Housing and care for older and younger adults with disabilities

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Housing and care for older and younger adults with disabilities

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TABLE OF CONTENTS

ABBREVIATIONS

ACHA	Assistance with Care and Housing for the Aged
ACT	Australian Capital Territory
AHURI	Australian Housing and Urban Research Institute
AIHW	Australian Institute of Health and Welfare
AIP	Ageing In Place
CDSA	Commonwealth Disability Services Act
CHP	Community Housing Program
CSDA	Commonwealth State Disability Agreement
CSHA	Commonwealth State Housing Agreement
CURF	Confidentialised Unit Record Files
DACS	Disability, Ageing and Carers Survey
DDA	Disability Discrimination Act
DSA	Disability Services Act
DSP	Disability Services Program
DVA	Department of Veterans Affairs
FACS	Department of Family and Community Services
HAA	Housing Assistance Act
HACC	Home and Community Care Program
NSW	New South Wales
NT	Northern Territory
PADP	Program of Aids for Disabled People
PRA	Private Rental Assistance
RA	(Commonwealth) Rent Assistance
SA	South Australia
SAAP	Supported Accommodation Assistance Program
SHA	State Housing Authority
TAS	Tasmania
VIC	Victoria
WA	Western Australia

EXECUTIVE SUMMARY

Introduction

This paper outlines research, by the Australian Housing and Urban Research Institute University of Sydney Research Centre, into the relationships between housing and care for younger and older adults with disabilities.

Project Aims

This project aims to inform policy and program delivery issues associated with achieving linkages, cooperation and efficiencies in housing, disability and care to create a 'whole of government' approach. It does this in three ways:-

1. the project analyses the housing and care circumstances of older and younger adults with disabilities nationally;
2. it identifies systematic variation indicating differences in State/Territory policies concerning housing markets;
3. it reviews and critically assesses policy and program approaches that enable better targeting of met and unmet need.

Previous research

While there is a considerable body of academic research relating to housing, disability and care, there have been very few studies that have looked at policy linkages across all three areas and the combined impact of policies in meeting unmet need. No study of this type has yet been carried out in Australia.

Previous research indicates that:

- Disability, housing and care are interdependent and the linkages are complex. Intersections, in terms of linkages between access, safety and dependency are not well understood or adequately researched, particularly in the Australian context.
- Community care services can effectively supplement informal support but diversity, fragmentation, financial caps and lack of coordination result in substantial unmet demand.
- Design and construction of private dwellings and cared accommodation settings has consistently failed to adequately consider the needs of adults with disabilities effectively increasing dependency and creating social exclusion.
- The capacity to 'Age In Place' depends heavily on the availability of informal care. Providing care can lead to economic disadvantage and increased risks of carers acquiring disabilities.

Policy Context

This paper examines the national policy context and maps some of the issues associated with coordination of policy initiatives at State and Territory levels. The current interest in linkages between housing, support and care arose in the early 1990s with the publication of the Mid Term Review of Aged Care and the National Housing Strategy. Consequently, the last ten years have seen a number of very significant reforms of legislation that have impacted on policy at Commonwealth, State/Territory and regional levels. Policy has been framed in a climate that increasingly seeks to maximise independence, improve customer satisfaction (choice, access and security) and service flexibility. At the same time, there has been

increasing financial restraint, market driven competition, privatisation, outsourcing, and funder/provider accountability.

Policy analysis reveals that:

- There is a lack of knowledge about the relative effectiveness of different packaging of income support, accommodation and care services;
- The lack of coordination, complexity and piecemeal nature of the current system are seriously impeding reform outcomes;
- The problems of compliance and consistency in regulating the private market are compounded by the trend towards the privatisation of housing ", user pays" and "self service" care options;
- There is a plethora of bureaucracies and routes through which funding for housing and support is provided. The current lack of coordination creates confusion and increases communication difficulties.
- Notwithstanding agreements between Commonwealth and State/Territory governments on reform and funding, the separate development of disability, ageing, housing and care programs has led to fragmentation and inequalities.
- The generally low level of public input by younger and older adults with disabilities in planning reform initiatives results in policy that fails to address consumer expectations and concerns.

Methodology

The study draws on four main data sources in addressing the aims of the study and the research questions.

- A comprehensive international literature review. Analysis of published and unpublished documents continues and will be examined in our final report.
- A systematic review of key policy documents, including annual reports and evaluations of policies, programs and services for ageing and disabled people at both the Commonwealth and State levels.
- The Disability Ageing and Carers Survey (DACS) Confidential Unit Record File (CURF) provides national data on met and unmet needs that are not directly associated with service delivery. It is sufficiently reliable, comprehensive and targeted in nature to yield the relevant information required for relating housing, disability and care circumstances of younger and older adults. Preliminary analysis of the data has commenced and is reported in this paper. The next stage will produce detailed data tables and identify predictors of unmet need regarding specific housing and care services.
- Assessment of key issues based on telephone interviews with more than 40 leading 'players'. The project user group representatives will recommend the interviewees. Informants will be selected to represent a balanced cross-section of States and areas of interest. Pilot interviews will be conducted to refine methods prior to full-scale interviewing.

Conclusion

There is no national framework for the coordinated and flexible delivery of accommodation and support services for younger and older adults with disabilities.

The foundations for policy generation and funding negotiations between the Commonwealth and the States are historically based, complex and mission focused. This division of responsibility hinders the efficient and equitable provision of services. Linkages are still primarily based on informal cooperative efforts that vary in their

effectiveness from State to State. Cost shifting and inefficiency arise because no single organisation has responsibilities in health, housing and cared accommodation.

This picture suggests that while policy reform directions are clear and much has already been achieved, there are still major issues associated with achieving a whole-of-sector or cross-jurisdictional basis for the appropriate care and management of older and younger people with disabilities. This is critical given that persons with high dependency needs often require the involvement of more than one health and aged care service provider.

Clearly more work needs to be undertaken in Australia to better understand clients with high care needs. This study will be the first of its kind in providing Australian data on the articulation of the health and care issues on the accommodation needs for younger and older adults with disabilities.

Chapter 1. INTRODUCTION

1.1. Introduction

This paper outlines research by the Australian Housing and Urban Research Institute centre at the University of Sydney which examines the relationships between housing and care for younger and older adults with disabilities. The research aims to inform the development of housing, disability and care policy directions influencing the housing and support options available to adults with disabilities.

The research context is one of an ageing population, rising expectations amongst consumer groups, and constraints on government expenditure. The research outlined in this paper will generate information on the relationships between housing types, care needs and service use by both younger and older adults with disabilities. This positioning paper reviews the literature (Chapter 2), describes the policy context for this study (Chapter 3) and presents the research methodology (Chapter 4).

The project will draw on three main sources. Firstly, a detailed analysis of policy relevant to individual Australian State/Territories. Secondly, the analysis of the Confidentialised Unit Record Files (CURF) provided by the 1998 Disability, Ageing and Carers Survey (DACS). This data will yield information about present housing circumstances and assistance, use of community services, and met and unmet needs with dwelling maintenance, household responsibilities, and personal care. Thirdly, the research will assess key issues by telephone interviews with more than 40 leading 'players', including Commonwealth and State policymakers concerned with housing, aged care, community care and disability programs.

1.2. Background

For many years, Commonwealth and local government have worked to improve housing options and choices for people with disabilities. For instance, 1941 saw the introduction of the Housing Act to ensure the provision and future growth of affordable public housing, including provision of housing to injured veterans. Older people and adults with disabilities have become an increasing priority for public housing authorities following their initial targeting under the 1969 Pensioners Housing Act. However the demand for public housing by older and younger people with physical and mental disabilities continues to outstrip supply.

More recently, a significant shift in community expectations about the creation of more equal opportunities and non-discriminatory access to housing and care services has increased the pressure on Australian governments to implement a restructured human service delivery system that is community-based whilst downscaling the larger cared accommodation options. Consequently, all States and Territories are now implementing strategies to enable older and younger disabled people to remain in their own homes as an alternative to institutional care, but this adds to the demand on already strained public resources.

The provision of both affordable and accessible accommodation options is a central tenet of current policy and is reflected in national legislation such as the Commonwealth Disability Services Act (CDSA-1986) and the Disability Discrimination Act (DDA-1992). The DDA[1] prohibits both explicit and implicit discrimination and whilst the DDA was amended in 2000 to enable the development

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[1] The Disability Discrimination Act always included the provision that would enable the creation of standards in certain specified areas e.g. employment, education, accommodation and public transport but did not include the provision to do this for access to premises.

of standards on access to premises currently no disability standards exist regarding access to premises. Additionally the area of domestic dwelling construction, and the impact on tenancies also remains far from clear (Raynor, 1997).

The foundations for policy generation and funding negotiations between the Commonwealth and the States are historically-based, complex and mission focused. The division of responsibility creates difficulties in efficient and equitable service provision (Burbidge, 1996a; Kendig, 1990a). For example Table 1-1 below, outlines some of the variations in primary responsibility for programs between the Commonwealth and the States:

Table 1-1: Breakdown of primary responsibility for welfare programs in Australia

Commonwealth responsibility	State/Territory responsibility
• Residential care for older people	• Residential care for younger persons
• Home and Community Care services (the Sates /Territories carry a forty per cent share of funding responsibility and devolved responsibility for implementation).	• Public housing (special tied grant support from the Commonwealth)
• Income support (i.e. Disability support pension)	• Health services (the Commonwealth provides specific program funding).

The Commonwealth and the States have an incentive to shift costs to community care. On the one hand, the Commonwealth has primary responsibility for residential care services for older persons, thus initiatives and incentives are in place to cap costs by restricting entry to these services (Burbidge, 1996a). On the other hand, States have primary responsibility for hospital care and so have an equally strong financial imperative to restrict and limit the number of bed days per admission. The Commonwealth and the States jointly fund Home and Community Care services for which demand exceeds available resources. Success in restricting both hospital and residential beds, in conjunction with limited community care and income support, has resulted in some vulnerable older and younger people becoming increasingly reliant on public housing authorities or becoming homeless. Madden (1996) found that an estimated 13,500 people with severe disabilities were not receiving the accommodation, support or respite services they required.

Weak program coordination was identified as the second biggest issue faced by public housing and accommodation programs in the National Housing Strategy discussion paper on the housing needs of people with disabilities (National Housing Strategy, 1992b). Poor coordination is fostered by the traditional separation of program and funding responsibilities between levels of government and an in environment where services are delivered by separate housing, health and community care agencies. Integrated approaches to housing and care delivery have been explored in policy reviews such as the 1993 Commonwealth's Midterm Review of Aged Care.

Commonwealth and State governments have recognised that accommodation and support needs are linked. For instance, Assistance with Care and Housing for the Aged (ACHA), Home and Community Care (HACC), Program of Aids for Disabled People (PADP) and other similar Commonwealth/State programs all seek to support people with disabilities and to prevent premature entry into cared accommodation (Alt Statis & Associates, 1996; Howe, 1992). In addition, pilot programs like the

'Housing and Care Linkages' program have been introduced and State government's are making attempts to better coordinate provision. For example, Victoria has introduced the provision of support workers in public housing projects for frail older people. Linkagesare still, however, primarily based on informal cooperative efforts, the effectiveness of which differs between States.

1.3. Aims of the study

This study aims to:

1. provide a national profile and analysis of the housing and care of older and younger adults with disabilities, including identification of their present housing circumstances and assistance, use of community services and met and unmet needs with dwelling maintenance, household responsibilities, and personal care.
2. identify systematic variation reflecting differences in State policies concerning housing markets.
3. review and critically assess policy and program approaches to better link housing and care programs.

The research differentiates between younger and older people with disabilities on the basis of household type. In the detailed analysis further distinctions will be made between these groups in terms of individual characteristics (i.e. type of disability, severity of disability and income) in conjunction with accommodation setting (i.e. type of accommodation, tenure, location etc.) and service use. The core groups for our analyses are:

− Younger adults with disability living alone
− Younger adults with disability living with others
− Older adults with disability living alone
− Older adults with disability living with others.

This framework recognises that living alone reduces access to informal care services and influences the crucial links between care, accommodation, income support.

The following are the principal research questions:

- What are the housing circumstances, service use and perceived degree of met and unmet housing and care needs amongst older and younger people with disabilities? (DACS Confidential Unit Record File analysis)
- To what extent does the provision of housing and care options differ between States and Territories and, if this difference is significant, why might this be so? (Policy review and analysis)
- How do the policymakers and service providers view the key issues and how might this create opportunities or barriers in achieving integrated, whole-of-government approaches? (Key 'player' interviews)
- Within the past decade, what housing and care 'packages' have been explored in the Australian context, and how do these differ from those available in other OECD countries (Top ten list developed from academic and policy review and key 'player' interviews).

Information addressing these key research questions will assist in guiding recommendations for potential strategies that may better link public housing and community services for younger and older adults with disabilities.

