



Australian Housing  
and Urban Research Institute

# **deinstitutionalisation and housing futures: positioning paper**

prepared by the

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## Table of Contents

<b>EXECUTIVE SUMMARY .....</b>	<b>2</b>
INTRODUCTION .....	2
PROJECT AIMS .....	2
POLICY CONTEXT .....	3
PREVIOUS RESEARCH.....	4
METHODOLOGY .....	5
CONCLUSION .....	5
<b>CHAPTER 1. INTRODUCTION .....</b>	<b>7</b>
1.1. <i>Introduction</i> .....	7
1.2. <i>Background</i> .....	7
1.3. <i>Aims of the research</i> .....	8
1.4. <i>Structure of the paper</i> .....	9
<b>CHAPTER 2. TERMINOLOGY .....</b>	<b>10</b>
2.1. <i>Introduction</i> .....	10
2.2. <i>Accommodation types and terminology</i> .....	10
2.3. <i>Definitional and measurement differences</i> .....	12
2.4. <i>Summary</i> .....	15
<b>CHAPTER 3. NATIONAL POLICY CONTEXT .....</b>	<b>17</b>
3.1. <i>Introduction</i> .....	17
3.2. <i>Deinstitutionalisation trends</i> .....	17
3.4. <i>Disability Service Legislation</i> .....	19
3.5. <i>Housing Policy</i> .....	23
3.6. <i>Summary</i> .....	25
<b>CHAPTER 4: LITERATURE REVIEW.....</b>	<b>27</b>
4.1. <i>Introduction</i> .....	27
4.2. <i>Aims of deinstitutionalisation</i> .....	27
4.3. <i>Deinstitutionalisation: background and context</i> .....	28
4.4. <i>Resigning disability services: issues and challenges</i> .....	28
4.5. <i>Australia: housing experiences and futures</i> .....	35
4.6. <i>Summary</i> .....	39
<b>CHAPTER 5. STUDY METHODOLOGY.....</b>	<b>40</b>
5.1. <i>Introduction</i> .....	40
5.2. <i>Methods overview</i> .....	40
5.3. <i>Fieldwork</i> .....	41
5.4. <i>Summary</i> .....	43
<b>CHAPTER 6. CONCLUSION.....</b>	<b>44</b>
<b>REFERENCES.....</b>	<b>46</b>
<b>APPENDIX A: ACCOMMODATION TYPES.....</b>	<b>53</b>
<b>APPENDIX B: LIST OF INTERVIEWED STATE/TERRITORY CONTACTS.....</b>	<b>54</b>

## **Abbreviations**

<b>ACT</b>	Australian Capital Territory
<b>AHURI</b>	Australian Housing and Urban Research Institute
<b>AIHW</b>	Australian Institute of Health and Welfare
<b>CDSA</b>	Commonwealth Disability Services Act
<b>CSDA</b>	Commonwealth State Disability Agreement
<b>CSHA</b>	Commonwealth State Housing Agreement
<b>DSA</b>	Disability Services Act
<b>FACS</b>	Department of Family and Community Services
<b>MDS</b>	Minimum Data Set
<b>NDAC</b>	National Disability Advisory Council
<b>NGO</b>	Non Government Organisation
<b>NIMBY</b>	Not-In-My-Backyard
<b>NSW</b>	New South Wales
<b>NT</b>	Northern Territory
<b>QLD</b>	Queensland
<b>SA</b>	South Australia
<b>SHA</b>	State Housing Authority
<b>TAS</b>	Tasmania
<b>UK</b>	United Kingdom
<b>US</b>	United States of America
<b>VIC</b>	Victoria
<b>WA</b>	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 that will examine the housing futures of intellectually disabled people who have been, or will be, deinstitutionalised. The study will document numbers of people expected to move from residential institutions into 'community' based living arrangements with each State/Territory over the next 10 years.

In 1999, 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. 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 and levels of deinstitutionalisation 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 aims to:

1. document the forward plans for deinstitutionalisation in each State and Territory, focusing on the 2000-2010 time frame;
2. review and describe 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. examine the broad policy implications of findings on the above and make recommendations for policy development;
4. involve service agencies directly in the research and in consideration of its findings; and

5. provide 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.

## **Policy Context**

This Positioning Paper reviews the policy context and framework for the development of disability accommodation provision in Australia. This reveals that:

- There is no national framework for the closure of large residential institutions in Australia. However, *Commonwealth Disability Services Act* in 1986 detailed in its Principles and Objectives the rights of disabled people to live within ‘community’ rather than segregated settings.
- Analysis of aggregate data by the 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 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 disabled people living in the general community.
- An emphasis on ‘reform’ rather than outright closure of institutions is reflected in the language used by each State/Territory to describe deinstitutionalisation processes. Terms such as ‘redevelopment’, ‘winding-down’ and ‘down-sizing’ indicate a commitment to deinstitutionalisation but do not necessarily signal closure programs.
- The development of separate Commonwealth and State/Territory policy 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 with 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.

- 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.
- People with disabilities represent almost 40 per cent of people receiving housing assistance (AIHW 1999: 134). Other groups assisted under the CSHA include homeless people, survivors of domestic violence, indigenous communities, refugees, new migrants and other households under stress as well as disabled people with complex support needs.
- Bilateral Agreements made between the Commonwealth and States recognise that housing clients have increasing complex support needs. A review of all CSHA Bilateral Agreements suggests that disability has not yet received the attention that it needs in the this key housing funding framework. It is the Crisis Accommodation Program (CAP) and the Supported Accommodation Assistance Program (SAAP) rather than the CSDA which appear to have been given more prominence.
- The CSHA and CSDA represent different styles of agreement. This may hinder the development of mutually reinforcing programs by disability and housing service providers concerning the housing futures of people expected to be deinstitutionalised.

## **Previous Research**

Research on the housing futures of intellectually disabled people within the Australian literature is limited. Nevertheless, research from a number of policy contexts, including Australia suggests that processes of institutional reform have been marked by community hostility, bureaucratic uncertainty and fiscal conservatism, together with parental concerns about the stability of future accommodation options for their children. A review of previous research shows that:

- The original aims of deinstitutionalisation were to provide disabled people with opportunities for as ‘normal a life’ as possible within ‘ordinary houses in ordinary communities’. This effectively has meant the opportunity to live in a ‘group home’.
- However, there have been notable shifts in expectations of housing outcomes from deinstitutionalisation in recent years. Disability activists have challenged stigmatising dualisms that construct ‘host’ communities as ‘normal’ and thereby

render the experiences of disabled people as 'abnormal'. In particular, the ability of 'group homes' to provide flexible, individualised care has been challenged.

- It is becoming increasingly common in the disability field to use the term a "a home of my own" to refer to a variety of different frameworks that emphasis control, choice and flexibility in terms of housing and support. These frameworks include both 'individualised funding' whereby funding is 'tied' to a particular individual and is portable between service providers, and 'supported living' approaches that provide flexible, individualised support to people wherever that might be.

## **Methodology**

In order to map future deinstitutionalisation plans primary data will be collected from all States/Territories. This will involve direct contact with staff of relevant agencies and require inter-state fieldwork to achieve the project aims. A mixture of data collection methods, including face-to-face interviews, telephone interviews and analysis of unpublished documentary materials will be adopted. To date:

- 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.
- Key informants also suggested or introduced team colleagues and individuals from other agencies that they felt appropriate to the development of the research. Contacts include policy officers, Non-Government-Organisation (NGO) workers as well as representatives of advocacy groups. Data were collected from both one-on-one interviews and via group interview formats.
- Analysis of published and unpublished documentary material is on-going. These include Strategic Plans, Budget and Business Plan documents, seminar materials as well as agreements between Disability Agencies and State Housing Authorities.
- Fieldwork and follow up discussions form the basis for the current study and provide grounded insights into disability service policy concerning the housing futures of intellectually disabled people who have been, or will be, deinstitutionalised.

## **Conclusion**

There is no national framework for the closure of large residential institutions for people



with a disability in Australia. While a nationally coordinated program may not be necessary, there is no centralised source of information on State/Territory deinstitutionalisation policy and as result, it is difficult to anticipate future national and sub-national housing need.

- While the AIHW collect data on accommodation services funded through the CSDA: these data are retrospective and do not provide estimates of future housing need.
- This study will document forward plans for deinstitutionalisation in each State/Territory focusing on the 2000-2010 framework. It will review and describe recent housing outcomes from deinstitutionalisation, drawing on evidence documented in Australia and other relevant policy contexts, and point to future pathways for disability and housing provision.

