. However, given that many large 'institutions' have downsized, if not entirely closed, there seems to be a case for re-thinking the current size-based definitions of institutions. The institutions of yesterday are not those of today or the future.
- There may be a case to improve disaggregation of data on deinstitutionalisation or bed closure. At the moment, AIHW data on numbers of people living in institutions on a State/Territory basis are not routinely broken down by primary disability type. It is thus difficult to assess numbers of people with intellectual or other primary disability types currently living in institutions.

Cross-policy integration

- The separate development of the CSHA and CSDA has served to undermine effective links between these two major national policy frameworks. This suggests that at a State/Territory level there is a need for junior policy officers upwards to talk together about bettering coordination of housing and other support outcomes for people. At the national level Agreements should be developed together rather than in isolation. This also applies to the development

of links with other specialist programs such as the Crisis Accommodation Program (CAP) and Supported Accommodation Assistance Program (SAAP).

Accessible housing markets

- People with disabilities often cannot meet their needs for secure, affordable and appropriate housing in the private market. Policies to address the inaccessibility of the private housing market might relieve the pressure for housing agencies to resource the provision of appropriate accommodation for this group.
- Facilitating access to an appropriate private rental market to accommodate more people with intellectual disabilities may also change the tendency of agencies to concentrate people with complex needs in the same places. This could lead to greater dispersal of services throughout the community and would therefore impact on service planning and delivery across a range of policy portfolios.

Multi-generational service provision

- It will not be easy for service agencies to acknowledge and integrate the views of those who are not direct users of disability services. Parents/advocates as well as care workers have a significant stake in disability service evolution. Balancing the tensions between different generations of parents who may have conflicting expectations about appropriate accommodation options is a dilemma.

Individualised funding

- The impact of the individualised funding framework, in which funding is tied to an individual and portable between services, is yet to be realised. The use of individualised funding in New South Wales, however, should have a significant and diverse impact on housing futures for people moving toward community living in that State.

Conclusions

A much more demanding accommodation support scenario seems to be settling upon Australia, driven both by demands for individual customised service provision and by parallel demands from some interests for 'sheltered villages' or centre-based care.

At the same time, social housing clients in Australia have increasing complex support needs. The development of coordinated responses to address the diversification of the client base and the need for individualised support are the main challenges for housing and disability services over the next 10 years.

Chapter 1. Introduction: Research aims and context

1.1 Introduction

This paper reports research by the Australian Housing and Urban Research Institute: University of New South Wales and University of Western Sydney Research Centre that examines the housing futures of people with disabilities who have been, or will be, deinstitutionalised.

This chapter states the research aims of the project, provides a summary of the Positioning Paper (<http://www.ahuri.edu.au/pubs/positioning/dehousfuture.pdf>), and outlines the structure of the report.

This Final Report represents the fourth milestone of the Australian Housing and Urban Research Institute (AHURI) project 'Deinstitutionalisation and Housing Futures'. This project:

1. documents the forward plans for deinstitutionalisation in each State and Territory, focusing on the 2000-2010 time frame;
2. reviews and describes the recent housing outcomes from deinstitutionalisation in Australia, drawing upon evidence documented in Australia and other relevant policy contexts, and noting any differences between State/Territory experiences;
3. has involved service agencies directly in the research and in consideration of its findings; and
4. outlines the broad policy implications of findings on the above and makes recommendations for policy development;
5. provides a methodological framework for similar, follow up studies of other social client groups affected by residential service reform, including people using psychiatric, aged care and correctional services.

The following research questions, formed the operational framework for the study:

1. what are the projected rates of deinstitutionalisation for each jurisdiction for the period 2000-2010?
2. in the past two decades, what have been the housing experiences of people who have been deinstitutionalised in Australia and are there similarities with the overseas experience?
3. have housing outcomes tended to differ between States and Territories?
4. what have been the main housing support mechanisms for people who have been deinstitutionalised?
5. what policies and practices might be instituted to improve the understanding and anticipation of trends in deinstitutionalisation?
6. what broad policy implications are raised by improved understanding of the housing outcomes from deinstitutionalisation?
7. what would be the costs to the public sector, and the community, of not securing adequate housing futures for deinstitutionalised service users?

1.2 A note on terminology

This report adopts the term 'people with disabilities' rather than 'disabled people'. Previous reports have used the term 'disabled people' in line with the work of disability activists, such as Paul Abberley (1991) and Jenny Morris (1993). Both Abberley and Morris argue that the term 'disabled people' serves a political purpose

by foregrounding oppression, or in other words, the socially imposed disabilities, that bears down upon impaired people. For example, Abberley (1991) argues that the 'humanisation' of terminology effectively depoliticises the social discrimination to which disabled people are subjected (see Gleeson 1999 for full discussion). Following feedback from colleagues in peak organisations as well as housing and disability service agency staff, we have decided to change the terminology used in this report. It has been suggested to us that the term preferred by Australian disability advocates is 'people with disabilities'.

The Positioning Paper (<http://www.ahuri.edu.au/pubs/positioning/dehousfuture.pdf>) reviews the terminology used to underpin and frame disability services in Australia. This reported State/Territory differences in definitions of institutions. All jurisdictions recognise CSDA Minimum Data Set definitions which define institutions as residential facilities located on large parcels of land that provide 24-hour support in a congregated setting of 20 beds or more. This is also referred to as 'congregate care'.

'Centre-based care' refers to two cluster housing developments (accommodating a total of 37 people with intellectual disabilities) that have been recently built in Queensland. These developments are unlike institutions of the past because they are both smaller and have been designed to facilitate the involvement of residents with the local community.

'Community care' refers to the establishment of 'care of individuals within the community as an alternative to institutional or long-stay residential care' (Jary and Jary 1999: 99).

1.3 Positioning paper

The first output from this research was a Positioning Paper that was published by AHURI in December 2000 (<http://www.ahuri.edu.au/pubs/positioning/dehousfuture.pdf>). The Positioning Paper describes the policy issues addressed through the project, provides a comprehensive review of the academic literature in relation to such issues, and details the research methods by which new information will be provided that will inform policy development. The Positioning Paper provides a conceptual and methodological context for the study and should be read in conjunction with this Final Report. Key aspects of the Positioning Paper are summarised below.

1.4 Deinstitutionalisation trends

Since the early 1990s significant numbers of people with intellectual disabilities have moved from large congregate care facilities into community-based options. On the basis of figures supplied by Commonwealth and State/Territory health and welfare agencies, Neilson Associates (1990) estimated the number of people with disabilities still resident in institutions. They suggested that in 1988 approximately 7,500 people with intellectual disabilities were living in large State or private residential centres or psychiatric hospitals throughout Australia. At least another 1,300 people with intellectual disabilities were estimated to be living in smaller hostel type institutions of 12-30 people each (Neilson Associates 1990: 8).

Since the introduction of the Commonwealth State Disability Agreement (CSDA) in 1991, the Australian Institute of Health and Welfare (AIHW) has collected data on accommodation services funded under the Agreement. In 1999, the AIHW estimated

that there were 4,340 people whose primary disability is intellectual¹ accessing institutional services on any given day. A further 630 people were living in hostels (AIHW 2000: 19).

Although these data are not directly comparable, they suggest that 2,500 people have moved from large residential institutions over the past 10 years. The number of people living in hostels has halved since estimates were produced in the Neilson Associates study in 1990.

Analysis by the AIHW of Australian Bureau of Statistics (ABS) data shows that institutional numbers declined during the 1980s and early 1990s. The number of people aged 5-64 years with a 'severe or profound handicap' who lived in establishments² declined, while numbers residing in households rose steadily over the past 20 years.

It should be noted that 'severe or profound handicap' refers to a wider range of disabilities than reported on in our research, which focuses on the housing futures of people with intellectual disabilities.

Figure 1.1 shows that estimates of the numbers of people with profound or severe handicaps living in households (rather than establishments) rose over the years 1981, 1988 and 1993. The increase between 1981 and 1993 was 42.9% or 104,900 persons. In contrast, the number of people who lived in establishments has dropped by 29.1% or 7,900 persons (in Madden *et al* 1999: 10-11).

Figure 1.1 Number of people with a profound or severe handicap aged 5-64 years by residence, Australia, 1981, 1988 and 1993

	No. with profound or severe handicap, '000			% change in numbers		
	1981	1988	1993	1981-98	1988-93	1981-93
Households	244.1	302.5	349.1	23.9	15.4	42.9
Establish'ts	27.0	24.2	19.2	-10.5	-20.8	-29.1

Source: Madden *et al* (1999: 11)

Most of the increasing demand for community care is coming from those already living in households rather than from those leaving institutions. However, evidence suggests that the reduction of places in institutions does not appear to have been matched by the development of services in the community. As Caltabiano *et al.* (1997) argue, this means that many people with disabilities have inappropriate living arrangements, or that families and carers lack basic support.

Research conducted by the AIHW indicates that there is a high level of unmet demand for accommodation services among the general community. The *Demand for Disability Support Services in Australia* reported a conservative estimate of 13,500 people with unmet need for accommodation, support or respite services

¹ The figures refer only to people whose primary disability is intellectual. There may have been additional people with an intellectual disability as a secondary disability (e.g. their 'primary' disability may have been identified as physical or acquired brain injury) living in institutions or hostel accommodation services.

² Establishments are defined by the ABS as hospitals, nursing homes, hostels, retirement villages and other 'homes'.

(Madden *et al* 1996: 53). A study undertaken in 1995 by the National Council on Intellectual Disability (NCID) found that 1,016 people with disabilities were now in 'crisis' because of lack of accommodation services (NCID 1995 in Madden *et al* 1996).

There have been no recent updates of the *Demand for Disability Support Services in Australia* study undertaken by the AIHW. However, anecdotal evidence suggests that those waiting for accommodation support five years ago could still be waiting. A letter published recently in the *Sydney Morning Herald* hints at this suggestion:

As parents of a severely intellectually disabled child, we know the heartache of the day-to-day life of our son, his siblings and his parents. Add to that the anguish of knowing that no provision has been made to date, nor is provision likely to be made, for him to live with dignity in a group home after his parents can no longer physically attend to his daily needs. When we die (our only certainty) or are infirm, our son will probably be let loose in a community that he can't cope with or be locked in an institution (letter to the *Sydney Morning Herald*, 09.11.00: 17).

In summary, the best statistical data available indicates that the numbers of people with disabilities living in institutions has fallen through the 1980s and 1990s.

1.5 Policy context

The last 15 years have seen a number of significant reforms that have reshaped social and housing policy frameworks in Australia, including a strategic emphasis on deinstitutionalisation and the restructuring of housing assistance. In particular, the *Commonwealth Disability Services Act 1986* (CDSA) detailed in its Principles and Objectives the rights of people with disabilities to live within 'community' rather than in segregated settings.

However, the 1986 CDSA created overlap and confusion in the funding arrangements for disability services by the different levels of government (Yeatman 1996). In 1991 the CSDA, was developed to rationalise these arrangements. The CSDA delineated areas of responsibility, making State and Territory governments responsible for accommodation and lifestyle services and the Commonwealth responsible for employment services (Maddison 1998).

The first CSDA required the introduction of legislation by each State/Territory that paralleled the 1986 CDSA. Between 1991 and 1993 each State/Territory introduced its own Disability Services Act. Attempts to operationalise the principles of the CDSA were undertaken and many institutions closed across Australia.

The development of separate Commonwealth and State/Territory programs on disability and housing further complicates the policy scenario. The 1991 Commonwealth State Disability Agreement (CSDA) was designed to be prescriptive and emphasised collaboration between different Commonwealth/State programs with particular reference to consultation between Disability Agencies and State Housing Authorities (SHAs).

The 1998 CSDA aimed to be more enabling and to facilitate variations in service delivery within each State/Territory. Consultation mechanisms included in the 1991 CSDA were not replicated in the second CSDA. An unintended consequence of this decision is that the second CSDA no longer explicitly requires consultation between disability and housing agencies.

This issue is recognised in the current Commonwealth State Housing Agreement (CSHA). The CSHA highlights the importance of linking housing assistance mechanisms with other Commonwealth and State/Territory social policy frames in order to support a client base with increasingly complex needs. However, disability does not appear to have received the attention that it needs in this key housing funding framework.