A user (reference) group was engaged to provide feedback and to ensure that research being undertaken encompasses policy 'user' perspectives. The user group consists of the following eight experts in the field:

- Ms Annette Donohoe, Commonwealth Department of Family & Community Services (FACS) [NSW]
- Ms Pat Occelli, Ageing and Disability Department (ADD) [NSW]
- Mr Arthur Rogers, Department of Human Services (DHS) [VIC]
- Mr Denys Correll, Council on the Ageing (COTA) [VIC]
- Mr Malcolm Downie, Department of Health & Human Services (DHHS) [TAS]
- Mr Mark Relf (PDCA) [NSW]
- Mr Mark Nutting, Department of Housing (DOH) [NSW]
- Ms Margaret Ward, Department of Housing (DOH) [QLD]

1.4. Structure of the paper

This paper provides a preliminary discussion of accommodation and care services currently available for older and younger adults with disabilities within Australia. Some comparisons are made to overseas initiatives but the primary focus is on Australian practices. Most prior research has concentrated on one of the three aspects of disability, accommodation or care, and very little published research exists on linkages and relationships between them.

The remainder of the positioning paper includes the following chapters:

Chapter 2 outlines the conceptual terminology and reviews disability incidence, prevalence, severity and its relationship to housing need. It also examines relevant national and international academic literature and identifies gaps in knowledge.

Chapter 3 reviews housing, disability and care policies at a national level and illustrates some of the issues associated with coordination of political initiatives at State and Territory levels.

Chapter 4 describes the methodology adopted in the Disability Ageing and Carers Survey analyses, review of policy material and policy interviews.

Chapter 2.   LITERATURE REVIEW

2.1.   Introduction

This chapter reviews the academic literature on people with disabilities and their service use, housing and care. It examines both national and international literature. However, all citations are specific to the Australian context unless otherwise identified.

In summarising the current knowledge base, gaps are highlighted within the literature with regard to the relationships and linkages among housing, care and support needs of younger and older adults with disabilities. The chapter is structured into sections as follows:

- Conceptual basis and definitions
- Older and younger people with disabilities
- Housing and living options
- Care options
- The economics of affordability
- Methods of linking housing, support and care.

Almost all younger and older adults with disabilities want to live independently and maintain control and identity in their own place. It is anticipated that spatial and ownership demands, needs, preferences and expectations will be rising in the future from both older and younger adults with disabilities.

2.2.   Conceptual basis and definitions

Research is framed around a conceptual understanding of how the intersection of accommodation, care and disability relates to met and unmet 'need'. These ideas are illustrated in Figure 2-1.

Figure 2-1: Conceptual understanding of the intersection of accommodation, disability and care

A number of key relationships are shown in the figure. The intersection of accommodation and care raises issues of 'safety' in terms of primary and secondary disability minimisation, formal and informal carer hazard reduction and risk minimisation. The intersection between disability and care relates to the continuum between independence and dependence, 'dependency' or 'burden of care', and the amount and quality of informal and formal support. The intersection of disability and accommodation raises issues of access to services and to premises. Levels of access, safety and dependency frame the 'needs' and point to implications for disability, housing and care linkages.

2.2.1. Disability

The concept of disability traditionally implies a focus on deterioration not on the full spectrum of ability and/or enablement (Chiriboga, Ottenbacher and Haber, 1999). Consensus has now shifted to a more social model where disability is the result of the transaction between an individual and their environment (Ustan, 1997). Whether or not a particular physical condition is experienced as disabling depends on the natural and built environment, the political, familial, social, cultural structures of a society and the interpersonal processes of the individual concerned (Brandt & Pope, 1997).

2.2.2. Care

For the purpose of this research the concept of 'care' is defined as responsibility assumed for provision of assistance to older and younger people with disabilities to ensure their health, safety and well being.

2.2.3. Accommodation

In the context of this research, the concept of 'accommodation' implies lodging or living-premises. This includes domestic sole, family and group households, and cared accommodation options. Domestic households include the full range of privately and publicly funded private dwelling options, whilst cared accommodation options include hospitals, residential aged care facilities, nursing homes, hostels, and other 'homes' such as children's homes.

2.2.4. Access

Within this paper, 'access' and 'accessibility' for younger and older adults with disabilities refer to the ability to exercise the right to enter or use housing or care services, programs and facilities, in such a way that is independent, equitable and dignified, irrespective of disabling restrictions (Dunn, 1996).

2.2.5. Dependency

Within the context of this research, the concept of 'dependency' refers to the degree of control and reliance delegated to others to ensure health, safety and well being of younger and older people with disabilities. This varies from other definitions such as reliance on others in meeting recognised needs (Rickwood, 1994). Dependence and independence exist on a continuum and, in heavily urban societies, it has been argued that all persons regardless of level of disability are in fact interdependent (Bould, 1990; Robertson, 1997).

Dependency in this context is not about implying that people with disabilities are dependent and others are not, but about understanding the 'burden of care' relative to service linkages and targeting need. Dependency measures are needed to assess

the need for care, as in the United Kingdom 'housing need' study conducted by McCafferty (1994). The Clackmannan/Townsend dependency measure (illustrated in Figure 2-2 below) was specifically designed to measure dependency within residential housing and involved detailed research into inter-item correlation. The Disability, Aged and Carer Survey, confidential unit record file information contains roughly comparable categories (Australian Bureau of Statistics, 1998). Further analysis using both functional and clinical criteria can provide information as to the extent to which dependency accounts for disability- related care need in Australia and/or how access to accommodation services meets these needs.
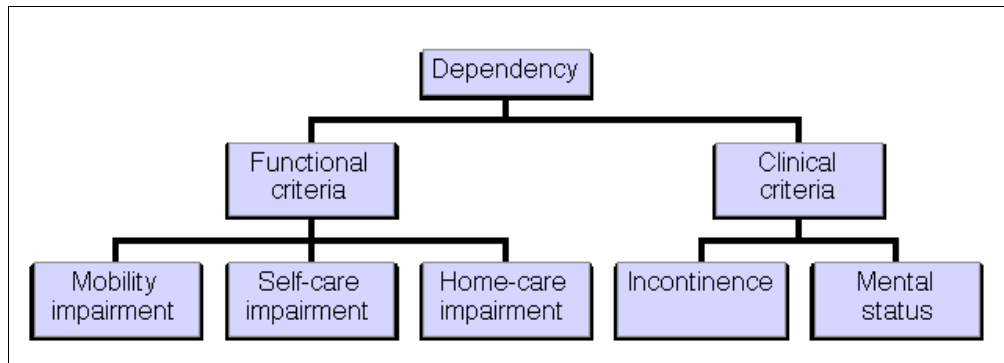
Figure 2-2: Components of dependency: Source (McCafferty, 1994)

2.2.6. Safety

In the context of this research, 'safety' implies freedom from risk or danger and suggests the degree to which a margin of security against risks or known harm is established to protect older and younger people with disabilities and their carers from accidents, injury and the onset of secondary disability. The concepts of safety and risk are significant given that the current political climate is increasingly one of 'managed risk' where negotiation of the level of risk between recipient and provider is viewed as a means by which individuals can exercise more autonomy (Golant, 1999).

2.2.7. Need

The concept of 'need' can be defined as a state, situation or condition experienced by younger and older adults with disabilities which, by its presence or absence, prevents normative function. A need implies a goal state and a measurable deficiency from the goal state. Needs define objectives of health, housing and care but are relative constructs that incorporate value judgements. Need has been described across three dimensions as follows:

- Normative need – This is based on assessment of performance against benchmarks that have been established based on some agreed gold standard assessment. In terms of disability, this translates to "functional means testing" usually based on some form of dependency measurement (Chiriboga *et al.*, 1999).
- Comparative need - This is usually based on statistical comparison of one region or locality against another. While it is effective in demonstrating inequality between regions 'comparative need' fails to adequately account for differences relative to geographical, historical and social factors of allocation.

- Felt need or expressed need – This is based on the difference between expectations and the actual service provided. It is often framed in terms of a particular solution. For instance, carers lobbying for more nursing home beds when the provision of in-home respite or day care services might just as effectively, if not more effectively, resolve the feelings of being stressed and overburdened.

2.3. Younger and older people with disabilities

Large numbers of individuals in our community experience functional limitations as a direct consequence of occupational health injuries, home accidents, road trauma, crime, genetic predisposition or inheritance, or the onset of chronic disabling conditions associated with the ageing process. Recent advances in medicine, rehabilitation and public health have increased life expectancy and are consequently associated with the rise in the prevalence of disability. These trends have created a convergence between the ageing and disability populations, with more older adults experiencing onset of disability in later life and more persons with life-long disability living into old age (Gething, 1999; Liebig and Sheets, 1998).

2.3.1. Disability incidence and prevalence

Determining the exact number of individuals with disabilities or limitations due to ageing is not an easy or precise task. Older people do not want to be socially stigmatised or to be thought of as disabled and people who are employed or are occupationally productive despite significant functional impairment also do not consider themselves 'disabled'. This interpretation is supported by US research which indicates that adults with disabilities define "being healthy" much more broadly than the mere absence of disability and conceptually closer to the ability to contribute to society (Stuifbergen, Becker, Ingalsbe, & Sands, 1990). Indeed, estimates vary depending on the definition of disability used and the source of the data (see the earlier discussion about terminology).

In 1998, an estimated 3.6 million people or 19% of the Australian population were classified as having a disability (Australian Bureau of Statistics, 1998). This is similar to data from other developed countries. For example, in the United States its is estimated that 20.3% of the population have disabilities (Czajka, 1984). In addition, it is apparent from surveys over the last 20 years that the incidence of recorded disability is increasing.

Within Australian States, there is a wide variation in both population densities and demographic characteristics and thus the number of people with disabilities in regional areas is far from uniform. People aged 65 years and over makeup 12 % of the population in Australia. South Australia has the highest proportions of its population over 65 years (14%), with the two Territories having the lowest proportions. Areas containing the highest concentrations of people 65 years and older are mainly located in coastal retirement areas. Of the ten statistical local areas (SLA's) with the highest populations aged 65 years and over, six were in Queensland (Australian Bureau of Statistics, 1996).

States like South Australia that have the largest population concentration of older adults consequently have disproportionate numbers of people with disabilities. Further examination of those living in rural and remote areas also indicates higher levels of disability per capita of population than those in capital cities. The connection between rural location and disability may be due to poorer access to health services, lower socioeconomic status and employment levels, exposure to comparatively

harsher environments, sparse infrastructure and occupational hazards (Australian Institute of Health and Welfare, 1998).

Australians are linguistically and culturally diverse and the diversity within the Australian population is increasing, particularly among the elderly, who are more likely to be disabled (Plunket & Quine, 1996). For instance, 29% of persons over the age of 65 years were born overseas and more than half of this group are from non-English speaking countries (Ethnic Aged Working Party, 1987).

Australian cross-cultural research indicates that people from non-English speaking countries generally have a lower incidence of disability but this varies significantly between sub-groups with Greek, Italian and other European women having quite high rates of disability (Ageing and Disability Department of NSW, 1996; Kendig & Russell, 1998; Mathers, 1994). Moreover, utilisation of housing and care services by disabled people from non-English speaking backgrounds has not been well explored although there is strong anecdotal evidence to suggest they are under represented in terms of formal service uptake (Chan & Quine, 1997; Cranny & Associates, 1998; Plunket & Quine, 1996).

Older women from culturally and linguistically different backgrounds are particularly vulnerable in that they are most likely to be living alone and on a low income, with a minimal or declining command of English and possibly reduced family support. This can lead to isolation, thus increasing psychological and physical susceptibility to illness (Cranny and Associates, 1998).

Literature on housing and care with a disability focus generally falls into one of several categories:

1. Ageing (a fairly large body of literature exists covering a wide range of subtopics of accommodation related concern ranging from relocation impact to dementia accommodation design)
2. Intellectual disability (this has been well researched and focuses on de-institutionalisation, social role valorization and community inclusion)
3. Psychiatric disability (this has been moderately well explored and focuses on insecurity of tenure and resultant homelessness)
4. Physical disability (this is scant but what does exist focuses on physical accessibility and discrimination law in relation to premises)
5. Sensory disability (this has hardly been researched in terms of accommodation impacts)

2.3.2. Disability severity

Of the people identified as having a disability Australia wide, over a million people had a profound or severe "core activity" restriction, that is in mobility, self-care, communication etc (Australian Bureau of Statistics, 1998). This is roughly comparable to the functional criteria which correlates with high dependency need, such as that in the Clackmannan/Townsend dependency scale (McCafferty, 1994). The people with the highest levels of core activity restriction are generally the most dependent on adequate care and support to have a reasonable quality of life and to achieve full community participation and integration (see previous discussion on dependency). Appropriate community accommodation improves quality of life by facilitating individual choice, privacy and feelings of control (Cusack, 1992; Wilson & Scott, 1995).