## **Chapter 1. Introduction**

### **1.1. Introduction**

This paper reports research by the Australian Housing and Urban Research Institute: University of New South Wales & University of Western Sydney Research Centre, that will examine the housing futures for disabled people who have been, or will be, deinstitutionalised. The research directly addresses a critical policy need in human services; namely, better intelligence on the current and projected patterns of deinstitutionalisation and the implications of these changes for housing, and related, support mechanisms.

This Positioning Paper is the first in a number of outputs from this AHURI project on Deinstitutionalisation and Housing Futures. The Paper:

- describes the policy issues to be 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.

Further outputs from this project will include a Work in Progress Report, a Findings Paper and a Final Report. The project will be completed by February 2001.

### **1.2. Background**

Deinstitutionalisation represents one of the most profound social policy shifts in the history of Western welfare states. All Australian States since the 1960s have embarked upon large scale restructuring of human services delivery, usually involving the closure and/or downscaling of institutions and their replacement by a variety of community care facilities and programs.

The separate State/Territory programs for future closures of institutions/beds are not centrally monitored or reported. Consequently, there is no readily available means for assessing the aggregate patterns of institutional change. As a result, it is difficult to both assess national and sub-national housing outcomes from deinstitutionalisation and formulate policies to anticipate and address these changes. This is compounded by the fact that both Commonwealth and State government responsibilities for funding accommodation and other services for disabled people tend to be discharged across several portfolios.

Through the collection of data via direct contact with relevant agencies in each State and Territory, this research will document forward plans for deinstitutionalisation in each State and Territory, focusing on the 2000-2010 time frame. The research will also review

and describe the recent housing outcomes from deinstitutionalisation in Australia, noting any differences between State/Territory experiences.

### **1.3. Aims of the research**

The project aims to:

1. document the forward plans for deinstitutionalisation in each State and Territory, focusing on the 2000-2010 time frame;
2. review and describe 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. examine the broad policy implications of findings on the above and make recommendations for policy development. This will involve surveying the views of service agencies and drawing on examples of practice from overseas as well as Australia;
4. involve service agencies directly in the research and in consideration of its findings; and
5. provide 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.

These aims raise the following principal research questions, which will form 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?

#### **1.4. Structure of the paper**

This paper examines the policy context of deinstitutionalisation within Australia. It describes developments in disability legislation over the past 15 years and highlights the changing priorities of housing policy. The literature review examines the housing impacts of deinstitutionalisation and shows that very little research has been conducted within the Australian context. Where research exists, it shows that deinstitutionalisation processes appear to have slowed and that many people continue to live within institutions. This reflects overseas research which suggests that community care policies can provide enabling environments for disabled people but that this potential has been limited by a number of factors, including policy gaps, program failure and under-funding.

The Positioning Paper includes the following Chapters:

- Chapter 2 outlines the terminology used in the current study. It reports differences in State/Territory definitions of institutions and deinstitutionalisation;
- Chapter 3 reviews current deinstitutionalisation patterns and trends toward community living. It examines Commonwealth and State/Territory legislation on housing and disability service provision.
- Chapter 4 reviews the recent housing outcomes from deinstitutionalisation in Australia, drawing upon evidence within Australia and other relevant policy contexts;
- Chapter 5 describes the methodology adopted in the current study.

## **Chapter 2. Terminology**

### **2.1. Introduction**

This chapter reviews the terminology used to underpin and frame disability services in Australia. A key premise of the current research focus is the importance of adopting a national approach toward the study of deinstitutionalisation, and disability and housing service evolution. Consequently, it is important to identify ways in which a common language/ terminology can be adopted across States/Territories to facilitate common policy approaches.

The Commonwealth State Disability Agreement (CSDA) requires that each State/Territory collect data on disability services funded under the Agreement. These data are reported annually through the CSDA Minimum Data Set (MDS). Each jurisdiction manages its own collection, with the AIHW collating and reporting on the data at a national level. The MDS represents the most significant determinant of definitions concerning accommodation support services and provides the most detailed and comprehensive source of data on disability services. However, while States/Territories adhere to MDS definitions of accommodation support services for data collection purposes, data from the current study suggest that understandings, definitions and the language used to describe accommodation services vary significantly between State/Territory disability agencies.

The use of varying definitions and adoption of different languages to describe accommodation and related services has been recognised. Research conducted by AIHW has attempted to describe differences in State/Territory definitions of accommodation related support services for disabled people (Maples and Madden 1996). In particular, Maples and Madden recognise that these definitional differences can pose problems when researching processes of deinstitutionalisation.

While the current study does not propose to refine accommodation and related support definitions it offers a window on State/Territory differences in the use of terminology concerning housing and disability policy. The first section draws on MDS definitions of accommodation support services and outlines terms used in the current study. The second section explores State/Territory variations in definitions of both institutions and deinstitutionalisation.

### **2.2. Accommodation types and terminology**

This section provides definitions of the terms used in the study. Definitions are based both on MDS definitions and derived from State/ Territory based documents on accommodation support services and types.

Unless stated otherwise, the following key terms will be defined as follows:

**accommodation support services:** the umbrella term used to describe services that provide accommodation to intellectually disabled people, and services which provide the support needed to enable a person with a disability to remain in their own home;

**supported accommodation:** residential arrangements that have support services integrated into the tenancy. These facilities include institutional, hostel and community villa type accommodation. The support services available help residents carry out activities of daily life that they may not be able to do alone or assist people to live as independently as possible.

**accommodation support:** covers a variety of community support arrangements that include attendant care and in-home support that assist disabled people to remain in individualised residential settings which offer a variety of tenancy arrangements.

Figure 2.1. Characterises accommodation types by physical scale. Institutions, hospitals and gaols are defined as ‘large’ developments. Large developments may accommodate between 20 and several hundred people. Medium accommodation types include cluster housing and village style developments, boarding houses and hostels, nursing homes and secure units. Between 10 and 100 people maybe housed within medium sized accommodation. Group homes and duplexes, family homes and flats are defined as small accommodation types that house from one person upwards (definitions of accommodation types may be found in Appendix A).

**Figure 2.1. Typology of accommodation types by physical scale**

Large	Medium	Small
Institutions	Cluster housing / village models	Group homes / duplexes
Hospitals	Hostels / boarding houses	Family homes
Gaols	Nursing homes	Flats
	Secure Unit	

### **2.3. Definitional and measurement differences**

This section reviews State/Territory differences in definitions of both institutions and deinstitutionalisation. Describing differences in State/Territory uses of key terms of terms such as ‘institutions’ is an important feature of understanding differing State/Territory policy contexts. It also forms the basis for comparing and projecting rates of deinstitutionalisation.

#### ***MDS definitions: institutions, hostels and group homes***

The MDS defines institution, hostel and group home as follows:

**institutions** are residential facilities located on large parcels of land that provide 24-hour support in a congregated setting of 20 beds or more. In many cases a range of residential and day services are provided on site.

**hostels** are defined as residential units that provides support in a congregated setting of anywhere from 6-20 beds. Hostels may or may not provide 24-hour care.

**group homes** provide combined accommodation and community based residential support to people in a residential setting. Usually, no more than 6 people live in any one house.

*Source: AIHW (200b)*

#### ***Congregate care facilities***

Among definitions used in various jurisdictions, location, size and style of accommodation are three criteria commonly used to identify institutions. First, the geographical segregation of institutional sites refers to the historical siting of ‘institutions’ on the outskirts of towns or cities that were designed to prevent contact with non-institutionalised communities. However, newer institutional designs or redevelopments, such as cluster style housing, have often continued this tradition of segregated geographical sites. The second defining feature of institutions is the physical scale including numbers of people who live there. Finally, the style of care provided by traditional residential approaches for disabled people, institutions, have packaged housing and services together. This means that people are required to live in the facility in order to obtain support services.

All States/Territories adopt the MDS definitions of large residential congregate care facilities. Every State/Territory includes the MDS definition of hostels as 'institutions'. However, States/Territories are aware of the problematic nature of classifying 'institutions' by number of beds alone and adopt, both informally and in documented form, wider understandings of institutions. This reflects the ways in which accommodated and related services are delivered within each State/Territory. The following is a sketch review of the different State/Territory definitions of 'institutions'.

**Queensland** identifies institutions on a range of factors including the style of care and physical attributes. This is documented in Queensland's *Policy Statement and Planning Framework for Institutional Reform: provision of community based services for people with disabilities currently accommodated in institutions* published in 1995. Features include number of beds, integration of accommodation and support, and amount of control over daily living routines. Queensland includes hospitals within their definitions of institutions. This is because some 110 intellectually disabled people live in hospitals operated by the Queensland Department of Health.