Within the CSHA, it is the Crisis Accommodation Program (CAP) and the Supported Accommodation Assistance Program (SAAP) rather than the CSDA, which are prioritised in all Bilateral Agreements between the Commonwealth and State/Territory governments. New South Wales is the only State to recognise explicitly the importance of coordinating housing support with the CSDA. Although, it should be noted that documented housing agreements do exist in each State/Territory and that these contain considerable shared housing/disability objectives (these Bilateral Agreements are accessible on each State/Territory government websites).

Separate CSHAs and CSDAs may hinder the development of mutually reinforcing programs by disability and housing service providers concerning the housing futures of people expected to be deinstitutionalised.

1.6 Previous research

This section addresses research question two and briefly summarises evidence presented in the Positioning Paper (<http://www.ahuri.edu.au/pubs/positioning/dehousfuture>) that reviews recent housing outcomes from deinstitutionalisation in Australia and other relevant policy contexts.

The original aims of deinstitutionalisation were to provide disabled people with the opportunity for as 'normal' a life as possible within the broader community (Maddison 1998). Normalisation (later, 'social role valorisation') demanded that service users had the right to the 'least restrictive living setting', meaning a care environment that restricts individual freedom only to the minimum extent needed to ensure broader community well-being (Shannon & Hovell 1993).

Historically, disabled people had been treated as though they were ill or a threat to society. It was felt that disabled people needed to be locked away to protect both themselves and the general community. These attitudes led to the development of geographically segregated residential facilities such as long stay mental hospitals, training centres and nursing homes (Evans 1996). Gleeson (1999: 154) argues that the:

oppressive experience of institutionalisation by people with disabilities was frequently characterised by, *inter alia*, material privation, brutalising and depersonalised forms of 'care', dangerous and/or unhealthy living conditions, a lack of privacy and individual freedom, and separation from friends and family.

Since the 1960s, disability movements across the Western world have sought to have institutional care replaced by a variety of community care networks. Proponents applied political pressure to have residents of custodial institutional settings rehoused into the relatively unrestricted living settings afforded by ordinary housing arrangements in mainstream communities (Wilmot 1997). Gleeson (1999:156) argues that deinstitutionalisation has been promoted by advocates in

'social justice terms as a restoration to service dependent people of their basic right to a valued living environment'.

This pressure meant that all Western governments, including Australia have embarked on major deinstitutionalisation programs and sought to replace large congregate care facilities for disabled people with community care networks. These networks have been largely built around small scale, neighbourhood-based facilities that sought to mimick 'typical' suburban homes. Such facilities have been commonly referred to in Australia as 'group homes'.

In more recent years, however, there have been notable shifts in expectations of housing outcomes from deinstitutionalisation. Disability activists have challenged stigmatising dualisms that construct 'host' communities as 'normal' and thereby render the experiences of people with disabilities as 'abnormal'. In particular, the ability of 'group homes' to provide flexible, individualised care has been challenged.

The move toward individualised funding may help facilitate access by disabled people to the diverse range of housing futures potentially available to the general populace. Individualised funding refers to funding that is 'tied' to a particular individual and is portable between service providers. While individualised funding is not necessarily a panacea it might be part of a differentiated framework for supporting disabled people. Such a framework would offer a range of accommodation types in different places, and would transcend the current tendency of support mechanisms to enshrine (if implicitly) the 'group home' as the only housing alternative to institutional 'care'.

1.7 Methodology

In order to address research question one, that is, to document future deinstitutionalisation plans primary data were collected from all States/Territories. This involved direct contact with staff of relevant agencies and required inter-state fieldwork to achieve the project aims. A mixture of data collection methods was adopted, including face-to-face interviews, telephone interviews and analysis of published as well as unpublished documentary materials.

Primary data has been collected from key contacts in each State/Territory. Field visits were conducted over a three-week period in mid 2000. A structured interview schedule was developed and covered three main themes: deinstitutionalisation, housing futures and policy implications.

During the course of the fieldwork, key informants nominated additional persons (often colleagues) whom they thought should be invited to contribute information. The pool of interviewees thus grew unexpectedly, and additional agencies (especially housing providers) were drawn into the research. This unanticipated broadening of the fieldwork delayed the research, but also ensured a richer understanding of the challenges faced by both disability and housing agencies.

The research is based on interviews with 51 individuals (see Appendix A).

A user group has been constituted for the study. This consists of key State/Territory contacts and their advisers. It also includes representatives from the Australian Institution of Health and Welfare, People with Disabilities (NSW) Inc and the National Disability Advisory Council (see Appendix B).

1.8 Structure of the report

The rest of this report explores research findings. It is divided into two parts. Part 1 of the report will answer research question 1 and focus on projected rates of deinstitutionalisation for each jurisdiction for the period 2000-2010 (please refer to section 1.1 for full details of the research questions). It examines disability and accommodation support services. This describes both deinstitutionalisation policy and factors that impinge on program development.

Part 2 of the report looks at key research questions 2 to 4 and describes recent housing outcomes from deinstitutionalisation, differences between States/Territory and explores the main housing support mechanisms. In particular, it looks at the links between housing and support policies for people with disabilities. It examines the housing futures for people with intellectual disability currently living in institutions. This section suggests that successful housing solutions for deinstitutionalised people are dependent on links between housing and disability service agencies.

The report concludes with policy implications emerging from the study. This will address research questions 5 to 7 which includes a discussion of the costs to the public sector of not securing adequate housing futures for deinstitutionalised service users.

Part 1 reviews disability and accommodation support services and contains the following chapters:

Chapter 2: Review of deinstitutionalisation policies and programs. This chapter reviews future plans for deinstitutionalisation and reports numbers of individuals to be relocated into community-based accommodation.

Chapter 3: Disability service evolution – debates and issues. This chapter explores disability service evolution and the factors that impact on recent as well as future deinstitutionalisation policies.

Part 2 reviews housing policies for disabled people and contains the following chapters:

Chapter 4: Deinstitutionalisation and housing futures. This chapter reports the expected housing futures of people with intellectual disabilities who will be deinstitutionalised over the next 10 years in Australia

Chapter 5: Successful housing solutions – debates and issues. This chapter examines housing service evolution and factors that impact on finding successful housing support policies for people.

Chapter 6: Policy implications. The report concludes with a chapter that reviews the policy implications of the research findings.

PART 1: DISABILITY AND ACCOMMODATION SUPPORT SERVICES

Chapter 2. Review of State/Territory deinstitutionalisation policies and programs

2.1 Introduction

This chapter reviews current State/Territory deinstitutionalisation policies and programs. It seeks to address research question 1 and reports numbers of people currently living in institutions and projects how many individuals will be relocated into community based accommodation over the next ten years (see section 1.1 for research question details). The chapter describes timeframes and strategic plans for each State/Territory and outlines their impact upon future deinstitutionalisation patterns.

2.2 Disability service strategic plans

The Positioning Paper describes the policy context for deinstitutionalisation in Australia (www.ahuri.edu.au/pubs/positioning/dehousfuture.pdf). The principles of each State/Territory *Disability Services Act* (DSA) are based on the *Commonwealth Disability Services Act 1986* (CDSA). These principles lay down the foundations for deinstitutionalisation policies. While they do not explicitly require institutional reform to take place they emphasise that individuals have the right to live in community-based settings. State/Territory DSAs have guided deinstitutionalisation processes and housing policies.

The strategic plans of State/Territory disability service agencies operationalise the principles of each DSA. These documents also provide the framework for the development and delivery of disability services in each State and Territory. Table 2.1 illustrates that each State and Territory operates under a strategic planning framework. These frameworks provide the foundation for planning, policy and development for disability services within each State/Territory. The development of strategic plans specific to disability service departments ensures that directions outlined within frameworks are fulfilled. There are two main strategic approaches:

1. Whole of department or government strategic plans that include sections or references to disability services. These plans will normally outline the strategic direction of the government. The plan may outline strategies that are the responsibility of one or more departments and may also detail the relationship with non-government organisations.
2. Specific service plans or action plans or strategic frameworks for disability services. These types of plans detail the strategic direction for disability services in the State/Territory. They also detail strategies for the development and delivery of disability services.

A review of State/Territory strategic and specific disability service plans reveals an emphasis on providing services that are flexible and responsive to the changing needs of individuals and their families. This approach promotes service provision that is tailored to individual needs. Within this model of disability service provision congregate care can exist as another (but not the only) accommodation choice.

Table 2.1 Departmental strategic planning documents

State/Territory	Strategy	Timeframe
New South Wales	Disability Policy Framework	December 1998
	Disability Action Plan	January 2000 – December 2002
Queensland	Government Strategic Framework for Disability	2000-2005
	Disability Services Queensland Plan	2000-2005
	Disability Services Queensland Business Plan	2000-2002
Victoria³	State Plan for Intellectual Disability Services	1996-1999
South Australia	Human Services Portfolio Strategic Plan	1999-2002
	Disability Services Planning and Funding Framework (draft)	2000-2003
Western Australia	Disability Services Strategic Plan	1996-2001
	Disability Services Draft Plan	2000-2005
Tasmania	Building for the Future Draft Positioning Document	2000-2003
Australian Capital Territory	Strategic Plan for Disability Services in the ACT	1999
Northern Territory	Disability Services Five Year Strategic Plan	1997-2001

Source: Study data

2.3 Future deinstitutionalisation trends

Table 2.2 outlines State/Territory projections of people expected to move from congregate care facilities, focusing on the 2000-2010 timeframe. It provides data on numbers of people currently living in institutions, numbers of people expected to leave institutions, percentage of people moving, and relocation timeframes.

³ Victoria aim to release the *Draft State DisAbility Services Plan* in the second half of 2001. The *State DisAbility Services Plan: Consultation Report* was released in December 2000.

These data suggest that there are approximately 6,000 people with intellectual disabilities living in institutions across Australia. The figure, however, is reported with a series of caveats.

These data are based on self-reported definitions of institutions (see Positioning Paper (www.ahuri.edu.au/pubs/positioning/dehousfuture.pdf) for full discussion of State/Territory differences in definitions of congregate care facilities). This means that this figure is very approximate. For example, in all States, apart from Queensland, people living in psychiatric and other hospitals who have intellectual disabilities have been excluded. This means that the figure is likely to underestimate the current numbers of people living in institutional care facilities.

Projections of numbers of people expected to leave institutions must be considered in two ways. In the longer term, only New South Wales has plans to close all of its large-scale institutions. Queensland, Western Australia and Tasmania have either closed or significantly down-sized their large-scale institutions. Victoria announced plans in May 2001 to redevelop its largest institution. This means that if devolution plans go ahead in New South Wales 2,500 people with intellectual disabilities will move into community-based living in the 2000-2010 timeframe. Other States report that an additional 850 people will be moving into community living within this timeframe.

An explanation of State/Territory data relating to Table 2.2 follows.

In New South Wales there are 2,500 people with intellectual disabilities living in institutions. These data include both government and non-government operated institutions. Projected figures reflect plans to close all large-scale residential centres by 2010.

Figures for Victoria refer to numbers of people with an intellectual disability living in government-operated institutions only. The exclusion of non-government operated institutions is likely to underestimate (by a small margin) total number of people with intellectual disabilities living in Victorian institutions.

In May 2001, Victoria announced the decision to redevelop Kew Residential Services (formerly known as Kew Cottages). Kew Residential Services is Victoria's oldest and largest institution. It currently houses 462 people. All residents will move to new homes either on the present site or elsewhere. Some 50 to 100 people will live on the Kew site in new homes. The redevelopment is expected to take six to ten years.

Queensland identifies institutions on a range of factors including the style of care and physical attributes. Figures are based on both people living in non-government organisations and all government-operated institutions including hospitals.

In Queensland, twelve non-government organisations have self-nominated as operating institutions. Some providers accommodate very small (e.g. six) numbers of people. This suggests that figures for Queensland provide a more accurate estimate of the number of people living in congregate care facilities.

Two cluster housing developments or 'centre-based care' run by Disability Services Queensland are not considered to be institutions and are not included in the figures. Unlike congregate care facilities of the past which were designed to segregate residents from the rest of the community, these cluster housing developments or forms of 'centre-based care' have been designed to facilitate community integration.