This group is also most likely to experience the highest levels of multiple disadvantages, meaning that disability severity is linked to reduction in accommodation choices and increased likelihood of premature entry into cared accommodation (Brooks, Davidson, Kendig, & Reynolds, 1998). Lack of

accommodation and care choices are compounded by unemployment, because for most of this group, reliance on income support precludes purchase from the private sector. As Gething (1999) makes clear, disability-related costs account for a large proportion of income that could have been saved or invested creating significant financial concern and further reducing security of tenure.

2.3.3. Younger people with disabilities

Since the early 1970s, Australia's birth rate has declined. The baby boomers, born around the late 1940s, are now entering their 50s. Within 10 years, this large group of people will be approaching old age. Advances in technology, medical care and community support mean that more people with longstanding disabilities who once would have died before reaching late adulthood, now have a life expectancy that approximates that of the general population (Gething, 1999; Office of Disability, 1999). This means that persons who became disabled early in life are ageing and ageing faster. For instance, chronic health problems typically associated with older age tend to surface earlier and have worse consequences (Burns, Batavia, Smith, & DeJong, 1990; Kahler, 1998). Additionally, this group has a much greater chance of re-hospitalisation than the general population, with some US studies reporting re-hospitalisation rates as great as 40% within the first year of discharge (Burns et al., 1990).

Younger people with disabilities differ from older people primarily in terms of their generational cohort and so have different life experience and expectations. As a group they are the first generation to be active in disability rights, and expect to exercise their rights by inclusion and participation in community life. Many have been part of the deinstitutionalisation process and already have high support needs so would resist reinstitutionalisation solely on the basis of advanced age (Kahler, 1998; Morgan, 1996).

Whilst many of the issues remain similar to those experienced by older adults, younger people with disabilities also differ from older people with disabilities in terms of the proportional prevalence of specific disability types. For example, if examining age variance by disability type based on analysis of individual record data from the 1998 Disability and Carers Survey (illustrated below in Figure 2-3), it becomes clear that a significantly greater proportion of people in the younger cohort experience intellectual and mental health problems.
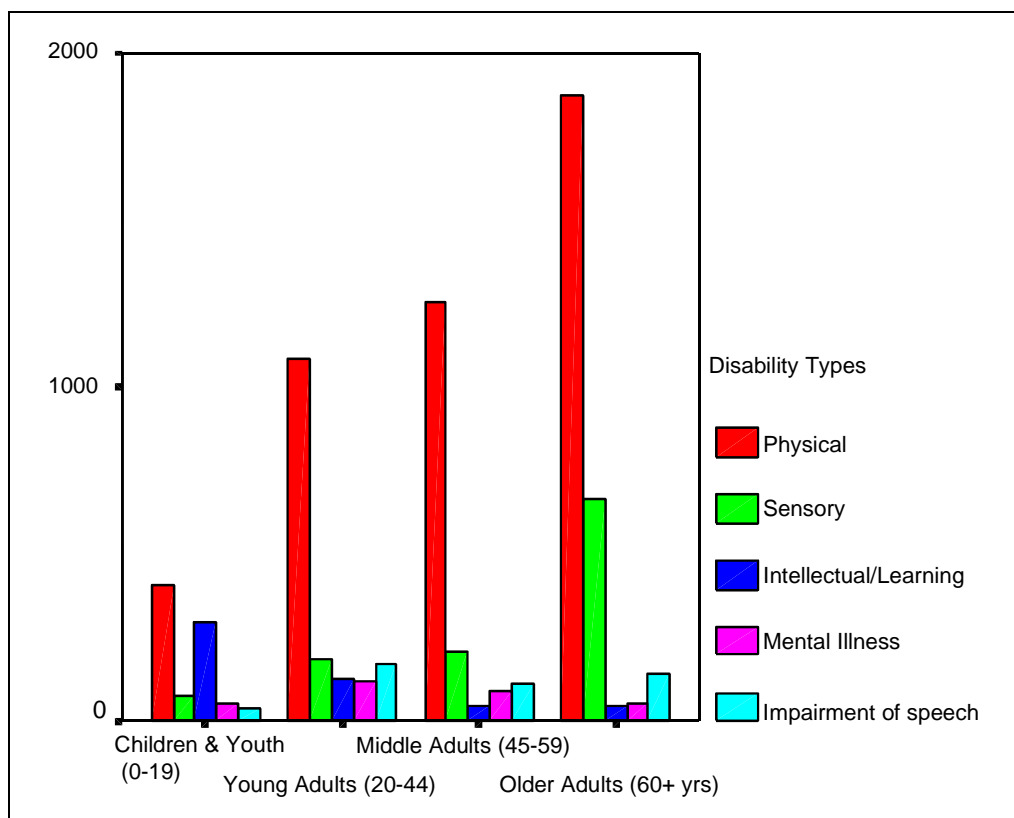
Figure 2-3: Variance between primary disability type by age

This difference in predominance of disability types between generational cohorts brings with it an increasing focus on deinstitutionalisation. In Australia, the Disability Service Act reforms of the 1980's saw the advent of massive deinstitutionalisation resulting in an increase in community placement.

The impact of deinstitutionalisation and disability bias is evident in the most recent statistics regarding the services provided or funded under the Commonwealth State Disability Agreement (CSDA). These indicate that 43% of services were provided to relatively young adults—that is those aged between 20 and 39 years- and that over 60% of the recipients of CSDA services had intellectual disability as their most significant disability (Australian Institute of Health and Welfare, 2000). A similar deinstitutionalisation trend in the US lead to a transfer of resources from the public to the private sectors as the major delivery systems for intellectual disabilities are typically private, non-profit, for-profit and/or public or quasi-governmental structures (Racino, 1999).

2.3.4. Older people with disabilities

Recent advances in medicine and material well being particularly in the most affluent areas of the world have resulted in dramatic changes in life expectancy. For instance in the UK almost half the adult population will be over 50 years of age by the year 2020 (Clarkson, Keates, Cleman, Lebbon, and Johnston, 2000). The same trend is also apparent in Australia, albeit at a slightly slower rate. In Australia by the year 2051, over a quarter of the total population will be aged 65 years or older (Australian Bureau of Statistics, 1996).

In terms of mortality and morbidity, there are promising signs that living longer is not automatically associated with disability. Furthermore, the highest health costs for older people can be directly related to acute interventions provided in the last two years of life. Nevertheless, ageing and disability are linearly correlated. For example, disability rises from 4% of children 0-4 years to 84% of those aged 85 and over (Australian Bureau of Statistics, 1998). Consequently, projections of expenditure that relate to new approaches in health care, which better target chronic disabilities and morbidity, have been projected to increase 10-20% (Kalisch, 2000).

Living arrangements of older persons are also significant as they are less likely to share accommodation with peers and are more likely to be living alone or with a spouse. According to the Retirement Income Modeling Unit (RIMU) estimates based on the Household Expenditure Survey Record 1993 (cited in the report of the Ministerial reference group, 1999) of people 65 years and over, significant numbers of older people also choose to live with their children. For instance, 11.5% women and 12.6% of men were recorded to live with their children (Ibid.).

The difficulties faced by older persons with disabilities are compounded by the fact that greater numbers of older people are now living alone, that is, without the assistance they would receive from a spouse or carer. Women's longevity and tendency to marry older men mean substantial numbers of women aged 65 years and older live alone, whilst older men are more likely to be living with a partner. In the over 80 age group, 54% of males compared to 16% of females were found to live with family and women (55%) were twice as likely to be living alone than men (27%) (Australian Institute of Health and Welfare, 1997).

The population of older people with disabilities is far from homogenous. For instance, people with dementia are a significant subgroup and dementia has very high social costs for family carers. The level of care needed depends not only on age and disability but also on gender, lifestyle, health, socioeconomic factors and constitutional influences. Medical advances are allowing a growing proportion of older people to survive to the oldest-old category (80+), with major economic and social consequences (McCafferty, 1994). It is important to ensure that enhanced survival is matched by maintenance in the quality of life.

2.4.   Housing and living arrangements

Accommodation options open to people with disabilities are shaped by a variety of factors including appropriateness, affordability and security of tenure and suitability of location. Racino (1993) writing in the US literature has argued that decisions about accommodation are all too often tied to the amount of care required and, therefore, accommodation choice for those with the highest care needs are the most restricted. The traditional continuum of accommodation options in relation to the level of care provided is outlined in Table 2-1 below. Firstly, independent accommodation designed for individuals and couples able to care for themselves. Secondly, low level care with living arrangement provisions that cater for some chronic limitations. Thirdly, high care accommodation provides more intense supervision, intermittent services and nursing care for those who are acutely ill and/or require ongoing high support.

Table 2-2: Traditional continuum of housing options in terms of care availability

Independent	Low Level Care	High Level Care
Home ownership	Retirement Communities	Intermix Residential Nursing Care
Rented Accommodation	Public Housing Complexes	Convalescent homes
Single Room Occupation	Residence with Family	Hostel Care
Condominium Ownership	Foster Care	Respite care
Apartment Dwelling	Hotel/Motel accommodation	Care Awaiting Placement (CAP)
Share Houses & Congregate life-styles	Home & Community Care	Secure Units
Housing Co-Operatives	Boarding & Rooming Houses	Hospital
Independence	⟵——————————⟶	**Dependence**

Source: adapted from (Kendig & Pynoos, 1996)

More recently, there has been a growing focus on community care services provided in people's homes (Golant, 1999). In the UK, as is now occurring in Australia, the primary objective of community reform is to cap budgets which in the past have created a bias in favour of residential and nursing home care by promoting instead wherever possible community-based care packages. However, whilst this strategy appears generally successful overall in meeting its set objectives, a report for a UK Royal Commission cited inadequacy of financial resources, insufficient development of policy and service models and the absence of organisational development and support mechanisms with an overall failure to 'satisfy need' (Henwood, 1999).

2.4.1.   Expansion of home based care options

The move to home-based care, individually tailored services, greater flexibility, more coordinated services and clients as active participants, which is now evident in policy reform in Australia, echo developments already underway in the UK, Sweden and the Netherlands (Boldy, Kendig, & Denton, 1993). The move to in-home care in Australia has resulted in a gradual shift in expenditure in favour of community care, which is provided under programmes like Home and Community Care (HACC) and Community Aged Care Packages (CACP) (Fine & Chalmers, 1998). These services provide:

- home help
- community nursing
- home modification and maintenance
- gardening assistance
- transport services
- food services
- allied heath services
- community respite services.

Community care services have enabled people with low to high care needs to remain in their homes and access the specific packages of services relevant to their care needs. These small locally-based services offer choice, however, the sheer diversity and fragmentation of what is on offer makes finding out who does what, for whom and where an almost impossible task (Fine, 1997). Furthermore, people with high

level needs often require a complex mix of services, with a primary entry level for assessment of care need and overall co-ordination (i.e., General Practitioner or ACAT referral). The limited resources available because of community services funding caps, limit the provision of service and flexibility of service options regardless of obvious need. Lack of adequate fee-for-service reimbursement precludes most General Practitioners from participating in community-based care forums, resulting in consequent ongoing co-ordination duplication (Fine, 1997).

2.4.2. Housing careers require lifestyle planning

In uncoupling health, accommodation and care, disability advocates argue that individual lifestyle planning processes become a valuable tool for housing and care decision-making (Steere, Gregory, Heiny, & Butterworth., 1995). However, the ability to do this effectively however, is hampered by lack of evidence concerning the information effectiveness and relative cost of rehabilitation and independent living programs (Fuhrer, Rossi, Gerken, Nosek, & Richards, 1990). The existing isolation of health from community care means that community-based care packages are support focused rather than rehabilitation or training focused. People with mature-onset disabilities are often excluded from rehabilitation, hence increasing their dependency on sometimes inappropriate care (Kahler, 1998).

2.4.3. Support for 'Ageing in Place'

Community Options, is a service model that enables people with high dependency needs to remain at home via case management and service purchasing. This was introduced into Australia in the 1990s following its success in the UK and the US. Early evaluation has demonstrated that clients appreciated the flexibility of support and security provided, whilst costs are lower on average than nursing home placement but substantially higher than traditional hostel care (Boldy et al., 1993). The success of Community Options and similar schemes has been dependent on 'community building' with affordable and accessible housing, and community care (Racino, 1999; Schaaf, 1990).

In 1984 Pennsylvania State Office of Mental Health, found significant differences in the ability to sustain community tenure depending on the community services utilised and community residential arrangements made. They concluded that determination of successful community tenure rested on an improved understanding of the importance of client satisfaction with residential arrangements (Hadley, McGurrin and Fye, 1993).

2.4.4. Home Maintenance

Accommodation occupied by older persons and those on the lowest incomes is typically older and more dilapidated. US data indicates that up to 8% (more than a million older people) live in homes with serious physical defects (Kendig & Pynoos, 1996). Whilst UK data indicates that up to 35% of private dwellings occupied by people with disabilities were unfit (Nocon, 1997). Australian data is not available, but it could be reasonably expected that a similarly high proportion of housing occupied by older people would also be inappropriate. Therefore, quality of housing has become a major concern for enabling delivery of home-based care.

