



## **ACKNOWLEDGEMENTS**

This material was produced with funding from the Australian Government and the Australian States and Territories. AHURI Ltd gratefully acknowledges the financial and other support it has received from the Australian, State and Territory governments, without which this work would not have been possible.

## **DISCLAIMER**

AHURI Ltd is an independent, non-political body which has supported this project as part of its programme of research into housing and urban development, which it hopes will be of value to policy-makers, researchers, industry and communities. The opinions in this publication reflect the views of the authors and do not necessarily reflect those of AHURI Ltd, its Board or its funding organisations. No responsibility is accepted by AHURI Ltd or its Board or its funders for the accuracy or omission of any statement, opinion, advice or information in this publication.

# CONTENTS

EXECUTIVE SUMMARY .....	1
1 INTRODUCTION .....	5
1.1 Introduction.....	5
1.2 Aims of the Study .....	5
1.3 Structure of the paper.....	9
2 CONCEPTUAL AND POLICY APPROACHES TO HOUSING AND SUPPORT ...	10
2.1 Introduction.....	10
2.2 Definition of “complex needs”, and identification of the target groups.....	10
2.3 Housing, Support and Linkages – Terminology .....	12
2.4 Epistemological and Methodological Issues.....	13
2.5 Alternative Paradigms relating to disability and mental illness.....	16
2.5.1 Paradigms and paradigm-shift .....	17
2.5.2 Current disability paradigms.....	17
2.5.3 The Social Model.....	18
2.5.4 The Social Model – Intellectual Disability and Mental Illness .....	19
2.5.5 The Community Living Principles .....	20
2.5.6 “Care” in the community .....	21
2.5.7 Poverty and income.....	22
2.5.8 Self-Determination and Individualised Funding.....	23
2.6 Social policy and the political context.....	25
2.6.1 Introduction.....	25
2.6.2 Neo-liberalism .....	26
2.6.3 Social Capital .....	27
2.6.4 Social Exclusion and the “third way” .....	27
2.7 Adopting a position for analysis.....	29
3 LITERATURE REVIEW .....	31
3.1 Introduction.....	31
3.2 Describing the Issue.....	31
3.3 Australian Research on Housing and support linkages.....	32
3.3.1 Disability and Housing.....	32
3.3.2 Deinstitutionalisation and the development of accommodation “models” ..	34
3.3.3 Housing and support for people with mental illness .....	34
3.3.4 Whole of government approaches to housing and support.....	37
3.3.5 Anti-social Behaviour.....	38
3.3.6 Women with Disability .....	39
3.3.7 People with Disability from CALD backgrounds .....	39
3.4 Universal Housing .....	40
3.5 Home Ownership and purchasing .....	41
3.6 Discussion.....	42

4	OVERSEAS APPROACHES .....	43
4.1	Introduction.....	43
4.2	New Zealand .....	43
4.3	Canada.....	44
4.4	USA .....	46
4.5	United Kingdom (UK) .....	49
4.6	Discussion.....	52
5	POLICY AND PROGRAM REVIEW .....	55
5.1	Introduction.....	55
5.2	Australian Government Frameworks.....	55
5.3	States and Territories .....	56
5.4	Brief analysis of government approaches to housing and support in NSW	58
5.5	Program Resourcing .....	59
6	METHODOLOGY.....	64
6.1	Introduction.....	64
6.2	Brief summary – benchmarks and indicators. ....	64
6.3	Methodological and Methods Overview .....	64
	REFERENCES .....	70

# EXECUTIVE SUMMARY

People with complex needs experience barriers in accessing housing, and maintaining stable housing environments over time. Current thinking about providing a range of accommodation to people with disability, and to people with mental illness, tends to be focused mainly upon service provision, with the development of housing and accommodation “models” built around the provision of specialist service supports. This limits the way that people think of housing for people with disability and mental illness, and has in the past limited the range of housing options to those associated with “cared accommodation”, such as group homes and small residences. Current initiatives to assist people with complex needs into, and to maintain, “ordinary” housing, are limited in their ability to support the large numbers of people who may want or benefit from such support.

## **Aims of the Project**

The project aims to focus upon the options for people in Australia with complex needs to access “regular” or “ordinary” housing, as distinct from “cared accommodation”, and have the required supports provided to them within such settings. The research looks critically at the current tendency to look toward “best-practice models” as the principal means to address the needs that are still apparent in both the supply of housing and the provision of support services. Rather, it adopts the position of those who will need to access housing and support, and views this provision as only one of a number of broad human rights outcomes that people are seeking to achieve after decades of exclusion from the mainstream community. The role of government departments, as policy makers and the focal point for innovation for such best-practice “models”, is also not adequately scrutinised when evaluating the factors, which determine the success of such arrangements. Thus, the technical mechanisms by which governments enable new housing and support arrangements, such as how funding is delivered to resource the arrangements, need to be considered as part of a more thorough critique. This is with a view to establishing a range of criteria which, when implemented, are more likely to guarantee success for future initiatives.

## **Epistemological and Methodological Issues**

There is a preference amongst policy makers for evidence-based research, and there is a tension between adopting a research stance that balances an “enlightenment” approach of achieving understanding from a wide knowledge base, and utilising strict evaluation criteria to assess the suitability and success of models and approaches. A realist synthesis approach to evaluation attempts to meet the need for rigorous evaluation of the practicality and suitability of approaches, whilst at the same time acknowledging and seeking to understand the broad social and political context in which approaches are used, and thus advocates a far more detailed understanding of what happens and why it works. With greater variables the opportunity to simply adopt “models” that appear to work in different contexts is reduced, but wider understanding of the context may provide insight into how similar approaches can be adapted to fit different locations.

The current preference for the adoption of models emerges from the paradigms in which disability is viewed in Australia. Most disability issues are viewed as service-related, and thus largely the responsibility of the States and Territories. Issues related to housing and support are viewed primarily as service-based problems, that need to be addressed through departmental responses, which now include agreements and initiatives across the different government departments responsible. Alternative paradigms relating to people with complex needs influence approaches in other countries, and are implicit within legislation and service approaches in Australia. In relation to housing and support, these emerging disability paradigms require:

- greater choice by people with complex needs about housing options, with the initial focus being on a choice of options typically available to other members of the community;
- greater choice within and control over the supports provided by service agencies within housing options of their choice;
- greater capacity for supports to be delivered in such a way as to address the needs of clients as they change, and as their chosen housing option changes.

## **Review of Research**

Currently there are service-based initiatives operating in Australia which have been evaluated favourably, in terms of their quality of life outcomes for people with complex needs, and the sustainability of their housing arrangements. However, the capacity for services to adapt and modify as individual service users' needs change needs to be studied over a long period of time to ascertain the true "success" of the current models.

Research has established the need for the separation of housing and support, yet also the complexity that such a separation adds to. Thus, the importance of linkages across different government departmental responsibilities is well established in research, and a number of factors that can assist in the success of approaches, both within specific service interventions, and across departmental relationships, have been identified

Research has established the need for whole-of-government approaches to address the systemic barriers that face people with complex needs who require housing. Service-based approaches tend to assess individual deficiencies and promote placement within services that will address or overcome these deficiencies. Such approaches can largely ignore the systemic causes of homelessness and lack of opportunity, and thus an approach which acknowledges these barriers, and asserts the right of people with disability and people with mental illness to equal participation in Australian society needs to be adopted. The ability to apply whole-of-government approaches across multiple layers of government raises political as well as policy challenges, to ensure that people with complex needs, and their housing requirement, have their needs considered within the political agenda.

Research has tended to focus on the provision of support to people with complex needs living in public/social housing. Taken from a rights perspective, there needs to be much more scrutiny upon the issue of housing supply, through a variety of channels, including private rental and the home purchasing market. The principle of "universal design" calls for the design and construction of housing that is accessible and adaptable; that can enable a person with impairment to live there; can guarantee the visitability of homes to people with impairment; can assist the home dweller to access the built environment; and can also assist the home dweller to remain in their home as they age and their needs change. The issue is one of regulation and incentive for private developers to design and construct according to these principles, and there is considerable difference across different, comparable jurisdictions, with the UK now requiring new private dwellings to be designed with these features.

## **International Approaches**

A brief literature review of international approaches to housing and support was conducted, and details in four countries are noted. Both Canada and the USA operate within a federal system, where the Provinces/States are responsible for the delivery of housing and support to people with complex needs. There are some examples of innovative service approaches, based on principles of self-determination and utilising mechanisms of individualised funding, which have impacted positively upon making available housing options other than group

homes and cared accommodation to people with complex needs. These approaches, however, have not directly addressed the issue of availability and supply of housing. The USA has a number of initiatives to provide people with disability with the opportunity to purchase their own home, and these involve creative approaches between government/housing bodies and home financing companies.

New Zealand and the UK have centralised governments, and both are addressing the issue of housing and support for people with complex needs through comprehensive national strategies. In New Zealand there is an articulated commitment to the social model of disability, accepting that much of the disadvantage experienced by people with disability results from social barriers. Housing and support is understood within the predominant “third way” social policy context, and contrasted with previous, neo-liberal approaches, where individuals were supported through income benefits. In the UK a similar third way approach is responsible for the range of initiatives and social policy approaches which address housing and support for people with complex needs. The goal of averting “social exclusion” in that country informs the various policy and program strategies that have to be implemented across a range of human service portfolios at the local authority level. The Social Exclusion Unit is located in the Office of the Deputy Prime Minister, and oversees a range of outcomes related to social exclusion that local authorities need to achieve. This arrangement acknowledges the social barriers that people with disability have articulated over many years through their social model of disability, and aims for strategies that improve general supply and individual opportunity to access available options. Existing infrastructure, established during the many years of neo-conservative government in the UK, are assisting in the implementation of programs and initiatives to support people with complex needs in their housing. Housing Associations are consciously adopting social model principles to enable individuals with complex needs to access suitable housing, and to receive the support they require to remain there.

Both New Zealand and the UK benefit from having government departments, independent of those which are responsible for the provision of housing and support, in charge of determining broad policy and monitoring progress toward it.

### **Australian Approaches**

The relationship between States/Territories and the Commonwealth Government of Australia drives the approach taken to the provision of housing and support to people with complex needs. Broad agreements exist to determine levels of funding that the Commonwealth grants to the States and Territories, to assume their responsibility for the provision of housing, services to people with mental illness (largely through the health systems), and services to people with disability. The CSTDA governs the latter, whilst the CSTHA governs the former, and the National Mental Health Strategy is a broad framework document that informs the approach to mental illness.

### **Methodology**

This positioning paper has put forward a range of perspectives on the issue of housing and support for people with complex needs, from information gathered through literature, policy and document review.

Further detailed investigation will take place through telephone interviews with key informants relating to people with mental illness and people with disability in each of the States and Territories in Australia. The interview respondents will be drawn from the relevant government departments that have responsibility for health, housing and disability services, and from peak advisory bodies that have a broad brief to consider issues such as housing and support for the three target groups.

In addition, three States, Western Australia, Victoria and New South Wales, will be canvassed to identify initiatives and approaches that address the issue of housing and support for people with complex needs, with an emphasis on people with intellectual disability in WA, people with mental illness in Victoria, and people with physical disability in NSW. In each state regional differences will be explored. The principle method will be face-to-face interviews with key informants representing the various government departments, and representatives of services and organisations that are involved in initiatives. Representatives of peak advisory bodies from each State will also be interviewed, as will representatives from the Real Estate Institute of Australia, and others who are involved in schemes that can enable people with complex needs to purchase their own housing.

In the course of interviewing policy documents and other literature will be gathered and analysed, and the final analysis will feed into the broader critique of the general approach to the issue of housing and support for people with complex needs. Finally some recommendations will be made regarding the strategic direction that should be adopted in Australia, and how this may be accomplished, based on evidence of successful achievement in Australia and overseas.

# **1 INTRODUCTION**

## **1.1 Introduction**

This paper outlines research by the Australian Housing and Urban Research Institute centre at the University of New South Wales which examines the factors that can broadly be said to work toward the “seamless” delivery of housing and support options to people with complex needs. The research aims to contribute toward the development of housing and support options that can assist adults under the age of 65 with physical disability, intellectual disability, or with a mental illness, to live successful, independent lives within the community.

The research context is a complex policy arena which attempts to draw together separate, service-based management and support delivery systems working cooperatively to deliver successful housing and support “outcomes” to clients who fit the criteria of having complex needs. The research from this project will look at how housing and support options can manage this complexity, and take account of the variables at a variety of levels within these systems that can better guarantee successful outcomes for individuals. There is also a focus on the current practice of policy makers to rely upon “models” of housing and support, and evaluations of their performance relative to stated aims, to inform program initiatives and the broader application of options to a broader constituency.

The research will draw on three main sources. Firstly, a literature review will outline some important conceptual and theoretical contributions that have not been adequately incorporated into the current practice of creating “pilot” initiatives, and which until now have remained marginal to research efforts with such a practical focus as the delivery of housing and support. Secondly, a literature search and review will identify broad policy initiatives, as well as particular program initiatives, both internationally and across Australia, which address the issue of delivering housing and support to people with complex needs. Thirdly, telephone interviews will be conducted with key government and advisory/peak body representatives in each State and Territory, to establish what is being done to facilitate access to and maintenance of housing to people within the three target groups, and to what extent these appear to be working. Finally, detailed interviews with key government and service provider informants within three Australian states, Western Australia, Victoria and NSW, will seek to determine the extent to which “models” of housing and support can adequately address the current range of needs in Australia, or whether the issue should be addressed more broadly at the social policy level, and what, if any, new directions such policy could take. The research is not seeking to identify “models” of housing and support, but rather to extend the range of variables that are considered when a successful approach has been identified, so that the appropriateness of that approach to another context can be more accurately assessed. To this end some critique of the notion of housing and support “models” needs to be undertaken prior to a consideration of Australian and international approaches to this issue.

## **1.2 Aims of the Study**

There are two separate but related issues or problems which this project aims to address. Firstly, like most research that has as its focus housing and support options for people with complex needs, and in particular those with physical disabilities, intellectual disabilities, and people with mental illness, it accepts that there are inequities in the way that people within these groups have access to housing, when compared to members of the general community, and that problems also exist with the provision of the services that are required to assist people with complex needs to access or remain in available housing. Previous research has established that people with significant levels of disability still remain largely

accommodated within “cared accommodation”, such as group homes or nursing homes, or living within the family home, meaning that many people are cared for by relatives (Bridge, Kendig, Quine and Parsons 2002). These options remain distinct from “regular” or “ordinary” housing options, which refer to the opportunities that people have to enjoy a housing career which affords some level of independence from both service providers and birth families. Initiatives that address the needs of people living in “ordinary” housing are emerging, although these face challenges within the large and complex system of support services that needs to be coordinated to effectively support a person with complex needs in the community (Bridge et al 2002). Similarly, people with mental illness face challenges in achieving linkages between the supports they require and suitable housing, with Reynolds, Inglis and O’Brien (2002) identifying one Victorian model, the Housing and Support Program model, as an effective, coordinated approach, and “community housing” as the preferred mode of housing provision, given its specialised and local knowledge.

This study focuses upon the options for people in Australia with complex needs to access “regular” or “ordinary” housing, as distinct from “cared accommodation”, and have the required supports provided to them within such settings. The notion of “ordinary” housing is a key component of the move away from specialised and institutional accommodation toward community-based options, as well as facilitating other opportunities for community participation and inclusion. To this end it will be necessary to review the literature to understand what the current state of play is for people with complex needs, both in terms of their access to a range of housing options similar to that available to other community members, and to support services that are required. By the end of the research it is anticipated that some successful approaches will have been identified, the variables which make them successful isolated and described, and some consideration presented of how policy-making in Australia can be influenced and guided by the success experienced by people elsewhere.

Secondly, this research looks critically at the current tendency to look toward “best-practice models” as the principal means to address the needs that are still apparent in both the supply of housing and the provision of support services. The notion of “seamless” delivery currently accepts a system-led understanding of separate service-based management and support delivery systems working cooperatively together to deliver successful housing and support “outcomes” to clients who fit the criteria of having complex needs. Because of this focus, there is perhaps a more limited critique available than there might be of all the factors that can and do impact on the success or otherwise of tenancy and support arrangements. For example, there is much greater emphasis on the joint agreements amongst government departments, and the nature of the service provided to facilitate support and housing, than there is upon the social policy or legal framework in which the broad issues of “access” or “inclusion” of people with disabilities in our society are deliberated and governed. The timely availability of services and special purpose housing are recognised as factors that determine success, more so than concern about service quality, the factors that best guarantee it, and the capacity for support to be available to all who require it. It is important to take account of the viewpoint of particular client groups who are recipients of services, as well as of the objectively determined reviews commissioned by program controllers and policy-makers.

Often, the views of clients with complex needs, for whom the arrangements are made, are canvassed largely in the form of satisfaction surveys for “consumers” of services. The issue of achieving housing and support is framed largely within a service system context, whereas for service recipients, the delivery of successful housing outcomes is viewed as only one of a number of broad human rights outcomes that they are seeking to achieve after decades of exclusion from the mainstream community. The role of government departments, as policy makers and the focal point for innovation for such best-practice “models”, is also not adequately scrutinised when evaluating the factors, which determine the success of such arrangements.

Finally, the technical mechanisms by which governments enable new housing and support arrangements, such as how funding is delivered to resource the arrangements, need to be considered as part of a more thorough critique. This is with a view to establishing a range of criteria which, when implemented, are more likely to guarantee success for future initiatives.

By taking this vantage point the research seeks to critique the notion of developing “models” of accommodation and support, which can be replicated and applied to particularly labelled population groups in a variety of environments to overcome problems such as security of tenancy and support in essential living tasks. The research proposes a framework that prioritises a range of factors as being as or even more important, than the type and standard of accommodation and the availability of formal service provision. Some of the support factors include:

- The extent of client self-determination and control over support arrangements as a key factor in successful tenancy outcomes, and what mechanisms are available to promote and enhance this;
- Methods of funding supports through the provision of resources directly to individuals or their representatives for the ‘purchase’ of supports specific to their needs;
- Simplification of the roles of services and government departments to enable people with complex needs to make choices and exert more control within complex arrangements;
- The broader policy implications of making service systems more responsive to individual need, and how amenable current welfare policies are to the notion of control of resources and outcomes by recipients;
- Current policy arrangements that enable the continuation of support funding when housing is privately owned by clients (or some other partial ownership arrangement is in place).

In terms of the housing issues, the following will be investigated:

- The availability of suitable housing, both in the private market, for sale or rent, and in the social/public housing market, to cater for the needs of people with complex needs;
- The extent to which current government policy and regulation (eg Australian Building Code) as well as local and State planning policies facilitate greater choice of housing and greater availability to people with complex needs in the future, and the efforts, if any, that are currently being made to increase choice of private housing for people with disabilities, most immediately those with physical and mobility impairments;
- Current policy arrangements between government departments that sustain housing and support arrangements, with a view to prolonging housing stability for people with complex needs

The specific research questions the project will address are:

1. What alternative paradigms, beyond the application of good housing models simultaneous with good quality support services, can be applied to the determination of whether support and housing arrangements for people with complex needs can be viewed as successful and “seamless”?
2. What benchmarks, or other markers of standards or quality need to be reached in order to determine the success of both housing arrangements and support arrangements, and the combination of both, which take account of objectively agreed outcomes and subjective wellbeing?

3. What broad housing options, both social/public housing and private housing, rental and purchase, are in place where linkages between housing and support for people with complex needs are successful, and what mechanisms ensure the continued provision of accessible housing stock and the ability to fund support to people living in fully or partially owned private housing?
4. What factors contribute to the successful coordination and delivery of housing and support to people in these target groups, in terms of particular support service and housing initiatives, and collaboration and cooperation by governments, between government departments, and services across and within sectors?
5. To what extent are the factors that determine success for people with complex needs, present in initiatives of support and housing to people in the three target groups across Australia, through consideration of particular initiatives delivered in each of the States and Territories?
6. By investigating initiatives in three states (NSW, WA and Victoria), how do the means of entry into support services and housing, and the methods of maintenance and support once there, impact on clients within such initiatives? To what extent do such initiatives differ in regional and rural areas, and how might future directions need to take account of regional differences?
7. What modifications to service and housing initiatives, and to collaborative and cooperative arrangements across governments, across government departments and across and within service sectors, need to be made to achieve a seamless on-the-ground delivery of support and housing to people with complex needs?

Details of the research methodology used to resolve these questions are presented in Chapter 6.

### *Indigenous Australians*

The importance of housing to indigenous Australians who have disability, and those who have mental illness, is noted and accepted. It is felt that the complexity and depth of the issue, as it relates to indigenous people, is beyond the scope of the current research for two main reasons. Firstly, the concept of “disability”, as it is defined, understood and lived within indigenous culture, is currently under-researched, and hence it is difficult to define a clear target group with any degree of clarity. Further to this point, disability tends to be experienced differently within different cultures, adding to the “complexity” of living with disability, requiring that in the case of indigenous Australians significant study would be required to address the current research topic within this project. Such additional study is not possible within the resources available to the project. Secondly, this research project is concerned with the policy and program intersection between housing and disability/health, and aims to collect information about the variances across States and Territories. The existence of specific indigenous housing and support services again extends the scope of the research beyond the resources available, and adds a degree of complexity to a project that already aims to report on a wide range of State, Territory and Commonwealth interventions.

The research’s fieldwork, however, will look at the linkages that are occurring within regional areas, and it is anticipated that indigenous people in some regions will be in receipt of the housing and support arrangements that are generally in place. Wherever possible issues that relate to indigenous Australians will be related in the project findings, and the complex policy challenges that the indigenous housing and support sectors face will be addressed within the discussions presented in the Final Report.

### **1.3 Structure of the paper**

This Positioning Paper provides an overview of the issues relating to the provision of housing and support for people with complex needs, the broad policy initiatives that have been established to address them overseas and in Australia, and particular program initiatives which have been set up to achieve the “seamless” delivery of both housing and support. The paper will be careful to bring to light information from previous research that has addressed these linkage issues, and to extend the understanding of the current programmatic approach to the provision of housing and support by considering broader “macro” issues of social policy, and “micro” issues of service support quality.

The remainder of the positioning paper includes the following chapters:

Chapter 2 addresses some epistemological and methodological issues before considering a range of paradigms that have emerged over the past forty years, and which now influence thinking about disability issues in particular.

Chapter 3 outlines the findings of an initial literature review, which identifies the issue from an Australian perspective, describes the research findings to date relevant to the target group, and canvasses some broad policy and program initiatives overseas which are endeavouring to address the issues of housing and support.

Chapter 4 provides a brief overview of approaches to the provision of integrated housing and support to people with complex needs, drawn from a number of comparable overseas jurisdictions. The aim here is to identify those approaches that have been deemed successful in bridging these service delivery issues, and also to understand the context in which this success has been achieved. Clearly, without the latter, any potential implications of these approaches to the Australian context would be relatively meaningless.

Chapter 5 describes the various administrative arrangements across Australia which govern programs and services, and the provision of housing, for people with physical/sensory disabilities, people with intellectual disabilities, and people with mental illness. Some description is provided of the frameworks that operate at the Commonwealth level, and then the broad legislative and strategic frameworks of each State and Territory are listed in tabular form.

Chapter 6 outlines the methodology that the research project will adopt when it comes to undertaking the further literature review and interviewing with key government and service provider informants.

## 2 CONCEPTUAL AND POLICY APPROACHES TO HOUSING AND SUPPORT

### 2.1 Introduction

This chapter begins by attempting to define, as far as possible, the scope and limitations of the concept of “complex needs”, as it applies to adults with physical or intellectual disability, or to those with mental illness under the age of 65. The age 65 has been chosen as it represents a significant category of people who can broadly be described as having a “disability”, and for whom the service systems tend to be State-based, as opposed to being supported by the Commonwealth-based aged care system. This is also to distinguish between those people who are regarded as having some sort of disability earlier in life, rather than as a result of the ageing process. The chapter will describe the target (“client”) groups, and the understanding this concept adopts of the provision of “housing” and “support”, and their “linkage”. It then considers the issue of “alternative paradigms” for looking at these linkages between housing and support for the target groups, which will establish a perspective for viewing the literature from Australia and overseas which defines and addresses the key issues.