Western Australia houses 735 people in hostel residential accommodation. Hostels provide accommodation and support for nine or more residents. These figures are for all people with disabilities. Forward figures refer only to those with an intellectual disability. This means that the percentage figure of people with intellectual disability moving into community-based options is an under-estimate.

There are two large institutions in South Australia: one government and one non-government operated. Both institutions house almost 700 people with intellectual disabilities.

Tasmania closed its only large government institution for people with intellectual disabilities in November 2000. Plans to assess the future housing and support needs of people living in hostel accommodation are to be developed.

The Australian Capital Territory and Northern Territory do not have large-scale institutions.

Table 2.2 Projected numbers leaving institutional care by target date

State/ Territory	Current nos. in institutions	Projected nos. leaving institutions	Percentage of those leaving institutions	Target date
NSW	2,500	2,500	100%	2010
Vic	822	462	56%	2011
Qld	1,284	125	10%	2003
WA	735	261	35%	2003
SA	688	75	11%	2002
Tas	160	TBA	TBA	TBA
ACT	N/A	N/A	N/A	N/A
NT	N/A	N/A	N/A	N/A

TBA = To be announced

N/A = not applicable

Source: Study data

2.4 Future plans for deinstitutionalisation

This section provides summaries of State/Territory activity in relation to forward plans for deinstitutionalisation. The summaries cover planning timeframes, State/Territory budget considerations and numbers of people to be relocated. Current and future policies are placed within the context of recent deinstitutionalisation programs.

New South Wales

In 1998, New South Wales announced a *12-year Plan for Devolution of all Large Institutions, 1998-2010*. New South Wales houses over a third (2,500) of all people with an intellectual disability living in institutions across Australia. Both government and non-government organisations provide institutional accommodation. Over the past 10 years approximately 450 people have been relocated from large residential centres to community-based options.

The New South Wales *State Government Budget 2000* released an additional \$14.5 million to fund deinstitutionalisation processes between 2001-2004. There is also an additional \$10 million in capital funding available between 2000-2002.

Stage 1 of the New South Wales devolution program included the Ageing and Disability Department (ADD)⁴ working with 83 people with disabilities, their families and advocates to consider options for living in the community. An expansion of stage 1 includes more than 300 people (with priority given to children and young people with intellectual disabilities living in large residential facilities).

By the end of stage 1 in 2004, more than 400 people with disabilities will have been supported to relocate to community based living arrangements.

New South Wales has also initiated a Boarding House Reform Strategy. The government is aware that a disproportionate number of people with disabilities are housed in Boarding Houses within the State. In 1998, the New South Wales government announced a \$66 million reform package. Since then, over 300 residents with high support needs have been relocated from Boarding Houses into community based supported accommodation with up to 24 hour care.

Victoria

In May 2001, the Victorian government announced the \$100 million land and residential redevelopment of its oldest and largest institution, Kew Residential Services. Over the next six to ten years all residents will move to new homes either on the present site or elsewhere in Victoria. Victoria has a long history of undertaking deinstitutionalisation programs and has closed four large training centres since 1990.

The redevelopment of Kew Residential Services means that all its residents will move to new homes either on the present site or elsewhere in Victoria. Some 20 new homes will accommodate 50 to 100 residents on site. This reflects the wishes of some parents and relatives to have their children housed in an environment that both promotes scope for greater access to and participation in community activities, while preserving the safety of sheltered living. The remaining residents will be relocated closer to family, friends and support services across Victoria.

A statement from the Victorian DisAbility Services Division argues that the redevelopment of Kew Residential Services represents a major turning point for people with disabilities in Victoria. It will address the poor housing and living conditions currently experienced by residents:

Over 460 people with an intellectual disability live in Kew Residential Services, which is the largest institution of its kind in Australia. Many residents live in units housing around 30 people in overcrowded and cramped conditions where, in many instances, up to 4 or 5 adults share a "bedroom" which is in fact a section of a partitioned dormitory and where there are communal lounge and dining rooms. This does not allow for a good quality of life for either the residents living at KRS, or the staff who support them (Victorian Department of Human Services (2001) accessed at <http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf>).

In addition, Victoria is currently developing a 10-year *DisAbility Services Plan* that will also cover deinstitutionalisation programs. This reflects a history of developing

⁴ In April 2001, the New South Wales government announced the establishment of a new Department of Ageing, Disability and Home Care. The new department will comprise the current Ageing and Disability Department, disability services in the Department of Community Services, and the Home Care Service (*New South Wales Government Press Release*, New Department of Ageing, Disability and Home Care, 05.05.01).

medium to long-term plans for disability services in this State. An example of such a plan was the *Ten Year Plan for the Redevelopment of Intellectual Disability Services 1988*.

Including Kew Residential Services, there are four large-scale institutions remaining in Victoria. They house a total of 760 people with intellectual disabilities.

In Victoria, institutions or training centres are viewed as not an appropriate option for most people with disabilities. It is recognised, however, that access to a training centre may be required for clients whose needs are so extreme that they cannot be met through smaller community-based supported accommodation or other options. Plenty Residential Services was purpose built on the site of a redeveloped institution (Janefield). It provides intensive support in a high-quality physical environment. This is a cluster-housing development that can cater for up to 102 people.

Victoria houses almost 50 per cent (428) of all people in Australia living in CSDA funded hostel-based accommodation (AIHW 2000: 38). These styles of accommodation services are managed by non-government organisations and can house up to 30 residents.

Queensland

Over the past 15 years, almost 1,000 people moved from both government and non-government institutions into community-based accommodation in Queensland. Current deinstitutionalisation policy is guided by two major policy documents. The first of these, the *Policy Statement and Planning Framework for Institutional Reform* was developed under a previous administration in 1995.

This document outlines a commitment to closure of government-administered institutions in Queensland. Since 1995, several changes of government have resulted in policy shifts. The outcome of these changes has been a policy framework that maintains a focus on the reform of institutions while also recognising the views of families seeking to have their family members supported in centre-based accommodation.

The second policy document is *Disability Services Queensland Strategic Plan 2000-2005*. This maintains a focus on finding alternative accommodation for people inappropriately accommodated in institutions and other forms of congregate care.

The *Disability Services Queensland Business Plan 2000-2002* reports that \$6 million was released to assist people with disabilities access accommodation support. This includes people with intellectual disabilities living in institutions.

Queensland continues its reform of the Basil Stafford Training Centre, its last large government-run congregate care facility. There are 80 people with an intellectual disability living in this facility. It is expected that 55 people will move out between 2000-2002. In recognition of the views of families seeking to have their family members supported in centre-based accommodation, the current Queensland government is committed to 'downsizing' rather than closing this institution.

In 2000, 12 non-government organisations that operate self-nominated 'institutions' approached the Queensland government to secure support for the reform of their facilities. The Non-Government Reform Working Group has been established to examine issues for reform. Some of these non-government 'institutions' house less than 20 people with intellectual disabilities. While funding decisions have not been confirmed at the time of writing, it is expected that some 70 people with intellectual

disabilities will be relocated from these non-government facilities to community housing over the next two years.

Some 110 people with multiple disabilities (intellectual disabilities and physical and/or psychiatric disabilities) live in health department psychiatric hospitals. A further 112 people with multiple disabilities that include intellectual disabilities are accommodated in two wards attached to general hospitals in Brisbane and Rockhampton. Funds were released through the *Disability Services Queensland Business Plan 2000-2002* to increase 'community access' for people living in health-operated facilities.

Two new cluster housing developments (accommodating a total of 37 people with intellectual disabilities) have been built in Queensland in the past two years with the design and location aiming to facilitate the involvement of residents with the local community. They cater for people moved from a large congregate care facility but whose families chose centre-based accommodation for them.

South Australia

South Australia continues its stated commitment to deinstitutionalisation. For example, it recently trialed a new community based accommodation model. This model was designed to assist 20 people who previously experienced difficulty making the transition from congregate to community care. The South Australian Disability Services Division is committed to creating more community accommodation places, with a concomitant reduction in the number of residential places in institutions.

South Australia has more people with an intellectual disability housed in institutions on a per capita basis than other States/Territories. There are two large residential facilities: one government run, the Strathmont Centre; and one non-government run, MINDA. There are 343 people living in the government-administered facility while 345 live in the institution managed by the non-government organisation.

There are approximately 550 people with an intellectual disability living in community-based accommodation in South Australia.

South Australia has purchased nine new group homes. By March 2001 it is expected that 25 residents will move into community options from its government-operated institution, Strathmont Centre. Another 50 older residents from Strathmont will move into a new nursing home. This is currently under construction.

At least in the short term, the majority of people currently living in institutions can be expected to continue living there. Plans for expediting the move of people who wish to leave institutions are currently being developed.

The Disability Services Division is working with the operators of the non-government facility, MINDA, on future plans to relocate some residents into the community. Plans have not yet been finalised.

Western Australia

Western Australia moved virtually all people living in large-scale government run institutions into medium size hostels and group homes between 1987 and 1998. Places in hostels are reported as institutional/large residential accommodation. In 1987, institutions represented over 86 per cent of government accommodation services. By 2000, this figure was 32 per cent. It is anticipated that by 2003, institutions will represent 27 per cent of government accommodation services in Western Australia.

However, hostel accommodation is now considered an inappropriate context to enhance the well-being of most people with disabilities. This is because it is viewed as smaller, but nonetheless, congregate care. Congregate care is viewed as inappropriate because of a raft of human rights issues. These include lack of privacy, lack of autonomy and control over one's environment, and exposure to abuse (see the Positioning Paper www.ahuri.edu.au/pubs/positioning/dehousfuture.pdf for full discussion of these issues as well as Chapter 3). Funds were allocated for the redevelopment of hostels in the Western Australian *Disability Service Commission 5-Year Business Plan 1996-2001*.

Both government and non-government organisations operate hostels. The closure of government-administered hostels has been a priority. At the time of fieldwork (early August 2000) a hostel housing 13 people was closed. However, limited resources mean that services are forced to adopt a slower process of 'winding down' rather than closing.

Non-government providers have also undertaken deinstitutionalisation programs. However, a number of non-government operated hostels that had closed have recently reopened in order to service demand for supported accommodation. In addition, beds have reopened in hostels. For example, one non-government organisation that had reduced institutional beds by 10 per cent is now at full capacity again: 28 beds.

The Disability Services Commission recognises that reopening both beds and hostels contradicts policies of community integration. However, with limited resources this represents the lower cost option compared with purpose building new group homes.

Nevertheless, it is expected that 261 people from both government and non-government operated hostels will move into community group homes by 2003.

Tasmania

In November 2000, Tasmania closed the Willow Court Centre, Australia's oldest institution for people with intellectual disabilities. This was its only large-scale institution. Community integration (deinstitutionalisation) has been a major philosophical and policy framework since 1987. This policy has ensured that almost 300 former residents have moved into new community-based services. At the beginning of community integration it was assumed that the institution would 'down-size' rather than close completely. However, the full redevelopment of services and sale of the site was actively planned from 1997.

Successive governments have accepted that community integration should not be a cost cutting exercise. Since 1987, around \$25 million in capital spending for new homes in the community has been invested. In November, the Minister for Health and Human Services, Judy Jackson, said that the closure of Willow Court completed the transition to a new era of client support in the community and that this investment:

is recognition by the Parliament that Tasmanians with intellectual disabilities have the same needs and the same rights as any other member of the community. And it recognises that those needs and rights entitle clients to a lifestyle in a community setting as close as possible to the lifestyle enjoyed by other Tasmanians (*Tasmanian Government Press Release, Minister Closes Door on Institutionalised Care, 17.11.2000*).

There are another 160 people with intellectual disabilities living in accommodation funded through the CSDA as 'institutions/large residential'. A further 88 people live in hostels (AIHW 2000: 39). This group of people live in non-government operated facilities. These facilities range from 6 to 60 beds. Elements of this sector are in the process of reform. Some providers intend to reorient toward aged care to meet the needs of their ageing client group while others wish to 'downsize' to small scale, neighbourhood-based facilities.

Australian Capital Territory

By the mid-1990s, the Australian Capital Territory had completed its deinstitutionalisation process. This involved the relocation of people from two hostels. Each hostel had four bedrooms that accommodated ten beds. The hostels were based on a villa or cluster-housing model and residents from them moved into group homes. The Australian Capital Territory government provides support in over 40 group houses located throughout the Territory.