**Victoria** classifies institutions in terms of MDS definitions. However, it is recognised that smaller cluster housing/cottage developments can share institutional features. Victoria has recently redeveloped an existing institutional site. While this service provides modern cluster-style housing it is nonetheless congregate not community care. Victoria recognises that nursing homes, which may receive funding through the CSDA for disabled people to receive accommodation support, may also have institutional features.

**South Australia** defines institutions through MDS classifications. South Australia continues to house significant proportions of intellectually disabled people within large congregate care facilities. However, they raise the difficulties of defining what is an institution and point to the problematic nature of defining 'nursing homes'.

**Western Australia** presents data in terms of MDS definitions of hostels and institutions. Western Australia moved those people living in large scale Government run institutions into medium sized hostels by the end of the 1980s.

**New South Wales** and **Tasmania** use MDS classifications of institutions and hostels to define congregate care. However, New South Wales is currently developing new means of classifying accommodation services. These definitions have not yet been released.

The **Australian Capital Territory** and **Northern Territory** have never had 'institutions' as defined by the MDS. Nevertheless, the Australian Capital Territory provided medium-sized institutional care in the form of two hostels that housed people in 4x10 bedded houses. These hostels were closed by the mid-1990s.



The Northern Territory does not have ‘institutions’ as defined under the MDS. However, a number of people with intellectual disabilities are accommodated in hospitals. The Northern Territory appreciate that small residential settings can have institutional features that reduce choice and control of residents.

***Deinstitutionalisation***

This study uses the term ‘deinstitutionalisation’ to refer to processes of moving intellectually disabled people from ‘institutions’ to smaller community based options. However, research data reveal differences in State/Territory descriptions of deinstitutionalisation. This may reflect the slowing of deinstitutionalisation and indicate a focus on ‘reform’ rather than radical change of current institutional living arrangements.

Different terms are used in each State/Territory to describe processes of deinstitutionalisation. These terms reflect variations in State/Territory policy context (Figure 2.3). Although different, these various terms all capture and reflect the following themes:

- mode of service delivery;
- service philosophy; and
- mode of accommodation transition.

**Figure 2.3. State/Territory terms used to describe deinstitutionalisation processes**

<b>State/Territory</b>	<b>Term</b>
New South Wales	Devolution
Victoria	Redevelopment
Queensland	Institutional reform
South Australia	Moving toward community living
Western Australia	Deinstitutionalisation / devolution
Tasmania	Community integration
Australian Capital Territory	Deinstitutionalisation
Northern Territory	Repatriation

**New South Wales** currently uses the term ‘devolution’ which reflects a staged approach

to deinstitutionalisation processes that aim to move all people who currently live in institutions into community based accommodation. On the other hand, **Victoria** decided to describe deinstitutionalisation in terms of ‘redevelopment’. This is because Victoria has redeveloped individual institutions through a combination of closure, infrastructural improvements and the development of new congregate care facilities.

**Queensland** adopts the term ‘institutional reform’ in order to indicate the wider dynamics of deinstitutionalisation. This includes improving quality of care for people living in institutions as well as supporting those moving to the ‘host’ community. **South Australia** uses the term ‘moving to community living’ to supplement the term deinstitutionalisation. This captures the expectation that people leaving from institutions will assume increasing independence and move through a number of community based accommodation options.

**Tasmania** also refers to deinstitutionalisation as ‘community integration’ to focus on forward processes. The objectives of community integration in Tasmania include relocation of residents and eventual integration of those people into the ‘community’.

**Western Australia** uses both the term ‘deinstitutionalisation’ and ‘devolution’ to indicate a clear move from large congregate care facilities into smaller accommodation options. ‘Winding down’ is also used to reflect the closure or ‘downsizing’ of current facilities.

**Australian Capital Territory** use the term deinstitutionalisation.

Finally, the **Northern Territory** adopts the term ‘repatriation’. Historically, disabled people from the Northern Territory were accommodated in institutions in South Australia. When South Australia began to deinstitutionalise in the mid-1990s, a number of individuals were ‘repatriated’ to the Northern Territory.

## 2.4. Summary

This chapter reviewed the terminology used to underpin and frame disability services in Australia. It shows that:

- The CSDA MDS is a national framework that guides the definitions of accommodation support services. All States/Territories report numbers of people funded through the CSDA using MDS definitions. This is the most comprehensive data collection on disability services and is reported at a national level by the AIHW.

- In addition to MDS definitions, each State/Territory adopts its own definitions of accommodation support services. Definitions can be intuitive and/or explicitly recorded in State/Territory policy documentation. How States/Territory define institutional care is dependent on the nature of service provided by their jurisdiction.
- Variations in terms used to describe deinstitutionalisation reflect current deinstitutionalisation policies in each State/Territory. A focus on reformist approaches to deinstitutionalisation rather than on total change to congregate care may be reflected in terms such as ‘redevelopment’, ‘institutional reform’ and ‘moving toward community living’.

## Chapter 3. National Policy Context

### 3.1. Introduction

This chapter reviews the national policies that frame the housing futures of disabled people. 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. The chapter begins by outlining both deinstitutionalisation patterns and community living trends before describing the evolution of national disability and housing policy.

### 3.2. Deinstitutionalisation trends

Since the early 1990s significant numbers of intellectually disabled people have moved from large congregate care facilities into community based options. Nationally, approximately 2,500 people have moved from institutions over the past 10 years. In 1988 approximately 7,500 people with intellectual disabilities were living in large residential centres or psychiatric hospitals (Neilson Associates 1990: 8).

In 1999, there were 4,340 people whose primary disability is intellectual<sup>1</sup>, accessing institutional services on the snapshot day of the 1999 CSDA MDS data collection. A further 630 people were living in hostels (AIHW 2000a: 19). Hostels provide support in congregate care settings and share similar characteristics with institutional accommodation.

*Analysis conducted by the Australian Institute for Health and Welfare (AIHW) of Australian Bureau of Statistics (ABS) data shows how institutional numbers declined during the 1980s and early 1990s. The amount of people aged 5-64 years with a 'severe or profound handicap' who lived in establishments<sup>2</sup> declined while numbers residing in households rose steadily over the past 20 years. Figure 3.1. shows that estimates of numbers of people living in households, with a severe or profound handicap and aged 5-64 years, rose over the years 1981, 1988 and 1993. The increase between 1981 and 1993 was 42.9% or 104,900. In contrast, the number of people who lived in establishments has dropped by 29.1% or 7,900 (in Madden et al 1999, pp.10-11). **Figure 3.1.** Number of people with a profound or severe handicap aged 5-64 years by residence ('000), Australia, 1981, 1988 and 1993*

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<sup>1</sup> 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.

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

	No. with profound or severe handicap			% change in numbers		
	1981	1988	1993	1981-88	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: Derived from table produced by Madden *et al* (1999: 11).

### ***Trends in community living***

Wen and Madden (1998: 8-9) suggest, in their paper exploring *Trends in Community Living among People with a Disability*, that downward trends in deinstitutionalisation are because of the increase in the number of people living with relatives. Between 1981 and 1993, there was an increase of 58,000 disabled people living with relatives. For people living with non-relatives and those living alone, the increases were about 12,000 and 10,000 respectively. Over the 12 year period, the total increase in people living in the community was about 81,000. In contrast, the total number of people living in establishments dropped by 12,000. This shows that the increase in the number of people living in the community was markedly greater than the decrease in the number of people living in establishments.

For Wen and Madden (1998: 9), this large difference suggests that deinstitutionalisation trends over this period (in terms of reduction in numbers living in institutions) are mainly driven by an increasing trend for people aged under 65 years, who need on-going support to remain in community settings. In other words, they suggest it is likely that decreasing numbers living in institutions are due largely to 'potential new service users remaining in community based living arrangements, rather than radical change for the current 'institutionalised' population' (Wen & Madden 1998: 16).

### ***Unmet need in the community***

Trends in community living 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. 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. This means that many disabled people have inappropriate living arrangements, or that families and carers lack basic support (Caltabiano *et al* 1997).

Research conducted by the Australian Institute of Health and Welfare 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 (Madden *et al* 1996: 53). A study undertaken by the National Council on Intellectual Disability (NCID) found that 1,016 intellectually disabled people were now in ‘crisis’ because of lack of accommodation services (NCID 1995 in Madden *et al* 1996). The NCID made available to the Demand Study team anonymised copies of 175 letters to the Hon. Jim Longley, the then New South Wales Minister for Community Services, in response to an interview on the ABC’s *7.30 Report* on 26 July 1994. Issues most frequently raised in NCID letters in relation to accommodation services can be summarised as follows:

- although care at home may be difficult for many, there is a lack of other options,
- for those who have accommodation, quality may often be poor,
- for many the distance from family makes visits difficult,
- there was a concern that accommodation should keep a person in their local area so not to sever links with family and friends.
- finally, there was a concern expressed about the closure of some accommodation services classed as institutions, as there were no alternatives provided and the responsibilities to find alternative accommodation was put onto parents.