In the US the Americans with Disabilities Act and the Fair Housing laws have worked to improve the provision of more adaptable and accessible public and private dwellings (Watson, 1990). This has been echoed more recently and forcefully in the UK, which became the first nation in the world to mandate basic disability access in every new home by passing the Visitable Homes Act in 1998. This Act requires that

every new home must have an entrance without steps, a downstairs bathroom, sufficiently wide halls, all doorways passable by wheelchairs and other elements of universal design.

2.4.5.   Adaptable housing

In terms of appropriateness, fully visitable, accessible or adaptable accommodation currently represents a miniscule percentage of the total housing market in Australia and has traditionally only been provided by public housing authorities. Given that public housing authorities manage less than 10% of our total housing stock it is clear that more needs to be done in terms of both new construction and in terms of retrofitting existing housing stock to redress this imbalance (Bridge, McAuley, & Woodruff, 1999).

People with disabilities have a right to access the same range of accommodation options as other members of the community including sharing with others or living alone (Bridge et al., 1999). Housing itself is a major determinant of quality of life. For instance, a Japanese study conducted by Zhao, Tatara, Kuroda and Takayama (1993) found that the cumulative survival rates of old people with good housing conditions were higher than those with poor housing conditions. They therefore concluded that the mortality of frail elderly people living at home is affected by housing conditions.

2.4.6.   The meaning of home

Emotional relationships are not just limited to people but include significant physical environments and this type of emotional attachment to physical objects and places usually begins in childhood (Marcus, 1997). A home fulfills many needs for the people who reside within them, including:

- a place of self expression (Clemson, Cusick, & Fozzard, 1999)
- a vessel of memories (Marcus, 1997); and
- a place of refuge from the outside world (Davison, Kendig, Stephens, & Merrill, 1993).

Younger and older adults with disabilities (as individuals) desire to create and maintain continuity with the world but may be restricted in their access to it, so emotional nurturance from familiar places becomes increasingly important (Hocking, 1997). Furthermore, a large scale qualitative study of older people in South Africa found that feelings of independence were strongly correlated with the ability to age within their usual residential abode (Frankental, 1979).

The complexities of meaning inherent in understanding housing need are highlighted by US research which found that the majority of the elderly do not make special alterations to their homes, nor do they choose housing based on any preconditions for easier living. They also do not spend time planning future alterations to their living environment and, given a choice, prefer living situations which reflect their present one (Wister, 1989). This may be explained by the fact that what older and younger adults with disabilities want from their housing can be different from what is perceived as rational by government and other interests (Kendig & Gardner, 1997).

2.4.7.   Home modifications

Accidents and injuries resulting from unsupportive home environments contribute significantly to morbidity and mortality and force moves to institutional settings (Public Health Association of Australia, 1993; Wylde, 1998). According to Pynoos, Tabbarah, Angelelli and Demiere (1998), there is general agreement that an

accessible, safe and supportive environment is vital to quality of life for younger and older adults with disabilities. Home modifications, such as ramps or handrails, allow a person to engage in major life activities more easily and help prevent accidents.

Moreover, a growing body of evidence supports the cost effectiveness of environmental interventions such as adaptable housing and home modifications. The Japanese initiated a program to provide universally designed housing stock which, although costly initially, has effectively facilitated 'ageing in place' and has proven to reduce government expenditure in the longer term (cited in, Wylde, 1998).

A study investigating Swedish public housing grants for home modifications indicated that the most common measures would have proved less expensive if they had been planned as "basic accessibility". The reasons why accessibility problems persisted were building traditions, lack of knowledge about disability and technical problems (Iwarsson & Isacsson, 1993). Adaptability is also a major feature of recommendations surrounding dementia care as relocation only serves to worsen confusion and distress (Alzheimer's Association Australia, 2000).

US studies suggest that access to home modification and equipment (such as assistive device technology) increases functional independence and the likelihood of remaining in one's home (Mann, 1997; Mann, Hurren, Tomita, & Charvat, 1995). A later randomised control trial additionally demonstrated lower health care costs, including costs related to institutional care and in-home nursing and case management visits (Mann, Ottenbacher, Fraas, Tomita, & Granger, 1999).

Inadequate services, lack of information about services and funding caps hamper the response to growing home modification need (Duncan, 1998a; Enders, 1991). In England, delays of up to 2 years in the provision of basic home modifications are still occurring (George, 1998). Long delays are also a problem in many areas within Australia (Phibbs & Higham, 1999) as is the substantial variability in program type and entry criteria (Kendig, 1990a).

Service delays and restrictions within home modification services are significant given that the community at large has limited familiarity with what can be obtained at competitive prices from the private sector. The almost complete lack of private sector service options has been attributed to manufacturers and the housing industry failing to anticipate great demand (Duncan, 1998b). Unfortunately, few government programs currently target these issues in Australia.

2.4.8.   Transition stress

Disabled consumers, families and healthcare professionals agree that appropriate consideration of accommodation can be a critical factor in reducing institutionalisation and in promoting integration and inclusion (Iwarsson & Isacsson, 1998; Public Health Association of Australia, 1993; Steinfeld & Danford, 1997). Disabled consumers consistently report that cared accommodation is a last resort and that they would prefer to live in their own house or apartment, either alone or with a spouse, rather than living with other health consumers (Cooper, 1996; Knapman, 1996; Tanzman, 1993). Moreover, re-housing to achieve higher levels of care creates 'transition stress' with consequent impacts on quality of life and greater incidence of mortality (Bruce, 1986; Clemson et al., 1999).

2.5.   Accommodation options

Although the Commonwealth Government recognises the need to provide a wider range of housing choices for both younger and older people with disabilities, the fact remains that, for many older and younger people with disabilities, current accommodation arrangements negatively impact on quality of life, independence and community participation. The issues associated with particular accommodation options are outlined below:

2.5.1.   Private dwellings

'Private dwellings' refers to accommodation within the community, which is either owned or leased by an individual. It is commonly referred to as an individuals' 'home'. Characteristic of private dwellings is sole occupancy, which is a term used to describe a situation where an individual, couple or family are residing in a household not shared by other people. Private dwellings include houses, units, flats, townhouses and villas. Whilst many OECD countries, including Australia, have targeted individual home ownership as an indicator of prosperity there are now indications that home ownership rates are falling, particularly for younger adults and those on low incomes (Kendig, 2000).

While the size, condition and quality vary enormously, the majority of private dwellings have stairs or other inaccessible features that create dependency and/or place younger and older people with disabilities and their carers at risk. In an English study the main response cited for relocation requests was to eliminate the demands made by stairs (Buckle, 1971).

Some of the key issues in terms of private dwelling choices are that purchasing a private dwelling is costly and cost increases with proximity to amenities and services, consequently better access to facilities and services involves premium rates. Younger people with disabilities may never own their own homes as unemployment and low incomes precludes many people with disabilities from following typical housing career patterns (Kendig, Browning and Young, 2000).

'Ageing in place' means that older adults who become disabled later in life have difficulty with home maintenance and may be at risk. Services directed at home modifications for people with low incomes are insufficiently funded and consequently waiting lists are common, whilst many people receive no assistance (Duncan, 1998b).

2.5.2.   Retirement villages

The 1980s saw the rise of age-specific housing including accommodation such as hostels and retirement villages. The attraction of these developments is that they are usually built to provide older people with a particular lifestyle and most include some level of support or care appropriate to the needs of the residents, taking the onus of responsibility off family and retaining levels of independence. Unfortunately, many of these types of housing have been located on the periphery of metropolitan areas, or in semi-rural locations, making them relatively inaccessible via public transport and isolating them from the support services of the city and suburbs (Wilson & Scott, 1995).

2.5.3.   Transportable Homes

Transportable homes include relocatable structures and manufactured homes such as campervans and caravans. These homes by their nature are small and basic in terms of facilities, many do not have toilets and are dependent on connection to power and water outlets such as in caravan parks or manufactured home estates. In addition to purchase cost, ongoing fees are charged for occupancy of a site and for connection to public facilities. Transportable homes are particularly popular in Queensland on the NSW South Coast, locations that attract retirees (Wilson & Scott, 1995).

Whilst transportable homes are generally more affordable, access and security issues make these unattractive for people with high care needs. Community support services are unavailable or restricted and site locations are often isolated from community services and facilities, creating increased dependency on informal carer support (Wilson & Scott, 1995).

2.5.4.   Private rental market

The private rental market includes houses units, flats, townhouses and villas, plus rental only accommodation such as boarding houses, rooming houses and private hotels. The key issue here is affordability. A third of private tenants pay more than 40% of their income in rent leaving little for other expenses (Kendig, 1990a). Moreover, rent levels have increased dramatically in recent years (Australian Housing and Urban Research Institute, 2000).

Whilst the Commonwealth offers rental assistance as do some State housing authorities, this is based on income and asset testing and the degree of assistance varies between States (Wilson & Scott, 1995). A recent Australian report highlighted affordability issues for private renters and showed that low-income earners generally pay rents similar to high-income earners. In addition, a significant number of the most vulnerable were in the most unsuitable housing and would be at risk of homelessness if forced to move, despite high level of rental assistance (Landt & Bray, 1997).

The next greatest issue of concern is the availability of rental accommodation, as there is severely limited appropriately designed stock (Physical Disability Council of NSW, 1998) and proximity to services are usually only available at premium rates further compounding affordability issues. Moreover, there is a reluctance by landlords to allow or to provide necessary fittings and fixtures, such as grab rails and ramps to their properties.

2.5.5.   Community housing

Community housing includes housing co-operatives, share houses, Abbeyfield houses and independent dwellings within retirement villages (much of which is government subsidised). It enables people to gain housing by pooling resources, however community-housing schemes are typically restricted to low income earners (Wilson & Scott, 1995).

Abbeyfield housing provides facilities within existing communities and generally has the same means testing criteria as public housing. The idea started in the UK in the 1950s and has been an option in Australia since the 1980s. The Abbeyfield concept provides groups of up to ten low income older people with a home-like supportive environment including guest rooms and an on-site housekeeper (Forsyth, 1992).

Independent dwellings within retirement villages, on the other hand, may be purchased or rented and allow residents some support and proximity to communal facilities and services. However, they are often located on the fringes of larger urban settings, creating difficulties for social inclusion within the wider community.

The issues in terms of community housing are threefold.

- Firstly, there is an assumption that only minimal care will be provided so as residents 'Age In Place' and as levels of disability increase this may result in forced transitions to cared accommodation.
- Secondly, renting or buying into this type of accommodation can be difficult, as there is considerable variations in supply depending on geographical location.
- Thirdly, like rental and private dwelling accommodation despite government subsidies, there are no legislative requirements for accessible design and so most community housing stock does not consider accessibility or adaptability in design or construction.

2.5.6. Public housing

A recent English audit commission report noted that the stock of social housing had shrunk by over a million dwellings since 1981 and that many high quality homes had been sold, meanwhile an increasing number of aged and disabled people needed assistance with accommodation (George, 1998). The situation is very similar here in Australia, where waiting times are often lengthy and are likely to increase as demand continues to outstrip supply. This is partly due to a 13% decrease in annual expenditure on public housing between 1989 and 1999 (Productivity commission, 2000) and the decreasing and limited construction of accessible or adaptable stock (Physical Disability Council of, 1998).

In addition, although disability is factored into the allocation of public housing, particularly crisis housing, it is not factored into rental rates which although increasing, are currently capped at 25% of income (Department of Housing, 2000). Whilst rental caps serve to protect tenant income they fail to allow sufficient residual income for people with high care needs to purchase equipment or care services in a market that is increasingly 'user pays'. Approximately 25% of public housing tenants have a declared disability and require ongoing support to sustain their tenancies (Department of Housing, 2000).

Additionally, as in the UK on-site managers, where they are available in large estates, have no formal responsibility for care management (McCafferty, 1994). Involvement of housing authorities in joint planning arrangements has typically been minimal and are usually not reflected in the day-to-day job descriptions of employees (Nocon, 1997). The focus on housing programs without adequate and coordinated consideration of disability and support need and their cost and provision demonstrates that community reform is still severely hampered by poor planning and weak linkages (National Housing Strategy, 1992b).

2.5.7. Cared accommodation

Many people with disabilities perceive the only alternative to staying in one's own home is to move to an aged care facility (Cooper, 1996). Regrettably, there are 1174 younger people with disabilities (i.e. predominantly those with multiple sclerosis, head injury etc.) currently residing in aged care accommodation facilities within Australia.