The *Strategic Plan for Disability Services in the ACT 1999* provides the framework for policy, planning and purchasing of disability services by the department. Strategies and actions detailed in the plans relate to one or more of the Plan's three key areas: unmet need, service quality and consumer outcomes, and systemic improvement. These reflect the key issues identified during the development of the strategic plan.

Northern Territory

The Northern Territory does not have large-scale institutions. Nevertheless, a number of people with intellectual disabilities from the Northern Territory were in the past housed in institutional accommodation in South Australia. The majority of these people were 'repatriated' to group homes in the Northern Territory during the mid-1990s when South Australia embarked on partial deinstitutionalisation of one its large institutions.

Accommodation Support Services are provided through a small number of non-government organisations. They are based on 'group home' models and all have waiting lists. The *Disability Services Five Year Strategic Plan 1997-2001* aims to address this crisis.

2.5 Summary

This chapter has reviewed future State/Territory plans and figures for deinstitutionalisation. It suggests that congregate care remains a significant feature of disability and accommodation support services in Australia.

- There are approximately 6,000 people with intellectual disabilities living in institutions in Australia. This figure must be treated with caution. It is based on self-reported definitions of institutions. Definitions of institutions vary by State/Territory and record different types of institutional facilities and include different kinds of disability.
- If devolution plans go ahead in New South Wales almost 2,500 people will move into community based options over the next ten years.
- Reports from other States suggest that that over 900 people can expect to move to smaller, more appropriate accommodation in the community by 2011. It is suggested that smaller accommodation is considered more appropriate because

it mirrors the way that the many non-institutionalised people live, e.g. in small-scale family-like units as opposed to large-scale congregate care facilities.

- There have been decisions made to reverse the closure of institutions in both Victoria and Queensland. The redevelopment of Kew Residential Services in Victoria is continuing. The Basil Stafford Centre in Queensland has been significantly downsized.
- In addition, Victoria has built a new congregate care facility to house people with higher support needs. While Queensland has developed two new cluster-style developments viewed as centre-based rather than congregate care.
- Both government and non-government organisations provide institutional accommodation. Deinstitutionalisation policy appears to focus primarily on government-operated institutions.
- Institutions run by non-government organisations will be required to close by the New South Wales government. In Queensland, non-government providers who self-nominated as operated institutions approached the government to secure support for reform of their facilities.

Chapter 3. Disability service evolution: debates and issues

3.1 Introduction

This chapter explores disability service evolution in Australia. It is based on a combination of primary data, previous research and secondary analysis of documents. The chapter examines the factors that appear to have impacted on both recent and future deinstitutionalisation policies. These factors include:

- changing policy priorities;
- government inquiries into institutional abuse;
- social pressure by various interest groups, such as relatives and advocates;
- resistance to change from organised labour;
- and the threat of NIMBYism.

3.2 Changing policy priorities

The changing nature of disability service provision is in part dependent upon the ideology of governments. The dynamic nature of politics is reflected in changing policy priorities. Clear (2000) argues that people with disabilities have achieved important citizenship gains in Australia. However, governments carefully manage the inclusion of people with disabilities. It is 'turned on' and 'turned off' as ideology and policy priorities dictate.

Labor governments in Victoria and Western Australia and Labor-Green coalition governments in Tasmania have been integral to the closure of large-scale institutions in each State. Between 1987 and 1998, the last of the large institutions in Western Australia closed. Tasmania closed the Willow Court Centre as recently as November 2000. The decision was announced to redevelop Kew Residential Services by the Victorian government in May 2001. This decision ended a long period of uncertainty for the residents, family and friends of people living at Kew.

During the early to mid-1980s, New South Wales experienced a significant period of institutional reform. During this period it was anticipated that all of its institutions would close by the by the late 1990s. However, in 1988 with the election of the Liberal-National Party funding for disability programs, including deinstitutionalisation policies, was either reduced or withdrawn. This means that New South Wales is considerably behind other States that continued deinstitutionalisation policies throughout this period. In 1998, under the Labor Government, Mrs Faye Lo Po', the New South Wales Minister for Disability Services announced a 12-year program to close all institutions by 2010.

Labor governments in both Victoria and Queensland, on the other hand, have reversed decisions to close institutions and retain or redevelop residential services onsite. This reflects pressure from some parents/advocate groups in these States to have their children accommodated in centre-based care.

3.3 Government inquiries

Government inquiries into abuse and neglect within institutions have contributed toward deinstitutionalisation policies. For example, Gleeson (2000) highlights that an inquiry in 1996 in New South Wales found evidence of an entrenched 'culture of abuse' in both public and private institutions (*Sydney Morning Herald*, 30.11.96:3). The report detailed accounts of sexual and physical abuse of residents with disabilities, both by staff and by fellow-residents. In April of the same year, a fire at Kew Residential Services an ageing institution in Melbourne killed nine disabled men (*The Australian*, 10.4.96:1).

In a later official inquiry into the fire, the Kew Residential Services parents' association (Kew Cottages and St Nicholas Parents Association) representing residents of the institution attributed the disaster to the facility's decrepit fire-safety system and the poorly-trained and under-equipped staff (see Gleeson 2000). At the same time, the State of Victoria's Office of the Public Advocate found that the government had neglected its duty to provide safe residential services for people with disabilities (*The Canberra Times*, 18.10.97:4).

Similar government inquiries concerning institutional abuse and neglect have been conducted in the other States, including Tasmania, Western Australia and Queensland. These inquiries have also contributed toward processes of deinstitutionalisation and institutional reform in these States. There have been no government inquiries concerning institutional care in South Australia.

3.4 Advocacy groups

Advocacy groups have been a key feature of deinstitutionalisation from its inception in Australia and exerted considerable pressure on governments. A recent move by the New South Wales government aims to increase peoples' access to "individual advocacy". This has involved moving away from funding State systematic and peak advocacy groups toward rewarding local groups that help individuals instead. It means that thirty-six advocacy groups will have to tender for \$4.7 million in funding by April 27 2001.

Mr Phillip French, executive officer of People With Disabilities (NSW) Inc argues, "the decision is clearly nothing more than a payback to those groups who have been critical of the Government's failure to address desperate levels of unmet need". He said it was an obvious attempt to prevent efforts to eradicate continuing neglect and abuse in particular disability institutions (*Sydney Morning Herald*, 09.02.01: 3).

The decision to redevelop Kew Residential Services in Victoria, on the other hand, has been applauded by Victorian advocacy groups. In responding to the announcement Mark Feigan, Executive Officer of Disability Justice Advocacy Inc said, 'this at last is the dawn of a new century for people with disability We applaud the governments action. The disability sector is united in praise for this long awaited decision'. In explaining this further Mark Feigan said:

The way we have institutionalised people with disability in the past has been shameful. People need proper support to live a fulfilling and rewarding life but that could never happen at Kew Cottages [Kew Residential Services]. People there were neglected and abandoned, and were prevented from having a worth-living life. Even more shamefully many residents lost their life in regular tragedies. These directly resulted from the neglect visited upon these people for most of the last century. There was a organised and pervasive disregard for common decency and the human rights of the residents".

Mark Feigan concludes that 'now the government has commenced a process that could see a renaissance for all Victoria's residents of institutions. After Kew a few more institutions still remain. We eagerly anticipate the closure of Plenty Residential Services and Colanda, where many hundreds of people currently reside, in the outdated conditions of the last century' (*Disability Justice Advocacy Inc, Press Release, Kew Cottages Closure: The dawn of a new century for people with disability, 04.05.2001*).

3.5 Families for reform not closure

It is incorrect to suggest that deinstitutionalisation has been supported by all families/advocates of residents. Deinstitutionalisation has often met fierce resistance from parents. These concerns have centred on the long term funding of community services and their son or daughter's future safety in the community (Chenoweth 2000).

In both Victoria and Queensland, relative/advocate associations have successfully countered community care rhetoric with an alternative construction of 'reform' that centred on the re-creation, not closure, of institutions through systematic improvements to infrastructure and services (Gleeson 1999: 5). This countercurrent seems to have influenced disability policies in both States. In both contexts governments now aim to retain institutional accommodation on sites previously designated for closure.

In Victoria, the Parents Associations of Kew Cottages and St Nicholas Parents' Association Inc (Kew Residential Services) in which a fire killed nine men successfully lobbied against the decision to close the institution by 2010. The current Labor government has announced plans to redevelop the site. This will involve building 20 new homes to house between 50-100 people.

A similar situation occurred in Queensland in 1996. The newly elected Coalition government abandoned institutional reform after strong public pressure from some family members. Chenoweth (2000: 89) argues that even when Labour regained power in 1998, 'the active and effective resistance to community living by approximately 30-40 parents, met with a commitment to build two centre-based options for remaining residents'.

3.6 Managing challenging needs

The complexity of support needs of clients still living in institutions appears to have contributed to the slowing of deinstitutionalisation in some jurisdictions in Australia. It also appears to have contributed to the development of new forms of congregate care. Deinstitutionalisation policies have tended to privilege people with milder intellectual disabilities and often left those with higher health and social support needs until last. This client group is often thought to present more of a challenge to housing and support service provision. However, there is evidence to suggest that people with higher support needs are those most likely to benefit from living in community rather than segregated settings (Picton *et al.* 1997a, 1997b)

Devolution policy in New South Wales is attempting to address this issue. It is based on moving all people from institutions into the community-based options irrespective of level of support needs. However, meeting the housing needs of people with complex needs represents a challenge. Victoria recently redeveloped one of its institutional sites (known as Plenty Residential Services) in order to house people

with high support needs and challenging behaviours. While this service provides modern cluster-style housing it is nonetheless congregate not community care.

3.7 Resisting redundancy

Other voices of opposition to deinstitutionalisation have included organised labour. Institutions had long been bastions of highly unionised labour, including both non-professional and 'lower order' professions (e.g., nursing staff). Although the circumstances differed widely at the national, regional, and even local, scales, deinstitutionalisation had potentially profound consequences for such workers. This includes loss of employment, redeployment, erosion of working conditions (including job security), reskilling, adaptation to new work practices, and deunionisation (Lloyd 1987; OPSEU 1980). Recently, industrial action delayed the closure of the Willow Court Centre/Royal Derwent Hospital in Tasmania. This action centred on fear of loss of livelihood.

The Willow Court Centre/Royal Derwent Hospital was based in a geographically isolated area. It was one of only two major employers in this area. The closure of this institution, and redeployment of staff, has major implications for both families of employees and the local economy in this region. The action was resolved and Willow Court closed in November 2000.

3.8 NIMBYism

States/Territories have adopted a variety of strategies to reduce the impact of NIMBYism on deinstitutionalisation policies. In some States, such as Queensland and South Australia, great efforts have been made to consult with local communities about future plans to site community care homes in their neighbourhoods. In Western Australia, an explicit policy of opening group homes without prior consultation with neighbours has been adopted.

In Western Australia it is argued that people with disabilities are like any other member of the community and therefore entitled to the same privacy. Those not disabled do not consult with neighbours concerning their plans to move into particular neighbourhoods and are not forced to relocate on the basis of neighbour's objections.

Victoria and the two Territories have tended not to undertake consultation exercises in terms of seeking consent from neighbours concerning location of group homes but may use consultation processes to facilitate introductions in the community.

Tasmania pays special attention to siting strategies for new group homes. One strategy includes building care homes as part of new housing initiatives, including social housing developments. This means that from the moment of initial occupancy, group home residents are part of an already established social housing client mix.

None of the above State/Territory disability agencies report NIMBYism as a current planning issue in relation to housing people with intellectual disabilities. All recognise that NIMBYism was a significant issue in the past.

New South Wales, however, recognise that the scale of devolution plans in the State will require sensitivity to the siting of new community care homes and potential for adverse community responses.

Reduction in the impact of NIMBYism may reflect a tendency to site new group homes in 'places of least resistance'. These places are often disadvantaged areas where neighbours, many of whom have complex support needs themselves, are less likely to object. It is recognised within the South Australian context that NIMBYism may become an increasing problem as plans to site group homes in more advantaged neighbourhoods are developed.