### 2.2 Definition of “complex needs”, and identification of the target groups

There is no firm agreement about the definition of the term “complex needs”. In policy terms the notion of “complex needs” has been addressed in two separate, but related contexts. The first is exemplified in the Victorian *Human Services (Complex Needs) Act 2003*. The definition adopted in this Act was developed to identify individuals who represent a danger or challenge to themselves, to services involved in their support, and to the general public. Specifically, to be identified as eligible under the Act a person must meet a particular definition:

This definition requires two or more diagnostic labels and a history of violence or dangerousness to self or others. In addition, and importantly, there is an essential requirement of beneficence in that an individual is not considered ‘eligible’ unless they would derive benefit from receiving co-ordinated services in accordance with a care plan (Gardner 2004, 3).

The diagnostic labels that render a person eligible, should they satisfy two criteria, are:

- having a mental disorder;
- having an acquired brain injury;
- having an intellectual impairment;
- being an alcoholic or drug dependent person (Gardner 2004).

The range suggested within this definition is clearly too narrow for the current research, and focuses the complexity of the need largely on individual characteristics. A broader application of the term “clients with complex needs”, which is directly relevant to issues of housing and support, is found at Shelter Northern Ireland (2005), an organisation that assists people to access and maintain housing. The status of “complex needs applicant” enables clients who meet certain eligibility criteria to obtain specialist supported housing or general housing with a care package (Shelter Northern Ireland 2005). Eligibility is determined on a points system, with the full complement of 20 points available to people who meet the following criteria:

- you need lots of support on a day to day basis to allow you to live in your home
- you currently have two or more sections of social services helping you. For example, an Occupational Therapist and the Disability team.
- you scored very highly on the support or care needs matrix
- you scored very highly on the functionality matrix (Shelter Northern Ireland 2005, 1)

This definition broadens considerably the understanding of “complex needs”, places it in the context of providing housing and support, and also is relevant to a range of options that the research aims to scrutinise, in particular those arrangements where general housing is accessed, and support, or “care”, packages are attached to assist the person in that accommodation.

The Standing Committee on Social Issues (NSW Parliament 2002) has reported on the needs of people with disability, and acknowledges that some people with physical disability have “complex care needs that require specialised supports in an appropriate environment” (p.27). The requirement to have supports indicates a level of complexity, and thus those people who are considered within this research project are those people with physical disability, intellectual disability, or mental illness who require support in order to maintain their daily lives.

Another aspect of complexity, which this research project assumes, is the difficult, and sometimes oppressive, social milieu in which people with disabilities exist. The “social model” (described below) insists that much of the disadvantage experienced by people with disabilities is as a result of the unfavourable social conditions that generally pertain, due to the prolonged exclusion of people with disabilities, which has led to a range of infrastructure and social policy being developed without their needs incorporated. Thus, the “ordinariness” of everyday life can be rendered complex by, for example, the requirement for a person with a physical disability to order a taxi instead of having the opportunity to catch public transport or easily access a private motor vehicle to get to a place of work or an appointment.

Rankin and Regan (2005) have utilised an individual and social framework to describe the complex, “interlocking” needs that impact on people’s housing and support arrangements, and to determine how the complexity of various disabilities, mental illness and substance abuse has led to many people falling “between the gaps between services” (p.1). The interrelationship between substance abuse, mental illness and social context further adds to the complexity, if solutions to a range of issues are to be found (see, for example, Robinson 2003 and Bessant, Coupland, Dalton, Maher, Rowe and Watts 2003).

The above discussion focuses primarily on the “complexity” of need attributable to particular individuals who are in need of housing and support. At this point in research it is customary to identify more exactly the characteristics of the population groups under scrutiny. However, as discussion below indicates, due to the increasing claims of people with disabilities to identify themselves as a movement, definition and classification of people with disability has become problematic and controversial ever since the introduction by the World Health Organisation (WHO) of the threefold classification of “impairment”, “disability” and “handicap” (Pfeiffer 1998; Hurst 2000). The subsequent revision of this classification raised similar concerns, despite the WHO insisting that the revision would incorporate elements of the “social model” within its framework (Pfeiffer 2000). However, it is unclear how the revised classification, the International Classification of Functioning (ICF), is currently applied within the Australian context, either in terms of how statistical data is collected, or how individuals

are assessed for programs and services. Thus, while the definition of the target groups will remain broad, the term “people with complex needs” is understood by this research to represent:

- people with physical or sensory disability, whose needs in relation to housing combine a requirement to have accommodation and the built environment physically accessible, a need for some assistive technology and mobility aids, and a range of personal support to assist them in personal and domestic tasks;
- people with cognitive impairment, either as a result of an intellectual disability or an acquired or organic brain injury, whose needs for physically accessible or adaptable housing may be less apparent in the short- to medium-term, but whose support needs may extend beyond assistance with personal and domestic support to complex case management and advocacy;
- people with a mental illness, whose needs in terms of housing are similar to those of people with intellectual disability and those with brain injury.

All of the above groups will face the challenge of experiencing stigma and social rejection, with people with mental illness particularly vulnerable to this.

### **2.3 Housing, Support and Linkages – Terminology**

Another issue of definition requires clarification. The notions of “housing” and “support” are frequently entwined within a single term, such as “independent living” in both the UK (Stewart 2004) and the USA (Shapiro 1993). In NSW significant reports that have looked at the issues confronting people with disabilities who require support to assist them in their housing refer differentially to “supported accommodation” and “accommodation support”:

*Supported accommodation* is used to refer to permanent out-of-home accommodation for people with disability, for example, group homes or semi-independent living in a house or unit. *Accommodation supports* refer to a far broader range of in-home and out-of-home supports that enable people with disability to maintain their current living environment such as Home and Community Care (HACC) services and respite services (NSW Parliament, Legislative Council, Standing Committee on Social Issues 2002, 3).

The category of housing and support that the current research is aimed at falls within both definitions, if “supported accommodation” includes support that is targeted at individuals within regular housing options, and if “accommodation support” can be broad enough to encompass housing situations outside of the original family home, and also the ability for clients to transition between different housing options. The terms “ordinary” or “regular” housing will be used throughout to indicate that the focus of the research is upon the ability of people with complex needs to access the full range of housing options that are generally available to members of the community. This includes tenancies in public housing and in the private rental market, and also home ownership.

The term “services” will refer, in the main to formal, funded agencies whose job it is to provide support to people with complex needs. Generally, these agencies will be specialist service providers who deliver social support and training to people, to assist them to live in their homes and also to gain access to a range of other opportunities available in the community. At times to emphasise the difference between these agencies and, say, services provided as part of a community housing company or housing association, they will be referred to as “specialist services”. Some differentiation may be required when talking about the arrangements in place for people with a mental illness, in which case these specialist services will be differentiated from “medical” or “clinical” services.

The issue of “linkages” is key to the research project. As will be seen in this section, the literature has long established that the provision of support to coincide with the provision of housing has been crucial in the success of tenancies and other measures of housing stability amongst the target population. The term “linkages”, then, refers to this planned delivery of both the social support and the housing support, and the arrangements that are in place to make this happen simultaneously.

Finally, the term “support” will be used throughout to indicate a professional transaction occurring between a professional service provider and a client with a complex need. Support relates to the individual as a discrete transaction, such as assisting with cleaning, or providing personal care, whereas “service provision” relates to the arrangements made (usually by management) which enable these “supports” to then take place. The terms “support” and “service” will not be used interchangeably within the report.

## **2.4 Epistemological and Methodological Issues**

As this paper regards as problematic the way that policy regarding housing and support for people with complex needs is currently addressed, it is necessary to consider literature that sees “traditional” methods as limited, and attempts to adopt an alternative. This section details one such alternative approach, and addresses very recent work on making housing research relevant to policy makers, as well as briefly considering the debate about ensuring that people with disabilities, as a marginalised group, have a powerful say in the research agenda that addresses their needs, and the way that research is carried out.

Pawson, Greenhalgh, Harvey and Walshe (2004) have articulated a “realist synthesis” approach to undertaking reviews of programs. Realist synthesis is proposed as a logical, rational and methodologically rigorous alternative to systematic review, which Pawson et al (2004) identify as following standard steps outlined by Campbell and Russo (1999) and Cochrane (2004). The authors advocate it as a method that requires policy makers to re-engage with the research process, and contribute to the intuitive nature of some of the techniques, rather than rely on an apparently objective evaluation tool to determine the outcome of programs previously engaged, and the direction of future programs:

In order to have a maximal impact realist review requires a well developed ‘institutional memory’ on the part of policy makers, commissioners and users of research syntheses. ... As the unit of learning drops down to the component processes of interventions and the theories that underpin them, users need to become more agile in picking up, utilising and re-utilising research results (Pawson et al 2004, 39).

The starting point for this approach is an attempt to understand “what works” in social interventions. Pawson et al (2004) argue that this “generative” model of inquiry is richer and more thorough in its approach than standard systematic reviews, as it seeks not to find out which interventions work best, but rather,

‘What works for whom in what circumstances, in what respects and how?’ ... What the policy maker should expect is knowledge of some of the many choices to be made in delivering a particular service and some insight into why they have succeeded and/or failed in previous incarnations. Captured as a pithy policy maker’s demand, the task might be expressed so: ‘Show me the options and explain the main considerations I should take into account in choosing between them’ (Pawson et al 2004, 3-4).

Pawson et al (2004) articulate a range of principles that underpin their realist synthesis approach. Firstly there is an acceptance of the theoretical underpinnings of social program/interventions, and the need for review to articulate these, especially where they are not made explicit. Secondly, in programs that involve services to individuals and groups the actions and reactions of these people are likely to impact on the outcome of the program, and, rather than view such involvement as “contaminants” to the evaluation findings, a realist approach would seek to understand the reasoning behind the actions and reactions of those people directly affected by the program. Thirdly, there is an acceptance of the complexity of most interventions, which involve multiple actors and many steps to reach completion, any or all of which are fallible at any stage. Thus, part of the review process should be “to inspect the integrity of the implementation chain” (Pawson et al 2004, 6). The fourth principle involves complications that arise at each of the many stages of an intervention, in particular caused by negotiations with others stakeholders, especially service users, who are invited to feedback into the process, and thus affect and direct its implementation. Reviews should accept these as legitimate interventions that have to be allowed for and which deserves examination. The fifth principle requires us to expect that similar interventions will result in both failure and success, when implemented in different setting and contexts. Four contextual factors, which can impact on the way the intervention is delivered, are highlighted:

- *individual* capacities of key stakeholders, especially of those charged with implementing the intervention;
- *interpersonal* relationships that support the intervention, including management, administrative and industrial relations matters;
- *institutional* settings, including the broad ethos of the organisation in which the intervention is operated, attitude of executive management and board etc.;
- *infra-structural* context, locally and wider, including the condition of the welfare system, funding guarantees, local opposition or support from interest groups etc. (Pawson et al 2004, 6-8).

The sixth principle indicates that interventions are likely to change and adapt, not only to local settings, but as a result of real or perceived difficulties noticed in previous applications, and the reviewer needs to account for the way that programs are “dynamically shaped” through this process. The seventh and final principle accepts that interventions will adapt internally when circumstances change or when they are perceived not to have worked, and are affected by the involvement of new staff with different ideas and skills. The reviewer’s responsibility is to capture these intended and unintended consequences within the review, describe rather than judge. In summary, these principles aim to counter the traditional evaluation dynamic of seeking to judge whether an intervention has been “successful”, and instead lead to studies which detail the complex workings of the program in question, with an expected result being the ‘fine tuning’ of the intervention rather than a definitive statement about its value for money (Pawson et al 2004, 12).

Whilst the realist synthesis approach is focused on the technique of program evaluation, it is clearly relevant to the making of broader policy, especially in an environment where “best practice models” are piloted, and then evaluated, as a means of determining their effectiveness and the potential for their replication more broadly to address a systemic issue such as the provision of housing and support to people with complex needs.

The question of how research can directly inform policy is addressed by Jones and Seelig (2005). Their paper begins with the observation that there is a current perception of a preference for evidence-based research to inform policy, and set out to test this out amongst AHURI (i.e. those predominantly concerned with housing) researchers and housing policy makers. They identify three models of research, namely “engineering”, “enlightenment” and “engagement”. The first is characterised by researchers providing empirical evidence, largely on a contractual basis, to policy makers or departmental officials who act clearly as the client.

The second is characterised by a more sceptical approach by researchers working independently, who see the research as drawing from broader conceptual traditions in an attempt to hierarchically influence the development of policy. The third, and clearly the chosen mediating approach, is characterised by much greater interaction between researchers and policy-makers, with both needing to engage with the political nature of policy and research, as much as the with the benefits of empirically driven evaluation (Jones and Seelig 2005).

Barnes (2004) has provided a summary of the intense debate and discussion that took place for several years about the inequitable approach taken historically to researching disability, and the attempt to ensure that people with disabilities were valued and equal partners in any research that took place about issues that concerned them. Barnes characterises “traditional” research as problematic, because of its broad acceptance that “impairment” is the prime causal link for “disability”, whereas a more “holistic” approach to disability issues in general would require there to be a prime consideration of the social, rather than individual, barriers that cause disability and disadvantage (Barnes 2004, 48-49). A radical alternative to traditional methodologies is the “emancipatory research paradigm”, which proposes control by people with disabilities of both the research agenda and the methods by which research is conducted, in particular the validation of personal experience as an important source of evidence for research findings. The notion of “empowerment” is crucial to the relations necessary for emancipatory research. The current research acknowledges the intent of this paradigm, in particular the validation of the experience of people with complex needs for whom the issues of housing and service delivery are pertinent, and attempts as far as possible to conform to the ideals of this paradigm within very limited parameters.

The current preference for evidence-based research and evaluation by policy makers may be in large part determined by the particular macro-policy environment in which matters of housing and support in general are considered in Australia. However, the effects of such research, if it is to inform future policy, will perpetuate a narrow, model-focused approach to a problem which is ultimately concerned with the enjoyment of basic human rights. The proposed model of engagement research by Jones and Seelig (2005) informs the dynamic fieldwork interviews that will be conducted with policy makers, administrators and service providers, to establish not only “what works” in the various initiatives that have been established to meet the housing and support requirements of people with complex needs, but also the political and other forces and tensions which impact on the workability of such programs. The realist synthesis approach of Pawson et al (2004) extends the scope of variables which can need to be considered before an approach can be reduced to a “model”, as well as the validity of adapting and changing models and approaches to suit environments and local challenges, both at the outset of a program and throughout its delivery. This will be important when attempting to establish an explanatory framework by which to explain the diversity of approaches to the issue of housing and support in the various State and Territory jurisdictions across Australia. Principles of empowerment within the emancipatory research paradigm are acknowledged, to ensure that the interests of people with complex needs are addressed at all levels of analysis.

Table 1 summarises the realist synthesis approach, and indicates its relevance to the current research project:

**Table 1: Application of Pawson et al. (2004) realist synthesis to this research analysis**

<b>Principles</b>	<b>Application to Research Findings</b>
1. Acceptance of theoretical underpinnings of social programs/interventions.	Identification of theoretical/values-based underpinnings of programs and initiatives, and within government departmental approaches.
2. Programs/initiatives designed to address human needs are likely to have their outcomes impacted by the actions of those the initiative serves.	Identification of the benchmarks of program “success”, and their capacity to incorporate subjective and other client impacts.
3. The complexity of implementation and interaction in any initiative renders each stage fallible, and the integrity of each stage should be recognised.	Determination of a range of attributes in each initiative which can be analysed to determine its impact on the clients served.
4. Negotiation with stakeholders at each stage can impact on, and direct, the initiative’s implementation.	Identification of the ability of programs to incorporate client direction in interventions, and how this impacts on any “models”.
5. Four contextual factors need to be taken account of: <i>individual, interpersonal, institutional and infra-structural</i> .	Description of the various contexts in which initiatives are delivered, to establish continuity and contrast of similar approaches in different locations.
6. Interventions/initiatives will change and adapt, not only to local settings, but also when difficulties are identified.	Looking at the capacity of initiatives to adapt, once problems are identified, especially where multiple departments are involved.
7. Interventions/initiatives will adapt internally when they are perceived not to be effective, and also by the input of new staff and new ideas.	Seeing the extent to which approaches respond to the factors that require them to adapt and change, and how well initiatives plan for change and innovation, and maintain the capacity to adopt new ideas.

In particular Principles 1 and 5 inform the questioning of the relationship between particular initiatives, programs and approaches that are currently in place to meet the housing and support needs of people within the three target groups (and what is not in place), and the social or specific policies toward these issues and toward the three population groups as a whole. The relationship between particular initiatives and approaches, and the local context, in which they are delivered, will be critical to our understanding of how applicable these approaches might be in other locations. In essence, are local differences so great as to significantly limit the usefulness of “models”?

## **2.5 Alternative Paradigms relating to disability and mental illness**

The first research question proposes that alternative paradigms exist within which to consider the issue of housing and support for people with complex needs. In turn this presupposes that the issue is currently viewed from a certain perspective or utilising a certain genre of research. This section will briefly critique the current way in which issues relating to people with disability tend to be dealt with, and also introduce alternative paradigms which look broadly at disability issues, and specifically at the issue relating to housing and support.

### 2.5.1 *Paradigms and paradigm-shift*

Paradigms, as conceptualised firstly by Thomas Kuhn, are academic “road-maps”, which guide the central questions and methods of research and general conduct within any particular academic discipline. Kuhn introduced the idea of a paradigm in his book *The Structure of Scientific Revolutions*, which challenged the assumption that scientific knowledge is increased in a cumulative manner (Ritzer 1992, 521). “Paradigm shift” occurs as a result of a range of factors within an area of discourse or a scientific or academic discipline, utilising the accepted conventions of that discipline and eventually establishing new rules and protocols against which others will eventually turn and new paradigms be formed.

The concept of shifting paradigms has been used to explain the changing approaches toward people with disability and those with mental illness. Michael Oliver (1996, 31) has indicated that the change in viewing disability from an individual, medical perspective to one which recognises its social origins constitutes a “paradigm shift”. Bogdan and Taylor advocate using an interpretist paradigm instead of the traditional, “objectivist” paradigm in research conducted about people with intellectual disability, claiming the latter to be too positivistic to allow for the perspective of the service users to be heard (Bogdan and Taylor 1994, 3-5). Cocks (1994) has written an extensive monograph advocating a shift in paradigms, away from domination by the human service industry, and toward the provision of more “natural” supports in the community. And previous AHURI research has asserted the importance of acknowledging paradigms when undertaking research that aims toward influencing policy (Jacobs and Arthurson 2003)

### 2.5.2 *Current disability paradigms*

A significant paradigm which governs the way that disability is conceptualised and discussed in Australia is that of disability as a “welfare issue”. Current debate about “welfare” in Australia centres around the policy of “mutual obligation” adopted by the neo-liberal Howard Government which was elected federally in 1996. People with disability, along with others who receive income benefits as their principal source of income, are more frequently being targeted for benefits reductions or cuts, in an attempt to break the “cycle of dependency” that is one of the justification for these new policies. Goggin and Newell (2005) have indicated how this new welfare paradigm is influencing people with disability themselves, who increasingly express their “faith in the market, entrepreneurship and self-reliance” (p. 66), whereas they believe there needs to be welfare policies that “draws on the life experience of Australians with disabilities” (p. 67).

For people with disability the provision of welfare has long been a double-edged sword, as the needs and aspirations of people with disability have tended to be expressed in terms of state welfare provision, which reflects the extent to which their lives are administered and managed by others (Ryan and Thomas 1980). Barnes, Mercer and Shakespeare (1999) have suggested that people with disability, along with women, black and minority groups, have been disempowered by the process and practice of welfare policies, such that,

... institutional and professional power in the design and implementation of social policies replicated existing social inequalities – rooted in patriarchy, racism and a disabling society (p. 129).

In particular the process of assessing need and establishing eligibility for benefits and services adopted a medical approach, inadequate to address the serious social exclusion that many people with disability experience both because of previous social policy such as institutionalisation, and failure to adapt social policy to fit the needs and expectations of people with disability amongst those of mainstream society (Barnes, Mercer and Shakespeare 1999). Drake (1999) has characterised the Australian approach to disability as

a cross between that of welfare and one which addresses civil rights, given the passing of rights-based disability legislation and disability discrimination legislation in the 1980s and 1990s respectively. However, he asserts that the disability services programs “are clearly informed by a primarily medical understanding of disability” (Drake 1999, 104). Goggin and Newell (2004) argue that the medical model is used to classify, categorise and, ultimately, to “govern” disability and people with disability in Australia, impacting on the “political judgements about who counts in society” (p. 56).

Stella (1996) has claimed that the significant changes in disability services, from the provision of institutional care to that of support in the community, was underpinned by the civil rights movements taking place in Australia and across the Western world. Certainly, change has been credited to strong ideological movements based on rights and liberty. The principles that caught the imagination of people with disability and their supporters are discussed below (see Section 2.5.5.) However, Rapley and Baldwin (1995) have attributed the movement toward deinstitutionalisation more to economic necessity and political expedience, than upon any adoption of principle, emphasising that progressive principles such as Normalisation were utilised by governments as the justification for such change. Important concerns of people with disabilities and their family members, around issues of quality of life are, argue Rapley and Ridgeway (1998), caught up in “corporate discourse”. This argument predates what are now common observations about the managerial discourse which disability services, and other general community services, operate within (Bessant, Watts, Dalton and Smyth 2005). Bessant et al (2005) indicate that managerialism adopts much of the neo-liberal ideology of the government “steering” not “rowing”, resulting in the contracting out of services and functions to the non-government sector. This in turn makes relations with community organisations contractual, and the economic rationalist underpinnings of managerialism also require separate government departments to determine the extent of policy largely by what their budgets will allow. Managerialism is paradigmatic, because it prescribes the limits in which certain aspects of public policy can be understood. In the cases of people with disability and those with mental illness, it is regarded as a service matter, the responsibility of government department at state and federal level, and subject to the budget constraints of the departments that govern it.

### *2.5.3 The Social Model*

An important paradigmatic shift has taken place in the UK and beyond, with some influence at the level of peak bodies here in Australia, through debate that has occurred over the past 30 years amongst people with disabilities themselves, who have developed a “social model” to challenge existing medical, charitable and welfare understandings of disability. The Social Model identifies traditional thinking about disability as belonging to an “Individual Model” of disability, a mode of understanding that places the cause of all disadvantage experienced by people with disabilities within their individual conditions (Oliver 1990; 1996).

The domination of the medical profession over services for people with disabilities has had a profound effect on the way the community perceives disability. The perception is largely negative, focusing on the inabilities of impaired people. Social Model writers believe that this negative, clinical, tragic view of disability underpins the vast majority of specialist services that are provided to people with disabilities the world over. Michael Oliver has stated that the problem of disability is located within the society, and not the individual with impairment (Oliver, 1996). Identifying how this disablement takes place requires scrutiny of the social processes and institutions that have served to exclude and segregate people with impairments. The Social Model identifies obstacles that disadvantage people with impairments, and which are commonly referred to as **barriers**. These barriers can be physical, organisational or attitudinal, and are usually based on prejudice, misunderstanding, stereotypical representation, ignorance and a lack of recognition of the requirements people with disabilities may have in order to participate in our society.

The social model views disability from a human rights perspective, which contrasts itself with medical, welfare and rehabilitation models (Oliver 1996). In a brief article about the lack of concern amongst the general population for the denial of basic human rights amongst the world's marginalised population, Marcia Rioux (2004) is critical of approaches which focus on "fixing" the impairments experienced by people with disabilities:

Making disability a health problem or a problem that resides in the individual deficit or shortcoming is inaccurate. Worse than inaccurate it also contributes to the oppression of people with disabilities. They are victims of judgements about what is normal in society. Just for a moment consider that the charity and care we give people with disabilities in an attempt to make them "normal" is actually a breach of their rights to be participating members of society (Rioux 2004, 1).

Rioux's point is relevant to a consideration of housing and support policy, in that there needs to be a much greater focus on the various systemic causes of the lack of availability of housing for people with complex needs, and upon individual supports which can equip a person with disability with the wherewithal to challenge these issues. Rioux's focus in this short piece is upon employment, where her research has indicated that "the single most important reason why people with disabilities weren't employed was because they didn't have transportation" (Rioux 2004, 2). As Rioux points out, this is an issue of public policy and infrastructure that has nothing at all to do with the deficits that may or may not be experienced by a person with disability.