There is also an acknowledged reluctance within the aged care industry to accept many people with disabilities because of the increased resources required for staff training and facility upgrading (Kahler, 1998). More stringent accreditation and safety guidelines (particularly for smaller facilities) have further compounded this problem. For instance, US research indicates that the overwhelming majority of fire fatalities in small board and care homes are residents with some form of disability and making increased fire safety affordable is difficult (Levin, Groner, & Paulsen, 1993). This situation highlights the current lack of choice in cared accommodation services particularly for prematurely aged or severely disabled people.

Both home support and cared accommodation options are even more restricted in rural communities (Foskey, 1998; Knapman, 1996). Not surprisingly, therefore, older people in rural and remote areas tend to be more concerned about residential care (Beidler & Bourbonniere, 1999; Canada Mortgage and Housing Corporation, 1991). This may be due to the fact that in some situations people need to leave their home towns to access appropriate care and support in the form of a residential care package (Sach, 1998).

With the advent of 'mobile hostels', 'hostel options' and 'nursing home options' via Community Aged Care Packages (CACPs) it has become possible to provide greater levels of in-home care. Better in-home care services have been linked to a perceived reduction in the need for cared accommodation (Australian Institute of Health and Welfare, 1995). However, current trends suggest this is not reflected in statistics of hostel use across Australia (McCallum, 1999).

It is assumed that continued demand for hostel services is the result of the combination of the increase in the population of older people with care needs and the difficulty in accessing the limited high care services currently available. Lefroy, Hobbs and Page (1984), in an Australian study, estimate that one nursing home place is needed for every three residents in a hostel. They also stressed the importance of having temporary acute hospital admissions available to avoid unnecessary transfer to a nursing home.

As a result of the unfavorable social stereotypes associated with nursing homes, the stated preference of people with higher care needs is to access an increasing level of care support in their existing hostel accommodation. Similarly, the combination of a reduction in funding of nursing homes in preference for community-based services and the increases in the life expectancy of people with disabilities has ensured the demand for high care nursing home and hostel services (Lefroy, Hobbs and Page, 1984).

2.6. Care options

Informal care and support networks play a critical role in community service provision, especially caring for frail older people and older people with disabilities living within the community. The majority of accommodation support outside cared accommodation options are provided informally by unpaid caregivers. Not only are informal carers responsible for maintaining people, often with high levels of functional dependence, within the community, but the absence of an informal carer has been identified as a significant risk factor in contributing to institutionalisation among the older population (Australian Institute of Health and Welfare, 1997).

2.6.1. Informal care

The growth of home-based care relies heavily on the availability of carers to provide the day-to-day support to people who are ill or disabled. More than 17% of people aged 50 and over are carers (Wolcott & Glezer, 1999). Whilst 75% of carers of severely handicapped older people are the spouse of the person requiring care, thus highlighting the extent to which older people are themselves carers. Women are nearly three times more likely than men to be primary carers in Australia. In addition, older people are more likely to be carers than younger people, with those aged between 65 and 74 years being twice as likely to be a carer compared with the overall population (Australian Bureau of Statistics, 1998).

The cost of caring is both personal (emotional and physical health decline) and financial (cost of care, loss of income and loss of opportunities for advancement and promotion) both in immediate and longer terms (Watson & Mears, 1996). The fact that the ability to 'age in place' depends on the availability of informal care is significant both because of the economic disadvantage experienced by carers and the increased likelihood that the physical demands of caring will result in acquired disability for the carer. Capping residential care cost depends to some extent on improving respite care benefits being provided to informal carers (Ball, 1990).

A Norwegian study, conducted by Lingsom (1992), contradicts the notion that family care of dependent elders is undermined by the introduction of formal state funded services. Her cross-sectional random national sample of 685 elders aged 66 and over living at home found instead that community services supplemented and supported informal family care.

2.6.2.   Formal care

Formally managed home health care services are the fastest growing health care sector in the United States (Geraci, 1997). This trend is echoed in Australia and other OECD countries (Kalisch, 2000). In the US aged care reforms have shifted primary responsibility for community-based managed care to the States. Likewise, the 1993 reforms to the British system of community care made case management the cornerstone of the system and gave primary responsibility for community care programs to local social service departments (Cox, 1997).

The costs in providing managed home health care are both direct and indirect. Indirect costs include injury and disability compensation payments for employees. Consequently, one of the most pressing challenges for Australian Homecare services is to make demonstrable improvements in occupational health and safety performance. For example, almost half of the occupational, health and safety claims made by Homecare staff relate to manual handling injuries (48.5 per cent of the total) (Home Care Service of NSW, 2000).

2.6.3.   Achieving individual tailoring & flexibility

In reducing the need for cared accommodation, more flexible and individualised means of supporting informal caregivers need to be developed. These need to better reflect individual need as expressed by caregivers and to fit the fundamental values and belief system of the family unit. Gitlin, Corcoran and Leinmiller-Eckhardt (1995) suggest that this is dependent on better understanding the personal meaning of caregiving, the way in which care is provided and the specific aspects of caregiving that are problematic.

In a study by Tanzman (1993) investigating the support preferences of mental health consumers there was a strong preference for outreach staff support that is available on call; few respondents wanted to live with staff. Consumers also emphasised the importance of material supports, such as money, rent subsidies, telephones and transportation, for successful community living. To accommodate consumers' preferences, it appears the mental health system needs to work towards providing flexible support, corresponding to the episodic nature of psychiatric disability, and to expand their advocacy for affordable housing and for increased income for people who depend on disability benefits and other entitlements.

2.7.   The economics of affordability

Both the degree of activity restriction resulting from disability status and financial status influence the level of formal support required for housing and care options. For instance, home ownership can be crucial to living comfortably on benefits and can offset costs for care, however, housing modification may be perceived as unaffordable (Kendig & Gardner, 1997). Low income homeowners have the advantage of being able to sell 'down'; borrow against their dwelling; or take up a reverse equity mortgage. However, all three options carry relatively high upfront fees and there is a shortage of suitable loan services (Burbidge, 1996b).

2.7.1. Income support

Considering the gap in superannuation and other retirement income sources, premature retirement and long term unemployment is often responsible for poverty and resultant homelessness, loss of dignity and elimination of life quality amongst the majority of ageing people (Kalisch, 2000). In addition, governments from Australia, Canada, Norway and the Netherlands are actively working to restrict access to disability income support by reducing the usage of non-medical criteria.

Kalisch (2000) also warns of the risks associated with decreasing flexibility and over rigorous evaluation criteria in terms of increases in morbidity, homelessness and social exclusion. This is particularly significant given that high dependency community care need is increasingly being shifted back to individuals and determined via the use of functional rather than medical criteria (see previous discussion).

2.8. Linking housing, support and care

To date, there is no 'best' single practice model for integrating care-services, applicable to Australia because of the wide diversity of needs and accommodation types (Fine & Chalmers, 1998). However, as in the UK and US, the common aim seems to be to find a means of funding care irrespective of accommodation setting (i.e. home, cared accommodation or hospital), whilst individuals would still be expected to carry the cost of housing, food and personal (material) expenses (Fine & Chalmers, 1998).

Given the current policy emphasis on costing care, there has been quite a bit of research aimed at predicting care needs. For instance, multivariate analysis was used in a large scale longitudinal population study conducted in South Western France, in order to identify the predictive factors most likely to account higher level dependency needs (Metzger, Barberger-Gateau, Dartigues, Letenneur and Commenges, 1997). It was established that age, absence of a phone in the house, cognitive decline, inability to do shopping and limited social contact with the family were all significant predictive factors.

A similar study carried out in Sweden by Lagergren (1996b), confirmed age as a factor but also showed some differences. They found the type of disability and self assessment of care need to be of the most significant factors. Dementia was the strongest individual disability factor. An analysis of changes over time illustrated the interdependence of care levels, for instance, increasing levels of disability of residents already in cared accommodation reduced resources and resulted in a near blocking of available beds (Lagergren, 1996a).

A Victorian study of 497 clients of Linkages (Community Options) projects found that client and carer characteristics varied by dependency, incontinence, sex and length of time as a client. However, capacity to predict costs was limited, as only 29% of variances could be easily accounted for (Kendig, Wells, Swerissen, & Reynolds, 1999). It is clear that more work needs to be undertaken in Australia to assist the identification of clients with high care needs so that care and housing needs can be better predicted and modeled.

2.9. Summary

This chapter reviewed the academic literature relating to disability incidence and prevalence and severity and their relationship to services, housing and care. It suggests that flexible thinking and some fundamental changes in the priorities and delivery systems of health, housing, urban planning and local government are needed. Whilst there has been much innovation and reform in the delivery of health and aged care services to younger and older people with disabilities, the growth in population numbers and higher expectations about quality of life are resulting in pressure for further change. This chapter highlights that:

- Disability, housing and care are interdependent, complex and intersections particularly in terms of linkages between access, safety and dependency, are not well understood or adequately researched particularly in the Australian context.
- Community care services can effectively supplement in-home support but diversity, fragmentation, financial caps and lack of coordination result in substantial unmet demand.
- Design and construction of private dwellings and cared accommodation settings has consistently failed to adequately consider the needs of adults with disabilities effectively increasing dependency and creating social exclusion.
- The ability to 'age in place' depends on the availability of informal care and providing care can lead to economic disadvantage and increased risk of carers acquiring disability themselves.

Chapter 3. POLICY REVIEW

3.1. Introduction

This chapter reviews the national policies that frame the housing, care and support needs of younger and older persons with disabilities. It builds on the issues outlined in the preceding literature review chapter and maps some of the issues associated with coordination of policy initiatives at State and Territory levels. This review is preliminary and State based variances will be further explored in future work on the policy interviews and review.

Governments traditionally simplify problems of program linkages by bundling care and accommodation setting into a single package. Facilitation of community inclusion and integration means this must be re-examined with a view to re-bundling and better integrating and or coordinating services to improve targeting and flexibility in response (Howe, 1992). Figure 3-1 indicates in general terms the range of existing accommodation, care and primary prevention and maintenance services on offer. It also highlights the traditional separation but implicit relationships between programmes and restrictions that limit flexibility. Furthermore, the widest part of each pyramid highlights where the current priorities for Commonwealth funding and responsibility are targeted.
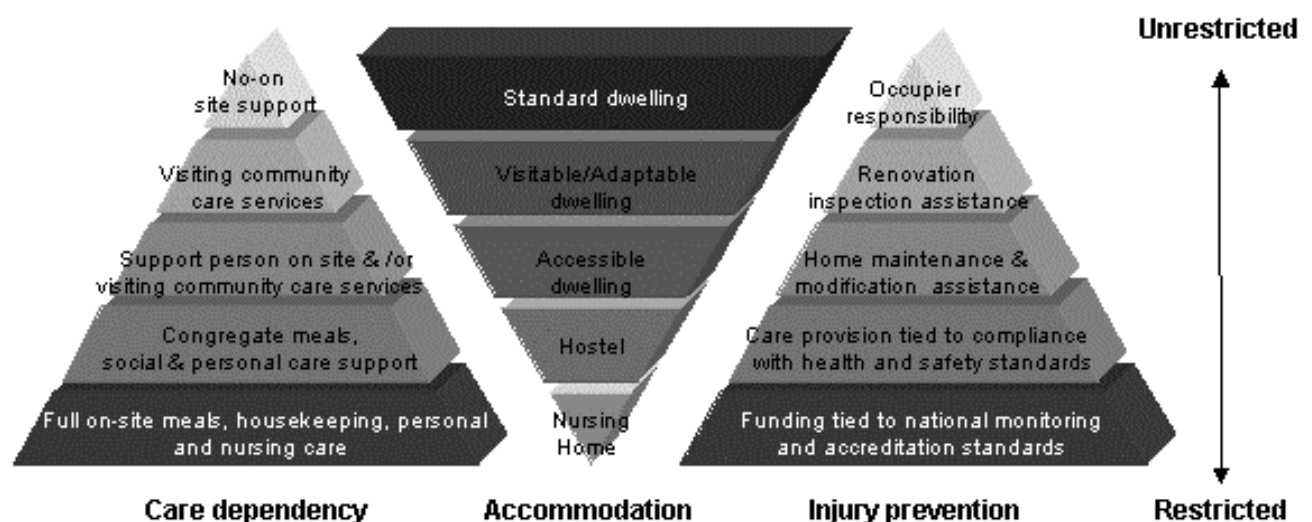

Figure 3-1: Relationships between housing, care and safety levels in terms of service restrictions and availability

Interest in linkages between housing, support and care arose in the early 1990s with the publication of the Mid Term Review of Aged Care and the National Housing Strategy (Howe, 1992). The last ten years have seen a number of significant reforms of legislation, which have impacted policy at Commonwealth State/Territory and regional levels. Connections between housing, urban policy, ageing and disability are relatively recent and incomplete in Australia with public housing, income and community support remaining largely separate operations with little integration or comprehensive coverage (Kendig and Gardner, 1997).

The proportion of national income directed to the public sector has steadily fallen in real terms since the 1980s, reflecting the difficult economic environment and changing political context in many countries including Australia (Kalisch, 2000). The 1990s also has seen increasing corporatisation in tandem with economic rationalism and welfare redistribution (Kendig & Gardner, 1997).