*Source:* derived from Madden *et al* (1996: 48)

There have been no recent updates of the *Demand Study* undertaken by the AIHW. However, anecdotal evidence suggests that those waiting for accommodation support five years ago are very likely to still be waiting. A letter published recently in the *Sydney Morning Herald* confirms 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).

### **3.4. Disability Service Legislation**

While there is no national framework for the closure of large residential institutions in Australia, all States/Territories have pursued deinstitutionalisation policies. The past 15

years have seen a number of significant reforms that have promoted processes of deinstitutionalisation and shaped housing policy in Australia. These have included major legislative and policy changes.

### ***Commonwealth Disability Services Act***

Although some States, notably Victoria and Western Australia had pre-empted the Commonwealth with their own progressive legislation on intellectual disability, the *Commonwealth State Disability Services Act 1986 (CDSA)* was a watershed (Clear 2000: 59). In 1983, the then Minister for Community Services commissioned the Handicapped Programs Review, which reassessed Commonwealth Assistance to disabled people. The review report, *New Directions*, was published in 1985 and advocated a policy emphasis on the individual receiving the services, rather than on the organisation providing them. The basic principle underlying the *CDSA* which implemented the recommendations of the review, was that 'positive consumer outcomes should be the rationale for program development' (Evans 1996: 3).

Accompanying the *CDSA* is a statement of the Principles and Objectives that were to be used as broad measures in evaluating the range of services assisted by the Commonwealth. The objectives of the Act were to:

- ensure that persons with disabilities received the services necessary to enable them to achieve their maximum potential as members of the community;
- ensure that services provided increased independence, employment opportunities and integration into the community; and
- promote a positive image of persons with disability and to enhance their self esteem.

The *CDSA* also promoted a broader range of services than those provided under the previous disability programs including an emphasis on innovative community housing options:

Accommodation support should not lock programs into one or two models. It should not be confined to group homes. It should be as flexible as the wide range of living options in the community generally and the ways that could be used to support individuals in those living options e.g. share houses or flats, co-tenancy or live-arrangements or married living arrangements, or drop-in support models (Department of Community Services 1987: 1 in Hardwick *et al*, 1987: 32).

### **Commonwealth State Disability Agreement**

However, the *CDSA* created overlap and confusion in the funding arrangements for disability services by the different levels of government (Yeatman 1996). In 1991 the

Commonwealth State Disability Agreement (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 that parallels the *DSA* and between 1991–1993 each State/Territory introduced its own *Disability Services Act* (Figure 3.2.). Attempts to operationalise the principles of the *DSA* were undertaken and many institutions across Australia were closed.

**Figure 3.2. State/Territory *Disability Services Act* by year enacted**

Year Enacted	State/Territory
1991	Victoria Australian Capital Territory
1992	Queensland Tasmania
1993	New South Wales South Australia Western Australia Northern Territory

The principles of each State/Territory *Disability Services Act (DSA)* are based on the *Commonwealth Disability Services Act 1986*. 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.

### ***National Standards for Provision of Disability Services***

All States/Territories and the Commonwealth have endorsed eight National Standards for the provision of services under the CSDA. This means that governments are obliged to meet disability service standards and develop appropriate quality improvement practices.

Three jurisdictions have developed their own supporting standards and performance indicators: namely, New South Wales, Victoria and Northern Territory.



*DSAs* and Disability Service Standards have the potential to impact significantly on housing outcomes because they emphasise the rights of disabled people to live in housing of their own choice in the community rather than in institutional accommodation.

### ***Consultation and the CSDA***

A key focus of the 1991 Commonwealth State Disability Agreement centred on consultation and planning across broad Commonwealth and State/Territory programs. The 1991 CSDA was designed to be prescriptive in order to bed down new administrative arrangements, roles and responsibilities and consultation mechanisms. It required that each State/Territory:

will consult and seek to agree on the establishment of broad program priorities and targets in respect of groups of persons with disabilities identified as a program priority, service types and regions (Section 6 (1)).

The CSDA necessitated that each State/Territory develop three year forward plans (reviewed annually) for those service types for which they had administrative responsibility. The preparation of this plan was to occur in consultation with consumer representatives and other relevant bodies, organisations and groups. Commonwealth and State/Territory disability agencies were made responsible for consulting across portfolios in their respective governments prior to finalisation of the forward plans in order to coordinate Commonwealth and State priorities. In particular, state housing authorities (SHAs) were singled out as important providers of services to disabled people. The 1991 CSDA highlights:

Consultation with the relevant housing authorities to ensure coordination with the Commonwealth/State Housing Agreement (section 6 (4)).

The 1998 CSDA aimed to be more enabling and allow for variations in State/Territory policy contexts. Consultation mechanisms contained in the first agreement assisted in establishing these processes. Most processes were not replicated in the second CSDA. However, an unintended consequence of this decision is that the CSDA no longer explicitly requires consultation between disability and housing agencies.

### ***Better Cities Program***

Consultation between disability and housing agencies was also a feature of another program that contributed toward deinstitutionalisation. The *Building Better Cities Program* was created in 1991-92 to promote a more integrated and strategic approach to urban development. It aimed in part to redevelop institutional sites in partnership with

Disability Services Agencies. The objective of institutional reform was elucidated as follows:

Many of our health and community services are currently provided through large and inappropriate institutions. In many cases this institutional care is expensive, absorbing much of the overall service budget. Reform of inappropriate institutional can have many benefits:

- more appropriate services and greater choices can be provided for individuals who are currently institutionalised, such as the frail elderly or people with disabilities;
- services will be able to be provided throughout the community, rather than concentrated in one or two locations in the city; and
- land currently occupied by these institutions may be released for alternative uses such as housing

*Source: National Capital Planning Authority (1996: 91).*

While the program, later renamed *Better Cities* was criticised for incoherence and failure to address basic urban problems its emphasis on institutional reform contributed to institutional closure programs in three States: Queensland, Tasmania and Australia Capital Territory. In Queensland, for example, a former institutional site had been earmarked for redevelopment for public housing.

However, Forster (1999: 158) makes the point that ‘whatever the merits or deficiencies’ of *Better Cities*, funding ceased under the incoming Howard government in 1996. In the case of Queensland, the institutional site was sold to University of Queensland rather than redeveloped for public housing. At the time of the sale, transitional plans were being prepared for fifty residents who were still living on site. All had to be re-housed temporarily until appropriate new accommodation was found.

### **3.5. Housing Policy**

The development of separate Commonwealth and State/Territory policy programs on housing and disability means that there are differences in the styles of agreement. In particular, there are differences between the two agreements concerning processes of consultation with other programs and human service providers.

#### ***Commonwealth State Housing Agreement***

The 1999 Commonwealth State Housing Agreement (CSHA) explicitly states the importance of developing links with specialist programs, which include the CSDA, in order to improve housing outcomes for those in need. The aim of the agreement is to provide appropriate, affordable and secure housing assistance for those who most need it.

Disabled people represent a significant proportion of those who receive housing assistance under the CSHA. People with disabilities, who make up about 17 per cent of the Australian population aged 15-64 years, are substantially over-represented in public housing, comprising 39 per cent of all those persons aged 15-64 in this form of tenure (AIHW 1999: 134). Other groups assisted under this Agreement include homeless people, survivors of domestic violence, indigenous communities, refugees, new migrants and other households under stress as well as disabled people with complex support needs. The Agreement recognises that the Commonwealth and the States:

must work together to improve housing outcomes for those in need through better linkages between programs under this Agreement and other Commonwealth and State programs, including those relating to income support, health and community services. In implementing this Agreement, both the Commonwealth and State will seek opportunities for coordination of programs within each level of Government and between Governments in order to improve outcomes for those assisted under this Agreement.

The CSHA comprises a multilateral agreement accompanied by a series of bilateral agreements. The multilateral agreement specifies the guiding principles, funding arrangements and operating procedures. It also specifies an outcome measurement framework based on bilateral information and a core set of nationally consistent indicators and data for benchmarking purposes.