From a social model perspective, the provision of housing to people with disabilities, or rather its lack, is regarded as part of the overall failing to plan urban infrastructures with those with impairments in mind. For Barnes and Mercer (2003), housing is a crucial part of a continuum that will enable people with disability to have opportunities for general social participation, including in education and employment, and the lack of suitable housing serves as one of the many "barriers" that leads to the continuing exclusion that people with disabilities experience. Barnes (1991) believes that the physical environment has been created without taking account of the mobility requirements of people with disability, and that this is perhaps the most visible context for the institutional discrimination experienced by this population group. Gleeson (1999) regards this exclusion of people with disabilities from the built environment as a form of oppression, especially within a capitalist environment, where inability to participate fully places people at a significant, competitive disadvantage. Stewart (2004) views the barriers within households and the built environment as a serious impediment to the capacity for people with disabilities to become independent. However, he also recognises that even when the physical barriers are remediated a serious issue of housing affordability places a major barrier to people with disabilities accessing required accommodation. Despite the ability of social housing to ensure that suitably accessible housing is available to people with disabilities, the arrangements in place lead to a perception of "welfare dependency" and of "special needs" housing that once more shifts the focus of attention upon the individual with disability, rather than on the broader social barriers of disadvantage (Stewart 2004).

#### *2.5.4 The Social Model – Intellectual Disability and Mental Illness*

The broad movement of people with disabilities in the UK have debated the extent to which it is a conceptual framework that adequately takes account of people with cognitive disability and those with a mental illness (see Crow 1996, Hughes and Paterson 1997, and Shakespeare and Watson 1997). Goodley (2004) contends that the social model can comfortably accommodate the lived experience of people with learning difficulties (the UK term for "intellectual disability"), and survivors of mental health systems (a common term for people known in Australia as those with "mental illness"). Goodley's argument rests upon

acceptance of an increasingly common theme in social model studies, namely that as well as the dimension of “disability” being socially constructed, the experience of “impairment” is also subject to construction and manipulation by, in particular, professionals. Barriers, according to this understanding, exist for people with intellectual disability and those with mental illness, within cultural practices, as well as within the physical and institutional environments (Goodley 2004).

The social model emphasises the social impacts of discrimination, stigma, denial of opportunity and oppression as more significant upon the disadvantaged status of people with disability than are individual matter of impairment or incapacity. This sociological focus on systems and social conditions is also evident in literature that addresses the housing and support needs of people with mental illness. Mulvaney (1998) has reported that people with a history of mental illness are more likely to suffer stigma and discrimination, and experience poverty and neglect than others in the community. In relation to housing, Mulvaney’s own research (1997), conducted in Melbourne, identifies a range of practical obstacles to successfully obtaining housing, including lack of access to transport to inspect prospective housing, a scarcity of information about housing options, lack of funds to meet rental bonds, and lack of funds to obtain furniture (Mulvaney 1998, 264). In addition, the difficulties experienced accessing and maintaining their accommodation places additional strain on the mental health of people with a history of mental illness, such that a direct correlation has been made between housing stability and mental health (Mulvaney 1998).

#### *2.5.5 The Community Living Principles*

As the discussion about the social model revealed, there is a general acceptance that disability, at least since the time of the Industrial Revolution (Oliver 1990; Ryan and Thomas 1980), and the emergence of the dominance of medicine as a discipline within western society (Foucault 1975), has been viewed primarily as an individual, pathological state that correctly is governed within medical or welfare disciplines. The powerful symbol of this controlling relationship between the state and its citizens with disabilities was the institution, and the process of deinstitutionalisation is thus symbolic of a significant paradigmatic shift away from these controlling influences. Normalisation (Nirje 1985; Wolfensberger 1983) is one of the Community Living Principles that is credited with driving the reform agenda that led to deinstitutionalisation, and their influence is still obvious within the Principles and Applications of Principles of the various disability services acts across Australia. Nirje’s original concept involved the “normalising” of the conditions which people with intellectual disability have the right to, such as accommodation, employment and social life, including choice. Social Role Valorization (Wolfensberger 1992) is more detailed, and has a greater focus on change required by the individual with disability, to ensure their disadvantage is not exacerbated by negative social perceptions.

In total the Community Living Principles represent a significant paradigm shift from previous discourse which naturalised the asylum and the institution as the correct accommodation for people with intellectual disability and mental illness, and also to some extent those with physical and sensory disabilities. The principle of developing the individual’s ability was used to provide people with skills, and the “dignity of risk” (Perske 1972) highlighted both the right of a person to make decisions and take actions that may be inherently risky, and the need to live experientially as a crucial element in adult development and maturation. Such principles, along with normalisation, helped to establish more regular accommodation options as suitable for people with disabilities. The Least Restrictive Alternative (Bachrach 1985) was an important principle established by legal precedent in the USA, when the incarceration of people in institutions, on the basis of their having a disability, was likened to the reaction of swatting a mosquito with a baseball bat. The denial of liberty inherent in such arrangements was regarded as unconstitutional, and led to the requirement of government agencies to provide a much broader range of accommodation options, more fitting to the accurately

assessed needs of the client with disability. The principle of the Least Restrictive Alternative influences the disability services legislation across Australia, but also more directly impacts upon guardianship legislation. Statements of principle are included in the various forms of guardianship legislation across Australia, and there is a good deal of similarity amongst the various pieces of State and Territory legislation, albeit with significant differences in interpretation of how the laws are to be enacted. For example, Carney and Tait (1997) have identified a stronger welfare focus within the NSW legislation, largely, they believe, because it was first drafted as part of a joint guardianship and disability services bill. By contrast, Victoria operates according to the “narrative of protecting civil status”, much more wary of using guardianship to protect individual circumstances because of the delegation of personal decisions to, in many cases, the state (Carney and Tait 1997).

### 2.5.6 *“Care” in the community*

The notion of “care” and how it is both understood and operationalised is important to how support to people with complex needs is delivered by services, in such a way as to enable their residence in ordinary housing. Current government discourse includes the term “care”, within the role of those “carers” of people with disabilities and the frail aged, who in turn qualify for the Carers Pension. The notion of care is also explicit and implicit within formal support arrangements, such as the Home and Community Care (HACC) Program, and the congregate care models of nursing homes and large institutions, referred to by Bridge et al (2002) as “cared accommodation”.

Michael Fine (2005) has written about the relatively recent break down in the division of the caring role, which prior to the mid-20<sup>th</sup> century was largely “informal”, namely conducted within the home environment, usually by women:

De-institutionalization, the new technologies of care and the emergence of community care approaches have broken down these divisions, with the result that formal and informal have gone from being alternatives (either/or) to partnerships, hybrids, new forms of mixed care (Fine 2005, 249).

Fine emphasises the intimate nature of much care, the extent to which this sensitive work is de-humanised in some hospital and nursing home settings, the low status and reward attached to those who undertake the work, and the tendency to conflate care and “support” with the result that too little attention is paid to this intimate transaction:

To ... assume that the very need for care can be reduced to arbitrary social convention, however, would be to ignore the prior ontology of physiological vulnerability that underlies the need for care in the first instance (Fine 2005, 253).

The distinction between “care” and “support” is important for two reasons. Firstly, the terms are often used interchangeably, and “care” and “carers” are terms used in common parlance to define a relationship that is both formal and informal (paid and unpaid). Clarity of expression will be important when understanding the various motivations and demands of people with complex needs for individualised support within their own homes, and to perhaps reach greater levels of clarity around the detail of what services can do, by including under the heading of “support” tasks such as personal care, domestic assistance, mobility assistance etc. Secondly, and more importantly, people with disability have written extensively (see particularly Morris 1996 and Wendell 1996) about the intrusion of professionals upon their bodies, and the very obvious (although some are more subtle) forms of control that others can wield over the lives of people with disability through these required tasks of “caring”. The ability to be in control of care tasks is critical to people with disability, and needs to be considered explicitly in this research when the issue of support, and the delivery of services, is studied in its relationship to the provision of housing.

### 2.5.7 Poverty and income

An important factor in the disadvantage experienced by people with complex needs, which impacts on their capacity to access suitable housing, is their levels of poverty and their access to adequate income. Mulvaney (1997;1998) has established the link between poverty and mental illness, and the impact this can have upon the range of suitable housing options available, and the consequent impact on a person's mental health. Gleeson (1998) has expressed frustration about the inadequate statistical data available to measure the current level of poverty experienced amongst people with disability in Australia, and focuses on areas where data is available, namely on access to employment, their income levels, and their access to social services and assistance (Gleeson 1998). In these areas Gleeson (1998) concludes that people with disabilities "remain marginal to mainstream employment markets" (p. 325), that because of this marginalisation "disabled people [sic] remain one of the poorer social groups in Australia" (p.327). However, one of the most significant conclusions of this overview of poverty is the lack of ability currently to assess what might be called the "levels of inclusion" of people with disabilities:

The problem of physical inaccessibility is, by nature, difficult to measure and has thus far not received the attention it deserves from social scientists (Gleeson 1998, 325).

Within the scope of "physical inaccessibility" lies access to housing and housing markets, as well as aspects of the built environment in general, including transportation systems and the means by which people with disabilities can access public as well as private spaces, the main focus of Gleeson's book, *Geographies of Disability* (1999).

An early study in Canada by the Roeher Institute (1990) related its research findings on housing and disability to the issue of poverty. This study described the residences in which people with disabilities lived as, by and large "poor places", and that the people living there also tended to be "poor people" (p.1). The research focused on funding arrangements, funding sources, and the interaction between the multiplicity of funds and entitlements available. The research concluded that policy options must embrace the principles of inclusion, citizenship and self-determination, and that a sense of the "ordinary" must be achieved both in terms of the housing provided and the services implemented to support individuals within that housing. In addition to greater availability of accessible and affordable housing, many of the strategies to achieving a more robust generic infrastructure, which reduces the need for a large and costly specialist service system, involve methods of ensuring that funds are accurately targeted to individuals, and that entitlements are pooled to enable support to be provided in chosen environments.

Parker and Cass (2005) have written about the current dominance of the medical model within government discourse about disability, such that people with disability are assessed for eligibility on the basis of a medicalised assessment, with the consequence that the social causes underlying disability and disadvantage are ignored, and the individual is cast as the "problem" within the welfare system:

While disability welfare reforms over the last 15 years have been characterised as promoting incentives for social and economic participation, the medical assessment model has been accompanied by a systematic disavowal of the significance of social, economic and labor market conditions in providing or constraining opportunities for participation (Parker and Cass 2005, 2).

Parker and Cass argue that the new welfare measures of the Howard Coalition government have served to associate the receipt of welfare benefits, such as the Disability Support Pension, with the notion of dependency. This signals a move away from income support as a

right to the recipient of welfare as a problem. Whilst the association with decreasing dependency has enabled the Government to utilise the positive language of the social model, the “participation” envisaged for people with disabilities does not involve workplace modification, and the “barriers” are of the individual’s, not society’s, making (Parker and Cass 2005).

The ability of people with disability to successfully enter the workforce and earn a living is one of the key concerns of the social model, and an area where significant systemic barriers have historically occurred. Its relationship to housing is direct, when the cost of purchasing property is considered, as well as the increased prices of privately rented property. Public housing is but one of the plethora of housing options that are available to members of the community, but for people with disabilities, for whom work is difficult or impossible due to the continuing barriers at the workplace, it is one of the few opportunities for a level of independence.

### *2.5.8 Self-Determination and Individualised Funding*

Bostock et al (2001) foreshadowed a move away from government reliance upon the group home model, facilitated by the introduction in NSW of individualised funding packages, which should “promote a wider range of housing futures” (p.10). The implementation of service delivery programs which utilise individualised funding on a large-scale, is becoming progressively more common in countries such as the USA, Canada and the UK. The linkage made between mechanisms of individualised funding, and the principle of “self-determination” make the shift paradigmatic. The concept of individualised funding is straightforward: instead of providing funds to services to, in turn, deliver support to as yet unknown clients with disability, funds are instead paid directly to the clients, who use them to either purchase services, or organise their own support arrangements by hiring their own attendants (Dowson and Salisbury 2001). A strong motivation for this shift is to enable the client to wield much greater control over the quantity and quality of support that is provided to her/him, as well as the ability to budget a set amount in a manner which best suits the individual, in order to obtain a package of support that best meets the person’s needs.

In the USA “self-determination” operates as a principle of individual liberty, as a broad policy initiative linked to mechanisms of individualised support and funding, and as a program operating for people with intellectual disabilities in a number of States. This program, entitled the Robert Wood Johnson Foundation Self-Determination Initiative, was funded from 1997 as demonstration projects in 19 locations across the USA, with \$5 million from the Robert Wood Johnson Foundation (Human Services Research Institute 1999). The ideological underpinning of the initiative and its link to the broader policy movement in the USA emerged from dissatisfaction with traditional service models, and the desire of families for themselves and their relatives with disability to lead a “normal” life.

Individualised funding is largely acknowledged to have emerged in Canada in the 1970s, used as a mechanism for enabling the deinstitutionalisation of a residential facility for people with intellectual disabilities (Shaddock 2001). Families of those living at the institution were greatly influenced by the Community Living Principles, in particular Normalisation and the Least Restrictive Alternative, and lobbied to maintain the levels of funding allocated to their family members, to which they were entitled whilst at the institution, and instead use this allocation to purchase services which were tailored to the individual’s requirements. It was initially, then, a mechanism for achieving alternative accommodation and support to that provided by the institution.

In the UK the Community Care – Direct Payments Act 1996 provides an opportunity for people with disabilities who are eligible for services, and who are “willing and able” to manage the funds allocated for these services, to have payments made to them direct, so

that they can purchase supports or hire their own assistants. The capacity of the individual to manage these arrangements at first made it hard for people with intellectual disability, mental illness and brain injury to utilise the option of having funds paid to the client, but the “Valuing People” government white paper (Department of Health (UK) 2001) addressed this, amongst other systems issues, for people with “learning difficulties” throughout the UK. Whilst the paper does explicitly address the goals of enabling people with learning difficulties to access direct payments, it is person-centred planning which is the principal driving force of the systems change envisaged within the UK (Department of Health (UK) 2001). Person-centred planning is also utilised within the previously mentioned self-determination and individualised funding arrangements, and has emerged from the Community Living Principles as a tool by which the wishes and needs of people with disabilities (often significant cognitive impairments) can be recorded comprehensively and creatively, and then used to drive the range of funded and “natural” supports and services that are required to meet these goals (O’Brien and Lovatt 2000).

Individualised funding and self-determination are significant disability service initiatives, but are not accepted uncritically. Askheim (2005) has characterised the debate about direct payments as an “old controversy” within welfare policy discussions, classically representing the clash between the neo-liberal and social democratic traditions. According to Askheim, the debate promotes the need for individual empowerment and choice-making by “rational, self-interested and well-informed individuals”, and the supremacy of the “market” in supplying required goods and services, against the “interventionist welfare state” (Askheim 2005, 248). He ascribes the strong individualistic ethos of the USA to the rise of the Independent Living movement in that country (the catalyst for the Centres for Independent Living that are numerous in that country, and also operate in many countries including Australia), and describes the approach taken in the UK by the New Labour government as “welfare pluralism”, and points out that the Direct Payments Act was introduced by the previous Conservative Government, as “part of its intention to reduce the public responsibility for welfare and leave it to the market” (Askheim 2005, 252).

Askheim (2005) argues that the existence of direct payments is not enough to guarantee good outcomes for people with disability – the amount that is offered, and its ability to cover the range of need that the individual has, is more important, and he believes this is a failing of the system in the USA. In addition, there is concern amongst administrators that legal action might be taken against them if malpractice is done to clients by user-hired assistants (Askheim 2005).

Self-determination in the USA enjoys support from the intellectual disability lobby, the physical disability movement, and the lobby of people with mental illness. Individualised funding projects in Canada are targeted at people with physical disabilities and intellectual disabilities alike. Both have their roots in the Community Living Movement, and can be seen as ideological in their aims, but also being grounded as practical mechanisms to overcome problematic program issues. Their strength is clearly their impact on the flexibility they provide to individuals in terms of support, and the ability of individuals to make choices about lifestyle matters such as housing, and have the support tailored to meet their needs, and to be in control over their support arrangements. Whilst their flexibility and user control can benefit the linkages aspect of the relationship between housing and support, it remains unclear how individually driven support will impact on the availability of suitable housing. It would appear logical that acceptance for change to the traditional way in which services are provided in the community is driven in part by the congruence with a neo-liberal agenda, or a social capital policy which takes a narrow view of driving social systems change through the individual, in much the same way that deinstitutionalisation was achieved through the adoption of normalisation principles in an economic rationalist agenda. In short, it is unclear how the demand that individualised supports will put on the “regular” housing market will be met.

## 2.6 Social policy and the political context

### 2.6.1 Introduction

This research project is concerned about social policy, and how it currently drives or provides oversight to the issue of provision of housing and support to people with complex needs. Bessant et al (2005) identify the purpose of social policy as endeavouring to discover what social problems or issues exist, what their causes are, and how they may be solved. A broad definition of what social policy encompasses is:

... social policy refers to what governments do when they attempt to improve the quality of people's lives by providing a range of income support, community services and support programs (Bessant et al. 2005, 4).

Despite the focus here being upon governments and their departments to address these social problems, Bessant et al. (2005) also identify the role of members of the community, including church groups and non-government organisations in the identification of problems and their solutions, and their overall engagement in the "policy-making community". Thinking about these "policy-making communities" provides a more sophisticated, if more complex, picture of the various agents and organisations that impact on the understanding of issues, and their potential solution, and suggests that influencing policy "drivers" may not be confined to targeting government employees.

Everett (2003) has written about the recent turn to scientific rationality in the making of public policy, with an emphasis on process, and less scrutiny upon the broader political judgments and decisions that ultimately determine the policy that then needs to be enacted. This brings into play the way that community discussion impacts on political decision-makers, how, in this case, issues of access to ordinary housing by people with complex needs, gets onto the "political agenda" (Everett 2003).

Everett distinguishes between the process of making policy and the decisions that take place at a political level by referring to the latter as a "play of power", and asserts that controversial or contentious issues cannot be resolved by policy process alone:

It is questionable whether the policy cycle can replace the 'play of power' – the political contest of determining 'who gets what'. Furthermore it is highly questionable whether the policy cycle can accommodate that political contest – certainly community consultation will not suffice (Everett 2003, 67).

Everett indicates that policy makers do not create the paradigm, but rather implement it. The pressure, then, is to make the decision-makers at a range of political levels (government, community leaders, NGOs, religious organisations, peak bodies, service providers etc.) understand that change needs to take place. Social policy commentators and analysts, such as Dalton, Draper, Weeks and Wiseman (1996) insist that it is critical to understand the historical and political context in which policy is made. The increasing dominance of the globalised economy in the 1990s led them to foreshadow declining wage rates, changes in workforce and the type of production undertaken in Australia, as well as the rapid rate of growth and change to be significant influencers on all policy matters. Bessant et al (2005) have identified that the differing ideological/paradigmatic viewpoints of structuralist theorists and neo-liberal critics impacts on the likelihood that matters will be considered as part of a social policy framework, especially when the "free market" is relied upon to negotiate and solve the issues that impact upon people in civil society. Depicting what may be regarded as "traditional" welfare policies as intrusive in the market economy, and ineffective at addressing problems of poverty and disadvantage, neo-liberal academics, such as Saunders (2004),

have engaged aggressively with the debate, not merely for the purpose of analysis, but to actively influence the major policy makers of Western countries (Bessant et al 2005).

Social policy, then, is not developed in a vacuum, and the political context in which it is forged and administered can, to some extent, determine in which direction it is able to continue. Pawson et al (2004) acknowledge the importance of the political climate in forming a complete understanding of how social care interventions work. To this end a brief consideration is required of the various political trends that have shaped policy around housing and support over the past decade.

### *2.6.2 Neo-liberalism*

Neo-liberalism is a political and ideological standpoint which gives primacy to the monetary economy in its approach to the management of the social system. Whereas “liberalism” referred to the rule of the free market, with as little government intervention as possible, and was developed as a set of ideas in the 18<sup>th</sup> Century, the rise of neo-liberalism over the past 25 has coincided with the fall of communism, the perceived “failure” of the welfare state in Western democracies following World War II, and the rise and spread of the global economy (Martinez and Garcia 2000). Treanor (2005) sees neo-liberalism as more than just economics, and as having a strong philosophical basis. Thus, nation states are now treated like companies, international competitiveness is the driving force of national economies, rather than internal social betterment, and the expansion of the “market” becomes the primary goal of people living within such a system.

One of the characteristics of neo-liberalism is the importance of the individual, and the requirement of the state to remain as non-intrusive as possible in personal affairs. In his discussion about support and care for people Fine (2005) distinguishes between the notion of the neoclassical market “consumer” and the process of “individualization”, which:

... calls for respect of individual autonomy at the same time as it seeks this respect as a mark of social interaction (Fine 2005, 254).

The reciprocity implied within this definition of individualisation upholds the strong emancipatory tradition of people with disability and the social model, whilst at the same time indicating that individuals interact with the social constantly, and that separation from society is not seen as a logical and necessary consequence of increasing self-determination. The role of housing is as crucial to the achievement of power and control over the intricacies of personal life, with a view to increasing autonomy and self-determination, as it is to ensuring that people with disability are able to interact with the social world to the same extent as others.

McDermott Miller (2005) has argued that the New Zealand Government embraced neo-liberal policies during the 1990s more than any other government of an English-speaking nation, with the argument of the state withdrawing from intervention in the economy being put into practice. The result of this was to address the social housing needs of citizens through individual income support policies, resulting in a cessation of the building of public housing, and the revision of income-based rentals to market-based rentals. The role of the state as a housing provider of any kind was revised to being the provider of “last resort” (Mc Dermott Miller 2005).

The policies of the current Howard Government in Australia are characterised throughout this research project as being neo-liberal in their intent, and the current term of Parliament, where the Coalition control both the House of Representatives, and the Senate, is likely to usher in reforms which practically apply neo-liberal policies to a range of social and economic institutions.

### 2.6.3 *Social Capital*

In 2001 the Federal Treasurer, Peter Costello, gave a speech to the Sydney Institute, entitled “Building Social Capital”, in which he deplored the decline in community engagement within Australian society, and spoke of the need for trust in a market economy, and the greater development of networks and associations within the community (Lyons 2001). This speech marked one of the first explicit, public engagements with the concept of “social capital” by a senior government minister, and anticipated the wide-ranging research conducted by the Productivity Commission on social capital (Productivity Commission 2003). This report provided an analysis of how social capital has been adopted as a contributor to social policy in other parts of the world, with the concentration being upon family and education, and encouraging volunteerism within the local community (Productivity Commission 2003).

Winter (2000a) has provided an excellent summary of the different definitions of social capital, beginning with that of Putnam, writing in the USA, who characterises social capital as a repository of resources that exist in the social and public domains, and includes networks, associations and individual relationships. His neo-liberalist perspective generally regards social capital as a civil good, arguing against the intervention of the state into affairs of the community. By contrast there are commentators who believe that there is “too much market” in daily community affairs, that these erode other, social, community values, and that what social capital is about is focusing on efforts to increase the stocks of communities to transact with one another on a basis other than that of the market economy (Winter 2000a). Coming from a tradition of social democracy, writers such as Eva Cox (1995) see social capital as a means to redress the imbalance imposed by economic rationalism, and to refocus the attention of society on indicators of community wellbeing rather than on those relating to the commercial market.

In addition to the different approaches underpinning debate about social capital, there is also a diversity of uses that are conceived for it. On the one hand Winter (2000b) points out that social capital is now used as one of the World Bank’s four indicators of its wealth accounting system. Social capital is also used as a paradigm underpinning broad social policy, and the discussion above, relating to the engagement of the Australian government with social capital, is indicative of a desire to include social and community issues within the dominant discourse of the market economy.

The social capital debate has tended not to engage with disability, with the exception of encouraging people into the workforce (Latham 1999). It is ultimately a concept that largely accepts the extent and the legitimacy of the existing social order, and aims to include all people to the extent that they enjoy the advantage of opportunity.

### 2.6.4 *Social Exclusion and the “third way”*

“Third way” politics is largely associated with the rise to power of New Labour in the UK. However, it also underpins the approaches of governments in New Zealand, Korea and Brazil (Giddens 2001). It represents a movement away from neo-liberal, economically rational government, but does not attempt to turn back to leftist, welfare politics:

Third way politics is about how left of centre parties should respond to change – not only to the changing ideological map itself, but to the transformations which stand behind this shift. There are three such transformations which are altering the landscape of politics – globalization, the emergence of the knowledge economy, and profound change in people’s everyday lives (Giddens 2001, 3)

The third way represents a significant shift in thinking from that of the neo-liberal approach. Firstly, the third way does not aim for less government, but does seek to reform and modernise government. Secondly, whilst government does not dominate the market or civil

society, it does intervene and regulate. Thirdly there is a role for the reform of significant social institutions, most notably the welfare state. Finally, the goal of creating an egalitarian society is not lost, but it is not to be achieved by redistribution of wealth alone. There are points of congruence with neo-liberalism too, most notably the acceptance of the dynamic of capitalism, and the increase of individual wealth as a means to the betterment of the community as a whole (Giddens 2001).