Additionally, there has been a shift in emphasis to encompass 'ageing in place' in tandem with massive deinstitutionalisation. These are both of significance in consideration of the housing and support needs of younger and older adults with disabilities. Australian aged care services in particular have undergone a series of substantial reforms in recent years under the rubric of the Aged Care Reform Strategy. Overall, there has been a progressive refinement of the targeting of available services to those most in need, defined in terms of both disability levels and financial resources (Gibson, Liu and Choi, 1993).

Policy has been framed in a climate that increasingly seeks to maximise independence, improve customer satisfaction (choice, access and security) and service flexibility while capping costs within an ever decreasing fiscal framework involving market driven competition, privatisation, outsourcing, and funder/provider accountability (Kalisch, 2000). The chapter begins by outlining the key disability, ageing, housing and care policies and legislation before illustrating the strengths, inconsistencies, gaps and weaknesses that impact on service outcomes at a State/Territory level.

3.2. The National framework for Disability/Ageing

The Commonwealth Disability Services Act –1986 (CDSA), Commonwealth/State Disability agreement -1998 (CSDA) and the Disability Discrimination Act-1992 (DDA) have all had a significant impact on policy directions by changing the focus to the individual with a disability and their needs and requirements. They are inclusive and are equally applicable in intent to both younger and older adults with disabilities. Under the CSDA, the Commonwealth has delegated specialist disability services to the States and Territories except for employment services.

The mid-term review of aged care that was launched in the early 1990's, echoed the push for greater individual choice and recognised that most older people would prefer to 'age in place'. The impact of these initiatives is reflected in a decomposition analysis undertaken by Gibson, Liu and Choi (1993) which shows that the proportion of aged persons in nursing homes has decreased substantially in Australia, particularly with respect to women. Nevertheless, greater dependency levels amongst those admitted to cared accommodation has increased the per capita costs for residential care (Bishop, 2000b).

Concurrently, the demand for home and community care services has continued to grow (Kalisch, 2000) along with increases in funding. In 1985-6 nursing home and hostel care accounted for 84% of aged care expenditure but by 1998-99 this had reduced to 76%, as a proportion of all expenditure. Over the same time period, home based service expenditure (HACC and CACPs) increased by 8% compared with residential care (Bishop, 2000b). Home-based care for the majority of recipients is cost effective but this declines as care need increases (ibid.).

The growing numbers of older people living on their own has combined with decreases in the numbers of older people with spouses and children to act as carers. Social changes, for example the increase in female workforce participation, are reducing the availability of unpaid carers and these changes can be expected to continue. Sustained community care underpinned by informal carer support also

requires income support and better access to 24 hour respite and occasional care (Russell & Bowman, 2000). Russell and Bowman (2000) go on to point out that this must be incorporated via policy and planning for both workplace and health service delivery approaches.

The most recent policy initiatives at a national level reflect a growing concern with funding and a shift in arrangements for financing care and support services. As the Australian Institute for Health and Welfare (AIHW, 2000) report indicates, the economic-based restructuring of welfare services involves a move towards output-based funding, whole-of-government approaches and increased focus on accountability, efficiency and effectiveness. This is illustrated by the rise of the purchaser–provider models that foster competition between service providers.

More economic change has been foreshadowed. For instance, two recent discussion papers concerning disability (Commonwealth Department of Family and Community Services, 1999) and ageing (Bishop, 1999) are concerned with assisting income generation for individuals through either retirement planning and saving schemes and/or through employment strategies. However, the difficulties faced by people with disabilities in achieving economic security places them at a double disadvantage in a truly market driven system.

3.3.   The National framework for Housing

Major reviews of housing policy and programmes at federal and state levels are resulting in greater emphasis on central planning, coordinated care services and legislative reform to encourage high density developments and better use of existing housing, land and infrastructure. The Better Cities Program and the National Housing Strategies[2] were early housing reform initiatives of the previous labour government, and while they are no longer operational they were significant in that they both advocated a more integrated and strategic approach to urban development. One outcome of the Better Cities Program was it's success in facilitating urban renewal and consolidation (National Capital Authority, 1996). However, while urban renewal and consolidation have increased urban density and made better use of existing community infrastructure, they have failed to provide sufficiently affordable and accessible private dwelling accommodation options (Troy, 1996).

Unfortunately, centrally located accommodation is typically also the most expensive. Further, insufficient consideration has been given to spatial provisions that typically suffer in the push to increase density. Wilson (1995) has highlighted these issues in the analysis of the 'New Homes for Old Program' that aimed to enhance older people's awareness of and access to a greater variety of housing options.

Some policies assumed that if housing choices were broadened through the provision of more medium and high density housing closer to services, that older people would not be as reluctant to move and would be better off. However, in a recent study it appears that these current attempts to improve housing choice for older Australians are based upon a misappraisal of the housing preferences of older people (Winnet & Phibbs, 2000). Encouragement of medium and high density housing for younger and older people with disabilities can result in housing that is inaccessible, unaffordable, financially unbeneficial and unpopular.

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[2] The National Housing Strategy included strategies which targeted both the needs of people with disabilities (1991) and housing for older Australians (1992).

Because of pressure to deal with the low income characteristics often associated with disability, the National Housing Strategy reform focused on targeting assistance to those most in 'need' and in addressing 'need' regardless of tenure status (Kendig & Gardner, 1997). Reform also involved capping accommodation costs at 25-30% of income, with a resultant impact on the availability and costs of governmental rental subsidies.

Current reform directions more recently outlined under the Commonwealth/State Housing Agreement (CSHA) include more government assistance for households to rent in the private market and reforms to public community and crisis housing assistance (Australian Institute of Health and Welfare, 1999). Furthermore, government policy and program changes reflect changing roles for the public, private and community sectors in the provision of housing assistance.

Public housing has narrowed targeting to people whose needs cannot be met adequately within the private market. The increasing numbers of older disabled persons living alone has led to their accounting for 30% of public housing occupancies. Consequently, State Housing Authorities are having to readjust housing stock in response, further reducing the availability and choice of housing stock available (Bishop, 2000a). Younger and older adults with disabilities are disproportionately represented in the public sector with 40% of public tenants now identified as having a disability (Australian Institute of Health and Welfare, 1999). This situation is compounded by the decline in affordability and home ownership rates within the general community (Kendig, 2000).

Consequently, overloaded public housing authorities are increasingly looking to community housing associations to create more affordable housing options for private renters. A key objective of community housing involves assisting tenants to establish and maintain an affordable, secure tenancy (RPR Consulting Pty Ltd, 1999). However, considerable variations in equity and accountability exist between projects and so a manual outlining the 'National Community Housing Standards' and 'National Competency Standards' have been concurrently developed (RPR Consulting Pty Ltd, 1999). The desire to improve consistency arose because of concerns about operations and security in combination with the fact that only a small number of States had previously developed codes of practice (ibid.).

National requirements apply to all cared accommodation within Australia but domestic construction is still the prime responsibility of States and Territories. Building regulations can ensure that new residential and commercial buildings meet the needs of all Australians throughout their life course. There appears to be general agreement that the ability of future cohorts to 'age in place' relies on housing design and construction that can be adapted to better support the occupant (Bishop, 2000a).

The Australian Urban and Regional Development review identified principles of accessible design and Standards Australia sets standards to create a framework for better designs. However, neither can be implemented in other than an *ad hoc* and piecemeal manner without political will and commitment from industry (Kendig, 2000). In the National Strategy for an Ageing Australia, the 'Attitudes, Lifestyle and Community Support' paper discusses the establishment of a coalition of community, building industry and government stakeholders to encourage and investigate innovation in this area (Bishop, 2000a).

Legislation relevant to housing construction include the DDA, the Building Code of Australia (BCA) and relevant Australian Standards. Table 3-1 shows the hierarchy of building control and its impact on accessible accommodation outcomes.

Table 3-2: Building control and its impact on availability of adaptable/visitable and accessible domestic dwellings

WHAT (constitutes building)	State Building Act (maybe incorporated into State Development Planning Act) regulates all new building and renovation of existing buildings. The Building Act calls up the Building Code of Australia, which is performance -based and public building focused.
WHO (may undertake building)	State Builders Licensing Act controls licensing of builders and allied trades. However, access is not a standard part of accreditation or training curricula
WHERE & WHEN (access is required)	The Building Code of Australia currently fails to specify the number of adaptable/visitable or accessible domestic dwellings. This is left to States to determine under State Environmental Planning Policies.
WAY (access is provided)	Although Standards Australia has developed a standard on adaptable housing there is currently nothing within the Building Code of Australia (BCA) to enforce it for domestic construction. No national standard exists for accessible housing construction although many housing authorities and local governments have produced guidelines.
WHY (access must be provided)	Commonwealth Disability Discrimination Act (DDA) can be used to ensure that all premises including accommodation services are non-discriminatory in nature. However, lack of available knowledge from case law hampers decision-making. Consequently, the domestic application is unclear.

Source: Adapted from (Murray, 1999)

The table highlights that there are no consistent guidelines or regulation at a national level and as a result both the way that accessible domestic accommodation is provided and where/when it is provided are unclear. There is no uniformity across States and little attention is paid to this area by the domestic construction sector outside of public dwelling provision.

The importance of coordination and prioritisation becomes particularly apparent when we consider the fact that new housing development occurs in the context of pre-existing provision. It must fit into existing service and transport infrastructure and conform to many other existing regulations including site use, structure and fire safety, to name but a few (Bridge et al., 1999). State governments are concerned about costly infrastructure such as roads and public services, whereas developers are interested in quick returns and minimising costs. The financial interests influencing land use continues to impede the ability to provide accessible and affordable accommodation (Kendig, 2000).

In summary, housing policies have a major impact on health and quality of life for younger and older people with disabilities. They reflect political pressures from building industries, prevailing ideologies, such as the value of home ownership, and historical legacies with little attention to the cooperative linkages needed between government departments and the construction industry (Kendig, 1990a). Furthermore, there is great variation between jurisdictions in the composition and range of housing assistance (Australian Institute of Health and Welfare, 1999). The Public Health Association of Australia (1993), has stated that comprehensive Australian data on the articulation of the health impacts of housing, particularly for people with disabilities and older people who are most vulnerable, is lacking but urgently needed.

3.4. The National framework for Care

The development of increasingly flexible packages of care is a hallmark of the newer reform agendas, as is the consumer-based focus of the Supported Accommodation Assistance Program (SAAP) standards which reflect the principles of client self-determination, and needs based service delivery. Other Commonwealth government policy directives underscore the value of including people with disabilities in policy development (Commonwealth of Australia, 2000).

Additionally, the Aged Care Act 1997 provided both a legislative base for a more unified aged care system whilst actively promoting 'ageing in place' via the linking of care and support services to the places where older people prefer to live (Commonwealth Government, 1997). The two objectives are naturally linked as the push to provide in-home support, although consistent with the preferred wishes of consumers, effectively reduces the cost of nursing home care. Financial indicators released by the Commonwealth Department of Health and Aged Care (1998) reveal that aged care services comprise around 0.7 per cent of GDP, or $3.85 billion, with residential care comprising 76 per cent of costs. The average cost of nursing home care is about $30,000 annually for each place (AIHW, 1999).

The Commonwealth government via the Department of Family and Community Services holds responsibility for funding, directing and monitoring both residential cared accommodation and Home and Community Care Services (HACC). The States however have devolved responsibility for HACC implementation.

3.4.1. Residential Cared Accommodation

The Aged Care Reform Strategy of the previous government, stimulated a plethora of innovation, including hostel innovations, help with 'staying put', movable units and initiatives in urban design and planning (Forsyth, 1992). However, the success and sustainability of innovation varied widely due in part to the amount of lead-time required and policy changes impacting on funding. In the new terminology, an aged care building is defined as an accommodation building where residents are provided with personal care services and 24 hour assistance to evacuate (Australian Building Codes Board, 2000). This rather broad definition, focusing on care, says little about design in terms of personal autonomy, location and homeliness, which are critical from consumer perspectives.

Recent restructuring has resulted in community and private sector organisations operating 99% of residential care services (Bishop, 2000b). Significant and recent reforms have been the amalgamation of nursing homes and hostels, the introduction of means-tested contributions for residential care and capital charges, and the establishment of the Aged Care Standards and Accreditation Agency (Australian Institute of Health and Welfare, 1999).

In amalgamating nursing homes and hostels, the Government has recognised that previous distinctions between nursing homes and hostels created a dual system that failed to recognise that many clients progress through a continuum of care needs. Nevertheless, the inflexibility inherent in the construction and design of cared accommodation facilities still prevents occupancy by residents with varying levels of dependency in the same facility (Sach, 1998). The distinction between hostels and nursing homes has been compounded by a significant proportion of low care places being occupied by people assessed as requiring high care needs (Commonwealth Department of Health and Aged Care, 1999) For instance, as at January 2000, people requiring high care occupied about 17.6% of low care places in NSW.