Some States/Territories report a small number of cases whereby 'host' communities find it difficult to accept the behaviours of some individual residents. This means that disability administrators are faced with the challenge of balancing the rights of a person with challenging behaviours to live in the least restrictive setting, and the social norms of the 'host' community.

Given the appropriate supports, all people with disabilities can physically live in community settings. However, people with disabilities who express themselves differently or have challenging behaviours with regards to social norms are often rejected or even harassed in community settings. This means a group home may prove to be a hostile environment in terms of the surrounding community.

In addition, challenging behaviours may lead to eviction in the public housing sector. Meeting the housing and support needs of people with challenging behaviours is a source of debate among disability and housing agencies. Housing solutions suggested, and in some instances built, include new congregate care facilities (Victoria) and cluster housing developments (West Australia) that aim to protect both residents and neighbours. Cluster-housing developments are often set apart from the communities in which they are situated and hence create space between neighbours. This may reduce tensions between neighbours who have differences in their behaviours. The debate is continuing.

3.9 Summary

This chapter has explored factors impacting on the ebbs and flows of deinstitutionalisation policies in Australia. It has suggested that a complex web of stakeholders have influenced processes of deinstitutionalisation and have had different impacts at different times in different States.

- Changes in State/Territory governments have significantly impacted on deinstitutionalisation over the past 10 years. The Willow Court Centre in Tasmania closed in November 2000 through the commitment of its Labour-Green coalition government.
- The election of a Labour government in New South Wales accelerated deinstitutionalisation and led to a commitment to close all large institutions by 2010. On the other hand, Labour governments in both Queensland and Victoria have reversed closure decisions at the request of some parents/relatives associations in both States.
- Recent official reports that shed light on abuse in Australia's large residential care facilities have also forced some reform initiatives. For example, the official inquiry into the fire that killed nine men in a Victorian institution prompted both redevelopment on-site as well some support for people wishing to move toward community living.

- While some advocate groups argue that reform has not gone far enough, disability service agencies err on the side of caution. The agencies point to the prolonged process of careful needs assessment to explain the slower pace of deinstitutionalisation processes, particularly for those clients with higher support or challenging needs.
- Resistance to institutional reform has also been raised through trade union movements who fear redundancy and/or loss of status and conditions as part of the deinstitutionalisation process.
- A variety of strategies have been adopted by relevant State/Territory agencies to reduce incidences of NIMBYism. This includes both explicit decisions to consult - or not - with local communities; housing planning strategies; as well as placing community care in places where people are least likely to object to their location.

PART 2: HOUSING AND SUPPORT POLICIES FOR PEOPLE WITH DISABILITIES

Chapter 4. Deinstitutionalisation and housing futures

4.1 Introduction

This chapter examines deinstitutionalisation and housing futures focusing on the 2000-2010 timeframe. The chapter addresses research questions 2 to 4. It provides summaries of State/Territory experiences of institutional reform processes and their impact on peoples' housing and support experiences. The chapter describes both recent as well as anticipated housing outcomes arising from deinstitutionalisation in Australia. Links between disability and housing agencies are highlighted.

4.2 Future housing outcomes

Chapter 3 suggests that at least in the short to medium term, institutions remain a significant housing future for many people who are currently living in congregate care facilities. Evidence from this study suggests that at least 6,000 people with intellectual disabilities are currently living in institutions in Australia. However, if State/Territory plans to relocate people go ahead, over the next decade, half of this group of people will move into community living.

4.3 Explaining accommodation support packages

People leaving institutions often require some sort of accommodation support. Accommodation support services can cover a variety of support arrangements. These include attendant care and in-home support that aim to assist people to maintain suitable residential arrangements.

These sorts of arrangements range from just a few hours per week to 24-hour live in or rostered support. Individual accommodation support packages are based on a set number of funded hours. These set hours are generally 60 hours per week per person. This means that a person with higher needs must combine their support funding with others. This is because their 60 hours of funded support per week will not buy the services necessary to meet all their needs. Combining funding for support packages allows people to purchase or afford 24-hour support, seven days per week.

A focus on sharing support packages is a feature of community-based accommodation across Australia. This focus appears to have driven housing design. A range of different accommodation types is noted across the States/Territories. These range from stand-alone suburban houses to duplexes, triplexes and cluster developments. All designs aim to maximise the potential to share support package resources.

4.4 State/Territory experiences

This section explores, for each State/Territory, recent as well as future housing outcomes of deinstitutionalisation. It highlights new forms of accommodation support packages that are tailored toward individual need. These individualised support packages have the potential to open a range of housing futures. The chapter also points to the move toward the redevelopment of centre-based forms of care.

The State/Territory summaries are as follows.

New South Wales

The decision to close all large institutions in New South Wales means that 2,500 people will be moving into community based accommodation by 2010. Their housing futures will be guided by individualised packages of support. This involves the development of transition plans.

Transition plans are developed in conjunction with a range of stakeholders. This includes the service user, relatives/advocates, disability and other service agencies. Transition plans aim to facilitate the most appropriate future housing and support outcomes for people leaving institutions.

Links between residents, advocates, the Ageing, Disability and Home Care Department (formerly Ageing and Disability Department), the Office of Community Housing and community organisations are crucial to this transition process.

It is anticipated that people currently living in congregate care facilities in New South Wales will experience a wide range of housing futures. It is expected that some people will take up tenancies in public housing, others will move into private rental accommodation, some people will move in with their family and friends. Others will move into both government and non-government operated group homes.

In New South Wales, like the other States/Territories, group homes predominate as the major community based housing and support option for people with disabilities. Almost 2,500 people are supported in 600 group homes in New South Wales.

Alternative models of accommodation, particularly cluster housing, have not been built most recently. However, Faye Lo Po' the New South Wales Minister for Ageing, Disability and Home Care has expressed that cluster housing could be a future option:

The problem with existing accommodation policy is that we seem to have created a situation where a four bedroom house in the suburbs has effectively become the only alternative to large congregate care facilities ... I would like to see enough flexibility in the policy to allow two or three houses in close proximity in the same street or neighbourhood, and to encourage shared care and share household arrangements (extract from speech made to NCOSS Conference 1998: 4-5).

The Minister's view is reflected in the wishes of some parents/advocate groups in New South Wales. One parents' group has presented the then Department of Ageing and Disability with a detailed proposal to build cluster-style village model for their children. The development is represented as an alternative to both group homes and institutions.

The parents draw attention to the use of cluster housing for older people and point to the benefits of living in a secure, supported environment. This environment, unlike institutions of the past, is viewed as accessible for services and amenities both 'on-site' and within the community. The parents identify that one of the advantages of cluster-housing or village models is that people can share support packages.

Victoria

The decision to redevelop Kew Residential Services means that over 460 people will move to new homes either on its present site or elsewhere in Victoria. The new homes will be built for the Kew residents across metropolitan and rural Victoria following consultation with residents, families and advocates. The Victorian DisAbility

Services will work closely with the Victorian Office of Housing to provide these new homes.

Between 50-100 people will live in newly constructed homes on the Kew site. In 1998, the Kew Cottages and St Nicolas Parents' Association Inc. submitted a proposal for the redevelopment of KRS to villa housing. They argue that on-site villa housing will provide the intensive care and high security that congregate living is better placed to give than small community-based houses. It not clear whether the design of the new housing developments on the Kew site can be described as 'villa housing'.

A residential sub-division will be created on the Kew site, however, enabling a development where some 50-100 residents of Kew Residential Services can live in community residences as members of a broader community with ample space. Having 'ample space' is considered important for the management of challenging behaviours. The website of the Victorian DisAbility Services Division describes the redevelopment in the following way:

The new homes to be built on the Kew site will look like houses typical of any suburb in Melbourne. Residents will all have their own bedrooms, and will have generous living areas. As the Redevelopment proceeds, other privately-owned houses will be built alongside and around the homes of Kew residents, so that a new 'suburb' will be developed on the existing Kew site (Victorian Department of Human Services (2001) accessible at the following website <http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf>).

Victoria has also designed 'back-to-back' houses to facilitate sharing support packages. These houses are similar to duplex models. They have different street frontages, however, with joining doors through the back gate.

Victoria has an explicit commitment to retaining congregate care facilities. The State recently redeveloped Janefield, one of its institutional sites, in order to provide care for people with high needs and severe behavioural difficulties. This facility is known as Plenty Residential Services. This service provides modern cluster-style housing within a congregate care setting.

Queensland

Queensland Department of Housing coordinates the Institutional Reform Housing Project. This is guided by the departments' housing strategy for people with disabilities. The strategy was launched as *A Home to Come Home To: Housing Strategy for People with a Disability 1997-2000*. A new strategy is currently being negotiated.

The existing strategy highlights the importance of delivering housing assistance that:

- Ensures that people live in ordinary housing in established communities rather than in segregated and isolated situations or grouped together with other people with a disability.
- Successful housing options in the community for people with a disability often rely on the availability of flexible, portable and individualised accommodation support and/or health services. People with a disability have a right, however, to access housing assistance irrespective of their support needs or the availability of support services;

- In living in the community, people with a disability should have the same kinds of opportunity as other people to choose where and with whom they live, and to choose housing from the range of housing assistance available to the rest of the community.

The Department of Housing adopts an explicit policy of separating the management of housing from management of health and other support services. All clients of public housing in Queensland have their own tenancy agreements. This aims to maximise a sense of home ownership and facilitate 'a house to come home to'.

Queensland is in the process of 'downsizing' its last large-scale residential facility from 80 to 25 places.

It is expected that 50 people will move into public housing. Tenants will live with two other people with disabilities. This means that support packages can be shared between three people. However, the separation of housing and support means that this is not a traditional group home arrangement.

Disability Services Queensland has recently built two new cluster housing developments: Bracken Ridge and Logan Lea. They house 37 people with higher support needs. The developments reflect the wishes of some parents to have their children accommodated in centre-based care. Unlike institutions of the past, the developments have been designed to facilitate involvement of residents in the local community. They are considered to be centre-based rather than congregate care.

South Australia

South Australia has no current plans to close its two large-scale institutions. However, there are plans to move 50 older residents into a nursing home that is currently under construction. Another 25 people will move into group homes.

The South Australia Community Housing Association (SACHA) works with housing associations that provide group homes for people with intellectual disabilities. SACHA acquires properties from the South Australian Housing Trust and renovates them in line with the requirements of housing associations. SACHA have no contact with housing association clients.

Disability services in South Australia recognise that there are limitations of the group homes model. They argue that 'group homes should be viewed as a stage in a deinstitutionalisation or downscaling exercise' (Priest and Bruno 1990: 1).

South Australia has assessed village-based models. However, this kind of provision is considered more suitable as a means to redevelop existing institutional sites rather than as a community based accommodation.

South Australia has also considered what they term as 'row houses'. In this housing model, two to four houses in the same row/terrace are connected via an adjoining door. Doors would be locked during the day but kept open during the night. This would allow one support worker to cover a number of residents needing night care.

Western Australia

A partnership arrangement exists between the Disability Services Commission (DSC) and the Ministry of Housing (Homeswest) in Western Australia. This is both a philosophical as well as practical arrangement. In terms of philosophy, DSC and Homeswest have worked together to develop a framework of 'normalisation' within their work.

Normalisation refers to the philosophical framework that demands that service users have the right to the 'least restrictive living setting', meaning a care environment that restricts individual freedom only to the minimum extent needed to ensure broader community well-being (Shannon & Hovell 1993). In other words, disabled people should live in ordinary housing arrangements in regular communities as part of mainstream society rather than segregated from it in institutions (Chenoweth 2000).

On the other hand, the Community Disability Housing Program (CDHP) provides community managed accommodation options for people with disabilities that require support to live independently in the community.

This is the product of a cooperative agreement between the Ministry of Housing, the Health Department of Western Australia (Mental Health Division) and DSC.

The CDHP commenced in July 1996 and replaced the Community Residential Tenancy Program (CRTP). Annual commitments to the program are negotiated between the Ministry of Housing and respective departments. An agreement to provide 60 houses per year started in 1995/96 and finished in 1997/98 under this program.

The Ministry of Housing leases properties to community organisations. This is on the condition that the tenants to be housed have appropriate support arrangements in place to help sustain independent living. In most cases this is support funded by the Disability Services Commission or Health Department.