The interventionist possibilities of government in the third way have led to some innovative social policies that address both the system and the individual. In the UK housing policy for those individuals and groups considered to be vulnerable, is increasingly captured by the broad, European initiative to address “social exclusion”. Edgar, Doherty and Meert (2002) have identified a strong human rights push for housing and access to housing as the basis for the initiative, which emerges as a response to the commitment made by EU member countries to address growing social issues in the 1999 Treaty of Amsterdam. The focus on social exclusion and vulnerability was honed in the European social agenda, agreed in Nice in 2000, with an understanding that alleviating problems and achieving social cohesion would be a task addressed by social policy in each member country (Edgar et al 2002).

Anderson (2000) provides an historical overview of the emergence of ‘social exclusion’ as a key concept in social policy in the UK and across Europe. Social exclusion adopts some aspects of the neo-liberal focus on individual responsibility for experiences of disadvantage, but accepting some elements of the traditional social-democratic “welfarism”, which stresses the structural basis to entrenched poverty and disadvantage. Anderson explains that the concepts of social exclusion is expedient, on the one hand, as it has enabled European countries to address social problems without acknowledging that their citizens live in “poverty” *per se*, but that, on the other hand, the concept is in fact broader than just a focus on poverty, and benefits from addressing a much wider range of both structural and individual problems:

Social exclusion, then, is viewed as exclusion from aspects of well-being and social participation taken as ‘usual’ among the majority within society and the comprehensive and dynamic nature of social exclusion can be acknowledged (Anderson 2000, 21).

This “dynamic nature” has led to its adoption at an overarching policy level, despite its obvious focus being on specific locales of disadvantage rather than on broad areas of policy neglect. In the UK, soon after the Blair “new” Labour Government came to power in 1997 the Social Exclusion Unit was established within the Office of the Deputy Prime Minister, and this unit has established Policy Action Teams (PATs) which examine one aspect of social exclusion (Anderson 2000). Similar innovations have been made in Scotland, where they have renamed their strategy the “Social Inclusion Network”, seeking to focus on aspects of inclusion, rather than exclusion. Anderson (2000) concludes his description of the background to these initiatives by sounding a note of caution about the current lack of articulation about what “social inclusion” is.

In Australia Arthurson and Jacobs (2003) have concluded that:

... it is apparent that the topic of social exclusion and its relationship to housing is ‘at the policy horizon’ and will shape future Australian research and policy agendas (p.1).

In their thorough review of social exclusion literature they consider its applicability to the housing and general policy landscape in Australia, and cautiously agree that housing will play an important, whilst perhaps not pivotal, role in the amelioration of systemic disadvantage and exclusion experienced by certain individuals and populations in the community. A

particularly useful application is the distinction made between “exclusion through housing” and “exclusion from housing” in debates about the regeneration of housing estates, extending the focus from just the former (Arthurson and Jacobs 2003, 24). The broad range of focus, on structure and agency, and the concept of housing as both a means and an end to strategies of social inclusion, make the policy of social exclusion a potential unifying paradigm for driving housing and support initiatives and linkages that address the requirements of people with complex needs.

## **2.7 Adopting a position for analysis**

The above discussion illustrates the complex milieu in which social policy is conceptualised around the requirements that people with complex needs have for support and housing. Currently social policy regarding people with disability is largely consigned to service-led responses at both the Commonwealth and State/Territory levels, with the additional consideration of people with disability within income support policy. Likewise, mental illness is regarded as a subset of general health policy, again administered through the States and Territories. However, the alternative paradigms stress the social origins of the disadvantage experienced by people with disability and mental illness, and point to the need for broad social policy changes at the political level, as opposed to policy reform within existing government portfolios. The social model is of primary importance when considering how to respond to issues that are as broad as the provision of housing and support, which involve multiple government portfolios and which require significant work to achieve attitudinal change that will enhance the capacity for progress.

The realist synthesis approach (Pawson et al. 2004) requires the examination of the broad social policy and political context when describing and evaluating initiatives. The various approaches adopted in Western democracies in the past three decades have been briefly sketched, and clear differences have emerged between neo-liberal and social democratic initiatives. Within Australia, recent social policy has been formed within a neo-liberal context, with the limitation of public housing provision, and a preference for addressing the needs of disadvantaged people through individual income supports (Bessant et al. 2005). The policy of “mutual obligation” has borrowed aspects of social capital discourse to place the disadvantaged individual as responsible for alleviating their situation, perhaps not directly to blame for their circumstances but having to utilise the “opportunities” for advancement that will remove them from the “cycle of dependency”. This has led to little, if any, discussion at government level about the responsibility within the broader system to ensure those opportunities exist. Employment, health and housing are increasingly becoming subject to free-market forces, with the idea of welfare provision being as a “safety-net” for those who either temporarily or permanently cannot participate in the marketplace. Mutual obligation is designed to provide the incentive to those who could participate to do so. Unlike policies that address social exclusion, there is little explicit acceptance within both neo-liberal policy and social capital that social infrastructure and distributive mechanisms are actually exclusionary.

The foundations of disability service support are more complex, with clear origins in rights-oriented principles, which inform the disability services legislation across the country, a social capital agenda of achieving strong linkages within the community to advance the status and participation of people with disability, but more recently a strong managerialist paradigm which separates human issues into manageable “silos”, each of which is limited by budgetary and policy restrictions. The issue of substitute decision-making, via guardianship, also impacts on the way that options are presented to people with cognitive impairments, and poses a challenge to the principle of self determination. An initial consideration of these perspectives, in comparison with the alternatives, suggest that policy approaches to housing and support for people with complex needs will be limited in their scope.

A brief summary of the approaches described in this chapter is given below:

**Table 2: Summary of political context and paradigms**

<b><i>Paradigm</i></b>	<b><i>Features</i></b>	<b><i>Application to Research</i></b>
Neo-liberalism	Strong belief in minimal government intervention. Reliance upon free market to drive social change. Strong endorsement of the interests of the individual	Housing is part of the market, and market forces will respond to demand. Assumption that people with disabilities, given equal opportunity as individuals, will impact on marketplace with demand.
Social Capital	Concern for community cohesions. Sees community capacity as undermined by excessive service intervention	Housing viewed as part of neighbourhood, focal point for renewal of volunteerism. Focus on relationships within neighbourhood.
Social Exclusion	Systems and individual focus. General disadvantage and deprivation due to systemic failures, as well as individual incapacities	Housing viewed within general neighbourhood renewal projects. Range of policies targeting inclusion of wide range of currently excluded groups.
Normalisation	Specialist service and individual focus. People with intellectual disabilities are entitled to the same conditions as everyone else	A range of housing options, beyond staffed and institutional accommodation, must be made available to people with disability.
Least Restrictive Alternative	Specialist service and individual focus.	Restrictive housing options should not be considered unless severity of disability warrant them.
Self-Determination and Individualised Funding	Principle of individual choice and control over support arrangements. Mechanisms to better guarantee tailored and responsive supports	Provides flexibility to support aspect, allowing chosen housing options and adapting to change in personal circumstances. Does not address system shortages of housing.
Social Model	Systems focus. Exclusion of people with disabilities due to social barriers	Sees a lack of planning for suitable housing, and describes exclusionary policies regarding housing in the community.

## **3 LITERATURE REVIEW**

### **3.1 Introduction**

This chapter reviews research conducted in, or related to, Australia, which investigates the linkages between housing and support services for people with complex needs. Whilst a growing body of research evidence is available for analysis, the focus to date has primarily been upon the linkage at the service level, together with the provision, largely, of social or rental housing.

### **3.2 Describing the Issue**

The problem that this research project sets out to investigate relates to the ability of people with complex needs to have access to a range of housing options that is broadly similar to the opportunities available to other members of the community, and to have the support available to them that will assist them to maintain these housing arrangements. In addition, it looks to establish a critique of existing approaches to identifying and addressing this issue of housing and support, largely through the delivery of program-based services and inter-departmental agreements, through an examination of what is happening in Australia and overseas.

The potential problems and issues related to this are threefold: supply of housing, availability of support, and the linkage of the two to assist the individual. In relation to housing, the extent of the problem of people with disability and those with mental illness accessing “ordinary” housing is not easily illustrated through the provision of statistical data. Bridge et al (2002) have analysed 1998 survey data which reveals that 65% (of all ages) of people with a significant disability are living in cared, residential accommodation. Of the remaining 35%, three quarters of these live with other people, which suggests that problems exist for those who do not have people to live with (Bridge et al. 2002). The age of the person with disability becomes significant when looking at the rate at which people with disability purchase or mortgage their homes:

Having a significant disability before old age significantly reduces the likelihood that a person would ever have the financial means to buy a home (Bridge et al 2002, 11).

The ability of people with complex needs to purchase their homes relies in great part on their levels of income. The Australian Institute of Health and Welfare (AIHW) has indicated that the number of people with disability, under the age of 65, now represents around 22% of the total population, and that in 2002 almost 660,000 people had the Disability Support Pension (DSP) as their income source, an increase of 62% since 1993 (AIHW 2003). Bridge et al. (2002) have highlighted the relationship between housing tenure and employment, with 55% of those purchasing a house in employment, whereas only 14% of those in public housing had jobs (Bridge et al. 2002). Data suggests that public housing remains the main independent living options for people with complex needs who wish to live outside of the family home. In 2002 32% of all “income units” in receipt of Commonwealth Rent Assistance were ones where the person had a disability (AIHW 2003). In the same year the number of public housing allocations to people with disability accounted for 41% of the total allocations (AIHW 2003).

In relation to the services provided to people with disability, the Minimum Data Set statistics allow for a comparison of service provided through a “snapshot” of one day (AIHW 2003). Accommodation support provision in 2002 represented 34% of all services provided across

Australia, with Victoria providing support to the highest number of people in this category (7,412, or 32% of the total), and NSW second (6,069, or 25% of the total). The overall percentage of people with disability receiving support across all states has remained constant at or around 34% for the past four years (AIHW 2003). Of the total number of people in Australia provided with accommodation support, 68% of these were supported in residential settings ranging from large institutions to group homes. The remaining 32% were supported at home, or in alternative, community-based placements. The AIHW has made a “conservative” estimate of the level of unmet need that exists for services to people with disability, indicating that in 2002 at least 12,500 people, who had disabilities requiring assistance 3-5 times a day, were either not receiving service, or service provision was inadequate to meet their needs.

Although the data does not accurately assess the level of supply of suitable housing to accommodate people with complex needs, there is an indication that a wide choice of housing may not be available, and that the shortage of service provision poses serious challenges to the ability of people with disability access support for their housing choices when they need it.

### **3.3 Australian Research on Housing and support linkages**

The issue of accommodation for people with disabilities has always been at the heart of disability service provision. In recent years a number of research projects have been commissioned in Australia to look at the issue of appropriate accommodation for people with complex needs. This section will briefly look at some of the most relevant Australian research reports, which focus on the linkage between housing and support for both people with disabilities and those with mental illness.

#### ***3.3.1 Disability and Housing***

Bridge, Kendig, Quine and Parsons (2002) have looked at the housing and support options available to people with disability, both those below 65 years and age, and those older. This research encompasses options provided in congregate care and staffed accommodation, as well as looking at opportunities for people with disabilities to live in ordinary housing, and to “age in place”. The findings indicate that there is a correlation between the restriction inherent in the housing model, and the severity of the disability of the person living there, the implication being that the more complex the needs of a person the less likely it is for them to be able to access regular housing options.

The Disability Support and Housing Alliance (DSHA 2001) has investigated the barriers that people with disability in Victoria experience in accessing high quality community based housing and support, and identified that the design and availability of accessible housing, together with individualised funding mechanisms to provide support, are the keys to achieving success. The focus of the research was on people with physical disabilities and high support needs, and began by establishing a set of principles regarding the entitlement of people with disability to the same opportunities as others, and that housing and support options for people with disability must offer choice and flexibility and control for the people living there (DSHA 2001). The report identified inflexible services, both in terms of their eligibility criteria, and the way that they operate, and the scarcity of affordable and accessible housing, as key elements in the current blockages to suitable housing options. The very low income of people with disability further disadvantaged their search for housing, exacerbated by the “higher than normal living expenses due to costs related to their disability” (DSHA 2001, 7). A key assertion of this report is the need to separate the issue of the provision of housing and support, and indeed to separate their administration, believing that the issue

needs to be conceptualised around the individual with needs, rather than through the provision of specialist services:

Housing and supports have traditionally been looked at in terms of “supported living programs”. We need to move away from this program mentality and look at housing and supports as separate but related issues. This approach frees people to think more creatively about possible options (DSHA 2001, 9).

The Disability Advisory Council (DAC) of the Victorian Department of Human Services undertook a study to understand the experiences of inappropriate support for people with disability, and possible solutions to the problems they found (DAC 2004). To determine what might be regarded as “inappropriate” the Council established three broad indicators:

- Quality of life is reduced for those in the household
- People are living in unsuitable or unnecessarily restrictive environments
- The best use is not being made of formal resources (DAC 2004, 8-9)

The research found that many people with disability were in inappropriate housing, including those in congregate care settings, and some people in shared housing where they had too much or too little, or staffed, support. There was a significant group of people whose current housing was insecure or unstable, including people who had moved recently and/or frequently, those living in housing provided by the Office of Community Housing, people living with an older carer, and many people who had complex needs such as challenging behaviour or significant medical conditions (DAC 2004, 48-49). The factors that made these groups vulnerable to inappropriate housing and support included:

- A shortage of housing
- Lack of compatible or integrated policies
- No choice and no planning
- Difficulty in obtaining the right amount of support
- Inadequate staff training
- Families struggling to cope (DAC 2004, 50-56)

Overall the lack of planning long-term for housing and support was regarded as one of the key reasons for the continuation of crisis-driven responses, and the lack of coordination within a complex support system also contributed significantly. The research developed a schema for planning for housing and support services, which included three phases:

**Table 3: Revised schema for housing and support services (adapted from DAC 2004, 103-104)**

Phase	Subject	Details
Phase One	Foundations/pre-requisites	Assistance with planning and advocacy; Choice of where to live and whom to live with; Individualised home equipment and modifications; Personal equipment and assistive technology; Assistance with maintaining tenure; Identification of family friends, support needs and support roles.
Phase Two	Independent housing and support dimensions	A range of variables within the following dimensions: - housing type - personal support type - personal support level - management and finances - tenure
Phase Three	Review and change over a lifetime	Planned review to respond to unexpected housing and/or support changes required; Assumption of choice to move to other location; Expectation of increase or decrease of support required over time.

This schema illustrates the complexity of the provision of support and housing, and the requirement to undertake key tasks at important moments in the housing cycle, as well as the flexibility and adaptability that is required at different times to ensure that support provided (both housing related and personal support) is not at once too intrusive or insufficient.

### *3.3.2 Deinstitutionalisation and the development of accommodation “models”*

The issue of providing housing and support to people with disability has developed along programmatic lines largely due to the process of deinstitutionalisation, and the principle of managed care which has emerged out of the need to provide alternatives. Bridge et al (2002) depict deinstitutionalisation as a key driver of disability accommodation and support policy, in particular the emergence of the group home as the dominant model of accommodation for those people moving out of institutions. Bostock, Gleeson, McPherson and Pang (2001) indicate that ideology has tended, at least in part, to drive changes in disability policy and service provision. Focusing specifically on deinstitutionalisation, they claim that the group home model has become the “blueprint” of alternatives to institutionalised support, which in turn is indicative of the dominance of service funding agencies driving the policy agenda regarding appropriate accommodation for people with disabilities. In order for a shift in focus to take place, the authors advocate a separation of housing and support, with a greater emphasis placed on the provision of housing, and the rights of individuals as tenants, prior to a consideration of the need for flexible supports. The DSHA report (2001) also advocates a move away from this program mentality and a refocus on housing and supports as separate but related issues. This approach frees people to think more creatively about possible options (DSHA 2001, 9).

### *3.3.3 Housing and support for people with mental illness*

Reynolds, Inglis and O'Brien (2002) have conducted detailed research of the factors that impact positively on people with mental illness, when housing and support are linked. Studying the Victorian Housing and Support Program (HASP), and in particular the way that

the Psychiatric Disability Support Services (PDSS) have delivered support within ordinary housing settings, they identify a range of factors within the support and housing arrangements, and external to them, which impact positively on the successful housing/tenancy and other lifestyle outcomes for the clients supported in this way. The main focus was on the provision of support, which required responses that incorporated the following:

- the capacity for assertive outreach due to the reluctance of many people to seek support and engage with services
- time to nurture and build a working relationship with the person
- the ability to accommodate unpredictable fluctuations in needs and capacities without jeopardising housing and critical support
- consistency in service providers providing support
- undertaking cross service coordination/case management where the person has no one to assist with this
- the development of crisis management plans in collaboration with the person which include clear and agreed ways that services will support the person when they are unwell and not able to make informed judgements
- effective approaches to address and balance the issues associated with the release of client information to other services and rights to confidentiality (Reynolds et al 2002, 43)

The report acknowledges the barriers to successful linkages caused by the complexity of the housing and service systems, and calls for greater cooperation and collaboration, and for the expansion and continued evaluation of models of housing and support which are known to be effective. In order to bolster the possibility of action at the systems level they recommend approaches that take place at the following levels:

- Arrangements between Commonwealth and State Governments – similar to SAAP, HACC and Disability, agreements to coordinate program areas which are the responsibility of either level of government;
- Government handling its own business – development of broad policies, and inter-departmental task groups, and perhaps co-located program initiatives;
- Government as a designer of programs and funder of services provided by others – the development of program specifications, as well as leading accountability for outcomes and evaluating the success of programs;
- Local service networks – interagency initiatives to ensure the cooperative approach of diverse services within a local area, to better provide coordinated support to those living in that area;
- Individual services – enhancing the coordination and quality of support provided to each individual (Reynolds et al. 2002).

The report stresses that individual needs and differences should be accounted for in the support and housing arrangements for any person, whether they have a mental illness, disability or not. Thus, the principles for achieving linkages between disparate housing and service systems remain similar for other groups.

O'Brien, Inglis, Herbert and Reynolds (2002) have done further research into the issue of housing and support linkages for people with mental illness, by conducting consultations with people with mental illness, to gauge their perspective on the way that the linkages need to occur. The research found that for people with mental illness there were four key elements which contributed to successful housing outcomes:

- 1) **They live in housing that they find acceptable**, and that does not make it very hard or impossible to manage particular disabilities or manifestations arising from their mental illness.
- 2) They have **support, medication and/or treatments that they trust, accept and find helpful**.
- 3) They demonstrate **a willingness and readiness** to tackle, with appropriate support, the individual daily challenges and difficulties living independently may present.
- 4) Major issues that may place their housing at **risk have been identified and addressed** (O'Brien et al. 2002, x, emphasis in the original).

The research addresses the problems faced by people with mental illness in relation to the achievement of stability in their housing, by balancing factors that relate to their individual conditions, and the pressures placed on them by a range of social and systems factors, including poverty, lack of opportunity, and stigmatisation:

Lack of community understanding of mental illness and the way it can affect people can lead to discrimination, stigma and fear. These responses can adversely affect and often compound difficulties of living in the community with a mental illness (O'Brien et al. 2002, 6).

The study finds that people with mental illness require from housing what is common amongst the general population: independence and choice; convenient location; safety and comfort; affordability; privacy; and social opportunity, including the capacity to entertain at home, and the proximity of local resources and infrastructure (O'Brien et al 2002). The study has also developed a comprehensive list of housing attributes that need to be considered when planning for successful outcomes, and a list of support attributes. Both lists highlight the need for a variety of options to be available, the importance of choice by individual clients in the success of both the housing and support arrangements, and the complexity of the housing and social service milieu that is required to provide the flexibility inherent in a system that creates so much choice within so many options. A further table addresses the linkages needs between housing and support, focusing on four areas:

- type of linkages
- nature of relationships between housing and support providers
- issues of client confidentiality
- nature of local service network (O'Brien et al. 2002, 22).

This framework concludes with a model of requirements for the effective provision of housing and support to people with a mental illness in general housing, which consists of a list of housing and housing policy and procedure requirements, mechanisms for effective coordination and linkages, and characteristics of local support services, including networking amongst local agencies (O'Brien et al. 2002, 23).

An important finding of the consultations with clients was the relationship between choice and housing satisfaction. Another finding indicated that it was important to clients to have the housing and support arrangements separate, enabling people to cope with the demands of daily life, and thus being more able to sustain their tenancies. There was a strong identification that formal support was one of the most important factors in the success of an individuals' tenancy, whilst factors that impacted negatively on housing stability included house maintenance, issues with neighbours, isolation, rental arrears and other financial problems. As well as highlighting the factors that contribute to the success of housing arrangements for people with mental illness, and the potential difficulties that need to be overcome, O'Brien et al. (2002) demonstrate the reciprocal benefit that stable housing has on the wellbeing of people with mental illness. Research of this nature enables us to view

secure housing, not as an end, but as the means by which a fuller and more inclusive lifestyle can be obtained, and, for many people, this involves the stabilisation of their condition and the ability to participate.

### *3.3.4 Whole of government approaches to housing and support*

An important focus of this research is the policy framework in which the issue of housing and support for people with complex needs is considered. The framework of social exclusion has been utilised by Robinson (2003) as one vantage point from which to view the problem of homelessness. Social exclusion, when applied to this problem, enables a shift from concerns about individual pathology and lack of social housing, and indeed a questioning of the construction of “homelessness” as a valid category to describe the range of experiences that currently are addressed within that single rubric. Robinson’s research (2003), which involved interviewing over 400 people who were described as “homeless”, revealed a wide diversity of housing and social careers, which indicates that a far more sophisticated, multi-factorial response was required across a range of government departments and community agencies than is currently on offer. The consultative nature of the report provided powerful insights into the issue of housing and support from the point of those affected by their impact, with a clear preference for ordinary housing in the community, and not “little enclaves, not mini institutions or anything else” (Robinson 2003, 40).

The plethora of funding bodies, service providers, and the dispersal of their skills and knowledge across State and Territory boundaries, continues to confuse and stymie efforts to bring cohesion to areas of need, such as support and housing for people with disabilities (Bridge et al 2002). As they summarise:

... the division of management and funding responsibilities, together with a narrow focus on accountability for outputs and costs within each of the program areas does not provide a sound base for provision of integrated accommodation and care (Bridge et al 2002, 46).

Bostock et al (2001) have found that the separation of funding and service functions between the States and Commonwealth “undermine[s] effective program linkages” (p.7). Similarly, the DSHA (2001) report highlights the complexity of funding and collaborative arrangements necessary within one State (Victoria) to enable housing and support arrangements to be delivered effectively. Despite the three important portfolio responsibilities of health, housing and social services falling within the responsibility of one department, the Department of Human Services (DHS), there still remain challenges to ensure that arrangements do not collapse because of the unavailability of support or housing to individuals when they require it. The report proposes that joint working parties or designated liaison positions be established to manage the cooperation required within DHS, and also that joint funding packages between the health and social service divisions to guarantee the support required by people with complex needs, including health/medical needs be considered. The report also indicates the need for collaboration between DHS and the Department of Infrastructure, which has oversight over the development of new property, in order for the majority of new housing to be built according to accessibility and visitability standards (DSHA 2001). Collaboration is also important at the level of State and Commonwealth Governments, to ensure adequate funds for increased disability services are made available, and the report call on greater cooperative efforts between the community and government, to widen the availability of community-based supports for those people with complex needs who will be living in local environments in the future.

Bridge et al (2002) have indicated that issues related to building and land regulation are the most common themes to be raised by policy makers when considering matters of housing

and support to people with disability. Second is income support, followed by housing agreements, all coming before community care issues, which was previously the most commonly articulated approach to addressing the problem. Bostock et al (2001) report that the generation of different models of accommodation is determined by whether housing or support policy is the driver. If the focus is on housing needs, then responses tend to be around modification, redesign of buildings, relocation, and other housing options accessed through rent assistance and grants. However, when the focus is upon support needs accommodation models reflect economies of scale and the aggregation of support packages which tend to lead back to the group home as a model (Bostock et al 2001, 45).