In the new 'intermix' model, there is no identifiable 'nursing home' or 'hostel', resulting in little distinction between the health, well-being or capacities of the residents. Families, consumer representatives and providers are concerned that the conglomeration of older people at various levels of physical frailty, cognitive impairment (e.g. dementia), psychological and psychosocial impairment (particularly among veterans) residing in the same facility, may impact on the lifestyle of other residents, and compromise the desired 'home-like environment'. Self-care has also demonstrated challenges for 'intermix' facilities, for example some residents may not wish to maintain independence despite possessing the capability.

However, rural and regional areas have special problems regarding insufficient funding and in gaining accreditation of facilities as policies, planning and service delivery are often based on urban models, better suited to higher population densities, and thus, less appropriate or effective (Gething, 1997). For instance small communities face difficulties meeting residential care service and accreditation standards (Foskey, 1998). Furthermore, the most recent policies include new standards and requirements that may be difficult to address in rural areas.

3.4.2.   Home and Community Care Services

The HACC Agreement was a major landmark as it signaled the opportunity for locally-based and more flexible delivery of care services to people in private dwellings. It specifically targets frail older people, younger people with disabilities and their carers in order to prevent premature or inappropriate institutionalisation (HACC Program, 1998).

Over half (58%) of those receiving HACC assistance reside with a carer and many carers are older adults themselves. For instance, in 1998 the number of people who were aged over 75 years and caring for people with disabilities was 133,330 (Bishop, 2000b). Recent HACC agreements reflect a move towards a more contestable environment as the new funding arrangements extend beyond community sector agencies to private providers (Bishop, 2000b).

The HACC access survey (Howe, Gray, Gilchrist, & Beyer, 1996) revealed that targeting was related to both budget and service delivery. Significant differences in HACC programs between the States, relating to management and administrative responsibility, also became apparent. Consequently, a reform framework to improve the efficiency and effectiveness of the HACC sector is underway. Reform measures aim to enhance and introduce economies of scale, increase purchasing power and linkages to other services, enable integration and reduce duplication of services.

There has also been considerable developmental work undertaken to improve data quality and collection systems (through the HACC Minimum Data Set). This has resulted in increased accountability and transparency, facilitating improved monitoring of HACC projects. It also allows more efficient targeting of resources on a local and regional basis.

Whilst the HACC program has recently received more funding (Australian Institute of Health and Welfare, 1999), services are still below what consumers are demanding. Additionally, the National Fee Principles, following the 1996/97 Commonwealth Budget decision, poses additional issues regarding access and affordability in the delivery of these services. For example, from January 2000 all clients were required to contribute to the cost of their HACC services unless their income assessment indicates that they are unable to do so.

Nevertheless, the charging of fees for all clients receiving Home and Community Care services, especially considering the 'income-poor' characteristics of the most vulnerable, raises equity concerns regarding amounts charged and the means by which clients are assessed as being able to afford fees. Unfortunately, this strategy conflicts with other policy adviser directions recently agreed to by the Commonwealth, which clearly state that policy advisers should assess and quantify the economic and social impact of policies on the lives of people with disabilities in the short, medium and longer terms (Commonwealth of Australia, 2000).

Minimisation of accommodation transitions and the facilitation of 'staying put' or 'ageing in place', require individual case management and whole-of -government approaches in which construction and regulation work together. One of the factors working against better linkages at present is that building regulation does not ensure that accommodation stocks are adaptable or accessible. At present, there is no national framework for regulating the implementation of adaptable housing standards for new building construction. The adequacy of dwellings depends on the design of both the dwellings and the neighbourhood - good design adds little to construction costs but is expensive if retrofitted after construction (Kendig, 1990b).

3.5. Linking Housing Support and Care

Linkage, has been a central tenet of the Aged Care Reform Strategy mid-term reviews and of the National Housing Strategy. Housing and support have traditionally been 'linked' or 'packaged' by the provision of cared accommodation options (Howe, 1992). Traditional packaging required accommodation transitions from private dwellings to cared accommodation providers (nursing homes and hostels). More recently the emphasis has shifted to community care, deinstitutionalisation and ageing in place. The complexity of disability, ageing, health, housing and care programs means that oversight and management must be split across a number of ministers and between Commonwealth and State/Territory levels. The devolvement of program responsibility to non-government and private sector organisations further complicates matters (Kalisch, 2000).

Table 3-3 summarises current national policy regarding Legislation, Agreements, Standards and Programs. The degree to which Standards are implemented depends on whether or not they are embedded in legislation. A quick perusal of the policy framework reveals:

- The large number of policies impacting on disability/ageing, housing and care services
- The piecemeal and historical nature of linkages. For example, many program initiatives are not directly linked to State funding agreements, National Standards or Acts.

The lack of integration and consistency between programs, which is compounded by a narrow mission focus in terms of outcomes and outputs

Table 3-4: National policy and legislative framework summary

	Disability/ageing	Housing	Care
Acts/legislation	• Commonwealth Disability Services Act – 1986 • Disability Discrimination Act-1992 • Aged Care Act 1997 • Commonwealth Equal Employment Opportunities Act	• Environmental Planning and Assessment Act • Housing Assistance Act – 1996 • Australian Building Code-1996 • Aged Care Buildings Regulation document – 2000	• Supported Accommodation Assistance Act – 1994
Agreements	• Commonwealth/State Disability Agreement-1998- 2003	• Commonwealth/State Housing Agreement – 1999-2003 - • Housing Assistance Determination – 1999	• Home and Community Care national standards agreement –2000
Standards	• Disability Transport Standard-2000 • Draft Disability Education Standard-2000 • HREOC Advisory Notes on Access to Premises - June 1997 • Disability Services Standards	• National Community Housing Standards • Adaptable Housing Standards-1995 • General requirements for access-New buildings-1998	• Supported Accommodation Assistance Program (SAAP) standards
Programs	• The National Strategy for an Ageing Australia: Independence and Self Provision Discussion Paper – 1999 • Prime Ministers Gold Medal Access Awards – 2000	• Australian Urban and Regional Development Review-1994	• Supported Accommodation Assistance Program (SAAP) 2000-2004 • Stronger Families and Communities strategy- 2000-2004 (early intervention, stronger families etc.) • National Respite for Carers Program

3.6. The State/Territory framework

All States have their own Acts and legislative frameworks that compound variation and increase inequality of services. Many State governments are trying to fill perceived gaps in national legislation and clarify program objectives, in conjunction with achieving efficiencies and satisfying electoral expectation. In the human services domain significant legislation includes disability rights legislation. For example, within NSW there is the NSW Anti-Discrimination Act of 1993 and major State-based policy initiatives, such as the introduction of the Healthy Ageing Framework and Government Disability Policy framework.

The construction and housing sectors are bound by a plethora of legislation and policy including consumer protection legislation aimed at private dwellings (for example, the NSW Fair Trading Act) and those aimed at cared accommodation (for example, *Residential Tenancies Act*, *Retirement Villages Act* and the *Nursing Homes Act,* housing trusts etc.). Table 3-5, compares the legislation relevant to the construction and renovation of private dwellings in the States of Victoria and NSW.

Table 3-5: Comparison of legislation relevant to housing construction and renovation in NSW and Victoria

NSW Legislation	Victorian Legislation
− NSW Disability Services Act –1993. − NSW Anti-discrimination Act-1997. − Home Building Act-1989 − Home Building Amendment Act-1999 − Building Services Corporation Legislation Amendment Act-1996 − Occupational Health & Safety Act-1983 etc.	• Victorian Disability Services Act-1991. • Victorian Equal Opportunity Act- 1995. • House Contracts Guarantee Act-1987. • Domestic Building Contracts Act-1995. etc.

Differences between the States in their definitions, funding caps and operational and legal precedents make it difficult to achieve a more flexible, equitable and responsive system for younger and older adults with disabilities. The fact that no one organisation has responsibilities in health, housing and cared accommodation creates pressures for cost shifting and inefficiencies. It suggests that while policy reform directions are clear and much has been achieved, there are still major issues associated with achieving a whole-of-sector or cross-jurisdictional basis for the appropriate care and management of older and younger people with disabilities. They often require the involvement of more than one type of health and aged care service provider.

3.7. Summary

This chapter has reviewed policy relevant to housing and care funding and service availability in Australia. Too often, there is a lack of coordination, communication and integration that creates a negative impact on the very people for whom the care and housing services are intended. It has long been argued that policy and funding changes are urgently needed if appropriate care is to be provided for younger and older people with people disabilities (Lefroy *et al.*, 1984). Some changes previously suggested include distinguishing between need for service-based on dependency and need for subsidy based on income assets (Kendig, 1990b).

This chapter highlights the need for more analysis of the current systems delivering health and related aged care. More research is required in order to determine what may be done to reduce or even remove the boundaries, both real and perceived, between services and service providers. State/Territory government departments require this information to enable more targeted, efficient and cost effective housing and care. This chapter highlights the following points:

• Lack of knowledge about relative effectiveness in different bundling of income support, accommodation and care services means that further and ongoing research is urgently required.
• Poor coordination, complexity and the piecemeal nature of the current system are seriously impeding reform outcomes.

- Problems of compliance and consistency are compounded by the trend towards privatisation of housing and care options.
- The value of identifying a lead employer and a single case coordinator. The plethora of bureaucracies and routes through which funding for housing and support is provided increases confusion and creates communication difficulties.
- Notwithstanding agreements between Commonwealth and State/Territory governments, the separation of disability, ageing, housing and care Acts, standards and programs reduces the effectiveness of State/Territory strategic and regional planning.
- The generally low level of public input by younger and older adults with disabilities in planning reform initiatives makes it difficult for policy to address consumer expectations and concerns.

Chapter 4.   METHODOLOGY

4.1.   Introduction

The study is based on four main data sources that address the study aims and research questions described in detail in Chapter 1, namely:

- An international literature review;
- A systematic review of key policy documents:
- Analysis of the Disability, Ageing and Carers Survey (DACS) 'unit record' file,
- Assessment of key issues based on telephone interviews with more than 40 leading 'players'.

4.2.   Comprehensive international literature review

Literature was reviewed and critically assessed to provide an overview of the current issues and trends; to identify current approaches, gaps and links within areas of disability, accommodation and care; and to enable critical assessment of approaches which better link housing and care programs. The literature consisted of both national and international academic publications within the past 10 years.

4.2.1.   Literature Searches

An information search path was developed for collection of the literature, consisting of:

- Automated searches
- Catalogue searches
- Internet searches
- Personal reference libraries

Automated searches were conducted through eleven 'Ovid' electronic databases, selected according to relevant descriptors. These included:

- Allied and Complimentary Medicine (AMED)
- Australian Public Affairs Information Service (APAIS)
- Australian Building Construction and Engineering Database (BUILD)
- Nursing and Allied Health (CINAHL)
- Education Resources Information Service (ERIC)
- Environmental Abstracts (EVA)
- Australian Family and Society Abstracts (FAMILY)
- Geobase
- Medline
- PsycINFO
- Web of Science

A key word strategy of 56 words associated with 'accommodation', 'disability' and 'care' was applied.

Library searches, which employed the same key words, were conducted using the University of Sydney's catalogue. This presented a further fifteen documents for our literature collection. Additional exploratory searches were conducted by applying our keywords to electronic search engines, including, Excite, Explorer, Hotbot, Netscape and Yahoo. This contributed an additional sixty references to our collection.

4.3. Disability Ageing and Carers Survey (DACS) Data

The DACS data was employed to address the first major aim of the study. The primary data source is the 'Confidential Unit Record File', which the ABS used as the primary unit of analysis for the 1998 Disability, Ageing and Carers Survey. This national survey provides detailed information on 37,580 individuals in private and non-private households (91% response rate) as well as 5,716 individuals in care institutions. The population data are available for each capital city, as well as the rest of each State, and also for areas with different levels of socioeconomic disadvantage. The following illustrates data items available on key topics:

- Housing Tenure: Households (outright owners; buyers; public tenants; private tenants; boarders; living rent-free) and institutions (hospitals; homes for the aged including nursing homes and hostels; homes other; retirement homes; hostels; hotels, motels, caravans; retired or aged accommodation, self care; religious and educational institutions; and Aboriginal communities).
- Dwelling Type: Separate house; semi-detached; flat attached; single and multi-story flat; caravan; and other.
- Personal Characteristics and Resources: Age; income; marital status; household structure; carer availability; education; labour force status.
- Physical Capacities: Levels and kinds of disabilities; long term health conditions; and severity of impairments.
- Needs, Unmet Needs and Sources of Assistance (including informal and service use) with property maintenance, transport, housework, meal preparation, mobility, paperwork, communication, and health care.