DSC prioritises devolution of hostels. It is anticipated that 261 people will move into group home accommodation over the next three years.

DSC encourages a variety of group home designs. The following are considered acceptable forms of accommodation:

- small group homes (housing 2-3 people) and medium group homes (4-5 people) in a duplex format;
- small group homes in a triplex or quadruplex format;
- clusters that do not involve more than 12 people in six small group home format;
- three duplexes that house up to 21-24 residents.

Western Australia reports that duplex arrangements are becoming more acceptable for people with behavioural difficulties. One to two people expressing significant problems are housed on one side and up to five people with fewer or no challenging behaviours on the second side. This is seen as a good model to ensure that staff are supported when dealing with people who have significant problems.

Western Australia intends to 'downsize' its older facilities in order to keep unit sizes to 20-24 people.

Western Australia still has a cluster housing development that incorporates ten units catering for 66 people. This is too large to be acceptable accommodation. Future efforts will focus on breaking up this facility into two clusters of 21-24 places. The additional 20 people will move to suburban style homes and duplexes.

Tasmania

Tasmania has closed its only large congregate care facility. Residents moved into a range of community-based facilities and houses on nine sites across Tasmania.

Between 1994 and 1998, Housing Tasmania bought 18 'family group homes'. A family group home is long term-supported accommodation. It houses up to four people with special needs requirements together in a family environment. Both government and non-government agencies provide accommodation support services. Housing Tasmania provides some (not all) of the asset infrastructure and ongoing maintenance.

Disability services in Tasmania view group homes as a transitional phase with a further move anticipated to a more independent setting. It is recognised that while a percentage of people are appropriately accommodated in group homes, a percentage could be better served by other housing options.

Plans to assess the future accommodation options of people living in hostels are being developed.

Australian Capital Territory

The majority of people with intellectual disabilities housed in the accommodation support sector in the Australian Capital Territory live in group homes. There are 173 people living in 63 operated homes. Another 163 people live in the non-government sector.

Northern Territory

Group homes are the predominant supported accommodation service available in the Northern Territory. Group homes are provided by three different non-government agencies in the three urban centres: Darwin, Katherine and Alice Springs. One non-government organisation wishes to develop cluster housing. This proposal is being considered by both disability services and housing in the Northern Territory.

4.5 Summary

This chapter has examined the housing futures of people currently living in institutions in Australia. It suggests that people are likely to experience two major housing futures: institutions and group homes. However, both sources of accommodation provision are under-going redevelopment in terms of style and design.

- The housing futures for people leaving institutions across Australia have tended to be driven by support requirements. This has led to the predominance of the group home model, whereby several people can share their support packages.
- A range of housing has been designed, modified and built to maximise the potential to pool support packages. These include duplex, triplex, quadruplex and cluster developments.
- Some parents/advocates have lobbied for village models or community based cluster-housing developments. Queensland has built two new cluster developments in order to provide centre-based care as an accommodation option.

- An array of arrangements between housing and disability service agencies exists. These arrangements have framed the delivery of successful housing solutions. Housing outcomes have been delivered via both public and community housing.
- Philosophical, practical and cost considerations have mediated housing solutions. The Western Australian DSC and Homeswest have worked together to deliver housing and support services based on principals of normalisation. Department of Housing in Queensland has adopted explicit an explicit policy of separating housing and support. This aims to maximise sense of home-ownership.
- The over-reliance on group models of accommodation is recognised by all States/Territories as problematic. New South Wales aims to provide individualised packages of support to people leaving its institutions over the next decade. This should promote a wider range of housing futures. However, for many people living in congregate care, housing choice remains constrained.

Chapter 5. Successful housing solutions: debates and issues

5.1 Introduction

This chapter examines factors that impact on the development of successful housing solutions for people with disabilities. Both primary data and previous research are used to facilitate the discussion. These factors include:

- different lead agency responses to accommodation and support provision;
- use of the group home as the blueprint community housing model;
- the development of service provision responsive to the diversity of client need;
- heterogeneity within the group of people with complex support needs;
- increased targeting of social programs toward people with disabilities;
- policies that lead to the over-concentration of service dependent people in particular suburbs.

The chapter suggests that a variety of philosophical, pragmatic and planning processes appear to mediate outcomes for people in housing need. This includes those to be deinstitutionalised.

5.2 Primary policy drivers

The development of different models of accommodation support is dependent on which agency is the primary policy driver — housing or disability (see Figure 5.1). This means that if the focus is on meeting individual housing needs then support packages can be designed to take account of housing requirements. This involves getting the housing right through modification, relocation or rent assistance.

On the other hand, if support services are the policy driver then it becomes logical to suggest that people share support packages by living together in group or similar. Given the enormous funding constraints resulting in the current dilemma that demand for support is significantly greater than the supply, aggregating support services appears to be a particularly attractive option.

Figure 5.1 Principal policy focus: housing or support?

If focus on HOUSING NEEDS	If focus on SUPPORT NEEDS
Modification Redesign Relocation Other housing options e.g. rent assistance, grants	Economies of scale Aggregated support packages leading to constant 'pull' back to group homes as an acceptable housing option

However, within the housing policy context no agency is suggesting, for reasons of economies of scale or financial imperatives, that people in housing need should be asked to share rooms, or to live in collectives or group homes or in clusters. This is

despite the equally significant funding constraints on providing secure, affordable housing for people in housing need.

5.3 Group home or no home?

The predominance of the group home model means that that in many States/Territories support agencies are the primary policy driver. There are notable exceptions. In Queensland, housing is recognised as the principal policy driver. However, addressing housing needs first presents the challenge of managing increased support costs. Nevertheless, Queensland have attempted to move away from group homes as the major model of community based housing.

Group homes are an important source of stable accommodation for people with complex needs. However, there is the problem that they have become the blueprint (and often only) model of housing provision. Simons and Ward (1997) argue that for the last decade and a half, in the UK at least, the debate about 'residential' services for people with disabilities has primarily been in terms of the shift from long-stay hospitals to 'community settings' in general and 'ordinary housing' in particular.

However, while the housing used may have been relatively 'ordinary', what happens inside it is often not. Simons and Ward (1997) suggest that most occupants do not have a chance to choose with whom they live. They are licensees, not tenants, with correspondingly little security of tenure. In organisational terms, the housing which people occupy and the support they receive are often inextricably bound up together. This means that it is very difficult to change one without changing the other. These circumstances undermine the rights of residents to individualised, tailored support.

The separation of housing and support is an important step away from an over reliance on this type of accommodation model. It is one way of giving greater force to the tenancy rights of the individual service user. This principle is explicitly recognised by the Queensland Department of Housing.

The Queensland Department of Housing aim to maximise peoples' sense of home ownership and control through tenancy agreements with individuals rather than agencies. It is recognised that people with additional support needs may have to share their accommodation support packages. This means that people may have to live together for pragmatic purposes. However, no one agency, whether housing, disability or non-government organisation, can exercise control over tenants housing and support arrangements.

5.4 Flexible service provision

There is a growing recognition in both disability and housing agencies that their services must become more responsive to the diversity of client need. In disability services there is a growing emphasis on providing services that are flexible.

This focus emphasises the need to tailor services to individuals rather than services imposing 'one-size-fits-all' models of accommodation support. This means that there is recognition of adopting accommodation and support models that move beyond the group home. As Taylor (1991: 108) notes in a review of individualised living arrangements in Wisconsin:

The concept is deceptively simple – find a home, whether a house, apartment or other dwelling, and build in the staff supports necessary for the person to live successfully in the community. Inherent in the concept is flexibility. Some people may need only part-time support or merely someone to drop by

to make sure they are okay. Others with severe disabilities and challenging needs may require full-time staff support. There isn't anything in the concept that precludes small groups of people from living together ... this, however, should be because they choose to live together and are compatible.

In the past, housing agencies have tended to provide bricks and mortar approaches to the delivery of housing outcomes. However, there is growing recognition that increasing numbers of housing tenants require extra support and that this support may be crucial to their ability to maintain the tenancy. This means that widening support arrangements with external agencies in order to facilitate successful tenancies will be central to improved housing services that are responsive to client need.

5.5 Recognising differences in housing need and access

People with disabilities are not a homogeneous group. There are groups within the disabled community who may have additional and special needs or specific access issues. Some of the people with greatest housing and support need include:

- Women with disabilities who may not be able to access housing in the private market that meets their special requirements.
- Children with disabilities who may not be perceived as having a housing need because of parental support. However, housing need may arise from a range of family circumstances, and in particular, the need for respite care.
- People with disabilities living in rural/isolated communities who may have additional problems of accessing housing and services. They may need to travel or move to cities or regional centres to access services and appropriate housing. This can mean losing social and family networks.
- People with disabilities from non-English speaking backgrounds who may not be able to access housing, information and/or services that are culturally relevant and appropriate.

5.6 Housing needs of Aboriginal and Torres Strait Islander people

There are housing programs that aim to meet the housing needs of Aboriginal and Torres Strait Islander people. Indigenous people face a higher level of housing disadvantage than non-indigenous members of the community.

Aboriginal people are also disproportionately represented within disability services. For example, while Aboriginal people represent 27 per cent of the total population in the Northern Territory, they constitute more than half of consumers receiving disability services (Territory Health Services 1997: 24). However, there is insufficient knowledge about the housing needs of people with disabilities from these groups.

5.7 Deinstitutionalisation and housing markets

There appear to be minimal direct impacts of deinstitutionalisation on housing markets. First, this is because relatively small numbers of people are leaving institutions. Second, even in circumstances where people leave institutions with individualised packages of support, the client relocation process is closely managed. This is generally within the public housing or community housing sector.

This contrasts with early deinstitutionalisation programs whereby people, particularly with psychiatric disabilities left having no home to go to. This often meant that deinstitutionalised people would become homeless (Dear and Wolch 1987).

The lack of impact on private housing markets also reflects the fact that people with disabilities often cannot meet their housing needs for secure, affordable and appropriate housing in the private market. This means that social housing has become the major provider of housing solutions for people with complex support needs.

People with disabilities represent almost 40 per cent of people receiving housing assistance (AIHW 1999: 134). There is increased targeting of social housing programs and specialised support programs towards this population group. This may increase the potential for 'residualisation' within the public housing sector (see Malpass 1990).

This has been the experience in other policy contexts. A recent study of British community care housing by the Joseph Rowntree Foundation painted a bleak picture of the accommodation choices open to people with disabilities. The Rowntree report found that much of the social rental housing used for community care had been relegated 'into a stigmatised and residual sector catering for those who have no other choices' (*The Guardian*, 2.7.97: 9).

The evidence was that people were frequently shifted from institutions into accommodation that was characterised as 'grotty flats on high crime estates' (ibid). Gleeson (2000) argues that this is hardly the enabling residential settings that disability activists and advocates have struggled for.

5.8 Geographies of care

Geographies of care refers to the geographical location of services aimed at supporting people with disabilities. These include residential services. Deinstitutionalisation processes or relocation packages at the individual level involve the development of detailed transition plans. These plans are developed in conjunction with a range of stakeholders. Stakeholders include service users and their relatives/advocates, disability support agencies and accommodation providers.

Service users and their relatives/advocates are asked to express preferences about what type of accommodation, and where, they wish to live in the future. State housing authorities have been well placed to offer accommodation in a variety of localities.

Housing agencies have a network of properties located throughout each State/Territory. This can help facilitate people to move to their community of choice. This may be particularly important for people who wish to move back to their community of origin, particularly if their former home is located many hundreds of kilometres from their institutional home.

However, public housing estates are often (but not always) situated in less advantaged suburbs. This can lead to isolation from services and amenities important to the maintenance of successful tenancies.

There is also an apparent over-concentration of community care homes in poorer suburbs. Disability agencies in many States/Territories report a reduction in the

impact of NIMBYism in recent years. This is in part due to decisions to site community care homes in disadvantaged neighbourhoods. These decisions are made for pragmatic reasons.

On the one hand, there are lower land and house prices in disadvantaged suburbs. On the other hand, disadvantaged areas are often viewed as 'places of least resistance'. This means that people are less likely to object to group home developments (Dear and Wolch 1987). There are increasing numbers of people with complex needs living in public housing. There is also the tendency to site community care homes in poorer suburbs. This may serve to compound the concentration of people who require additional support in particular places.