The principles guiding the development of the Agreement are:

- to assist those whose needs for appropriate housing cannot be met by the private market;
- to provide housing assistance to those most in need and without discrimination;
- flexible housing assistance arrangements to reflect the diversity of situations within the jurisdictions;

*Source: AIHW (1999: 131)*

### ***CSHA Bilateral Agreements***

The Bilateral Agreements between the Commonwealth and each State/Territory are designed to facilitate flexibility in the delivery of housing assistance by each jurisdiction. All Bilateral Agreements recognise that the client base of public housing has increasingly complex support needs. SHAs have a reasonable concern that people with disabilities have appropriate supports to be maintain successful tenancies. This means that housing agencies must move away from providing ‘bricks and mortar’ solutions and work more closely with disability along with other service providers to improve housing outcomes.

A review of all Bilateral Agreements suggests that disability has not yet 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 have been given more prominence. New South Wales is the only State to explicitly recognise the importance of coordinating housing support with the CSDA. However, it should be noted that detailed housing documents do exist at State Level that contain considerable shared housing/disability objectives in Queensland and Western Australia for example.

### **3.6. Summary**

This chapter has provided an overview of the national policy context for disability and housing legislation. It has shown that:

- The *Commonwealth Disability Services Act 1986* marked a watershed in disability legislation in Australia. The transition from institutions to community-based services became a major purpose of the *CDSA* and the policies surrounding it.
- Current downward trends in deinstitutionalisation (in terms of decreasing numbers living in institutions) are due largely to potential new service users remaining in community based living arrangements, rather than radical shifts in the current ‘institutionalised’ population.
- 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 accommodation among disabled people living in the general community.
- The development of separate Commonwealth and State/Territory programs on disability and housing further complicates the policy scenario. The 1991 CSDA was designed to bed down new administrative relationships, roles and responsibilities and hence emphasised collaboration between different Commonwealth/State programs with particular reference to consultation with State Housing Authorities.

- The 1998 CSDA aimed to facilitate differences in service delivery by each State/Territory. This meant that consultation mechanisms were not included 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.
- Disabled people represent one of the most significant social housing client groups. Almost 40 per cent of all those receiving housing assistance under the CSHA report a disability.
- The CSHA and CSDA represent different styles of agreement. This may hinder the development of positive programs between disability and housing service providers concerning the housing futures of people expected to be deinstitutionalised.

## **Chapter 4: Literature review**

### **4.1. Introduction**

This chapter reviews academic literature in relation to deinstitutionalisation, housing and community care in Australia and other key policy contexts. It examines challenges to deinstitutionalisation and discusses housing responses. The chapter reports shifts in community expectations of the housing outcomes of deinstitutionalisation in recent years and highlights client focused approaches to housing and support frameworks.

### **4.2. Aims of deinstitutionalisation**

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). 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).

Historically, disabled people had been treated as though they were ill or a threat to society and should be locked away from it. These attitudes led to the development of geographically segregated residential facilities such as long stay mental hospitals, training centres and nursing homes (Evans 1996). However, since the 1960s, all Western governments 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 mimic ‘typical’ suburban homes. Such facilities have been commonly referred to in Australia as the ‘group home’.

However, there have been notable shifts in community expectations of housing outcomes from deinstitutionalisation in recent years (Ellis 1998). Disability activists have challenged stigmatising dualisms that construct host communities as ‘normal’ and thereby render the experiences of disabled people as ‘abnormal’. At the same time, ‘host’ communities are increasingly diversified. During the 1960s, the creation of ‘group homes’ mirrored a homogenised model of white, middle class values and aspirations around accommodation options: ‘ordinary houses in ordinary streets’.

This model of typical home life has been rendered increasingly anomalous by broad currents of social and cultural change in recent decades. Social pluralisation – measured

by changes in household structure, ethnic background and cultural diversification – has been associated with a greater plurality of housing experiences and accommodation choices amongst the general community. This poses a challenge to disability and housing policy to meet the housing needs of disabled people who will be deinstitutionalised in ways that reflect an emphasis on flexibility, individuality and choice.

#### **4.3. Deinstitutionalisation: background and context**

The impetus for institutional reform has come from a number of sources. Negative publicity concerning conditions within institutions characterised by material privation, brutalisation, depersonalised forms of ‘care’, separation from family and friends as well as dangerous and/or unhealthy living conditions highlighted the oppressive nature of institutionalisation (Gleeson 1999). The development of the principle of normalisation, firstly in Scandinavia (Nirje 1969) and the United States (Wolfensberger 1972) promoted the rights of intellectually disabled people to ‘live a normal life’ and later ‘socially valorised life’. This included the right to live in the ‘community’ rather than in segregated facilities placed on the outskirts of towns.

This means that advocates have promoted deinstitutionalisation in social justice terms as the restoration to service dependent people of their basic human right to a valued living environment (Oliver and Barnes 1993). For service users, deinstitutionalisation has promised the right to the ‘least restrictive living setting’, meaning a care environment that restricts the freedom of disabled people only to the minimum extent to ensure broader community well being. In this sense, deinstitutionalisation radically changes the accommodation and living arrangements of service dependent people by moving people from large segregated, stigmatised living environments into smaller, mainstream housing options.

#### **4.4. Resigning disability services: issues and challenges**

The Australian based literature on deinstitutionalisation has tended to focus on the therapeutic outcomes of the relocation of people with intellectual disabilities from large congregate facilities to community based settings. An array of studies exist to show that, where deinstitutionalisation processes have been properly planned, relocated persons experience improvements in their standards and quality of life. This literature uses a range of instruments that aim to measure and observe changes in adaptive behaviours, such as self-care, domestic, community and choice-making skills (Emerson and Hatton 1994).

In Australia these findings are based on a number of evaluation studies including the St Nicholas Hospital (Cummins and Dunt, 1988; Project Evaluation Committee, 1988), Caloola Training Centre (Picton *et al*, 1997a, 1997b), Challinor Centre (Young *et al* 2000), and the Richmond Program (Moloney and Taplin 1990). Young *et al* (1998)

provide a comprehensive review of Australian evaluation studies. A small but growing number of studies focus on the qualitative experiences of people with intellectual disabilities and their stories of moving into the wider community (Bramston and Cummins 1998; Johnson 1998).

Whatever the outcomes of this policy shift have been on those involved, deinstitutionalisation programs appear to have slowed in the last decade. For example, a recent case study of resettlement policies in Scotland found that deinstitutionalisation is largely in disarray, with particular difficulties in planning, financial arrangements and inter-agency collaboration (Stalker and Hunter 2000). This is reflected in the policy experience of several other Western countries, including Australia, suggesting that the slow down may be in part, the result of community care programmes being obstructed by community hostility, bureaucratic uncertainty, fiscal conservatism and in some cases, opposition from parents/advocates associations (Chenoweth 2000; Dear, 1992; Grob, 1995).

### ***NIMBYism***

Local resident opposition to neighbourhood facilities, often portrayed as the NIMBY syndrome, has been cast as obstructionist both by community care advocates and by social geographers who have studied the phenomenon. As several in-depth studies have shown (e.g. Dear & Taylor, 1982), such opposition has in many instances been motivated by prejudice and erroneous beliefs about the nature of care facilities and the people who use them. Commentators in a range of countries — including the USA (Dear & Wolch, 1987), Canada (Joseph & Hall, 1985; Taylor, 1988; Piat 2000), Australia (Gleeson, 1996) and New Zealand (Shannon & Hovell, 1993) — have argued that NIMBY reactions threaten the entire process of deinstitutionalisation by creating (often bitter) political and legal resistance to the establishment of care homes. Dear and Wolch (1987) have shown that North American service agencies have responded to the prevalence of NIMBYism by adopting ‘avoidance strategies’ as part of their siting criteria for community care homes. The outcome of avoidance strategies has been the concentration or ‘ghettoisation’ of care networks in ‘places of least resistance’, frequently low income and declining inner city neighbourhoods.

### ***Reforming institutional care***

In many places, relative/advocate associations have countered community care debates with an alternative construction of ‘reform’ that centred on the re-creation, not closure, of institutions through systematic improvements to infrastructure and services. For example, drawing their inspiration from European (especially Scandinavian) initiatives (e.g., see Christie, 1989), some relative/advocate groups propose that ‘sheltered villages’ or clusters of small residential units be established as alternatives to both large institutions and dispersed community care networks.