The way that support is provided is important, however, to ensuring that people with complex needs maintain their tenancies. Bostock et al (2001) foreshadowed a move away from government reliance upon the group home model, facilitated by the introduction in NSW of individualised funding packages, which should “promote a wider range of housing futures” (p.10). The DSHA report (2001) also strongly promotes individualised funding as a mechanism that can allow for greater flexibility in the provision of supports as and when they are needed to assist a person with disabilities in housing.

### *3.3.5 Anti-social Behaviour*

The focus of this research is primarily about access to housing for people with complex needs, and the mechanisms available to them to remain in suitable housing. However, stigma and discrimination are significant experiences in the lives of people with complex needs, and the way that the community, and government departments, respond to their needs and presentation can impact on their housing careers. The concept of “anti-social behaviour” (ASB), in the context of housing, broadly relates to the committal of crimes and vandalism, to neighbourhood disputes and activities, such as playing loud music or littering, which causes a public nuisance. Jacobs and Arthurson (2003) indicate that the perception of tenants and housing staff affected by anti-social behaviour is that its cause is usually attributable to young people, but there is also a belief that many incidents are directly attributable to policies of deinstitutionalisation of people with mental illness, and their placement in public housing accommodation. In NSW the Department of Housing (2005) has recently introduced changes to the Residential Tenancies Act 1987, which include the imposition of “Acceptable Behaviour Agreements” on tenants who have a record of anti-social behaviour. Such agreements will require the client to receive services to support them, and breaches of the agreement will result in loss of tenancy.

In the UK, the National Strategy for Neighbourhood Renewal report on anti-social behaviour (2004) indicates that ASB is a widespread problem, more prevalent in deprived neighbourhoods, where the actions of a small minority can have a significant, detrimental effect on the majority of households. Vulnerable people, including those with complex needs, are regarded as being especially affected by fear of crime being perpetrated against them. Problems associated with cause and policing are the lack of any single agency to take responsibility for the problem, real policy gaps and a lack of protection of those most at risk (National Strategy for Neighbourhood Renewal 2000). Concerted planning and the implementation of a wide range of services, is the response to anti-social behaviour in the UK. The recent *Respect Action Plan* (Home Office (UK) 2005) indicates that many of the social problems that emanate and take place within local neighbourhoods and communities are to be tackled by a range of strategies, that include tough law and order measures combined with accessing necessary supports for those who require them. This broader approach is being adopted due to the success to date of the crackdown on anti-social behaviour, which has resulted in over 6,500 Anti-Social Behaviour Orders (ASBO) being issued since the initiative began in 2000 (Home Office (UK) 2005).

### 3.3.6 *Women with Disability*

Women with disabilities are regarded as particularly vulnerable and disadvantaged in regard to housing and support. Comparisons to their male counterparts indicate that they are under-represented in the workforce, over-represented in public housing and in statistics related to poverty and violence, and vulnerable also to homelessness:

Housing situations are precarious for many women with disabilities. A decline in the supply of low cost housing, an increase in unemployment and the level of poverty, and changes in the service delivery policies of specialist services, have increased the risk of homelessness for many Australians (WWDA 2004, 1).

The article focuses on issues within SAAP services that can lead to the risk of homelessness for women with disabilities who are experiencing crisis. As well as issues of discrimination and lack of staff understanding and training, the lack of general accessibility within crisis housing renders a woman not “self-managing” and restricts their ability to enter the accommodation (WWDA 2004).

The gendered social roles of society, albeit subject to change, are demonstrated in stark relief when we consider the issue of women with disability as mothers and carers. Litwinowicz (1999) has written about her experiences of raising a child, and the difficulty in obtaining accommodation that is suitable for raising a boy as he grows and develops. Not only do the changing needs of the parent need to be accounted for, the proximity of local services and the safe passage to basic community facilities, like parks and playgrounds, are demonstrated by personal stories of women with disabilities. Such perspectives need to be taken account of when making policy determination about housing and people with complex needs.

### 3.3.7 *People with Disability from CALD backgrounds*

The Multicultural Disability Advocacy Association (MDAA 2003) has written about the problems faced by people with disability, including those with mental illness, from a CALD background, who wish to access public housing in NSW. The report analyses the efforts made by the NSW Department of Housing to address issues systematically, through their strategic documents, the Disability Action Plan and the Ethnic Affairs Priorities Statement. However, the report makes the assertion early on that there is a problem of a lack of linkage between the two initiatives, such that the needs of people with disability from a CALD background tend to fall through the gaps.

People with disability from a CALD background experience similar issues of lack of affordability to be able to pay market rent, as do others with disability. However, they are likely to be more disadvantaged when it comes to dealing with staff of the Department of Housing, often due to communication problems and the lack of experience staff have in dealing with both people from different language backgrounds and people with disability (MDAA 2003). This can lead to:

- underestimating the needs of clients;
- failure to understand why private rental is not suitable for some people;
- refusal to approve transfers (MDAA 2003).

The report also indicates that in some instances there is a lack of empathy displayed by the staff of the Department toward people with disability, and provides a case study of a woman whose mental illness was exacerbated by a Department of Housing investigation into why her ex-husband was occasionally staying at the residence, when in fact she required additional

assistance from him to manage the children (MDAA 2003). In general the report asserts that people with disability from a CALD background do experience quite intrusive investigations of allegations made against them.

People with disability from a CALD background also experience difficulty when trying to access public housing, with problems stemming from language and communication. The report indicates that people with disability from CALD background largely do not understand the “housing system”, and experience difficulty in:

- accessing priority housing;
- filling in application forms and transfer forms;
- remaining in public housing;
- gaining access to timely and good quality repairs (MDAA 2003).

Whilst many of the issues are similar to those described in other reports of the housing experiences of people with disability, there are clearly problems that are felt more keenly and experienced to a greater degree by people with disability from a CALD background, such that issues of cultural diversity must be considered when addressing the linkages required between housing and support.

### **3.4 Universal Housing**

One of the key strategies to ensuring that people with disabilities have access to a wide range of housing options is the design and building of “Universal Housing”. Universal housing, as a concept, is critical of the short-sighted nature of current house design, and aims to ensure that housing is built to be adaptable to the needs of people as they change throughout their lifecycle. Universal design is based on seven principles, which refer to design, construction and the addition of refinements to create a living space which:

- 1) meets the needs of people across a range of abilities and ages
- 2) meets the changing needs of its owners over time (i.e. age, disability, family changes, caring for ageing parents)
- 3) is well integrated within the community
- 4) adapts to respond to the economic needs of its owners both now and in the future
- 5) enables home owners to occupy dwellings for longer periods through improving the “convenience” a home can offer
- 6) incorporates functional features which are aesthetically compatible with housing expectations
- 7) incorporates features that add quality, marketable features to the home (Starr 2005, 17)

Universal housing, then, goes beyond merely making housing “accessible” to people with physical impairments, or ensuring that some housing stock is “adaptable”. The concept promotes the usability of housing designed to such standards by the whole of the population, as enabling individuals and families to grow and age, and manage change within the same home environment. The Australian Network for Universal Housing Design (ANUHD) sees the adoption of these principles as key to economic and environmental sustainability, as well as working strongly for the inclusion of people with disabilities in the community (Herd, Ward and Seeger 2003).

Starr (2005) has conducted extensive research on the approaches to Universal Housing Design in 6 countries – Australia, Norway, Japan, USA, Canada and the UK. In drawing comparison across the six countries Starr uses an analytical framework which includes looking at the legislation that supports universal housing, the statutory building laws which

guide design and construction, and other legislation which guides visitability and adaptability of buildings. All countries have a statutory building code, but only the UK mandates basic visitability of all newly constructed housing by having them built to accessible standards (Starr 2005). In Norway, there is a very high rate of home ownership (only 25% of homes are rented) combined with extensive post-war construction of small, detached housing, and a small (4%) social housing sector. A key strategy in Norway has been to encourage home ownership, as renting is regarded as a “poverty trap”. The Norwegian State Housing Bank (Husbanken) is an institution unique to that country, with its dual purpose of financing around 50% of all mortgages in Norway, and implementing the government’s policy regarding the provision of tax advantages to property owners (Starr 2005). Another contributor to the accessibility and affordability of owned housing in Norway is cooperative housing, which accounts for 14% of all housing in the country:

Cooperative housing is attractive to potential homeowners as the cooperative takes the financial risk for planning and construction and assumes the mortgage obligations from Husbanken (Starr 2005, 51).

In the UK there are no financial incentives to build according to universal housing design standards, yet since 1999 changes to the Building Regulations have meant that all new housing has to be built to visitability standards (Starr 2005). The review of Part M of the Building Regulations in 1998 resulted in this change.

Universal design is about accessibility and adaptability, so that a range of people with differing needs can have ready and easy access to suitable housing when it is required. It is also about ensuring that housing can be built with a lengthy future in mind, such that people can remain living there 25 years or so after they move in, should they wish to. The rapid ageing of the community requires social policy to address this need to “future-proof” housing (Starr 2005). Whilst there are initiatives in Queensland and South Australia to move toward a more integrated approach to the development of universal housing, this has not resulted in mandated requirements for standards of accessibility to be reached in new housing (Starr 2005):

While State based initiatives have supported the development of more accessible housing, without a national strategy or code of practice, the implementation of accessible practices in housing is largely reliant on local government initiatives and developer goodwill (Starr 2005, 22).

### **3.5 Home Ownership and purchasing**

Amongst the options for “ordinary” housing is that of home purchasing. Communities Scotland (2004) has reported that, despite the growth in home ownership in Scotland overall, the likelihood of people with disability (the actual terminology used is “long-standing limiting illness, health problem of disability”, or LTLI) living in social housing is twice that of people without disability, with the rate of households where people with LTLI are housed being half as likely to be mortgaged as those without. Somewhat unsurprisingly the research indicates that the major barrier facing households where there is a person with LTLI is finding a suitable house at an affordable price (Communities Scotland 2004). The research found that not only do people with disability require more expensive housing (due to the adaptations required), they are more likely to earn less and have increased financial outlays because of other expenses related to their health and/or disability (Communities Scotland 2004).

Hagner and Klein (2005) identify the cost of housing to be the foremost obstacle to home ownership by people with disability, with the median income of people with disability being 60% of that of those without disability, and people with disability up to four times as likely to

live in poverty as those without disability. This US study focuses on the capacity of people with disability to successfully access mortgages, and notes the various forms of discrimination that can affect various groups, including people with disability, when having applications for mortgages assessed. In general, discrimination against people with disability, in relation to home purchase and rental, is on the increase (Hagner and Klein 2005). Their study focused on the criteria used to determine the “credit-worthiness” of an individual applying for a mortgage, and concluded that people with physical disability were more likely to have loan applications approved than those with developmental disability, and that the chance of approval was consistent with the rate at which people with physical disability were preferable for employment over those with developmental disability (Hagner and Klein 2005). On the strength of their findings they recommend that opportunities to establish a credit rating be created for those people with disability who currently find it hard to get a mortgage, including taking on responsibility for the payment of bills in a family or group home setting, and ensuring that payment is made in a timely fashion. At a systemic level the authors recommend the establishment of partnerships between disability services, advocates and mortgage lenders, to enable lenders to understand better unfamiliar circumstances and contexts and thus better focus their lending criteria (Hagner and Klein 2005).

### **3.6 Discussion**

Research to date has tended to emphasise social/public housing as the main market for people with disabilities and those with mental illness who wish to live in “ordinary” housing. Bostock et al (2001) have recognised the burgeoning demand for housing that the process of deinstitutionalisation has caused, and advocate for greater access by this population group to private rental markets. The problems of housing for people with complex needs are as much about the supply of suitably accessible and affordable housing, as they are about the availability of adequate supports to meet people’s needs. Principles of universal design are important in ensuring that supply is available, not only in social housing, but in the private rental market and for purchase. The issue of home purchasing for people with disability does not currently receive enough attention, either from research or with policy makers. Yet clearly the desire to own one’s one home is both a typical housing option for many members of the community, and an option which provides great security of tenure.

## 4 OVERSEAS APPROACHES

### 4.1 Introduction

This chapter provides insights into the way that housing and support to people with complex needs are addressed in other, comparable jurisdictions overseas. It also provides some examples of innovative approaches to the issue of housing and support. In addition to conducting a literature review, key personnel in the UK, Canada and the USA, were contacted directly, to provide information and to recommend further contacts. Posting of the research project's information sheet on two disability discussion lists also led to useful responses. The information provided does not attempt to be comprehensive in nature, but does endeavour to describe the approaches taken overseas utilising the framework that will be used to analyse approaches in Australia.

### 4.2 New Zealand

#### *Policy and Administrative Arrangements*

Disability services in New Zealand are administered through the Disability Services Directorate within the Ministry of Health. The Directorate is organised into five sections, with two operational sections administering disability services across both the North and South Islands. The Directorate is currently responding to the requirements of the NZ Disability Strategy, and has already separated the responsibilities for disability services between those for people over 65, which now go to the local Health authorities for funding and administration, and those for people under 65, which remain centralised (NZ Ministry of Health 2005).

The New Zealand Office for Disability Issues is a division of the Ministry of Social Development. It has three main roles:

- lead, monitor and promote the New Zealand Disability Strategy
- provide policy advice on disability issues, and lead strategic and cross-sectoral disability policy across government; and
- support the Minister for Disability Issues (NZ Office for Disability Issues 2005,1)

The office was established in 2002, and does not provide direct disability services. Instead it provides advocacy across the range of government departments which have to respond to the requirements of the New Zealand Disability Strategy (2001). This strategy was developed to provide an overarching framework in which to address the issue of inclusion of people with disabilities in New Zealand, and adopts a strong social model stance, which identifies the existence of "barriers" to basic social participation (NZ Disability Strategy 2001). The first statements about the issue to be addressed strongly acknowledge the role of society in promulgating the problems faced by people with disabilities:

We live in a disabling society. The New Zealand Disability Strategy presents a plan for changing this.

Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments.

Disability is the process which happens when one group creates barriers by designing a world only for their way of living, taking no account of the impairments other people have (NZ Disability Strategy 2001, 3)

The 15 objectives of the Strategy are written from the point of view of people with disability, and they impact upon the whole range of government services, and areas of the community

where the government can influence attitudes. Objective 8 refers to supporting “quality living in the community”, and addresses the need for people with disabilities to have the opportunity to live in their own homes in the community. This objective has been divided into two parts: “living in the community”, and “moving around the community”, the latter referring to transportation systems. A number of initiatives have been taken with regard to community living, including within the Housing New Zealand Corporation which has started a disability audit process to assess the accessibility of all of its housing, and implemented a Suitable Homes Service to provide case management to people with disability to find them suitable homes. Eighty seven houses were also added to the community housing portfolio, of which many were available to people with disability, and modifications and adaptations were carried out to 570 properties (NZ Office for Disability Issues 2005).

The New Zealand Housing Corporation has expressed its commitment to researching best practice in housing management by providing funds to “kick-start” The Centre for Housing Research Aotearoa New Zealand (CHRANZ). A recent report from this centre (McDermott Miller 2005) has provided a comprehensive overview of issues that constitute a housing challenge to people with disabilities. Data analysis found that the main segment of people with disability were those with a physical disability, and that the housing requirements related to mobility impairments were very much akin to those related to the needs of people who were ageing. There was a much greater contrast in socio-economic status between the general population and those people with intellectual disability and mental illness. These findings suggest that different emphases are required for different disability groups, with a significant impact on the availability of accessible housing for those who are ageing and people with physical disabilities, and greater access to income-generating opportunities, perhaps through support programs, for people with intellectual disabilities and psychiatric disabilities (McDermott Miller 2005). The report proposes that future research topics for the centre focus primarily on accessible housing and other creative and “smart” design processes. Additional housing research topics include upgrading the analysis of household data, to get a clearer picture of the extent of demand for housing, and getting details of the number of people with disabilities living in inappropriate settings.

#### *Initiatives of Housing and Support*

The literature search did not reveal any specific initiatives that related to the provision of ‘ordinary’ housing and support. However, the Disability Services Directorate is considering the implementation of individualised funding to assist in providing support to younger people with disabilities who have complex needs, and who require a more targeted approach to ensure that their needs are met. The implementation of individualised funding is expected to be slow and staged, as currently the mechanism for assessment lies within the local health authorities, and the movement is away from funding through those authorities for younger people. However, there is a commitment by the Directorate that individualised funding is a mechanism that should be widely available to people with complex needs (Ministry of Health (NZ) 2003).

### **4.3 Canada**

Canada has a federal/provincial system for addressing the needs of people with disability, and those with mental illness, similar to that of Australia. Disability and housing services are administered at a provincial level, utilising funds that come from the Federal Government, which has tax revenue responsibilities.

Porter (2003) has written that there is no explicit recognition of the right to adequate housing written into provincial laws in Canada, although the a lack of housing clearly assaults fundamental rights in the *Canadian Charter of Rights and Freedom*, even if the *Charter* does not explicitly refer to the right to adequate housing (Porter 2003, 3).

The *Poor Places* research (Roehrer Institute 1990) established the link between disability and poverty in Canada, at a range of levels. More recent research conducted in Winnipeg, specifically about people with disability who are dying (Stienstra and Wiebe 2004), has restated this linkage for people with disability living in the core area of that city, leading to many people living in unsafe neighbourhoods. The report paints a bleak picture of a lack of accessible housing, inadequate supports, and a difficult trade-off between having socialisation and support in a congregate setting, and having privacy and accommodation for close family in individual, but inadequately supported, housing. In general, people did not know where they would be living at the time of their death (Stienstra and Wiebe 2004).

A report on the housing issues for people with physical disabilities in British Columbia was published in 2001 (Options Consulting 2001). This report identified barriers in the design and construction of accessible and adaptable housing, the lack of availability of support for those already in housing, and the lack of availability of income resources when needed, as well as the location of wheelchair-accessible housing. One of the barriers to choosing “adaptable” housing over “accessible” housing is the absence of funding available to suitably adapt the housing at the time when the person might need it. The report also details the range of housing “models” and support approaches which are available, and attempts to match the possible linkages between the two. When the option of “individual dwellings” is considered for housing, the only support option available is that of “individualised supports” (Options Consulting 2001, 60).

However, some unique system reform is taking place in British Columbia, where the support system for people with developmental disabilities has recently (July 2005) been transferred to a community-based Permanent Authority for Community Living British Columbia (CLBC). Crawford (2004) reports that this authority has taken over the responsibility of administering disability services, from the government, emerged after a Liberal government came to power in BC in 2002, but was primarily concerned with the unsustainability and inequity of the existing system in its current form. It aims to provide accountability to government for the way that resources are spent, but also back to people who use services and their families. An innovation of this has been the opportunity for some clients to utilise individualised funding, which has been useful for those who do not easily “fit” into existing service arrangements, and which enable them to access options alternative to institutional settings (Crawford 2004). Recent communication with key strategic planning executives within the CLBC indicates that the initiatives there are targeted very much at the service side, and that one area of need remains the interface with housing, to ensure supply, and to establish protocols to ensure cooperative and collaborative arrangements across sectors.

#### *Service Initiatives*

A number of service initiatives have emerged as a result of the increasing capacity for people with disability to receive directly the funds they are allocated for service provision, and to use those funds to resource support options that they control. One mechanism, which is working for people with intellectual disability, developmental disability and also for people with physical disability and mental illness, is the “Microboard” (Perry 2000). Microboards are constituted as small, trust associations, operating as non-profit agencies, which can operate supports for an individual with disability across different funding areas. A small group of committed volunteers is established around an individual to assist that person to determine what their support needs are, to plan for those needs, and to apply for and administer the resources required to support the person’s needs. Outcomes have included the successful establishment of housing and accommodation options outwith the traditional models of the group home or family home (Perry 2000). The Vela Microboard Association provides advice and practical support to microboards across British Columbia, and help to ensure that standards relating to decision-making by the client and accountability to funding bodies are maintained.

Also in British Columbia the BC Coalition of People with Disabilities (BCCPD), from 1997-2004, sponsored an Individualized Funding Community Development Project. The potential for utilising support funds from existing hospital (institutional) arrangements was made possible by the Choices in Supports for Independent Living (CSIL) option, then available through the Ministry of Health (BCCPD 2005). The project was funded by the British Columbia Ministry of Children and Family Development throughout its seven year history, and assisted people to make the transition to life in community housing through peer support, intensive work to find the “ideal” solution for the individual, and then delivering supports whilst also developing support networks (BCCPD 2005). Such arrangements were able to bring about the transition of a woman with a complex medical condition, ventilator-dependent quadriplegia, from a hospital setting into cooperative housing in the suburb of her childhood (personal communication). Support arrangements included paid assistance from a trusted friend, and additional daytime assistance from workers who were supervised by the friend and by the client herself. A range of assistive aids was brought to enable as many tasks to be undertaken by the woman as possible within the house.

## 4.4 USA

### *Housing*

The United States of America administers its housing and support through its State administrations, although there are federal funds available that can enable people with complex needs to access accommodation options outside of the residential facilities. The US Department of Housing and Urban Development (HUD) provides a range of information resources to people with disabilities, relating to the availability of suitable housing in each State, and the range of programs that can assist people with disabilities to live in their own accommodation. Each local jurisdiction has a Public Housing Authority (PHA), which works with HUD and local community organisations to assist people with low incomes, including those with disability and mental illness. HUD operates a Section 8 Home Choice Voucher program, which qualifies low-income families (including individuals) for a voucher which limits the rent they pay on a suitable home to 30-40% of their income. PHAs also generally offer “First-Home Buyer programs”, in the form of a “silent second mortgage”, with interest deferred. Other financing is required, but this can assist in the purchase of a home, providing the cost of housing in the area is not too high.

As well as providing direction and funding to the various state housing authorities, HUD enables people to purchase their own properties, provides funds for modifications, and provides guidelines for accessible housing design (HUD 2005). The Office for Fair Housing and Equal Opportunity within the Department deals with complaints of discrimination made by people with disabilities.

In the USA, the National Home of Your Own Alliance was funded by the Administration on Developmental Disabilities established in 1993 to enable people with disability to have the opportunity to purchase their own home. The initiative did not include multiple buyers in one property (similar to “equity housing” provisions), nor the situation of a person with disability living in a home owned by another (such as family or friend), nor two people purchasing together who were not in a committed relationship. This was to give clarity to the initiative and to maintain a “clear focus on seeking a disseminating ways to overcome the obstacles to home ownership” (National Home of Your Own Alliance 2005).

A project in Kansas, USA, has promoted home ownership amongst people with disabilities. The Living Independently in Northwest Kansas (LINK) project received a grant to initiate the Home of Your Own (HOYO) project for the area, channelled through a local housing association. This program offered technical assistance to people with disabilities, and the area was targeted because of the limited housing options within a rural area, which in turn

made purchase a viable choice (Beneke 1999). The program targeted individual assistance at those who sought to purchase a home, including assistance with accessing finance and locating a suitable home. The project benefited from the involvement of a local bank, to establish credit and gain finance. Within the first year about 12 participants with disability had been assisted (Beneke 1999).

The Fannie Mae Foundation provides home loans to low-income people in the USA, and has a mortgage product available to people with disability. This enables people with disability to play a low deposit on a home of around \$500, and to garner a range of income sources to pay the loan, including negotiation with local service agencies to look at the potential for funds to assist in regular payment (Fannie Mae 2005).

### *Service provision*

In line with changes made in other Western countries, services to people with disabilities in the USA have altered considerably in the past twenty years. Significant numbers of people with disabilities are supported in the community, and in some States innovative funding arrangements have allowed for flexible support and housing arrangements. Changes in the funding of services to people with developmental disabilities has taken place too, with a dramatic rise in the numbers of people supported by non-state agencies between 1982 and 2002 (49% to 86%), and a shift in the financing of community services to federal-state cost sharing, with the federal government's contribution rising by 227% between 1991 and 2000 (Stancliffe and Lakin 2004). There has also been a general move away by state governments from program funding, toward individualised funding and a needs-based allocation of resources (Stancliffe and Lakin 2004).

Progress in service delivery to people with disability the USA has been made, not so much by government-crafted social policy initiatives, but by civil rights movements and the testing of issues in court (Drake 1999). The Least Restrictive Alternative/Environment was forged from cases that challenged the restriction of liberty of people with disabilities in institutional settings, and was a major catalyst in the devolution of many institutions (Bachrach 1985). In 1999, the "Olmstead decision", as it came to be known, led to state governments being required to provide their services in the "most integrated setting appropriate", after the US Supreme Court had ruled the previous mode of service provision to be discriminatory under the Americans with Disability Act 1990 (Stancliffe and Lakin 2004, 5). In the 1960s and 1970s significant civil unrest took place by students with disabilities, at first lobbying for access and accommodation on the campuses of American universities, which led to the formation of the Independent Living movement of people with physical disabilities (Shapiro 1993). This movement has transformed into Independent Living Centres across the country, which work to enable people to live in independent housing, and have their supports tailored to their individual needs (Independent Living USA 2005).