5.9 Summary

This chapter has examined the factors that influence accommodation and support policies. It has suggested that links between housing and disability agencies underline finding successful housing solutions for deinstitutionalised people. It has highlighted that:

- The development of different models of accommodation support is dependent on which agency is the primary policy driver - housing or disability.
- Disability agencies are guided by the need to provide appropriate support services. Limited resources often result in the financial imperative to aggregate support packages. This leads to a constant 'pull' back to group homes as an acceptable housing option.
- Housing agencies on the other hand exist to expand housing choices available to people disadvantaged in the private housing market. It is recognised that people with disabilities may need specialist housing assistance. This may include modification of existing buildings or purpose building new dwellings or spot purchasing dwellings where existing housing is unsuitable.
- The predominance of the group home model suggests that in many States/Territories support agencies are the primary policy driver. Packages of support are often shared between two and nine people in this model.
- Each State/Territory is reviewing the strategic development of disability services. There is an emphasis on providing services that are responsive to the changing needs of individuals across the whole of their lives. This focus emphasises the need to tailor services to individuals rather than services imposing 'one-size-fits-all' models of accommodation support.
- Minority groups within the disabled community may have additional and special needs.
- There are increasing numbers of people with complex needs living in public housing. There is also the tendency to site community care homes in poorer suburbs. This may serve to compound the concentration of people who require additional support in particular places.

Chapter 6. Policy implications

6.1 Introduction

This chapter explores policy implications arising from this study. It is divided into three main sections that address the following research questions:

- what policies and practices might be instituted to improve the understanding and anticipation of trends in deinstitutionalisation?
- what broad policy implications are raised by improved understanding of the housing outcomes from deinstitutionalisation?
- what would be the costs to the public sector, and the community, of not securing adequate housing futures for deinstitutionalised service users?

At the beginning of this study it had been anticipated that deinstitutionalisation significantly impacts upon local housing markets and that people moving from institutions lead relatively diverse housing careers.

However, data from this study suggest that relatively small numbers of people with intellectual disabilities can expect to move from institutions to community living in the near future.

The study also reveals that the client relocation process tends to be closely managed in disability services and that the group home remains the major community housing model. It therefore appears that deinstitutionalisation has minimal impacts on housing markets and that the housing experiences and choices of people with intellectual disabilities remain highly constrained.

However, there is also a deep pool of latent demand that will not manifest itself in its entirety at one time. The breadth of this need underscores the importance for a careful synthesis of the housing and support policies. Some 90 per cent of people with disabilities live in the community and have never, and will never, live in an institution. Official estimates suggest that at least 13,500 people with disabilities in Australia are in urgent need of accommodation/lifestyle support (Yeatman 1996). People with Disabilities (NSW) Inc. suggest that 8,000 are in critical need of accommodation support services in New South Wales alone. This underlines the importance of planning for the housing and support needs of people with disabilities who are currently, or will be, in need of stable accommodation.

6.2 Policies and practices to improve the understanding of deinstitutionalisation trends

Information sharing

In order to improve the understanding and anticipation of deinstitutionalisation trends and wider housing and disability support provision, there is a need for greater information sharing between key State/Territory and Commonwealth agencies. The Commonwealth could contribute much to the improvement of housing and disability support programs through an information brokerage role, which would see it facilitate discussion between States/Territories about program development and new policy

innovations. This could be promoted through newsletters or regular conferences with delegates from disability and housing agencies across Australia.

There is an increasing recognition of the importance of cross-policy coordination. At the most recent meeting of the Housing Ministers, on 13th October 2000 in Adelaide, Ministers expressed their full support for addressing issues associated with the accommodation and support requirements of people with complex needs. In February 2001, a two-day forum was held in Sydney to explore both stable accommodation for people with complex needs and strategies for preventing homelessness. The aims of this forum were to offer States and Territories with an opportunity to:

- learn from research in the area of complex needs;
- share information and identify the strengths and weaknesses in current service provision;
- discuss and potentially develop future policy directions, and
- develop a proposal to present to the Housing Ministers Advisory Committee (HMAC).

The seminar was attended by a variety of senior policy makers, including representatives from housing agencies, health, disability and community services. Findings from this project were presented at the seminar. This project has contributed to the aim of greater information sharing, both through its reports and early findings seminar.

Data collection

The AIHW provide an excellent service for planners and providers of housing and support service through collation and co-ordination of sources on CSDA funded service provision in Australia. The CSDA Minimum Data Set Collection is the national framework that guides the definitions of accommodation support services in Australia. Given that many 'institutions' have downsized, if not entirely closed, there seems to be a case for re-thinking the current definitions of institutions. The institutions of yesterday are not those of today or the future. It is recognised that the diversity of definitions used by different States/Territories to describe institutions have long, rich histories. It may be important, however, to identify ways in which a common language/terminology can be adopted across States/Territories to facilitate common policy approaches.

Disaggregation of data

There may be a case to support improved disaggregation of data on deinstitutionalisation or bed closure. At the moment, AIHW data on numbers of people living in institutions, on a State/Territory basis, are not routinely broken down by primary disability type. It is thus difficult to assess numbers of people with intellectual or other primary disability types currently living in institutions.

6.3 Policy implications of improved understanding of the housing outcomes from deinstitutionalisation

Cross-policy coordination

The improved understanding of the housing outcomes from deinstitutionalisation has highlighted the problematic development of separate Commonwealth and State/Territory policy programs on housing and disability. It is significant that there is little coordination between the main national housing and disability policy frameworks: the CSHA and the CSDA. The separate development of the CSHA and CSDA may hinder the development of mutually reinforcing programs by disability and housing service providers concerning the housing futures of people with complex support needs, including people expected to be deinstitutionalised.

There have been no formal processes for expert policy makers in housing agencies and disability service providers to comment on the development of each agreement. It should be noted that detailed policy documents do exist at State/Territory level that give effect to shared housing and disability objectives. However, links only occur if agency staff take the initiative and develop co-operative endeavours between the relevant organisations. These informal, ad hoc links meet with varying degrees of success, depending on the State/Territory in question.

This suggests the need for joint working initiatives. At a State/Territory level there is a need for junior policy officers upwards to talk together about bettering coordination of housing and other support outcomes for people. At the national level agreements should be developed together rather than in isolation. This also applies to the development of links with other specialist programs such as the CAP and SAAP. A joint working party could be established to aid cross-policy coordination of these key funding frameworks.

Accessible housing markets

The social housing sector is a major provider of housing solutions for people with complex support needs. This reflects the fact that people with disabilities often cannot meet their needs for secure, affordable and appropriate housing in the private market. There is wide recognition that there must be inter-agency cooperation to ensure the success of public housing tenancies. The HMAAC sponsored 'stable accommodation for people with complex needs' seminar reflects this recognition.

It is acknowledged that the growth in numbers of people with complex needs is likely to exert increasing pressure on housing resources. This suggests that there is also a need to address the inaccessibility of the private housing market for people with additional support needs. This would involve the mobilisation of a cluster of initiatives that aim to address discrimination within the private market. This could relieve some of the likely future pressure on state housing agencies to resource the appropriate provision of accommodation for this group.

Policies to open up access to the private housing market may also circumvent the potential to create 'service ghettos' or suburbs of service dependent people. On the one hand, public housing estates are often isolated from services and amenities. These services may be crucial to the development of successful tenancies.

On the other hand, fears of NIMBYism have resulted in the tendency to site community care homes in areas where people are viewed as least likely to resist. These have often been poorer neighbourhoods. This can lead to the over-

concentration of people with higher support needs in places that are already struggling with the effects of multiple deprivations.

Tackling these 'avoidance strategies' may also have long-term implications for service delivery. Supporting people with complex need will demand work across a range of policy portfolios including housing, health, disability, workplace, community and crisis accommodation services.

Facilitating housing futures in the private market could help disperse people with complex needs throughout the community. This could help shift the balance away from a focus on support driven housing solutions towards a focus on individual housing need.

Multi-generational service provision

Accommodation support services cater for different generations of service users and their families. This means considering all stakeholders in 'multi-generational' service systems. On the one hand, evidence provided by one peak organisation, People with Disabilities (NSW) Inc., suggests that many younger people with disabilities and their families would like individualised community based accommodation. This may mean share houses, individual or co-tenancy or live-in arrangements.

Some parents/advocates, however, have affected deinstitutionalisation policy in unexpected ways through their support for congregate facilities. But these facilities are not like the institutional facilities of the past. They are based on 'sheltered village' models, cluster housing developments and 'centre-based care' – clusters of residential units established as alternatives to both large institutions and dispersed community care networks.

Gleeson (2000: 5) suggests that for such groups, it may be argued that deinstitutionalisation represented 'a shift from security to insecurity, a change from the assurance derived from knowing that one's relative was in lifelong institutional care to the uncertainty of a new and open service regime'. In particular, anxiety has been centred among older parents who feared what would happen to their children once they had died. This sense of insecurity can be placed in the wider context of the neo-liberal restructuring of welfare state and the rolling of services (see Gleeson 2000).

Ensuring inter-generational equity and sustainability in the housing options developed presents agencies with a challenge. The over-development of new cluster housing for currently institutionalised residents may lead to unfairness for future generations. Cluster housing is a feature of disability support services in Victoria, Queensland and Western Australia. It is being considered in New South Wales and the Northern Territory. The Australian Capital Territory closed its two cluster housing developments in the mid-1990s. There may be a danger that future generations of people with disabilities will be placed in these facilities in spite of wanting a community based option.

Individualised funding

In traditional approaches to policy and the provision of disability supports, congregate programs and block funding to community agencies have guided policy and practice. However, many disability groups have been demanding more individualised approaches to the provision of disability supports. Individualised funding refers to funding that is 'tied' to a particular individual and is portable between service providers. Depending on the level of funds available, this can ensure flexibility in matters including choice of service provider and housing. It can be used to support

people who live within a group home setting as well as to promote access to a wider range of housing options. In other words, individualised funding may enable people:

to choose for themselves the types of housing that they want (and can afford) and the types of supports they wish to use within the range of available options, just as any other member of the community (*National Housing Strategy* 1991: 8).

While individualised funding is not necessarily a panacea it might be part of a differentiated framework for supporting people with disabilities. Such a framework would offer a range of accommodation types in different places. This would allow some families to choose centre-based care for their children and would transcend the current tendency of support mechanisms to enshrine (if implicitly) the 'group home' as the only housing alternative to institutional 'care'. The move toward 'client focused' services and individualised funding would mean that more service users would have the ability to determine their own accommodation and support packages, opening up a much more complex support scenario.

The shift from funding services to funding outcomes for consumers is evidenced in the Strategic Plans of disability agencies across Australia. All plans emphasise the development of flexible or individualised funding and service models, which are responsive to the choices and changing needs of individual consumers rather than the needs of services providers and program requirements. The ways in which individualised funding options are offered differs depending on the State/Territory.

However, the impact of individualised funding is yet to be realised. Across Australia individualised funding appears to be less of an issue for people with intellectual disability who require 24-hour support. This reflects the limited number of service providers who can offer specialised 24-hour care. It applies more to people with physical or psychiatric disability who require drop-in or attendant care and can choose from a range of available services. Nevertheless, New South Wales proposes to offer packages of care tailored to their individual need for people moving from its large institutions. This should have a significant and diverse impact on housing futures for people moving toward community living in New South Wales.

6.4 Costs to the public sector, and the community, of not securing adequate housing futures for deinstitutionalised service users

Social justice and citizenship

The costs of not securing adequate housing futures for people moving from institutions is the failure to secure the citizenship rights of a marginalised group of people. Housing is a basic human right. It is a question of asking what would be acceptable for every person, and basing housing provision – and support services on principles of equity for everyone, regardless of whether they have a disability, or are young, or old or a newly arrived migrant or refugee.

People with disabilities (especially people with acquired brain injury, mental health problems and intellectual disability) are also significantly represented in SAAP and CAP services – through which many meander into social housing programs.