This form of opposition also articulates a view of the service user as vulnerable. Anxiety was centred amongst older parents who feared what would happen to their children once they themselves died. Evidence suggests that parent anxiety reflected the deepening sense of general insecurity in the broader community that has been documented by social scientific analysis since the 1980s. In Australia this larger source of insecurity is at least partly attributable to the restructuring of welfare services since the early 1980s and fears about long term funding of community services (McKay, 1993). For example, Maddison (1998) found that lack of funding for community care and respite services meant that many parents had felt forced to place their disabled children within institutional care settings. This fear of lack of social and financial support also prompted parents to express a strong interest in the idea of ‘village’ type developments. At the very least, parents felt that they should have the option to accommodate their children in cluster-style housing where support packages could be shared and children would be safe.

Maddison (1998) conducted focus groups with families of disabled children, both those who made use of institutional care and also those who lived with their disabled children on a full-time basis. She found that families wanted the same housing that is presently available to people with a disability, that is: single/two person dwellings, shared accommodation and group homes a maximum of four people staffed 24 hours/day. However, rather than being scattered throughout the community they wished to ‘create their own community’ around a ‘village green’ of a communal recreation area. The term ‘intentional community’ was used to describe this concept as families felt they were ‘intentionally’ creating a range of formal and informal networks by designing an environment where those networks could be maximised and encouraged.

However, development of ‘sheltered villages’ has often been fiercely opposed among professional service providers and key service user advocacy groups. They have tended to dismiss the views of relative/advocates as obstructionist and wedded to morally inferior models of care. Racino *et al* (1993) argue that while cluster-style developments can have advantages in terms of residents of being able to share support packages, they remain institutional facilities owned by organisations rather than residents and can inhibit community integration. By contrast, relative/advocacy groups regard ‘sheltered villages’ as communities – affective and therapeutic – and ‘ordinary society’ as acommunal; that is, unable to socialise and care for the ‘vulnerable’ service user.

### ***Neo-liberalism and fiscal conservatism***

The neo-liberal restructuring of the welfare state and its goal of ‘improved resource utilisation’ is the central feature of social policy debates across advanced capitalist societies. In a range of countries, including Britain (e.g. Eyles, 1988; Jary & Jary, 1991), New Zealand (e.g. Kearns *et al*, 1991 & 1992; Kelsey 1995) and the United States (e.g. Dear & Wolch, 1987), it has been argued that the prioritisation of cost savings over service quality and extent by public agencies has been a major reason why community

care networks have never materialised on a scale sufficient to support the needs of many socially-dependent persons. In Britain, Lewis and Glennerster (1996) have argued that the main purpose of new community care strategies in the 1990s was to rein in social security spending. The under-resourcing of deinstitutionalisation and replacement support networks means that community care is hardly likely to provide the sort of enabling environment which disabled people require in order to secure their needs for material well-being and social participation.

### ***Transinstitutionalisation***

Lack of funding for community care policies has led to the phenomenon of ‘transinstitutionalisation’ whereby disabled people are moved out from institutions without adequate supports and then enter other institutional settings such as shelters, prisons, nursing homes or psychiatric hospitals (Hudson 1991). Chenoweth (2000: 86) argues that this simply replaces ‘one form of institutional custody with another’. Armstrong (1997) argues that the rise of numbers of people with intellectual disability within the criminal justice system corresponds with the deinstitutionalisation of state facilities.

According to evidence presented to a state parliamentary committee inquiring into the increase in the prisoner population in New South Wales, one in five prisoners in the state is intellectually disabled (*Sydney Morning Herald*, 28.05.00: 5). It also corresponds with a lack of supported accommodation in the community *per se*. For example, reports suggest that a young man with autism had to spend six months in jail because the Department of Community Services in New South Wales could not find him a home. Aaron O’Doherty had been sentenced to three months jail for malicious wounding but was refused parole for an extra six months because no suitable accommodation was available for him outside the prison (*Sydney Morning Herald*, 25.01.00: 6). This suggests that gaols have become *de facto* congregate care facilities because community accommodation options are so scarce.

### ***Residualisation in social housing***

A recent study of British community care housing by the Joseph Rowntree Foundation painted a bleak picture of the accommodation choices open to disabled people. 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:Society 9). The evidence was that disabled people were frequently shifted from institutions into accommodation that was characterised as “grotty flats on high crime estates” (ibid) — hardly the enabling residential settings that disability activists and advocates have struggled for. Again, government financial stringency was identified as a major cause of the housing problems. As the Rowntree Foundation put it:

Community care policy makes many claims about enabling people to live more independently and direct the course of their own lives. These claims do not square with the findings from the ... Foundation's Housing and Community Care Programme. There is much poor quality accommodation, haphazard funding of support services, lack of access to housing to those who want to move from a family or institutional setting, and reliance on a limited range of specialist service provision (Joseph Rowntree Foundation 1997:1).

### ***Group home or no home***

Research carried out by Etherington and Stocker (1994) found that intellectually disabled people leaving long stay hospitals had little or no choice about where they lived. The research was carried out in two London boroughs and involved interviews with fourteen people still in hospital and twenty who had moved into various forms of accommodation, including small shared houses, hostels and accommodation with a 'host family'. They argue that while there are many positive aspects to the process of moving:

people who are still living in the hospital should know that they can have the choice of another house if they don't like this house. They might be scared that if they don't choose this house, they won't get out and they might have to come back and live in the hospital (Etherington and Stocker 1994: 1).

This is confirmed by other British research that points to the predominance of residential homes for intellectually disabled people and consequent lack of housing choices for individuals. Simons (1995) sets the scene with a critique of the small-scale residential care home or 'group home' which has become the blueprint model of housing provision. He argues that:

Most people with learning difficulties have not had the chance to choose the kind of house they live in, the people they live with, how they are supported or who they are supported by. If people do have a choice, then it is either between different residential care homes that happen to have a vacancy.... Or there is sometimes the additional option of trying supported lodgings or some form of adult placement.... The way a house runs is much more likely to be determined by the way that it is staffed, or by issues like safety regulation, than by the people who live in it' (Simons in Watson 1997: 21).

### ***Community based housing or housing segregated in the community?***

There is a growing body of evidence that examines the appropriateness of community based accommodation options. Chenoweth (2000: 85) points out that 'many deinstitutionalisation efforts have transposed the same structures, routines and cultures of institutions out into community settings where they stand in sharp contradiction to the goals of community living'. This means that large institutions have merely turned into

many smaller ones scattered throughout the community. Simons and Ward (1997) argue that for the last decade and a half, in the UK the debate about 'residential' services for disabled people has primarily been in terms of the shift from long-stay hospital to 'community settings' in general and 'ordinary housing' in particular. However, while the properties used may have been relatively 'ordinary', what happens inside them is often not; many small-staffed homes have retained institutional characteristics. 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 they occupy and the support they receive are often inextricably bound up together; it is impossible to change one without changing the other, making it difficult to adapt the services to the individuals involved.

Nevertheless, in the UK at least, new housing resources continue to be directed mainly toward shared housing or residential home and progress is measured in terms of the number of new places created within these forms of accommodation. Macfarlane and Laurie (1996) are highly critical of what they term the 'special needs economy' and give an example of one UK local authority's community care plan that listed numerous group homes and residential homes for a range of specific groups, including large-scale facilities accommodating between seven and twenty-two people. They refer to this as the 'thirty year strategy for incarcerating disabled people' (Macfarlane and Laurie 1996: 32).

### ***Separating housing and support***

The separation of housing and support is seen as a way of giving greater force to tenants rights and control by individual service user. Racino *et al* (1993) point out that in traditional residential approaches, housing and support services are packaged together, requiring a person to live in a certain type of accommodation to obtain a certain level of support. By separating housing and support services, people can obtain support services wherever they live. They argue that this allows, but does not ensure, choice by the disabled person in a variety of areas, including with whom and where they want to live. Opening up opportunities to allow the full range of tenancy and ownership arrangements to individuals moving from institutions, from short assured tenancies, full assured tenancies and partial and full ownership options is the main means of achieving these goals. However, Petch *et al* (2000) point out that in Scotland for example, despite strong recommendations from a number of national reports, including Scottish Homes, there was evidence of professionals disputing the intention of housing providers to grant full tenancies.

Collins (1996) examined the kinds of relationships between housing and support services and how these different relationships affect the rights of service users. She found that security of tenure and choice are often not recognised as applicable to people with learning difficulties. Even when housing and support are separated, service users do not always experience the split in functions as a real benefit to themselves. For example, she argues that:

the dependence of the housing associations on the competence of the care agency, coupled with the existence of a contract between those two which is not balanced by a contract between the user and the care agency, tends to ensure that the relationships between housing and support agencies takes precedence over the resident's licence to remain in their home (in Watson 1997: 24).