The primary source of funding for developmental disability services in the USA is Medicaid, with combined funding from both federal and state governments through Medicaid constituting 77% of the total \$34.5 billion spent on total services in the 2002 financial year (Braddock, Rozzolo, Hemp and Parish 2004). The Home and Community-based Services (HCBS) Waiver program has played an increasingly important role in the delivery of community-based services to people with developmental disabilities, with services providing case management, personal care, assistive technology, home modification, day programs, amongst a range of other services to those living in the community (Braddock et al 2004). These waivers are available to all people regardless of which state they live in, but the services that are associated with the program differ from state to state, as does the amount allocated to each waiver. A comprehensive survey of the Waiver program in Minnesota (Lakin, Hewitt, Larson and Stancliffe 2004) revealed a higher than average take-up of waivers in that State, with a small number being utilised for the purpose of providing support to people living in their own home.

### *Mental illness*

Similar to disability, issues relating to people with a mental illness are the responsibility of State-based health departments. Initiatives differ from State to State, although people with mental illness are also able to access the Medicaid and other provisions available to people with disability, including the Self Determination programs described below. Houghton (2001) has provided an overview of evaluatory research conducted on a housing and support initiative in New York in the 1990s. This research tracked 4,679 homeless people mental illness who were placed in “service-enriched” housing that, in many instances, was specially constructed to house them. The level of support varied in the housing options provided, with some receiving considerable amounts of social and clinical support, but with 523 people also receiving rental subsidies in existing housing (Houghton 2001). By 2001 3,615 units were still being supported by specialist social and clinical services (Houghton 2001). Focusing mainly upon the savings to social, housing and other services, the research found that the cost reduction on average to the various services was \$12,145 for those people placed within these serviced environments. The bulk of the savings were derived from the decrease in use of medical and mental health services by the residents.

### *Initiatives*

The Robert Wood Johnson Foundation Self-Determination Initiative began in 1997/98, to enable 19 participating states to pilot a scheme whereby people with disabilities were provided directly with the resources allocated to them, in order for them to control the way that supports were provided (Human Service Research Institute 1999). Mechanisms of individualised funding were introduced to provide a range of effects, including improving individual outcomes, across the participating states. In Michigan, as in other States, the most significant outcome measures involved the range and quality of decisions made by those people who participated. Head and Conroy (2004) report that out of an inventory of 35 choice domains, the choice of apartment or house was the domain where the fourth-highest improvement in choice was recorded over a period of 3 years, with the choice of whom to live with ranking immediately above it.

The Autism Living And Working (ALAW) organisation provides “self-determined” housing to people with autism, as a result of a grant obtained from the Pennsylvania Self-Determination Housing Project in 1995 (ALAW 2005). This group has worked to obtain affordable and accessible housing for eligible clients, prioritising the notion of choice, and have established people in the following, rental and purchased, housing options:

- three men sharing a three-bedroom twin home;
- one man living in a subsidized apartment;
- one woman sharing a three-bedroom apartment with two other women, with disabilities other than autism;
- one man living in a dorm at college (ALAW 2005, 1).

## 4.5 United Kingdom (UK)

In the UK the problem of housing for people with complex needs has not just been about accessibility, and the provision of adequate support, but also about the quality of the housing provided, and the opportunities for people with disabilities to participate in the rental and home-purchasing markets in the same manner as other members of the community. Drake (1999) indicates that the Housing Act 1980 had detrimental effects on the ability of people with disabilities to participate on an equal footing with others, as tenants were not allowed to purchase their specially designed housing in the same way as other citizens, effectively excluding them from the windfall that the buoyant housing market was providing. This in turn has contributed to the further polarisation of the urban landscape, with significant differences being observable between those who own their homes, and those who access social housing as renters. The condition of housing occupied by the most marginalised groups, including people with disabilities, continues to be poor, with 25% of people with disabilities living in housing that “stands in need of basic amenities such as indoor toilets or lacks appropriately adapted facilities such as stair lifts and baths” (Drake 1999, 126). A further consequence of the policy to sell council houses to tenants other than those with “special needs” has been the reduction in the availability of properties generally to house those people who require social housing, and a consequent increase in the number of homeless people (Drake 1999).

Currently one of the most significant drivers of policy regarding housing and support for people with complex needs in the UK is the framework that addresses the issue of social exclusion. One of the first initiatives of the Blair New Labour Government in 1997 was to establish the Social Exclusion Unit, which now operates from within the Office of the Deputy Prime Minister. This unit aims to eliminate social exclusion experienced across the whole community, not only by people with complex needs, by targeting systemic barriers, as well as enabling groups and individuals to have access to opportunities to participate (Social Exclusion Unit 2005). Policy Action Teams (PAT) address the specific issues related to groups, such as people with complex needs, and include members outside of the civil service who can provide their insight and expertise to the strategic plans that are developed.

One of the mechanisms used in England to operationalise the policies that address social exclusion are the Local Strategic Partnership (LSP) bodies, established within local authority boundaries, which serve the purpose of bringing together the various public, private, community and voluntary sectors in the area. Established under the Neighbourhood Renewal Unit, the LSPs target areas of social deprivation, and, by working jointly and cooperatively, aim to improve social outcomes including worklessness, crime and housing, and to narrow the gaps between rich and poor in England (Neighbourhood Renewal Unit 2004).

### *Provision of services and housing*

In the UK support to people with disabilities, and those with a mental illness, are provided through local authorities Social Service departments. Local authorities in the UK assume responsibility for the full range of public and social services, including education and health, and receive allocated grants from the central Government. A range of supports is available, to complement basic health, personal support and income initiatives, such as the “Supporting People” programme. Again administered through the local authority health and social service departments, the support provided by this programme includes debt counselling, form filling and the provision of emergency alarms (directgov 2005). The program was launched in 2003 to provide better quality of life to vulnerable people, both in terms of their capacity to live independently, and to maintain their tenancies. The program works through local authorities, and involves partnership between local government, probation, health, non-government organisations, housing associations, support agencies and clients (Supporting People 2004). People with complex needs, including those with disability, are amongst those that the

program targets. The program is the responsibility of the Office of the Deputy Prime Minister, and operates through the contracting by Administrative Authorities of the supports and services that an individual requires. Salford City Council was one of four authorities to receive an award for their approach to this program. The three groups of people with complex needs that this research looks at are addressed amongst the groups of people considered vulnerable in that area. Support provided to people within the program include assistance with:

- Paying housing-related bills, including rent
- Making sure that homes are secure and personal safety is upheld
- Helping with benefit claims and filling in forms
- Helping people to look after their own money
- Helping people to take control of their own home (shopping and cleaning) (Salford City Council Supporting People 2005, 1)

The Supporting People program utilises the resources of the UK Housing Associations, which became key players in the provision of housing to people with complex needs in the era of the Tory Government throughout the 1980s and early 1990s. Within the Housing Association sector there appears to be a significant recognition of both the Social Model and Social Exclusion, as overarching principles of social policy to which the associations must measure up. The National Housing Federation (2004) released the “Level Threshold” document, which provides statements of principles and key actions that aim to “bring disability issues and access to housing into the mainstream of housing association thinking (p.3). The four principles which guide the key actions are:

- Dismantling barriers
- Removing discrimination
- Developing an action plan
- Showing commitment (National Housing Federation 2004, 4)

All of these principles acknowledge the failure of society to include and provide for people with disabilities, with the first statement being strongly influenced by the social model:

People are disabled by the **inaccessibility** of the built environment and society’s negative attitudes, rather than by their impairments. This approach promotes the removal of barriers to inclusion, be they design, attitudinal or institutional (National Housing Federation 2004, 4, emphasis in the original).

The strategies section addresses the need for better design, good communication with tenants with disabilities, the involvement of people with disabilities on boards of management, and the role that housing associations must play in enabling people with disabilities to be part of the broader neighbourhood.

#### *Disability Policy Approaches*

An important initiative in the UK has been the move toward direct payments of funds for support to the service recipients. The Community Care Directs Payment Act 1996 required local authorities to enable people with disabilities to receive their support entitlements in the form of a direct payment, to allow them to purchase services directly or to hire their own support assistants. However, the take-up of direct payments by people with mental illness was slow, and a research project undertaken to determine the reasons for this (Spandler and Vick 2004) revealed that, while direct payments was acknowledged to be one of the few social service initiatives that directly stemmed from the expressed preferences of people with

disabilities to exercise self-determination over their supports, it was nonetheless complex and challenging, requiring assistance from a range of people with specialist knowledge of how the service system works.

Whilst it canvasses issues of specialist service delivery that go beyond the matter of whether direct funding is available, the “Valuing People” white paper (Department of Health (UK) 2001) also considers the difficulties that people with learning disability (intellectual disability) have had in making use of the Direct Payments Act. The strategies for augmenting usage of direct payments by people with learning disabilities involves increased responsiveness by services to the needs of people to be more independent, and the implementation of person centred planning mechanisms to enable choice and decision making, essential to the successful operation of direct payments. Learning Disability Partnerships Boards, established in local authority areas, provide practical support to people with learning disabilities, and their families, to make the decisions that will drive their support. The white paper has also set broad objectives regarding people with learning disability and their families having greater choice and control over where they live, acknowledging that many people still live in the family home because more independent options are not available to them. The paper recommends cooperative efforts across departments within local authorities, and prioritises efforts to move to independent living to those who are living currently with their families (Department of Health (UK) 2001).

#### *Mental Health and Social Exclusion*

The Social Exclusion Unit’s 2004 report, entitled “Mental Health and Social Exclusion”, aimed to address the issues of treatment, support, employment and housing, among others, within this broad framework (Social Exclusion Unit 2004). It identified that 80% of people with mental illness live in regular housing, and that some of the problems they encounter, as a result of their mental illness, are homelessness and rental arrears. Strategies to alleviate problems are aimed at housing providers and social services, who are, respectively, encouraged to:

- liaise and work cooperatively with mental health and social care workers;
- understand the nature of mental illness as requiring lengthy hospital admissions from time to time;
- take an active role in notifying the Housing benefits Agency if a person is admitted to hospital;
- draw up agreements with individuals if there are concerns about mental health issues, and working cooperatively with case workers and care workers around these:

and

- establish referral protocols with housing providers for individuals;
- develop collaborative working arrangements with housing providers (Social Exclusion Unit 2004).

The paper also advocates the development of protocols amongst the various housing, health and care agencies that provide support to people with mental illness in the local authority areas. The final fact sheet of the report provides information about how local authorities can address all of the areas that relate to mental illness and social exclusion. Practical suggestions include:

- including mental health as one of the priority areas in the Local Strategic Partnerships;
- setting up networks of specialist and mainstream experts in the various areas of need (employment, education etc.);

- establishing protocols for working across areas of responsibility;
- regular consultation with people with mental illness and their carers;
- directories of service providers;
- community education (Social Exclusion Unit 2004).

There is a commonality of theme, then, across the three policy areas of disability, mental health and housing, all relating to the need for flexibility and cooperation, as well as proactive support to enable people to remain in their housing.

## 4.6 Discussion

The realist synthesis approach requires an understanding of the broad political and social policy context in which approach to meeting specific challenges takes place. This brief look at how housing and support are being addressed overseas appears to indicate that amongst countries which have long shared common values regarding the place of people with disabilities in the community, and the appropriate means by which to deliver services, there are significant variations in the approaches to the provision of accommodation. Table 4 provides a brief overview of the different approaches in each country:

**Table 4: Different approaches to housing and support across 4 countries:**

Country	Political System	Policy Framework	Initiatives
New Zealand	Central Government	NZ Disability Strategy under NA Office for Disability Issues.	Consideration of individualised funding to target responses to those with complex needs.
Canada	Federal/Provincial	In British Columbia, support system transferred to Permanent Authority for Community Living.	Individualised funding and peer support to enable people to live in community accommodation.
USA	Federal/State	Medicaid Waivers (support) Section 8 Home Choice Voucher.	National Home of Your Own Alliance. Self-Determination projects for people with disability, and people with mental illness.
UK	Central Government	“Valuing People” Social Exclusion Unit Direct Payments Act 1996	Learning Disability Partnerships boards Supporting People (Housing Associations)

In the UK and New Zealand the centralised government structure allows for a broad strategic direction to be implemented more easily than in federal states, such as Canada and the USA, and, to some extent Australia. Bessant et al (2005) describe the Australian federal system as a “double centralisation”, with historically strong State governments (and weak local governments) being gradually usurped by increasing centralisation in Canberra, resulting in the Australian federal state system being the most centralised of all Western federal state systems. In New Zealand and the UK, however, the central government makes broad social policy, and the local authorities carry out their service and administrative responsibilities according to policy and with the funds provided by the central government.

As well as the advantage of the centralised approach to policy making, both the UK and New Zealand have established separate departments to act as watchdogs and ensure that a whole-of government approach is taken to meet broader social goals for people with complex needs. In New Zealand a positive strategic framework provides a whole-of-government

approach to guiding the variety of strategies that are needed to address the complex interplay of housing provision and the delivery of support. Importantly, the NZ Disability Strategy is predicated on an understanding of the social barriers that have created the disadvantage experienced by people with disabilities, and the strategies proposed within the document require these barriers to be removed. This both acknowledges the responsibility of society to change the way it functions, in order to accommodate (in the broad sense) the needs of people with disabilities in all its facets, and the requirement of government departments of all types to ensure that they are doing their utmost to foster more inclusive practices across the board. The issue of housing and support is treated within a holistic framework, and the requirement of department who do not have a disability services mandate to contribute becomes self-evident.

There is evidence of service-oriented initiatives in the USA and Canada, which have assisted people with disability and those with mental illness to access ordinary housing, as well as a range of other, less restrictive options to the traditional residential facilities of institutions and group homes. A range of initiatives also exists in the USA to provide opportunities to people with disabilities to purchase their own homes. However, despite the national availability of Medicaid Waivers, and Section 8 Housing Vouchers, the capacity of individual States to vary the amount and flexibility of the former means that there is no uniformity within the USA about people with disability getting access to the housing and support they require. The USA has a strong movement of people with disability and their families, which have formed coalitions and groups, such as the Centres for Independent Living, and the Self-Determination movement, which in turn have garnered resources to support innovative and flexible support arrangements. These initiatives, such as the Robert J Wood Self-Determination projects, have enabled people with significant disabilities to access ordinary housing across 19 States in the USA.

The UK appears to have the most comprehensive policy framework, as well as the coordinating power of the Social Exclusion Unit in the Office of the Deputy Prime Minister, which at least bears the promise of a range of funded initiatives aimed at providing people with complex needs with the same housing options as are available to other people. The problems of managing diversity are acknowledged and addressed, and there is a considerable amount of overlap amongst the various housing and disability/mental health service documents, as well as oversight by the coordinating role of the Social Exclusion unit. Mechanisms of person-centred planning to operationalise the “Valuing People” strategy, together with the Direct Payments legislation, demonstrate a commitment to the principle that client-focused support must include strong mechanisms for client control of the support that is provided. The adoption of social model principles within the charters of housing associations, indicates a willingness of government and organisations to assume some responsibility for the current barriers to housing experienced by people with complex needs, as a first step to addressing those needs over time.

When weighing up the comparisons and contrasts of a highly centralised government policy system, such as those in the UK and New Zealand, and the dispersed policy making of a federal system, such as those of the USA, Canada and Australia, there would appear to be some merit in a uniform approach to an issue as fundamental as the provision of adequate housing and adequate support. This chapter has identified examples of innovation in jurisdictions that exist within federal systems, but indicates that such innovations are not available to all people with disability or mental illness who may live outside of those jurisdictions. There appears to be a good deal of political discretion within federal systems about the approach that is taken to providing housing for people with disability and people with mental illness, and the extent to which the responsible government will address it as a matter of priority. The centralised system appears to have the benefit of making local authorities accountable to a set of determined principles and outcomes, such that greater uniformity might be expected across a larger area. This has important implications for the

capacity of people with disability and people with mental illness to consider housing options as part of a larger suite of lifestyle decisions that include choice of location in which to live. It also has an impact on the extent to which government departments and local service agencies are required to work together, in order to meet common goals which are set and monitored by a government office, whose purpose is to further the wellbeing of a particular group within the population. In this way, the centralised approach would appear to have considerable advantages in making the efforts to achieve suitable housing and support arrangements more cohesive and more purposeful.

## 5 POLICY AND PROGRAM REVIEW

### 5.1 Introduction

This section will briefly address the national and state/territory frameworks for addressing the housing and support requirements of people with complex needs in Australia. The three target groups are dealt with through two different service delivery streams in each State or Territory, with the provision of housing being undertaken by a different department or division within the jurisdictions. There are national frameworks and agreements that determine these, which are discussed first.

### 5.2 Australian Government Frameworks

#### *Mental Health*

The National Mental Health Strategy commenced in 1992, for an initial period of five years, with the aim of reforming service to people with mental illness, both in terms of the quantity and their quality (Whiteford, Buckingham and Manderscheid 2002). The strategy prioritised consumer rights, and looked at areas such as prevention, primary care services, monitoring and accountability, and link between the mental health sector and other sectors. By the end of the five years Federal expenditure on mental health had increased by 55%, with State and Territory increases in funding being less even and varying from 0.1% in Victoria to 38.8% in Western Australia (Whiteford et al. 2002). The Strategy was renewed in 1998 for a further 5 years, and then in 2003 was renegotiated to form the National Mental Health Plan 2003-2008 (Department of Health and Ageing 2002). This plan has adopted a “population health framework”, on the understanding that mental health occurs within the community, is impacted by the community, and also impacts on the community (Australian Health Ministers 2003). As well as reiterating the themes of the first two phases of the National Mental Health Strategy, the Plan requires a ‘whole-of-government’ approach to the delivery of services to people with mental health problems. The plan does not have this as a distinct priority area, but aspects of it are captured within the area of “increasing service responsiveness”. One of the objectives attached to this calls for “improved access to a range of community-based care alternatives” (Australian Health Ministers 2003, 20). Linked to the idea of increasing the range of options for people with mental illness, and for additional services to provide support for people with mental illness, are Objectives 13 and 15, which call for increased rehabilitation options and for the recognition of the role of non-government services in the provision of support (Australian Health Ministers 2003).

Funding for mental health services is the responsibility of the States and Territories, and resources are made available through the various health portfolios. Initiatives such as the Housing Assistance Support Program (HASP) in Victoria, and the current Housing and Support Initiative (HASI) in NSW, are funded through the health departments of those states.

#### *Disability*

The Commonwealth Disability Strategy (CDS) is targeted at Australian Government departments, with the view to making government services accessible to people with disability. The CDS is relevant at the level of departmental policy and practice, but does not provide an overarching framework under which to consider the whole range of issues that concern people with disability, such as inclusion, broad participation in employment, education and civil society etc.

The Commonwealth State/Territory Disability Agreement (CSTDA) is the key framework document for organising and resourcing the various service responses that are provided. The rights of people with disability are articulated within the Principles and Objectives of the Commonwealth Disability Services Act 1987, and subsequently reiterated in the various legislation enacted across the States and Territories following the signing of the Commonwealth State Disability Agreement in 1991:

This provided for the rationalisation of roles and responsibilities for disability services between the Commonwealth and States. Employment programs and funding were maintained as the key Commonwealth government role and accommodation as a State responsibility (Clear 2000, 68).

The purpose of the CSTDA is to determine the level of funding that the various states receive from the Commonwealth to spend on disability services, and to articulate the areas of responsibility taken by each level of government. Initiatives for the provision of ordinary housing are not addressed within the CSTDA, but broad responsibility for addressing accommodation and support for eligible clients falls to the States and Territories.

#### *Home and Community Care (HACC) Program*

In addition to the disability services resources provided through the CSTDA, the Home and Community Care (HACC) Program delivers support to people with disabilities in their own home. The HACC Program is a joint Commonwealth and State/Territory funded initiative, which funds services that are delivered to frail aged people and younger (under 65) people with disabilities to enable them to remain living in the community (HACC 2002). The HACC Program is part of a broader framework of community and health services that are delivered across Australia, and are funded jointly by the Australian and State/Territory governments (HACC 2002). It is administered through the various disability service departments in each State and Territory. The objective of the HACC Program is to provide essential community services to frail aged people and people with disabilities, and “to promote and enhance the independence of people within these client groups wherever possible prior to their admission to long term residential care” (Australian Government Department of Health and Ageing 2004).

#### *Housing*

The Commonwealth State/Territory Housing Agreement is the framework that guides the provision of housing and housing initiatives across Australia, with each State and Territory receiving Commonwealth funds and administering housing services. The Commonwealth Disability Strategy requires all government departments to make their services available and accessible to people with disabilities, so each State and Territory has its own Disability Action Plan.

### **5.3 States and Territories**

This research project will look in some detail at the broad policy frameworks which inform the initiatives to enable people with disability, and those with mental illness, to access housing and the support they require, in order to sustain their tenancies or their home purchase arrangements. For the purpose of this paper the broad legislative and strategic planning framework of each State and Territory is presented in tabular form (see Table 6, page 60), with a brief description provided.

The rights of people with disability to participate on an equal basis with other members of the community, and to have their choices and lifestyles supported by disability services, are articulated within disability services legislation. However, the capacity for the current

disability services legislation to enable Australia to meet its human rights obligations has long been questioned:

In the Commission's view the [Disability Services] Act does not provide a legal framework that advances Australia's efforts to discharge its international human rights commitments. The Act fails to focus on people with a disability themselves and their needs and rights. It focuses instead on funding services which provide disability support (Australian Law Reform Commission 1996).

The end point of campaigns in the 70s and 80s was the enactment of this legislation, in which strong principles of human rights were afforded a priority. Yet the current focus of criticism of reports has been the inability of government departments to deliver the type of outcomes envisaged by the legislation (Coalition for Disability Services 2005).

A further point for consideration is the relationship of guardianship legislation to the delivery of services that people with cognitive impairments may require. In terms of this research this impacts mainly upon people with intellectual disability, and those with mental illness, who have been deemed to have a lack of capacity in decision-making in particular areas of their lives, and for whom a substitute decision-maker has been appointed. The use of guardianship to make available to individuals the services that they require has been noted by Carney and Tait (1997), although this practice is more prevalent in NSW than it is in States such as Victoria, Western Australia and South Australia, where the role of the Public Guardian is taken on by the Public Advocate, who is also charged with investigating complaints about the service system, and making recommendation for systems changes (Carney and Tait 1997).

Mental health legislation serves the function of determining the rights of individuals with mental illness, when they may become unwell, and as such is more about prescribing the limits of intervention that may require the deprivation of liberty, as well as the standards of treatment that a person might expect, than it is about determining a regulatory framework for community-based services. The recent report on mental health services across Australia (MHCA 2005) is scathing about the lack of focus on the provision of many basic services, including housing and support, to respond to the need that has been identified for many years.

Importantly, no legislation regarding the provision of services to people with complex needs provides entitlement to the services that are proscribed. This means that mechanisms other than law are required to meet challenges such as the provision of housing and the support required to assist people with complex needs in that housing. As services are funded to meet broad organisational outcomes, and are accredited against service-based standards, there is little incentive other than goodwill and responding to community pressure to develop the complex networks that are required to make initiatives and responses happen. The existence of arrangements such as memoranda of understanding across government departments, such as exist in NSW between DADHC and Housing, and Health and Housing, go some way to addressing the whole-of-government frameworks that are needed to find solutions for issues like housing and support. However, there appears to be an increasing trend toward more formal action plans and frameworks across government, especially those departments where joint initiatives are common.

## 5.4 Brief analysis of government approaches to housing and support in NSW

### *Policy and Program Frameworks*

This section provides an initial discussion into the approach that is being adopted within one State in Australia, NSW. NSW has been chosen as currently there is significant debate under way regarding the type of accommodation “models” that can be introduced to enable a wider choice to people with disability (largely intellectual disability), while at the same time the Housing and Accommodation Support Initiative (HASI) is being rolled out to enable people with mental illness to live in accommodation in the community, supported by NGOs.