The DACS is the fourth comprehensive national survey to measure disability undertaken by the Australian Bureau of Statistics (ABS, 1998). A key premise of the current research is that by correlating data from the CURF we will be better able to understand and comment on the nature and extent of met and unmet needs. Clarification of terminology becomes critical as this study is collapsing some of the fine grained data categories to achieve a meta analysis of relationships between data categories.

The population data are available for each capital city as well as the remainder of each State and for areas with different levels of socioeconomic disadvantage. It is important to note that the survey was carried out in two parts, a household component and a cared accommodation component. While the questions for the cared accommodation component were similar to those contained in the household component some minor question modification and terminology differences exist as a consequence of different survey forms and data gathering methodologies being used, and this limits direct comparisons.

4.3.1. Terminology

Some of the terms used in the DACS (whilst defined to facilitate comparisons at a national and international level being based on Standard Australian Bureau of Statistics (ABS) definitions and World Health Organization (WHO) terminology) do vary from other survey tools being used to monitor performance within Australia. There are several data collections and assessment instruments in current use which have relevance to our anticipated data comparison and analysis (Ryan, Holmes, & Gibson, 1998) but they differ from the DACS in that they reflect data about actual occasions of service and not perceived need:

- Aged Care Assessment Program Minimum Data Set (ACAP MDS)
- Commonwealth/State Disability Agreement Minimum Data Set (CSDA MDS)
- Home and Community Care Minimum Data Set (HACC MDS)
- Client Information and Referral Record (CIARR)
- Community Options Projects form (COPS)

The 1998 Disability, Ageing and Carers Survey has at its core concepts and terminology relating to data collected at different levels: person/household and cared accommodation/disability/carers.

4.3.2. Person level data

- Age – young, middle, older (adults)
- Sex – male, female
- Socio-economic status – income, education, employment
- Geographical location – capital city, rest of State
- Living arrangements – lives alone, lives with at least one other

4.3.3. Household and cared accommodation level data

- Household
- Tenure type
- Home maintenance
- Home modifications
- Cared accommodation

Table 4-1 characterises the private and cared accommodation sub categories available within the DACS data. The meta-level categories proposed for our research are listed alongside. These meta-level categories more closely approximate other data gathering typically used by policy makers and in the literature. However, the number of categories and separation of tenure are a significant variance from other national reporting formats. For instance, the HACC MDS does not include most cared accommodation categories and also codes accommodation settings and tenure as one item for example, "private residence- owned/purchasing" (Australian Institute of Health and Welfare, 1998).

Table 4-1: Typology of dwelling types by analysis level

DACS - Dwelling types	DACS CURF sub categories disaggregated	Meta-level analysis
Household	• Separate house • Single storey semi-detached/row/ or terrace house/town house • Two or more storey semi detached /row/ or terrace	• Separate
	• Flat attached to house • House or flat attached to shop/office	• Attached
	• Other single or two storey flat/unit/apartment • Other single or two storey flat/unit/apartment or house/town house	• Low rise apartment
	• Other three storey flat/unit/apartment • Other four storey or more flat/unit/apartment	• High rise apartment
	• Caravan/houseboat/camping out • Hostels for the homeless/night shelters/refuges/guest and boarding houses • Hotels/motels/short term caravan parks	• Temporary & mobile dwelling
Cared accommodation	• Dwelling in retirement village • Retirement home • Retired or aged accommodation (selfcare)	• Retiree (self care)
	• Hospitals-General • Hospital-other	• Hospitals
	• Homes for the aged	• Homes for the aged/retired
	• Homes-other	• Homes-other
	• Religious and educational institutions • Aboriginal settlements/other	• Other special dwelling

Table 4-2 characterises the private dwelling tenure sub categories available within the DACS data. The meta-level categories proposed for our research are listed alongside. These meta-level categories more closely approximate other data gathering typically used by policy makers and in the literature.

Table 4-2: Typology of dwelling tenure by analysis level

DACS – Dwelling tenure	DACS CURF sub categories disaggregated	Meta-level analysis categories
Private dwelling	• Owner without a mortgage • Owner with a mortgage	• Home owner
	• Renter-private • Renter-public • Renter-other • Boarder	• Renter
	• Living rent free • Other	• Other

4.3.4.   Disability level data

- Disability
- Core activity restrictions

Table 4-3 characterises the main disability restriction sub categories available within the DACS data. The meta-level categories proposed for our research are listed alongside. These meta-level categories more closely approximate other data gathering typically used by policy makers and in the literature.

Table 4-3: Typology of main disability restriction by analysis level

DACS - Main disability restriction	DACS CURF sub categories disaggregated	Meta-level analysis categories
Conditions	- Chronic or recurring pain - Breathing difficulties - Blackouts - Incomplete use of arms/fingers - Difficulty gripping - Incomplete use of feet or legs - Restricted in physical activity/work - Disfigurement/deformity - Loss of speech	• Physical
	- Loss of sight - Loss of hearing	• Sensory
	- Difficulty learning/understanding - Head injury/stroke/brain damage	• Intellectual/Learning
	• Nervous or emotional condition	• Mental illness
	• Long term condition that restricts activity	• Not specified

Table 4-4 characterises the core activity restriction sub categories available within the DACS data. The meta-level categories proposed for our research are listed alongside.

Table 4-4: Typology of core activity restriction level by analysis level

DACS - Core restriction levels	DACS CURF sub categories disaggregated	Meta-level analysis categories
Range	• Profound	• High support indicated
	• Severe	
	• Moderate	• Low support indicated
	• Mild	

4.3.5.　　Carer level data

- Need for assistance
- Receipt of assistance

Table 4-5 characterises the assistance type sub categories available within the DACS data. The meta-level categories proposed for our research are listed alongside.

Table 4-5: Typology of need for assistance type by analysis level

DACS - Need for assistance	DACS CURF sub categories disaggregated	Meta-level analysis categories
Assistance type	- Self care - Mobility - Communication - Health Care	Functional indicators
	- Housework - Meal preparation - Property maintenance	Home maintenance indicators

Table 4-6 below, characterises the assistance type sub categories available within the DACS data. The meta-level categories proposed for our research are listed alongside.

Table 4-6: Typology of receipt of assistance by analysis level

DACS - Receipt of assistance	DACS CURF sub categories disaggregated	Meta-level analysis categories
Relationship to recipient	- Partner - Parent - Child - Other relative - Friend	Informal only
	- Government organisation - Private non-profit organisation - Profit making organisation	Formal only

4.3.6.　　Scope, Coverage and Significance

The DACS survey collected data from people with disabilities, from people aged 60 years and over and from their carers. The minimum age of 60 was set as the criteria for older persons data collection in order to maintain consistency with the 1998 and 1993 surveys (Australian Bureau of Statistics, 1998). Coverage rules ensured that only one person per household was selected and that both urban and rural area in all States and Territories were sampled. A criterion for inclusion in the cared accommodation samples was an expected residency of at least three months. All the data available about respite care need and usage was collected on the basis of interview with a primary carer.

Exclusion criteria eliminated all non-Australian residents and persons residing in jails and correctional institutions. Also excluded were people living in remote, sparsely populated areas of Australia. In States such as the Northern Territory, however, this

is potentially significant as such people account for approximately 20% of the State population (Australian Bureau of Statistics, 1998).

Like all survey methodologies there is the risk of both sampling and non sampling errors. However, these were controlled for and a relative standard error of less than 25% is considered sufficiently reliable for most purposes (ABS, 1998). All interviewers received extensive training and electronic data collection with inbuilt data checks was used for all processing. The DACS survey data is particularly significant as it represents the most comprehensive survey of the general population to determine disability, care and support needs unlike the Minimum Data Set collections which only gather data about actual occasions of formal service provision provided by government funded service providers.

4.3.7. Data Analysis

The data analysis which will be reported in subsequent reports will consists of two parts

- *Descriptive Statistics (broad coverage)*
- *Logistic regression Analysis (predicting unmet need)*

4.3.8. Descriptive Statistics

Quantitative data from the DACS survey regarding housing accommodation will be cross-tabulated by the characteristics, resources, and capacities of older and younger adults with disabilities in different locations and care needs, unmet needs, and sources of assistance. The DACS CURF files only contain capital city and rest of State geographical data for confidentiality reasons. Thus in order to provide comparison on a State level the most significant correlations for disability, housing and care will have to be purchased separately from the ABS.

After discussion with the project user group, it was decided that typologies could be effectively employed to analyse variances and present factors within and across groups. The typologies will attend to the group type/category, factors of variability and housing tenure type.

Typology groups will consist of:

- Younger adults with a disability living alone
- Older adults with a disability living alone
- Younger adults with a disability living with a carer
- Older adults with a disability living with a carer

Factors of variability relating to the person will include:

- Disability type and level (severity)
- Income/wealth
- Service usage

Factors of variability relating to the accommodation will include:

- Type of accommodation
- Ownership
- Tenancy arrangements
    - Private ownership (house, flat)
    - Private tenant
    - Public Tenant

- Location

Crucial care/accommodation interface issues relating to the following six key policy areas will be determined for each of the group/housing variances.

- Income support
- Housing agreements
- Disability agreements
- Community care
- Residential care
- Building and land regulation

DACS data and policy /interviews will inform this investigation of key policy areas, with support from relevant policy documents.

4.3.9.   Logistic Regression Analysis

Logistic regression will be applied, where relevant, to identify ways in which personal characteristics and resources, housing circumstances and geographical location best 'predict' unmet need and use of specific housing and care services.

4.4.   Policy Review

Initially this project proposed to conduct a separate review of policy documents to ascertain current initiatives and interviews with policy makers to explore key issues from a policy makers' perspective. After discussion with the project user group, it was decided that the policy review and interviews should be conducted concurrently. This allows for key topic areas to be closely interrelated with questions in the policy interviews. The document review will provide support and further investigations into key policy areas identified and discussed in the policy interviews.

A critical review and assessment of key policy and program approaches has begun through systematically reviewing key policy documents. The review includes legislation and programs for ageing and disabled people both at the Commonwealth and State level. It includes

- Statements
- Annual reports
- Evaluations of policies, programs and services

4.4.1.   Policy Document Searches

Policy materials have been collected through two main avenues

- Internet searches
- Contacting government departments and organisations

4.4.2.   Policy Document Analysis

To enable comparative analysis, documents collected have been entered into a policy review table, which identifies the policies/legislation and programs for each of the eight States and the Commonwealth across three distinct areas:

- Disability/Ageing
- Housing
- Care

4.5.   Policy interviews

Qualitative methods will be used to identify and explore current key policy issues. This involves content-analysis of telephone interviews with more than forty leading players, including Commonwealth and State policymakers concerned with housing, aged care, community care and disability programs. Individual interviews will allow us to gather a broad selection of perspectives from key informants.

Key government action areas in policy and programs are considered to be:

- Income support
- Housing agreements
- Disability agreements
- Community care
- Residential care
- Building and land regulation

The following five areas provide a focus on long-term policy trends:

- Deinstitutionalisation of younger people with disabilities.
- 'Ageing In Place'.
- Recognition and support of carers.
- Rising expectations/advocacy of consumer rights.
- Who pays (user pays/governmental responsibility)?

4.5.1.   Sampling frame

Our user-group representatives will provide recommendations of informants and a snowballing technique will be used to gather contact details for potential informants. Informants will be selected to represent a balanced cross-section of States and areas of interest. Coverage will be across States, consisting of seven sampling governmental units (one per State plus the Commonwealth); and for each program/policy area, across housing and care, and across older and younger people with disabilities.

4.5.2.   Interview schedule

Interviews will be exploratory and semi-structured, addressing key topic areas, guided by key research questions (described in Chapter 1). No specific questions will be used, rather representatives will be invited to give their perspectives on key issues for the future including:

- An overview of current status of integration between housing and care for younger and older adults with disabilities (i.e. degree of unmet need, priorities, barriers and opportunities)
- Particular program innovations underway and recommendations for integration of housing and care for younger and older adults with disabilities
- Service provider initiatives to better integrate housing and care for younger and older adults with disabilities.

4.5.3.   Interview Process

Pilot interviews will be conducted early in March 2001 with our project user group. The pilot will assist in identifying issues and will provide feedback regarding changes to the interview structure.

Selected nominees will receive a letter of invitation to participate in an interview, consent form and a subject information statement, explaining the nature of the interview.

A response to the letter of invitation and a signed copy of the consent form, received by the RSVP date will be required for interview participation. Telephone interviews will then be conducted at a mutually agreed time.

4.6. Summary

This chapter has outlined the methodologies chosen to further understand and comment on the nature and extent of met and unmet needs for younger and older adults with disabilities. It highlights that:

- The DACS CURF is a national framework that is sufficiently reliable, comprehensive and targeted in nature to yield the relevant information needed for correlating housing, disability and care at a meta-level so as to be able to predict need for younger and older adults.
- A systematic review of key policy documents, annual reports, budgets and evaluations of policies, programs and services for ageing and disabled people at both the Commonwealth and State level is being conducted and will be refined by the information received in interviews with policy officials.

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