### ***Supported living rather than supported housing***

Reflecting an increasing frustration with the inherent limitations of residential care, the last five years have seen increasing interest in the idea of 'supported living'; enabling intellectually disabled people to live in 'homes of their own', providing flexible, individualised support to people wherever they might be (Simons and Ward 1997). This approach has been a feature of the US context for some time and is designed to move supports to where people live and adapt environments and supports to them rather than creating specially designed residences or forcing to adapt to their environment. Klein argues that 'it is not a model, the answer or some new magic. It is, however, a way of viewing people and assisting them in ways that enable them to receive supports they need to live in the home they want' (in Allard 1996: 102). Allard (1996: 103) states that from this definition follow a number of important principles or values:

- developing an individually based plan, not facility or program based plan;
- creating flexible supports and services;
- enabling people to control their own homes;
- separating housing from support services;
- using both informal and formal supports that blend together creative, naturalistic and less bureaucratic responses to individual needs;
- assisting connections to the community;
- enabling and supporting choices that individuals make.

Allard argues that there is a wide range of interpretations of supported living that all centre on 'having choices' as the first and foremost principle. 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 together and are compatible.

#### **4.5. Australia: housing experiences and futures**

Few Australian based studies have examined the housing futures of intellectually disabled people who have been, or will be, deinstitutionalised. The Federal Government in 1985 commissioned Le Breton to write a handbook that covered residential services and people with a disability (Le Breton 1985). This report describes the need for community based accommodation that allows flexibility and least restriction on the individual in order to enable that person to live in his/her desired living option. The accommodation options outlined in the report include: family home, group homes with a variety of support services, independent living in flats and other accommodation types. The handbook provides a comprehensive checklist of the challenges involved in moving people from institutions into community based accommodation and covers planning and management processes, staffing issues and how to choose suitable residences. However, while the handbook acts as an important source of information on residential services it does not project future rates of deinstitutionalisation or cover State/Territory plans for institutional reform.

#### ***The housing impacts of deinstitutionalisation***

Neilson Associates (1990) provide the most comprehensive example of research that explores the housing impacts of deinstitutionalisation in Australia. This report provides a picture of Commonwealth and State government policy concerning deinstitutionalisation at the end of the 1980s. Empirical data is reported from across Australia, with particular attention given to New South Wales, South Australia and Victoria. This study reported that the Australian experience of deinstitutionalisation of large congregate care facilities had mainly affected people with psychiatric disabilities. In general, mental health authorities did not develop effective replacement housing and community support systems. It was assumed that people would return to their 'family homes' or previous living arrangements, or would be placed in privately owned boarding houses licensed to provide personal care. More limited numbers of intellectually disabled people had been moved from institutions into the community. The study found that these people fared better than those with psychiatric conditions, and continued to receive support services, particularly via 'group homes' or hostel based accommodation. However, this research predates the introduction of more recent Commonwealth and State/Territory legislation relating to accommodation services. Nevertheless, it offers a baseline against which to assess current and projected rates of deinstitutionalisation and housing futures of intellectually disabled people.

#### ***The Valued Norm***

In 1994 the then Ageing and Disability Services Directorate of the Department of Community Services (CDS) released a discussion paper intended to inform public debate

on supported accommodation for disabled people in NSW. The paper was called *The Valued Norm* and focused on ‘how accommodation and support models are bought together to meet individual need’ (Campbell 1994: 11). The document provides practical examples of what contemporary approaches to supported accommodation might look like and how they could be financed. It introduces four core criteria to help consumers and service providers evaluate various approaches. These criteria are:

1. Does this approach (or setting) reflect the everyday expectations of people of a similar age or stage of life?
2. Does this approach (or setting) enable the consumer to feel comfortable about being themselves and behaving in a way consistent with their cultural background?
3. Is this approach (or setting) appropriate to both women and men? Can they become involved in the same range of activities?
4. Does this approach (or setting) ensure that people with disabilities lives beside people without disabilities?

Models of supported accommodation are represented in terms of a continuum. Congregate facilities and whole-of-life support sit at one end of the continuum with private residences with drop-in support at the other. The document provides a useful overview of supported accommodation options available in New South Wales in 1994 and outlines the ten types of dwellings viewed as adaptable and acceptable accommodation for disabled people (Figure 4.1). Both the positive and negative aspects of each type of accommodation are presented.

**Figure 4.1. Examples of housing viewed as appropriate for disabled people**

1. Terrace Houses/Town Houses (2-3 bedroom) Attached dwellings usually 2 storey attached by a vertical wall.
  - outside spaces often small and divided between front and back – may not be appropriate for people requiring access to open areas,
  - issues of integration and access require careful consideration as these residences are often constructed in rows in busy locations.
2. Villa Units (1-3 bedroom) Attached dwellings, one storey, attached by a vertical wall.
  - positive for mixture of ownership and rental,
  - external areas don’t always connect.
3. Multiplex (1-3 bedrooms) A group of more than two dwellings with ground access to all.
  - noise transfer issues need to be carefully considered,
  - outside space may be limited.
4. Dual Occupancy e.g. ‘granny flat’. A second dwelling on a piece of land.
  - offers privacy and crises support if necessary,
5. Freestanding Housing (2-6 bedroom). Once considered the ideal model – now seen as just one of many options.

**Figure 4.1. cont**

6. Duplex (1-3 bedrooms) Two units divided by a horizontal separation
  - often larger than villas and home units.
7. Duplex/Semi-Detached (2-3 bedrooms) Two units divided by a vertical wall.
  - often larger than villas with increased privacy and space around the house,
  - could be appropriate for person with challenging behaviours with support next door,
8. Home Units (1-3 bedrooms)
  - outside spaces may be limited,
  - physical access to upper storey a key issue: installation of an elevator may improve capital gain opportunities though may also be cost prohibitive.
9. Integrated (1-4 bedroom per dwelling) Five or more dwellings developed as a house/land package.
  - economies of scale: capital acquisition cost benefits,
  - overcomes problems of privacy through physical separation of housing,
  - opportunity to more efficiently provide support,
  - access to peer support and networks,
  - one-bedroom house possibly more appropriate for people with challenging behaviours to increase privacy for all residents,
  - integration of people with and without disabilities is essential with this model,
  - could have negative implications associated with an image of congregate care including the potential for institutional behaviour of staff.
10. Large Freestanding Residence (10-12 bedrooms).
  - less restrictive option for a specific group of people who have profound and multiple disabilities and are dependent on ongoing and intensive medical support and personal care,
  - only acceptable as a respite facility or as an alternative to residence in a nursing home or hospital for the above group,
  - maximum average number of residents with separate bedrooms: 10 – dormitory accommodation is not acceptable,
  - provides potential for overnight/weekend stays for families,
  - issues to lessen institutional image and practice need to be considered,
  - potential for staff to get to know people better.

*Source: Campbell (1994: 33-35)*



### ***Changing norms and diverse housing careers***

There have been notable shifts in community expectations of housing outcomes of deinstitutionalisation in recent years. Family/guardian groups in conjunction with some services users, have begun to question established community housing models, notably the 'group' home, on the basis that such options are 'formulaic' and unable to suit the diversity of client and family needs (Ellis 1998). A growing number of studies in Australia report examples of people 'moving beyond the group home' into accommodation of their own choice with support tailored to suit their individual needs (Cochrane 1999; van Dam and Cameron-McGill 1994). This was the scenario envisaged by the *National Housing Strategy* in 1991 who reported that Australian society was moving towards a highly disaggregated housing and support service system:

Whereas past housing options included living at home or living in an institution, tomorrow they will include a bewildering array of all sorts of options ranging from full or part equity in home ownership, to cooperatives, to shared housing, to improved access to private rental housing, to fully supported 24 hour accommodation, to respite and crisis accommodation, to improved boarding houses and to a range of local housing solutions which have been developed in local communities. Life for people with disabilities will take on the same complexity as that of the wider community (*National Housing Strategy* 1991: 8).

### ***Individualised funding***

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. Depending on the level of funds available, this can enable 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 general 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'.

#### 4.6. Summary

This chapter has reviewed academic literature in relation to deinstitutionalisation, housing and community care in Australia and other key policy contexts. It suggests that deinstitutionalisation policies make many claims about enabling people to live more independently, but these claims do not necessarily square with the reality of lack of access to housing for those who want to move from residential settings and reliance on a limited range of specialist provision. This chapter highlights that:

- The original aim of deinstitutionalisation was to provide disabled people with opportunities for as ‘normal a life’ as possible within ‘ordinary houses in ordinary communities’. In practice, this largely meant the opportunity to live in a ‘group home’.
- There have been notable shifts in expectations of housing outcomes from deinstitutionalisation in recent years. Disability activists have challenged stigmatising dualisms that construct ‘host’ communities as ‘normal’ and thereby render the experiences of disabled people as ‘abnormal’. In particular, the ability of ‘group homes’ to provide flexible, individualised care has been challenged.
- However, in the UK at least, new housing resources continue to be directed mainly toward shared housing or residential home and progress is measured in terms of the number of new places created within these forms of accommodation.
- The disaggregation of the housing and support service system may promote access to a wider range of housing outcomes and ensure that housing careers for people with disabilities will take on the same complexity as that of the general populace.