With regard to people with disability the NSW Department of Ageing, Disability and Home Care (DADHC) has embarked upon a process of consultation, beginning with a discussion document entitled, *Models of Supported Accommodation for People with a Disability* (DADHC 2004), which set out a range of supported accommodation “models” that could provide an alternative, and hence a wider range of options, than the current supports available to people with disability. Alternatives to groups homes, large residentials and in-home support (such as attendant care) are being sought because of increased demand, the need for flexibility as individual needs change, a greater emphasis upon community participation as an outcome for those who use services, and increased opportunities for those who have previously lived in institutions, or whose complex health care needs have been unable to met outside medical facilities (DADHC 2004). New responses are also sought for people with “severe challenging behaviours who may put themselves and others at risk of harm” (DADHC 2004, 3).

In relation to people with mental illness the NSW Health’s framework report (2002) provided policy advice and strategic direction, in recognition of the fact that housing stability is sometimes disrupted by poor mental health, and that housing stability can, in turn, make a positive contribution to good mental health. The Housing Accommodation and Support Initiative (HASI) has been funded jointly by the NSW Department of Health and the NSW Department of Housing, to “improve housing stability and community participation for people with mental illness through community based accommodation and coordinated support services” (SPRC 2005, ii).

The Department of Housing is clearly concerned to ensure that its tenants with complex needs are housed successfully and receive the support they require. However, until recently very little funded support existed for people with complex needs to live in, for example, public housing. The recent expansion of the HASI program to target people already living in rental accommodation (known as “HASI II”) represents one of the very few initiatives that specifically aims to assist people with mental illness. Whilst DOH is involved in such initiatives to achieve its social justice charter and to make tenancies work for people with complex needs, it is also required to manage the tenancies of others, and has clearly been required to act against what it regards as “anti-social behaviour” that is sometimes exhibited by people with complex needs who do not receive support. The changes to the Residential Tenancies Act 1987, and the introduction of Acceptable Behaviour Agreements (Department of Housing 2005), could constitute a barrier for those people who require support but cannot obtain it. Whilst not intended to discriminate against people with complex needs, there will be an increasing onus on such tenants to gain support if either they are to access public housing in the first place, and to remain there. The lack of entitlement to services impacts negatively on this possibility. The Department of Housing has tackled the challenges posed by housing people who require supports from agencies and departments outwit its own jurisdiction by entering into agreements, such as the Joint Guarantee of Service for People with Mental Health Disorders or Problems (known as “JAGOS”), along with Aboriginal Housing, DoCS, and NSW Health. The Housing and Human Services Accord has recently been drafted, between Housing and the NSW Human Services Agencies, to identify the people in the

various target groups that require assistance in social housing, to establish the roles of the various departments and agencies and the principles under which they operate, and to determine the governance arrangements across departments and agencies (NSW Department of Housing 2005). This agreement is proposed to cover arrangements with the departments that currently provide support to people in the three target groups that this research is concerned about.

This brief snapshot of NSW indicates a number of things. Firstly, the problem is being addressed by the government departments that have responsibility for disability, mental health and housing respectively. Secondly the problem is viewed differently by each department, with DADHC concerned to fulfil its charter to provide “supported accommodation”, Health concerned about housing and support as part of the overall wellbeing of clients, and Housing concerned to maintain tenancies for its vulnerable tenants, but also to ensure that people with complex needs do not engage in anti-social behaviours. Thirdly, joint agreements and initiatives by all are required to address the various problems, but there appears to be no overarching framework across government that conceptualises the issue from the point of view of the right to inclusion by currently marginalised groups.

## **5.5 Program Resourcing**

Finally, an extremely important consideration, when investigating the approaches taken to meeting the housing and support needs of people with disability, and people with mental illness, are the resources that are provided, usually by governments, to establish and maintain both the housing and support components. This section will provide a brief overview of the range of initiatives and funding programs that are in place to address these issues for the target groups, either directly or as part of a mainstream approach. It is anticipated that the fieldwork will reveal that resource limitations and opportunities will play a significant role in the capacity of the various jurisdictions to address the housing and support needs of people in the three target groups.

The Supported Accommodation Assistance Program (SAAP) is a significant provider of assistance to people who experience homelessness, with the AIHW (2005) estimating that at the end of 2003-2004 there were 1291 SAAP services across Australia, providing support to 1 in every 130 people in Australia. Levels of funding to support people in need of SAAP services in this period totalled just over \$321 million across Australia (AIHW 2005). The current SAAP Agreement, SAAP V, commits approximately \$932 million of Commonwealth money to the program, and \$878 million of State and Territory money over a five year period. There is also a requirement for SAAP to provide better assistance to people with a range of support needs, which may include people in the three target groups (AIHW 2005). There are no disability-specific programs available within SAAP, however, numbers of people with mental illness are provided with support through those initiatives which target homelessness. Despite a continued increase in the funding of SAAP since 1996-1997, at which time funding levels were just over \$200 million per annum, there is still considerable unmet demand for SAAP services. The AIHW (2006) has estimated that 52% of adults and unaccompanied children who apply for immediate SAAP assistance will be turned away on an average day, and this figure rose to 56% when accompanying children were taken into account.

The extent to which SAAP is regarded as one possible funding and program vehicle for addressing the issue of people with disability, and people with mental illness, accessing and maintaining their housing, will be raised during the fieldwork. As accommodation for people in these groups has been considered in the past a matter for specialist provision, there has been little pressure on SAAP from disability and mental health service providers. Assisting people to access and maintain accommodation in the community has largely focused on private rental and social housing provision. Affordability of private rental accommodation is a

significant barrier to people in these groups having ready access to a wide range of options, as is the accessibility of stock for many people. The Commonwealth Rent Assistance (CRA) scheme is a Commonwealth initiative for individuals and families, in the form of a non-taxable income supplement, to enable them to rent properties in the private rental market. In June 2004 24% of Centrelink clients were in receipt of CRA benefits, which pay up to 75 cents for every dollar paid by each “income unit” above the maximum rent threshold (AIHW 2005). In 2003-2004 just under \$2 billion was spent Australia-wide on CRA, an increase from the figure of \$1,788 million in 1994-1995 (AIHW 2005). Assistance such as bond, relocation expenses, cash assistance, as well as advice and information, is available through Commonwealth State Housing Agreement (CSHA) funding (AIHW 2005).

Public Housing is a significant provider of regular accommodation to people with disability and people with mental illness. Funding for public housing authorities is provided by the Commonwealth through the CSHA, and a total of \$1.3 billion was spent by the Commonwealth, States and territories governments in 2004-2005. The Commonwealth’s estimated contribution to the States and Territories through the CSTHA in this period was \$941 million, with a further \$175 million spent on the Supported Accommodation Assistance Program (SAAP) (Family and Community Services, 2005). However, the Commonwealth’s contribution of \$1.3 billion is down significantly from the levels of 1994-1995, where funding was close to \$1.9 billion. Hall and Berry (2004) have studied the effects that the cutbacks in real levels of capital funding are having on the operating budgets of State and Territory housing departments, and conclude that the fall of 25% between 1990-91 and 2000-01 has contributed to the reduction of housing stock in Australia since 1996-97. The research points out that the income (revenue) that housing authorities in Australia have received in the same period has risen by 7.5%, annual spending in real terms has increased by 38.2% on average across all authorities (Hall and Berry 2004). These figures suggest that housing authorities are continuing to address issues of capital acquisition, modification and tenancy, but under tighter funding constraints which are jeopardising the ongoing viability of such operations.

The CSTDA is the source of funding from the Commonwealth for all the States and Territories that is used to provide support in accommodation to people with disability. In 2004-2005 the total spent on disability services across all States and Territories was just over \$3.6 billion (Productivity Commission 2006). The Commonwealth’s estimated contribution to the CSTDA in 2004-2005 was just under \$570 million (Family and Community Services, 2005). The breakdown for the three States where the research fieldwork takes place was as follows:

**Table 5: Funding for disability services 2004-2005**

Type of service/Amount of Funding	NSW	Victoria	Western Australia
Accommodation Support	\$652,826,000	\$515,473,000	\$157,017,000
Community Support	\$85,608,000	\$146,146,000	\$49,720,000
TOTAL service delivery	\$940,030,000	\$922,738,000	\$265,209,000

Funding for mental health support is provided mainly by the States, through their overall Health budgets. In 2003-2004 63% of the total \$3.4 billion was funded by the States, with the Commonwealth contributing \$1.3 billion (Productivity Commission 2006). There is significant variance across States and Territories about the way that resources are allocated, with NSW allocating less than 5% of its mental health budget in 2003-2004 on community residential programs, and even less on non-government organisations, which also provide residential options for people with mental illness (Productivity Commission 2006). This contrasts with Victoria, where around 10% was allocated to NGOs, and over 15% allocated to community residential facilities, and with Tasmania where over 30% was allocated to community

residential facilities. The bulk of funds for mental health are spent on in-patient or other clinical services. It is important to note that it is left to the discretion of each State or Territory jurisdiction to determine how the mental health budget is spent. During the writing of this paper the Council of Australian Governments has considered the current crisis in mental health services across the country, and made a commitment to devise an Action Plan that includes improving funding to the States and Territories. This will be considered in greater length in the Final Paper.

**Table 6: Summary of Interstate disability service, legislative and framework arrangements**

State/Territory	Legislation	Departments	Disability, Mental Health and Housing Frameworks	General Strategic Framework	Integration of frameworks	
					Yes	No
<b>NSW</b>	NSW Disability Services Act 1993  Mental Health Act 1990	Department of Ageing Disability and Home Care Centre for Mental Health (NSW Health) NSW Department of Housing	Disability Action Plan 2000-2002  NSW Mental Health Plan 2005-2010  NSW Interagency Action Plan			
<b>Victoria</b>	Victorian Disability Services Act 1991  Mental Health Act 1986	Department of Human Services (Disability Services Division) Department of Human Services (Mental Health Division) Department of Human Services (Housing Division)	Victorian State Disability Plan 2002-2012  New Directions for Victoria's Mental Health Services 2002-2007 Partnerships for Better Housing Assistance 2004-2009	Growing Victoria Together (2001-2010)	✓	
<b>Western Australia</b>	WA Disability Services Act 1993 Mental Health Act 1996	Disability Services Commission Office of Mental Health (Dept. of Health) Department of Housing and Works	"Partnerships" Roadmap (between Govt and NGOs) Mental Health Strategy 2004-2009 Strategic Housing Policy for People with Disabilities			
<b>Queensland</b>	Queensland Disability Services Act 1992 Mental Health Act 2000	Disability Services Queensland  Queensland Mental Health (Dept. of Health) Department of Housing Queensland	Strategic Framework for Disability 2000-2005  Queensland Health Mental Health Strategic Plan 2003-2008 Strategic Plan for People with Disability 2001-2006 Joint Ministerial Statement (Housing and Disability) leading to Memorandum of Understanding	SmartHousing		✓

State/Territory	Legislation	Departments	Disability, Mental Health and Housing Frameworks	General Strategic Framework	Integration of frameworks	
					Yes	No
<b>South Australia</b>	SA Disability Services Act 1993 South Australia Mental Health Act 1993	Department of Families and Communities Office of Social and Community Housing (DFC)	Disability Framework 2002-2007  Affordable Housing Innovations Project	Social Inclusion Initiative		✓
<b>Tasmania</b>	Tasmanian Disability Services Act 1992 Mental Health Act 1996	Department of Health and Human Services (disability, mental health and housing)	Disability Framework for Action (Dept. of Premier and Cabinet) Strategic Plan 2005-2010 Affordable Housing Strategy 2004-2008	Tasmania Together		✓
<b>Northern Territory</b>	NT Disability Services Act 2003 NT Mental Health and Related Services Act 2002	Department of Health and Community Services (disability and mental health) Territory Housing (Dept of Local Govt., Housing and Sport)	Strong Creative Communities – Strategic Plan 2005-2008			
<b>ACT</b>	ACT Disability Services Act 1991 ACT Mental Health (Treatment and Care) Act 1994	Department of Disability, Housing and Community ACT Health  Department of Disability, Housing and Community	Challenge 2014 (Disability framework) ACT Mental Health Strategy 2003-2008			

## **6 METHODOLOGY**

### **6.1 Introduction**

This chapter describes the methodology of the study. It reviews the methods adopted by the current study to gather knowledge about initiatives that have successfully achieved a seamless match between the provision of housing and support to people with complex needs, both internationally and in Australia, and to identify the particular policy contexts in which these initiatives operate, whilst at the same time aiming to inform policy such that future initiatives can focus on the availability of “ordinary” housing to people with complex needs.

### **6.2 Brief summary – benchmarks and indicators**

This paper has sought to present the issue of housing and support provision to people with complex needs as more than one of program delivery through government departments. Rather, utilising a social model framework, it becomes a problem of achieving inclusion for people who have traditionally been marginalised from society. Housing and support represent, therefore, both an end and a means by which much greater participation can be enjoyed.

Models of housing and support in some other jurisdictions clearly aim to meet broader goals of social inclusion, which match the overall goal for participation that is promoted by the social model. These broader social policy and political contexts result in more ambitious and wide-ranging strategic plans, which may influence in turn the plans of other departments and agencies. Attached to the notion of strategic plans is the performance indicator, the benchmark which has to be reached in order to determine if progress is being made. The research will investigate what broad outcomes are envisaged across the States and Territories in Australia, and what are the indicators of success that the various departmental officers believe effectively reflect a strategy that is working. Added to this will be consideration of how the unique, individual needs and aspirations of people with complex needs are acknowledged and counted amongst the broad indicators of success or otherwise.

### **6.3 Methodological and Methods Overview**

The purpose of this positioning paper has been to demonstrate that the provision of housing and support to people with complex needs, in this case those with physical disability, intellectual disability, and mental illness, is a topic which garners a range of perspectives and approaches. It has set out to illustrate that a number of important paradigms tend to be missing, or at least de-emphasised, when considering the issues from the point of view of service provision, and that for many people with disability the achievement of successful housing is a struggle for equality of opportunity, and the starting point for independent living and the capacity to participate in other aspects of social life. The inclusion of social model and perspectives of social exclusion within consideration about housing and support would render indicators of success that value quality of life improvements, and measures of social participation, equally as important as statistics regarding increased tenancies and reduced crisis interventions.

Section 2.4 details the realist synthesis approach which Pawson et al (2004) advocate for adoption when evaluating programs and initiatives, and which is being broadly used to determine the approach taken to considering the initiatives of housing and support that this research uncovers. The findings from interviews and additional policy review data will be

synthesised according to the principles that Pawson et al (2004) describe, attempting to achieve a rich description of contextual factors that are relevant to the initiatives and approaches that have been found. A strong emphasis will be placed on the relationship between broad social policy regarding people with disability and people with mental illness, in terms of their inclusion and participation in society, and the specific policies that require program or other resource implementation, most importantly those that focus on housing and the provision of supports. Given the importance that Pawson et al (2004) accord to the theoretical underpinnings of policies and approaches, consideration will be given to any paradigms or philosophies that inform the approaches taken, in particular, by service departments which are responsible for the development of policy and the funding of responses to meet the needs of clients. Any clashes between policies, or policy directions, will be noted, as will clear barriers to implementing policies if they clash with broader political directives. Where thinking has altered, such that paradigms have shifted, this too will be examined.

The main methodology used throughout this research is qualitative, with the use of secondary data review, literature, policy and document review, as well as telephone and face-to-face interviews. The perspective of this project places a strong emphasis upon the views and experiences of people with complex needs, and to a large extent the project aims to achieve policy changes that will bring about better outcomes in housing and support for people with disability, and those with mental illness. However, the scope of this research does not allow for detailed consultation with clients of services that support people in housing, although peak bodies that broadly represent the systemic issues of people with disability and those with mental illness will be consulted.

#### *Literature, document and policy reviews*

The literature review was conducted using a variety of methods, including the existing knowledge and resources of the researcher, and recommendations for research by the extensive network of contacts relevant to both disability and housing issues. In addition Internet search engines were utilised to identify housing and support initiatives that were relevant to people with disability, and to people with mental illness. To date the review has determined that current policy approaches to the provision of housing and support to people with complex needs in Australia is often limited to considerations of “models” of service provision. There is an understanding that whole-of government approaches are required to cover the range of support and housing issues that need to be addressed to make such arrangements work successfully. Many of the factors that assist in successful approaches have been captured by previous research, and are presented in the current positioning paper. In addition, the paper has attempted to articulate a range of current and emerging disability service paradigms, consistent with disability service legislation, that frame differently the issue of access to housing people with complex needs should enjoy. The perspective of the social model brings the issue of rights to the fore. The literature has also analysed the broad political and social policy contexts in which the issues of housing provision and the delivery of support are viewed and addressed.

To a large extent the literature review and policy review presented in this positioning paper has addressed the concerns of the first question:

1) What alternative paradigms, beyond the application of good housing models simultaneous with good quality support services, can be applied to the determination of whether support and housing arrangements for people with complex needs can be viewed as successful and “seamless”?

#### *Policy and Documentation Review/Telephone Interviews*

Some initial policy and documentation review has taken place within the positioning paper, after retrieval of documents from literature searches. The second part of the research

involves telephone interviews with key informants from within State and Territory government departments responsible for disability and mental health services, and for housing. In addition, telephone interviews will be held with departmental equivalents within the Commonwealth Government, and representatives of the Real Estate Industry of Australia will be contacted also. The purpose of these interviews will be to determine what initiatives exist at a broad level across Australia, that assist people with complex needs to access and be maintained in “ordinary” housing, and to access any policy or other strategic documentation that relates to this. Specifically the telephone interviews will address the following questions, which have already been partially addressed within the positioning paper:

3) What broad housing options, both social/public housing and private housing, rental and purchase, are in place where linkages between housing and support for people with complex needs are successful, and what mechanisms ensure the continued provision of accessible housing stock and the ability to fund support to people living in fully or partially owned private housing?

4) What factors contribute to the successful coordination and delivery of housing and support to people in these target groups, in terms of particular support service and housing initiatives, and collaboration and cooperation by governments, between government departments, and services across and within sectors?

5) To what extent are the factors that determine success for people with complex needs, present in initiatives of support and housing to people in the three target groups across Australia, through consideration of particular initiatives delivered in each of the States and Territories?

#### *International Case Study*

The research aims to provide some evidence of initiatives “in action”, and the positioning paper has indicated that both New Zealand and the United Kingdom have broad social policy frameworks that provide an umbrella for the issue of housing and support to people with complex needs to be addressed. Both also have a centralised government overseeing policy, and funding local authorities to fund and/or implement the programs of support and housing. However, the UK framework is considerably further advanced than that of New Zealand, and the research will focus on two case studies within the UK to enable a comparison between initiatives conducted within a metropolitan area, and in a regional/rural area.

As well as addressing the questions relating to the factors that contribute to successful housing and support outcomes for people with complex needs, the case studies will answer the following question:

2) What benchmarks, or other markers of standards or quality need to be reached in order to determine the success of both housing arrangements and support arrangements, and the combination of both, which take account of objectively agreed outcomes and subjective wellbeing?

#### *Fieldwork Interviews*

The research project enables detailed interviews to be conducted within three States in Australia; Western Australia, Victoria and New South Wales. Interviews will be held with departmental officials in each of these States, representing the various departments that support people with disability and mental illness, and those which have responsibility for housing. Peak bodies in each State will also be contacted and interviewed. In addition to the previous questions, the interviews seek to gain information about the following questions:

6) By investigating initiatives in three states (NSW, WA and Victoria), how do the means of entry into support services and housing, and the methods of maintenance and support once there, impact on clients within such initiatives? To what extent do such initiatives differ in regional and rural areas, and how might future directions need to take account of regional differences?

7) What modifications to service and housing initiatives, and to collaborative and cooperative arrangements across governments, across government departments and across and within service sectors, need to be made to achieve a seamless on-the-ground delivery of support and housing to people with complex needs?

The three States have been chosen because of the proportion of the Australian population that they house (especially NSW and Victoria), the diverse geography of each (and in particular WA, for its size and the remoteness of many regions), their bureaucratic organisation, and the historical precedent that underpins the development of their various service systems. In all 3 States an initial review of the current structure of the systems that guide housing and support for all three target groups will be conducted. In addition the detailed fieldwork will be conducted because of the following characteristics:

- **Western Australia** has a Local Area Coordination (LAC) program, which aims to match people with disabilities (mainly intellectual) to services that will directly meet their needs. The capacity of a service-led, individualised initiative to address issues of access to mainstream housing will be looked at.
- **Victoria** has a well-established program of housing and support assistance to people with mental illness. The Housing and Support Program (HASP) has been in existence for over ten years, and has been evaluated twice. The longevity of this program provides an opportunity for questioning about the challenges that have presented themselves within this timeframe, and there will be consideration of how political and policy changes, as well as current community concern over mental health, has impacted on the way the initiative in Victoria is run and resourced.
- **NSW** has recently embarked on a similar initiative for people with mental illness (Housing and Support Initiative – HASI), which has been partially evaluated, and is also concerned with developing “models” of accommodation for people with disability, beyond the group home. Interviews within NSW shall canvas disability and mental health services, as well as housing, and there will, in addition, be a specific focus on initiatives that assist people with physical disability.

Fieldwork in the three States will provide opportunities to understand the issues that help and hinder the provision of seamless housing and support to people with complex needs, both within government departments, and across the services and agencies that are in place to enable the support arrangements to take place. In addition, any differences between approaches taken in regional and metropolitan areas will be recorded, through interviews with key players in chosen areas in each State.

A summary of the research questions, and the methods used to address them, is presented in Table 7.

**Table 7: Research questions and methods**

<b>Research Question</b>	<b>Literature Review</b>	<b>Policy Review</b>	<b>Document Review</b>	<b>International Case Study</b>	<b>Telephone Interviews</b>	<b>Interstate Interviews</b>
What alternative paradigms, beyond the application of good housing models simultaneous with good quality support services, can be applied to the determination of whether support and housing arrangements for people with complex needs can be viewed as successful and “seamless”?	✓			✓		✓
What benchmarks, or other markers of standards or quality need to be reached in order to determine the success of both housing arrangements and support arrangements, and the combination of both, which take account of objectively agreed outcomes and subjective wellbeing?		✓	✓	✓	✓	✓
What broad housing options, both social/public housing and private housing, rental and purchase, are in place where linkages between housing and support for people with complex needs are successful, and what mechanisms ensure the continued provision of accessible housing stock and the ability to fund support to people living in fully or partially owned private housing?	✓			✓	✓	✓
What factors contribute to the successful coordination and delivery of housing and support to people in these target groups, in terms of particular support service and housing initiatives, and collaboration and cooperation by governments, between government departments, and services across and within sectors?	✓	✓	✓	✓	✓	✓
To what extent are the factors that determine success for people with complex needs, present in initiatives of support and housing to people in the two target groups across Australia, through consideration of particular initiatives delivered in each of the States and Territories?		✓	✓			✓

<b>Research Question</b>	<b>Literature Review</b>	<b>Policy Review</b>	<b>Document Review</b>	<b>International Case Study</b>	<b>Telephone Interviews</b>	<b>Interstate Interviews</b>
By investigating initiatives in three states (NSW, WA and Victoria), how do the means of entry into support services and housing, and the methods of maintenance and support once there, impact on clients within such initiatives? To what extent do such initiatives differ in regional and rural areas, and how might future directions need to take account of regional differences?		✓	✓			✓
What modifications to service and housing initiatives, and to collaborative and cooperative arrangements across governments, across government departments and across and within service sectors, need to be made to achieve a seamless on-the-ground delivery of support and housing to people with complex needs?	✓	✓	✓		✓	✓

## REFERENCES

- Anderson, I. 2000. Housing and social exclusion: the changing debate, in I. Anderson and D. Sim (eds), *Social Exclusion and Housing: Context and Challenges*, Chartered Institute of Housing and The Housing Studies Association, Coventry, pp. 6-21.
- Arthurson, K. and Jacobs, K. 2003. *Social Exclusion and Housing*, Australian Housing and Urban Research Institute, Southern Research Centre.
- Askheim, O. P. 2005. Personal assistance – direct payments or alternative public service. Does it matter for the promotion of user control?, *Disability and Society*, Vol. 20. No. 3, pp. 247-260.
- Australian Government Department of Health and Ageing (2004). *Home and Community Care Program minimum Data Set 2003-2004 Annual Bulletin*. Australian Government Department of Health and Ageing, Canberra.
- Australian Health Ministers. National Mental Health Plan 2003-2008, Australian Government, Canberra 2003.
- Australian Institute of Health and Welfare (AIHW) 2003. *Australia's Welfare 2003*, AIHW, Canberra.
- Australian Institute of Health and Welfare (AIHW) 2005. *Australia's Welfare 2005*, AIHW, Canberra.
- Australian Institute of Health and Welfare (AIHW) 2006. Demand for SAAP accommodation by homeless people 2003-2004, *Bulletin*, Issue 34.
- Australian Law Reform Commission. 1996. *Making Rights Count: Services for people with a disability*, Review of legislation administered by the Department of Health and Family Services, Commonwealth of Australia, Canberra, Report No. 79.
- Autism Living and Working (ALAW Incorporated) 2005. Self Determined Housing (home page), available [online]: <http://www.autismlivingworking.org/Self-Determined.htm>
- Bachrach, L. 1985. Deinstitutionalisation: The Meaning of the Least Restrictive Environment, in Bruininks, R & Laken, K. (eds.), *Living and Learning in the Least Restrictive Environment*, Brooks, Baltimore, pp 23-35.
- Barnes, C. 1991. *Disabled People in Britain and Discrimination: A Case for Anti-Discrimination Legislation*, Hurst and Co., London.
- Barnes, C. 2004. Reflections on Doing Emancipatory Disability Research, in J. Swain, S. French, C. Barnes and C. Thomas (eds), *Disabling Barriers – Enabling Environments (2<sup>nd</sup> Edition)*, Sage Publications, London, pp. 47-53.
- Barnes, C. and Mercer, G. 2003. *Disability*, Polity Press, Cambridge
- Barnes, C. and Mercer, G. and Shakespeare, T. 1999. *Exploring Disability: A Sociological Introduction*, Polity Press, Cambridge.