For example, it is estimated that between July 1996 and June 1997, 21,496 clients were accommodated by services funded under the SAAP in Queensland. An additional 28,192 people seeking crisis accommodation were turned away from SAAP services in the same period. Throughout Queensland, 21 per cent of people accommodated in SAAP services received a disability pension (Department of Housing Queensland 1997: 8).

A survey of emergency housing providers in Queensland in 1994 estimated that 7 per cent of SAAP users had an intellectual disability (Madden and Maples 1996: 46). In spite of this, the development of specialist support services within the social housing sector, and the interface of social housing programs with specialist services in the health and community services area remains underdeveloped.

Another cost of not securing adequate accommodation support services is the possibility of unmet and latent need emerging in clumps (e.g. cohort of parents no longer able to care) and overwhelming service agencies. The AIHW publication *Disability and Ageing: Australian population patterns and implications* (2000b: 152) describes the implication of the continuing trend toward community living:

In 1998, 606,600 people aged 5-64 years with a severe or profound core activity restriction were living in households, while only 20,000 people were living in supported accommodation. One of the implications of this trend is that people with a disability are increasingly reliant on informal carers to providers the assistance they need (AIHW 2000b: 152).

Analysis of the demographics of the carer population reveal that in 1998, 450,900 Australians, or 2.4 per cent of the total population, were primary carers of people with a disability. Of those primary carers aged 65 years and over, 9,700 (10 per cent) were parents of the main recipient (AIHW 2000b: 151). This is significantly higher than the number of people with intellectual disabilities currently living in Australian institutions.

The Victorian *State DisAbility Services Plan: Consultation Report* (2000) also raises the fears of older parents about determining appropriate accommodation and support for their children when they are no longer able to continue caring. People with a

disability and their parents wanted greater certainty in planning for the future and they want this to start early. As one parent states:

Ageing carers need support to plan for the future ... for their children to be appropriately accommodated before they are no longer able to provide support (Department of Human Services 2000: 56).

6.5 Conclusions

In order to conclude this study, this report will re-summarise its key findings under each of its research questions:

Research question 1. Forward plans for deinstitutionalisation 2000-2010

There are approximately 6,000 people with intellectual disabilities living in institutions in Australia. This figure must be treated with caution. It is based on self-reported definitions of institutions. Definitions of institutions vary by State/Territory and record different types of institutional facilities and include different kinds of disability.

Devolution plans in New South Wales means that almost 2,500 people will move from institutions to community based options over the next ten years.

Reports from other States suggest that that over 900 people can expect to move to smaller, more appropriate accommodation in the community by 2011. It is suggested that smaller accommodation is considered more appropriate because it mirrors the way that the many non-institutionalised people live, e.g. in small-scale family-like units as opposed to large-scale congregate care facilities.

There have been decisions made to reverse the closure of institutions in both Victoria and Queensland. The redevelopment of Kew Residential Services in Victoria is continuing. The Basil Stafford Centre in Queensland has been significantly downsized.

In addition, Victoria has built a new congregate care facility to house people with higher support needs. While Queensland has developed two new cluster-style developments viewed as centre-based rather than congregate care.

Research questions 2 to 4. Main housing outcomes from deinstitutionalisation.

The housing futures for people leaving institutions across Australia have tended to be driven by support requirements. This has led to the predominance of the group home model, whereby several people can share their support packages.

This reflects the overseas policy context whereby the group home has become the blueprint, and often the only community housing model.

The over-reliance on group models of accommodation is recognised by all States/Territories as problematic. New South Wales aims to provide individualised packages of support to people leaving its institutions over the next decade. This should promote a wider range of housing futures. However, for many people living in congregate care, housing choice remains constrained.

The development of cluster housing is a source of debate. Western Australia aims to downsize existing developments. Queensland has built two new cluster

developments in order to provide centre-based care as an accommodation option. Victoria provides cluster housing but in the form of a congregated setting.

Research questions 5-7: Policy implications

If genuine housing solutions for people with complex support needs depend on the development of working relationships between housing and disability agencies, then there is a need for greater dialogue and information sharing between key State/Territory and Commonwealth agencies. The separate development of the CSHA and CSDA may undermine the provision of effective programmes aimed at achieving stable accommodation for people with complex needs unless Commonwealth, State/Territory health, housing and disability agencies take a more co-ordinated approach.

Such co-ordination could improve the understanding and anticipation of deinstitutionalisation trends and address the wider issues of housing and disability support provision.

This suggests the need for joint working initiatives. At the national level, agreements could be developed *together* rather than in isolation. This also applies to the development of links with other specialist programs such as the Crisis Accommodation Programme (CAP) and Supported Accommodation Assistance Programme (SAAP) sector (see National Evaluation Team 1999).

The development of new funding frameworks that 'tie' funding to individuals (individualised funding) and are portable between service providers could improve individual client control and choice in housing and support. This would also meet agency goals to give clients more choice.

Consideration of the issues and policy directions that bear on the inaccessibility of the private housing market might suggest ways to relieve the pressure on housing agencies to provide appropriate accommodation for this group. This could lead to greater dispersal of services throughout the community and would therefore impact on service planning and delivery across a range of policy portfolios.

Another challenge for agencies is to ensure that housing options meet the aspirations of current and future clients while also being effective long-term investments of public money. The over-development of new group houses for currently institutionalised residents may lead to unfairness for future generations. There may be a danger that future generations of people with disabilities will be placed in these facilities in spite of their wanting individualised options in the community.

Service agencies also need to acknowledge and integrate the views of those who are not direct users of disability services. Parents/advocates have a significant stake in disability service evolution. It will be difficult to balance tensions among different generations of parents who may have conflicting expectations about appropriate accommodation.

To conclude, this study has provided estimates on the numbers of people with intellectual disabilities to be deinstitutionalised, focusing on the 2000-2010 timeframe. It has suggested that the housing futures of people leaving institutions remains constrained with a continuing reliance on the group home model of supported accommodation.

The study also suggests, however, that a much more demanding accommodation support services scenario seems to be settling upon Australia, driven by demands for both individual customised service provision and by parallel demands from some interests for 'sheltered villages' or centre-based care.

At the same time, social housing clients in Australia have increasing complex support needs. The development of coordinated responses to address this diversifying client base and need for individualised support is the main challenge for housing and disability services over the next ten years.

The fluid housing and support scenario facing policy makers underlines the need for research that explores alternatives to group home accommodation models. These alternatives will have to satisfy the housing aspirations of service users themselves, but also the views of other key socio-political interests, such as relatives/advocates and care workers.

Research on the post-institutional housing landscapes of Australia remains limited. Well-honed research on alternative models for post-institutional housing could do much to enhance the knowledge base of policy makers and thereby reduce the potential for costly conflict between key stakeholders in the care and supported housing sectors.

References

- Abberley, P. (1991) Disabled People: Three Theories of Disability. Occasional Papers in Sociology, no.10, Bristol: Department of Economics and Social Science, Bristol Polytechnic.
- Australian Institute of Health and Welfare (1999a) Australia's Welfare 1999 Australian Institute for Health and Welfare, Canberra.
- Australian Institute of Health and Welfare (1999) Community Housing Mapping Project, Data Report, Australian Institute for Health and Welfare, Canberra.
- Australian Institute of Health and Welfare (2000a) Disability Support Services Provided under the Commonwealth/State Disability Agreement: National data 1999, Australian Institute for Health and Welfare, Canberra.
- Australian Institute of Health and Welfare (2000b) Disability and Ageing: Australian population patterns and implications, Australian Institute for Health and Welfare, Canberra.
- Caltabiano, M., Hill, R. and Frango, R. (1997) 'The challenge to inclusion: context and policy issues', in Caltabiano, M., Hill, R. and Frango, R. Achieving Inclusion: Exploring Issues in Disability, Centre for Social Welfare Research, James Cook University of North Queensland, Townsville.
- Chenoweth, L. (2000) 'Closing the Doors: insights and reflections on deinstitutionalisation', *Law in Context*, Vol 17, No 2, pp. 77-100.
- Clear, M. (ed.) (2000) Promises, Promises: Disability and Terms of Inclusion, Federation Press, Sydney.
- Dear, M. and Wolch, J. (1987) Landscapes of Despair: From Deinstitutionalisation to Homelessness, Polity, Cambridge.
- Department of Human Services (2000) State DisAbility Services Plan: Consultation Report, Department of Human Services, Melbourne.
- Department of Housing Queensland (1997) A House to Come Home To: Housing strategy for people with a disability 1997-2000, Housing Queensland, Brisbane.
- Jary, D. and Jary, J. (1991) Dictionary of Sociology. London: Harper Collins.
- Gleeson, B. (1999) Geographies of Disability, Routledge, London.
- Gleeson, B. (2000) Rethinking Community Care, *Research Paper 1*, Urban Frontiers Program, University of Western Sydney.
- Hardwick, J., James, J. and Brown, F. (1987) Accommodation and Employment Policies for People with Disabilities, University of New South Wales, Social Welfare Research Centre, Sydney.
- Lloyd, A. (1987) Payment by Results: Kew Cottages' first 100 years, Kew Cottages and St. Nicholas Parents' Association, Melbourne.

Madden, R., Wen, X., Black, K. Malam, K. and Mallise, S. (1996) The Demand for Disability Support Services in Australia, Australian Institute for Health and Welfare, Canberra.

Madden, R., Shaw, J., Holmes, B., Gibson, D. and Wen, X. (1999) The Shift To Community Care and What is Driving it, Paper presented at the NCOSS conference, August 1999.

Maddison, F. (1998) Disability, Institutional Reform and De-institutionalisation: The Queensland Experience, Unpublished M.A. thesis, Department of Anthropology and Sociology at the University of Queensland.

Malpass, P. (1990) Reshaping housing policy : subsidies, rents and residualisation, London : Routledge, 1990.

Maples, J. and Madden, R. (1996) National Data on Accommodation and Related Services for People with a Disability: an exploration, Welfare Division Working Paper Number 10, Australian Institute for Health and Welfare, Canberra.

Morris, J. (1993) Independent Lives? Community Care and Disabled People, Basingstoke, Macmillan.

National Evaluation Team (1999) SAAP III National Evaluation. Family and Community Services, Canberra.

National Housing Strategy (1991) The Housing Needs of People with Disabilities: Discussion Paper, National Housing Strategy, Canberra.

Neilson Associates (1990) The Housing Impacts of Deinstitutionalisation, Australian Government Publishing Service, Canberra.

Oliver, M. and Barnes, C. (1993) 'Discrimination, Disability and Welfare: from Needs to Rights', in Swain, J., Finkelstein, V., French, S., and Oliver, M. (eds.) Disabling Barriers - Enabling Environments, Sage, London.

Ontario Public Service Employees Union (OPSEU) (1980) Madness! Ontario's Mental Health Breakdown, OPSEU, Toronto.

Priest, P. and Bruno, C. (1990) From Nursing Home to Group Homes: A Partial Downscaling Exercise, Paper prepared for Intellectual Disability Services Council, South Australia.

Picton, C., Cooper, B., and Owen, L. (1997a) Evaluation of the relocation of the Aradale and Mayday Hills clients project, Department of Human Services, Melbourne.

Picton, C., Cooper, B., and Owen, L. (1997b) Evaluation of the Relocation of Caloola Clients Project: A Three Year Follow-up of Former Caloola Training Centre Clients, Department of Human Services, Melbourne.

Ripper, P. (1997) 'Institutional Reform and Disability Legislation', *Abstract: The Newsletter of the Australian Disability Network*, 1, 1, 21.

Simons, K. and Ward, L. (1997) The early years of supported living in the UK, Joseph Rowntree Foundation, York.

Shannon, P., and Hovell, K. (1993) Community Care Facilities: Experience and Effects, report prepared for Dunedin City Council and Otago Area Health Board, Dunedin.

Taylor, S. (1991) 'Toward individualised community living', in Taylor, S., Bogdan, R., Racino, J. (eds) Life in the Community: case studies of organisations supporting people with disabilities, Paul Brookes Publishing Company, Sydney.

Territory Health Services (1997) Disability Services: Five-Year Strategic Plan 1997-2001, Territory Health Services, Darwin.

Yeatman, A. (1996) Getting Real: The Final Report of the Review of the Commonwealth/State Disability Agreement, Australian Government Publishing Service, Canberra.

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