## **Chapter 5. Study Methodology**

### **5.1. Introduction**

This chapter describes the methodology of the study. It reviews the methods adopted by the current study in order to systematically review the current policy framework and document forward plans for deinstitutionalisation and expected housing futures.

### **5.2. Methods overview**

The current research aims to provide a centralised source of information on State/Territory deinstitutionalisation plans and, specifically, on the numbers of people moving from institutional accommodation. It aims to answer the following research questions:

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?

In order to map future deinstitutionalisation plans primary data will be collected from all State/Territories. This has involved direct contact with staff of relevant agencies and required inter-state fieldwork. A mix of data collection methods has been adopted, including face-to-face interviews, telephone interviews and analysis of unpublished documentary materials.

The collection and analysis of published and unpublished documentary materials, including literature on overseas policy contexts, will provide the basis for review of housing outcomes from deinstitutionalisation in Australia.

In addition, the research project has a strong focus on the policy implications of providing a centralised source of data on future rates of deinstitutionalisation. It poses the following 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?

Broad policy implications of the project will be addressed through both critical analyses by the study team and in-depth discussions with service agencies. Consideration will be given throughout the study to the relevance that analysis and findings have to the understanding of housing outcomes for other social client groups. We do not propose a major data gathering exercise for other client groups, but will assemble those relevant materials that emerge during this study that would assist in follow up investigations of other areas of special housing need. In the writing up of final reports, key convergences and divergences with other social policy domains will be noted, where apparent and where warranted.

### **5.3. Fieldwork**

Fieldwork was conducted over a three week period in mid-2000 with some follow up work. Disability Administrators were contacted in each State/Territory. Disability Administrators are normally government managerial level staff with responsibility for planning and managing the deinstitutionalisation process. They also oversee the collection of disability service provision data. The Disability Administrators were informed of the aims of the study, its source of funding and asked to participate in the research.

In five States/Territories, the Disability Administrator agreed to act as the key research informant. These include New South Wales, Victoria, South Australia, Western Australia and the Northern Territory. The Disability Administrators in Queensland and Tasmania, while happy to act as the key research informants, directed the research team to individuals directly involved in managing deinstitutionalisation in that State/Territory (names of key State/Territory contacts can be found in Appendix B). Tasmania has only one remaining large residential institution and the Coordinator of the Redevelopment Project agreed to act as the informant. In the Australian Capital Territory the Manager of Disability Policy acted as the key informant.

Key State/Territory contacts were asked to participate in a structured interview. Copies of the interview schedule and research proposal were posted to all key informants prior to meetings in order to maximise question response. The interview schedule covers three main areas: deinstitutionalisation, housing futures and policy implications. These focused on definitions, legislative and policy framework guiding deinstitutionalisation and the development of housing support mechanisms.

Interviews lasted, on average, between two and five hours.

In addition, key informants either suggested or introduced team colleagues and individuals from other agencies that they felt appropriate to the development of the research. This process of 'networking' or 'snowballing' expanded the initial fieldwork in order to provide a more in-depth analysis of the housing futures of people who will be deinstitutionalised. These contacts include program coordinators, policy officers, non-government workers as well as representatives of advocacy groups. Data were collected from both one-on-one interviews and via group interview formats.

In addition, the project team has been approached by representatives of the National Disability Advisory Council (NDAC) who advise Senator Jocelyn Newman, Minister for Family and Community Services on disability policy in Australia. The NDAC convene a Working Party on deinstitutionalisation and wished to contribute to the research. The project team has also independently contacted both national and state based advocacy groups in order to represent the views of disabled people and their relatives. These interviews have been conducted via the telephone.

Furthermore, representatives from seven State/Territory Housing Agencies were interviewed. These interviews were not documented in the original proposal because disability agencies are the primary source of information on disability accommodation support services and hold the responsibility for managing deinstitutionalisation processes. However, the review of Commonwealth and State/Territory policy on housing programs and its emphasis on prioritising those with complex needs revealed the importance of contacting State Housing Authorities.

In some cases, key informants from disability agencies had independently invited representatives from housing authorities to join a group discussion on meeting the housing needs of disabled clients. In other cases, they were able to direct the project team to relevant individuals in housing agencies. Finally, project team members contacted Housing Agencies directly. The study was not intended to engage Housing Agencies directly and had not allocated funded staff time to provide this perspective on meeting the future housing needs of people who will be deinstitutionalised. Consequently no formal interview schedule was designed for these meetings.

At this stage of the research, interviews have taken place with 50 individuals.

This qualitative interview exercise has been accompanied by a review of documentary evidence provided by States/Territories. This includes Strategic Plans, Business Plans, raw figures on numbers living in supported accommodation services, evaluation of deinstitutionalisation projects, as well as departmental material presented in the form of workshops. Department of Ageing and Disability, New South Wales aim to provide written responses to the interview schedule. Departments of Housing in Queensland and the Northern Territory will also provide written responses on current policies in relation to disability and public housing. Territory Health Services will provide figures on numbers currently funded in supported accommodation. The process of asking key State/Territory contacts to comment on interpretation of data is continuing.

#### **5.4. Summary**

This chapter has reviewed the methodology of the current research project. It confirms that the project methods are proceeding as stated in the original proposal and shows that:

- 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. Interview schedules were sent to key contacts prior to field visits to maximise data collection.
- Key contacts introduced fieldworkers to additional contacts whom they thought would benefit research project development. This included policy officers, non-government workers as well as representatives of Advocacy groups.
- In addition, initial fieldwork has been expanded to include representatives from State/Territory housing authorities. This reflects a recognition on behalf of the project team the shifts in housing policy and its emphasis on meeting needs of clients with complex has implications for the housing futures of people who will be deinstitutionalised.

## Chapter 6. Conclusion

Deinstitutionalisation represents one of the most profound social policy shifts in the history of Western welfare states. All Western governments have sought to replace large congregate care facilities with community care networks. Models of accommodation provision have tended to be premised on ideals of providing ‘ordinary houses in ordinary streets’ and centred on the development of ‘group homes’.

Research from other policy contexts, including Australia show that the restructuring of welfare services have posed barriers to deinstitutionalisation policies. At the same time, disability activists have challenged stigmatising dualisms that construct host communities as ‘normal’ and thereby render the experiences of disabled people as ‘abnormal’.

In particular, disability activists have challenged the model of the ‘group home’ as an inflexible and inappropriate model of housing for many disabled people. During the 1960s, the creation of ‘group homes’ may have mirrored a homogenised model of white, middle class values and aspirations around accommodation options. However, a diverse range of ‘housing careers’ are now potentially available to the general populace, reflecting demographic changes in household structure, ethnic background and different ‘lifestyles’.

As we move into the 21<sup>st</sup> century, disability and housing service providers will be expected to meet the housing needs of disabled people who will be deinstitutionalised in ways that reflect an emphasis on flexibility, individuality and choice.

This is no nationally coordinated institutional closure program in Australia. However, deinstitutionalisation processes are guided by the Principles and Objectives of the *Commonwealth Disability Services Act 1986*. These Principles aim to ensure that services facilitate ‘independence, employment opportunities and integration into the community’ for disabled people across Australia.

The introduction of the 1991 Commonwealth/State Disability Agreement has been credited with driving forward developments in disability services in each State/Territory. In particular, the 1991 CSDA required that each State/Territory introduced legislation that paralleled the *CDSA* including its emphasis on ‘community integration’. However, there is no centralised source of information on State/Territory deinstitutionalisation policy and future institutions/bed closure.

Nationally, there are approximately 4,883 people with intellectual disabilities currently residing in large residential centres in Australia. A further 630 people live in hostels that share similar characteristics to institutions.

While the Australian Institute of Health and Welfare collect data on accommodation services funded through the CSDA their data are retrospective and do not provide estimates of future housing needs.

This study will document forward plans for deinstitutionalisation in each State/Territory focusing on the 2000-2010 framework. It will review and describe recent housing outcomes from deinstitutionalisation, drawing on evidence documented in Australia and other relevant policy contexts, and point to future pathways for disability and housing provision.



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