Beneke, K. 1999. Housing and Independence: How Innovative CILs Are Breaking Down Barriers to Housing for People with Disabilities, Independent Living Research Utilization, available [online]:[www.ilru.org/html/publications/readings\\_in\\_IL/housing.html](http://www.ilru.org/html/publications/readings_in_IL/housing.html)

Bessant, J., Coupland, H., Dalton, T., Maher, L., Rows, J. and Watts, R. 2003. *Heroin users, housing and social participation: attacking social exclusion through better housing*, Australian Housing and Urban Research Institute, RMIT-NATSEM Research Centre.

Bessant, J., Watts, R., Dalton, T. and Smyth, P. 2005. *Talking Policy: How social policy is made*, Allen and Unwin, Crows Nest.

Bogdan, R. & Taylor, S.J. 1994. *The social meaning of mental retardation: Two life stories*, Teachers College Press, New York.

Braddock, D., Rizzolo, M., Hemp, R. and Parish, S. 2004. Public Spending for Developmental Disabilities in the United States, in R. Stancliffe and K. Lakin (eds), *Costs and Outcomes of Community Services for People with Intellectual Disabilities*, Paul H. Brookes Publishing Co., Baltimore, pp. 22-44.

Bridge, C., Kendig, H., Quine, S. and Parsons, A. 2002. *Housing and care for older and younger adults with disabilities*, Australian Housing and Urban Research Institute, Sydney Research Centre.

British Columbia Coalition of People with Disabilities (BCCPD) 2005. Individualized Funding Web-Based Resource Centre, available [online]:  
<http://www.bccpd.bc.ca/s/IFP.asp?ReportID=86255>

Bostock, L., Gleeson, B., McPherson, A. and Pang, L. 2001. *Deinstitutionalisation and housing futures: final report*, Australian Housing and Urban Research Institute, UNSW-UWS Research Centre.

Campbell D.T. and Russo, M.J. (eds). 1999. *Social Experimentation*, Sage, Thousand Oaks.

Carney, T. and Tait, D. 1997. *The Adult Guardianship Experiment: Tribunals and Popular Justice*, The Federation Press, Sydney.

Clear, M. (ed) 2000. *Promises Promises: Disability and Terms of Inclusion*, Federation Press, Sydney.

Coalition for Disability Services. 2005. *An End to the Silence: The Crisis in Supported Accommodation for People with a Disability in NSW*, Coalition for Disability Services, NSW.

*Cochrane Reviewers' Handbook 4.2.0*. (updated March 2004). The Cochrane Library

Cocks, E. 1994. *Encouraging a paradigm Shift in Services for People with Disabilities*, Centre for the Development of Human Resources, Edith Cowan University, Social Research and Development Monograph No. 9.

Communities Scotland. 2004. *Mind the gap: evaluation of owner occupation for disabled people in Scotland*, Research and Evaluation Department Communities Scotland, Edinburgh.

Cox, E. 1995. *A Truly Civil Society: The 1995 Boyer Lectures*, ABC Books, Sydney.

Crawford, C. 2004. *Gathering Momentum: Mobilizing to Transform Community in B.C.*, Roeher Institute, Toronto.

Crow, L. 1996. Including All of Our Lives: Renewing the social model of disability, in J. Morris (ed.), *Encounters with Strangers: Feminism and Disability*, The Women's Press, London.

Dalton, T., Draper, M., Weeks, W. and Wiseman, J. 1996. *Making Social Policy in Australia: An introduction*, Allen and Unwin, St. Leonards.

Department of ageing Disability and Home Care (DADHC). 2004. *Models of Supported Accommodation for People with a Disability*, available [online]: <http://www.dadhc.nsw.gov.au/DADHC.htm>

Department of Health (UK) 2001. *Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century*, available [online]: [www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf](http://www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf)

Department of Health and Ageing. 2002. National Mental Health Strategy (information), available [online]: [www.health.gov.au/internet/wcms/publishing.nsf/Content/mentalhealth-mhinfo-nmhs-index.htm](http://www.health.gov.au/internet/wcms/publishing.nsf/Content/mentalhealth-mhinfo-nmhs-index.htm)

directgov 2005. Disabled People, available [online]: [www.direct.gov.uk](http://www.direct.gov.uk)

Disability Advisory Council (Victorian Government Department of Human Services) 2004. *Experiences of inappropriate accommodation support for people with a disability*, Department of Human Services, Victoria.

Disability Support and Housing Alliance. 2001. *Living not existing: Flexible support and housing for people with a disability*, DSHA, Victoria.

Dowson, S. and Salisbury, B. 2001. *Foundations for Freedom: International Perspectives on Self-Determination and Individualized Funding*. Baltimore: TASH.

Drake, R. F. 1999. *Understanding Disability Policies*, Macmillan Press Ltd, Hampshire.

Edgar, B., Doherty, J. and Meert, H. 2002. *Access to Housing: Homelessness and vulnerability in Europe*, The Policy Press, Bristol.

Everett, S. 2003. The Policy Cycle: Democratic Process of Rational Paradigm Revisited?, *Australian Journal of Public Administration*, Vol. 62, No. 2, pp. 65-70.

Family and Community Services. 2005. *Department of Community Services Budget Statement: 2004-2005*, available, [online]: [http://www.facs.gov.au/internet/facsinternet.nsf/VIA/budget2004-05/\\$File/05partc\\_budget\\_statement.pdf](http://www.facs.gov.au/internet/facsinternet.nsf/VIA/budget2004-05/$File/05partc_budget_statement.pdf)

Fannie Mae. 2005. Affordable Housing Solutions – Loans for People with Disabilities (Home Page), available [online]: <http://www.fanniemae.com/housingcommdev/solutions/loansdisabilities.jhtml?p=Affordable+Housing+%26+Community+Development&s=Affordable+Housing+Solutions&t=Loans+for+People+with+Disabilities>

Fine, M. 2005. Individualization, risk and the body: sociology and care, *Journal of Sociology*, Vol. 41, No. 3, pp. 247-266.

Foucault, M. 1975. *The Birth of the Clinic: An Archaeology of Medical Perception*, Vintage books, New York.

Gardner, J. 2004. "Client complexity, compulsory care and human rights", conference paper delivered at the Australian Guardianship and Administration Committee Symposium on Clients with complex and exceptional needs: the challenge for policy makers, administrators and service providers, 30<sup>th</sup> April 2004, Adelaide.

Giddens, A. (ed) 2001. *The Global Third Way Debate*, Polity Press, Cambridge.

Gleeson, B. 1998. Disability and Poverty, in R. Fincher and J. Nieuwenhuysen (eds.), *Australian Poverty: then and now*, Melbourne University Press, Carlton, pp. 314-333.

Gleeson, B. 1999. *Geographies of Disability*, Routledge, London.

Goggin, G. and Newell, C. 2005. *Disability in Australia: Exposing a social apartheid*, UNSW Press, Sydney.

Goodley, D. 2004. Who is disabled? Exploring the cope of the social model of disability, in J. Swain, S. French, C. Barnes and C. Thomas (eds), *Disabling Barriers – Enabling Environments (2<sup>nd</sup> Edition)*, Sage Publications, London, pp. 118-124.

Hagner, D. and Klein, J. 2005. Home Ownership for Individuals with Disabilities: Factors in Mortgage Decisions, in *Journal of Disability Policy Studies*, Vol. 15, No. 4, pp. 194-200.

Hall, J. and Berry, M. 2004. *Operating Deficits and Public Housing: Policy Options for Reversing the Trend*, Australian Housing and Urban Research Institute, RMIT-NATSEM Research Centre.

Head, M. and Conroy, J. 2004. Outcomes of Self-Determination in Michigan: Quality and Costs, in R. Stancliffe and K. Lakin (eds), *Costs and Outcomes of Community Services for People with Intellectual Disabilities*, Paul H. Brookes Publishing Co., Baltimore, pp. 219-240.

Herd, D., Ward, M. and Seeger, B. 2003. Included by design: A national strategy for accessible housing for all, paper presented at the National Housing Conference, Adelaide, November 2003, available [online]: [www.anuhd.org/national\\_housing\\_conference03\\_paper.html](http://www.anuhd.org/national_housing_conference03_paper.html)

Home and Community Care Program. 2002a. *HACC National Guidelines Summary*. Canberra: Commonwealth of Australia. Available [online]: [www.health.gov.au/internet/wcms/publishing.nsf/Content/hacc-pub\\_pg\\_npg.htm/\\$file/pg\\_npgsm.pdf](http://www.health.gov.au/internet/wcms/publishing.nsf/Content/hacc-pub_pg_npg.htm/$file/pg_npgsm.pdf)

Home Office (UK) 2005. *The Respect Action Plan*, available [online]: <http://www.homeoffice.gov.uk/documents/respect-action-plan>

Houghton, T. 2001. The New York/New York Agreement Cost Study: The Impact of Supportive Housing on Services Use for Homeless Mentally Ill Individuals

Housing and Urban Development, Department of (US) (HUD). 2005. Home Page – people with disabilities, available [online]: <http://www.hud.gov/groups/disabilities.cfm>

Hughes, B. and Paterson, K. 1997. The Social Model of Disability and the Disappearing Body: towards a sociology of impairment, *Disability and Society*, Vol. 12, No. 3, pp. 325-340.

Hurst, R. 2000. To Revise or Not to Revise?, *Disability and Society*, Vol. 15, No. 7, pp. 1083-1087.

Human Services Research Institute. 1999. *The Robert Wood Johnson Foundation Self-Determination Initiative: Year One Impact Assessment Report*, Human Service Research Institute, New Jersey.

Independent Living USA. 2005. Independent Living Centres – home page, available [online]: [www.ilusa.com/links/ilcenters.htm](http://www.ilusa.com/links/ilcenters.htm)

Jacobs, K. and Arthurson, K. 2003. *Developing effective housing management policies to address problems of anti-social behaviour*, Australian Housing and Urban Research Institute, Southern Research Centre.

Jones, A. and Seelig, T. 2005. *Enhancing research-policy linkages in Australian housing: an options paper*, Australian Housing and Urban Research Institute, Queensland Research Centre.

Lakin, K., Hewitt, A., Larson, S. and Stancliffe, R. 2004. Home and Community-Based Services: Costs, Utilization, and Outcomes, in R. Stancliffe and K. Lakin (eds), *Costs and Outcomes of Community Services for People with Intellectual Disabilities*, Paul H. Brookes Publishing Co., Baltimore, pp. 91-127.

Latham, M. 1999. From a trapeze net to a trampoline, *Access*, Vol. 1, No. 5, pp. 6-7.

Litwinowicz, J. 1999. In My Mind's Eye: III – Early days of parenting, in M. Wates and R. Jade (eds), *Bigger than the sky: Disabled Women on Parenting*, The Women's Press, London.

Lyons, M. 2001. *The commonwealth government and charities: conspiracy or confusion?*, available [online]: [http://www.accord.org.au/social/commentaries/conspiracy\\_confusion.html](http://www.accord.org.au/social/commentaries/conspiracy_confusion.html) Accessed 05/09/05

McDermott Miller. 2005. *Housing Choices for Disabled New Zealanders*, Centre for Housing Research, Aotearoa.

Martinez, E. and Garcia, A. 2000. What is "Neo-Liberalism"? A Brief Definition, available [online]: [www.globalexchange.org/campaigns/econ101/neoliberalDefined.html](http://www.globalexchange.org/campaigns/econ101/neoliberalDefined.html)

Mental Health Council of Australia. 2005. *Not For service: Experiences of Injustice and Despair in Mental Health Care in Australia*, MHCA, ACT.

Ministry of Health (NZ) 2003. *Individualised Funding: Guidance and Good Practice*, Ministry of Health, Wellington.

Morris, J. (ed.) 1996. *Encounters with Strangers: Feminism and Disability*, The Women's Press Ltd, London.

Multicultural Disability Advocacy Association. 2003. *Hitting the Roof*, MDAA, Harris Park.

Mulvaney, J. 1997. *Housing Needs of the Mentally Ill*, Swinburne Centre for Urban and Social Research, Melbourne.

Mulvaney, J. 1998. Psychiatric disability and community based care, *Health matters: A sociology of illness, prevention and care*, eds. A. Peterson and C. Waddell, Allen and Unwin, Sydney, pp. 256-271.

- National Home of Your Own Alliance. 2005. Home Page, available [online]: <http://alliance.unh.edu/nhoyo.html>
- National Housing Federation. 2004. *Level Threshold: towards equality in housing services for disabled people*, available [online]: [www.habinteg.org.uk/pages/levelthreshold.html](http://www.habinteg.org.uk/pages/levelthreshold.html)
- Neighbourhood Renewal Unit. 2004. Local Strategic Partnerships, available [online]: [www.neighbourhood.gov.uk/partnerships.asp](http://www.neighbourhood.gov.uk/partnerships.asp)
- NSW Department of Housing. 2005. *NSW Housing and Human Services Accord (the Accord)*, available [online]: <http://www.housing.nsw.gov.au/newspublications/ReshapingPublicHousing/Human%20Services%20Accord.pdf>
- NSW Health Department 2002. *Framework for Housing and Accommodation Support for People with Mental Health Problems and Disorders*, NSW Government Action Plan, Sydney.
- NSW Parliament. Legislative Council. Standing Committee on Social Issues. 2002. *Making It Happen: final report on disability services*, Sydney, Report No. 28.
- New Zealand Disability Strategy 2001, available [online]: [www.odt.govt.nz](http://www.odt.govt.nz)
- New Zealand Ministry of Health. 2005. Disability in New Zealand, available [online]: [www.moh.govt.nz/disability](http://www.moh.govt.nz/disability)
- New Zealand Office for Disability Issues 2005. Home Page, available [online]: [www.odt.govt.nz](http://www.odt.govt.nz)
- Nirje, B. 1985. "The Basis and Logic of the Normalization Principle", *Australia and New Zealand Journal of Developmental Disabilities*, Vol. 11, No. 2, pp 65-68.
- O'Brien, A., Inglis, S., Herbert, T. and Reynolds, A. 2002. *Linkages between housing and support – what is important from the perspectives of people living with a mental illness*, Australian Housing and Urban Research Institute, Swinburne-Monash Research Centre, Ecumenical Housing Inc.
- O'Brien, J. and Lovett, H. 2000. Finding A Way Towards Everyday Lives: The Contribution of Person-centred planning. In O'Brien, J. and O'Brien C.L. (eds.), *A Little Book about Person Centred Planning*. Toronto: Inclusion Press.
- Oliver, Michael 1990. *The Politics of Disablement*, The Macmillan Press, London.
- Oliver, M. 1996. *Understanding Disability: from theory to practice*, Macmillan Press Ltd, Hampshire.
- Options Consulting. 2001. *Housing and Supports for People with Physical Disabilities: A Planning Framework for the Vancouver/Richmond Health Region*, Vancouver/Richmond Health Board, Vancouver.
- Parker, S. and Cass, B. 2005. New Paradigms of Disability in Social Security Law and Policy in Australia: Implications for Participation, in *Disability Studies Quarterly*, forthcoming publication.

Pawson, R., Greenhalgh, T., Harvey, G. and Walshe, K. 2004. *Realist synthesis: an introduction*, ESRC Research Methods Programme, University of Manchester, available [online]: [www.ccsr.ac.uk/methods](http://www.ccsr.ac.uk/methods)

Perry, L. 2000. *What is a Vela Microboard?* [Online]. Available: <http://www.microboard.org>

Perske, R. 1972. The dignity of risk, in W. Wolfensberger (Ed.), *The principle of normalization in human services*, (pp. 194 - 200), National Institute of Mental Retardation, Toronto.

Pfeiffer, D. 1998. The ICIDH and the Need for its Revision, *Disability and Society*, Vol. 13, No. 4, pp 503-523.

Pfeiffer, D. 2000. The Devils are in the Details: the CICH2 and the disability movement, *Disability and Society*, Vol. 15, NO. 7, pp. 1079-1082.

Porter, B. 2003. The Right to Adequate Housing in Canada, Centre for Urban and Community Studies, Research Bulletin #4.

Productivity Commission 2003. *Social Capital: Reviewing the Concept and its Policy Implications*, Research Paper, Ausinfo, Canberra.

Productivity Commission. 2006. *Review of Government Service Provision*, available [online]: <http://www.pc.gov.au/gsp/reports/rogs/2006/>

Rankin, J. and Regan, S. 2005. Meeting complex needs in social care, Institute for Public policy Research, available [online]: [www.ippr.org.uk/articles/index.php?article=211](http://www.ippr.org.uk/articles/index.php?article=211).

Rapley, M. and Baldwin, S. 1995. Normalisation - Metatheory or Metaphysics: a Conceptual Critique, in *Australia and New Zealand Journal of Developmental Disabilities*, Vol. 20, No. 2, pp. 141-157.

Rapley, M. and Ridgeway, J. 1998. 'Quality of Life' Talk and the Corporatisation of Intellectual Disability, in *Disability and Society*, Vol. 13, No. 3, pp. 451-471.

Reynolds, A., Inglis, S. and O'Brien, A. 2002. *Effective Programme Linkages – An examination of current knowledge with a particular emphasis on people with mental illness*, Australian Housing and Urban Research Institute, AHURI Swinburne-Monash Research Centre and Ecumenical Housing Inc.

Rioux, M. 2004. Disability and Human Rights, *Perspective*, available [online]: [www.abc.net/au/rn/talks/perspective/stories/s1043538.htm](http://www.abc.net/au/rn/talks/perspective/stories/s1043538.htm)

Ritzer, G. 1992. *Contemporary Sociological Theory (3<sup>rd</sup> Edition)*, McGraw Hill Inc., New York.

Robinson, C. 2003. *Understanding Iterative Homelessness: The case of people with mental disorders*, Australian Housing and Urban Research Institute, UNSW-UWS Research Centre.

Roeher Institute 1990. *Poor Places: Disability-related residential and support services*, The G. Allan Roeher Institute, York University, Ontario.

Ryan, J. and Thomas, F. 1980. *The Politics of Mental Handicap*, Penguin Books, Harmondsworth, England.

Salford City Council. 2005. Supporting People (home page), available [online]: <http://www.salford.gov.uk/living/housing/sup-people.htm>

Saunders, P. 2004. *Australia's Welfare Habit: And how to kick it*, Duffy and Snellgrove, Sydney.

Shaddock, T. (2001). Self-Determination Trends in Australia. In *Common Sense*, Issue 8, pp. 19-21.

Shakespeare, T. and Watson, N. 1997. Defending the Social Model, *Disability and Society*, Vol. 12, No. 2, pp. 293-300.

Shapiro, J. 1993. *No Pity: People with Disabilities Forging a New Civil Rights Movement*, Three Rivers Press, New York.

Shelter Northern Ireland 2005. "Complex Needs", available [online]: <http://northernireland.shelter.org.uk/advice/advice-1316.cfm>, accessed 14/01/05

Social Exclusion Unit. 2005. Home Page, available [online]: [www.socialexclusion.gov.uk](http://www.socialexclusion.gov.uk)

Social Exclusion Unit. 2004. *Mental Health and Social Exclusion*, available [online]: [www.socialexclusion.gov.uk/page.asp?id=257](http://www.socialexclusion.gov.uk/page.asp?id=257)

Social Policy Research Centre (SPRC). 2005. *Housing and Accommodation Support Initiative: Report 1: Summary*, Social Policy Research Centre, Sydney.

Spandler, H. and Vick, N. 2004. *Implementing direct payments in mental health: An evaluation*, HASCAS, London.

Stancliffe, R. and Lakin, K. 2004. Context and Issues in Research on Expenditures and Outcomes of Community Supports, in R. Stancliffe and K. Lakin (eds), *Costs and Outcomes of Community Services for People with Intellectual Disabilities*, Paul H. Brookes Publishing Co., Baltimore, pp. 1-22.

Starr, A. 2005. *Report by Amelia Starr, Churchill Fellow, 2003-2004*, The Winston Churchill Memorial Trust of Australia.

Stella, L. 1996. Normalisation and Beyond: Public Sector Residential Care 1965-1990, in E. Cocks, C. Fox, M. Brogan and M. Lee (eds.), *Under Blue Skies: the social construction of intellectual disability in Western Australia*, Edith Cowan University, Western Australia.

Stewart, J. 2004. Housing and Independent Living, in J. Swain, S. French, C. Barnes and C. Thomas (eds), *Disabling Barriers – Enabling Environments (2<sup>nd</sup> Edition)*, Sage Publications, London, pp. 149-154.

Stienstra, D, and Wiebe, R. 2004. *Finding Our Way home: Housing Options in Inner-City Winnipeg for People with Disabilities who are Dying*, Canadian Centre on Disability Studies and Winnipeg Inner City Research Alliance, Winnipeg.

Supporting People 2004. *What is Supporting People?*, Supporting People, Supporting Independence, Office of the Deputy Prime minister (UK), available [online]: <http://www.spkweb.org.uk/NR/rdonlyres/06E6FD41-4804-4B78-BDD9-343EC58117A2/4165/WhatisSuppPeopleLP.pdf>

Treanor, P. 2005 *Neoliberalism: origins, theory, definitions*, available [online]: <http://web.inter.nl.net/users/Paul.Treanor/neoliberalism.html>

Wendell, S. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability*, Routledge, New York.

Whiteford, H., Buckingham, b. and Manderscheid, R. 2002. Australia's National Mental Health Strategy, in *British Journal of Psychiatry*, Vol. 180, pp. 210-215.

Winter, I. 2000a. Social capital and public policy in context, in I. Winter (ed), *Social capital and public policy in Australia*, Australian Institute of Family Studies, Melbourne, pp. 1-16.

Winter, I. 2000b. Major themes and debates in the social capital literature: The Australian connection, in I. Winter (ed), *Social capital and public policy in Australia*, Australian Institute of Family Studies, Melbourne, pp. 17-42.

Wolfensberger, W. 1983. "Social Role Valorization: A Proposed New Term for the Principle of Normalization", *Mental Retardation*, Vol. 21, No. 6, pp 234-239.

Wolfensberger, W. 1992. *A Brief Introduction to Social Role Valorization as a High-Order concept for Structuring Human Services*, Training Institute for Human Service Planning, Leadership and Change Agency, Syracuse University, New York.

Women With Disabilities Australia (WWDA) 2004. 'Unjustified Hardship – homelessness and women with disabilities', available [online]: <http://www.wwda.org.au/housing04.htm>

## **AHURI Research Centres**

Queensland Research Centre  
RMIT-NATSEM Research Centre  
Southern Research Centre  
Swinburne-Monash Research Centre  
Sydney Research Centre  
UNSW-UWS Research Centre  
Western Australia Research Centre

## **Affiliates**

Charles Darwin University



Australian Housing and Urban Research Institute  
Level 1 114 Flinders Street, Melbourne Victoria 3000  
Phone +61 3 9660 2300 Fax +61 3 9663 5488  
Email [information@ahuri.edu.au](mailto:information@ahuri.edu.au) Web [www.ahuri.edu.au](http://www.ahuri.edu.au)