

Housing and care for younger and older adults with disabilities

Author/Contributor:

Bridge, Catherine; Kendig, Hal; Quine, Susan; Parsons, Amanda

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Final Report

Housing and care for younger and older adults with disabilities

authored by

Catherine Bridge

Hal Kendig

Susan Quine

Amanda Parsons

**Australian Housing
and Urban Research Institute**

Sydney Research Centre

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TABLE OF CONTENTS

Acknowledgements	ii
List of Figures	v
List of Tables	v
Abbreviations	vi
Executive Summary	vii
Chapter 1: Introduction and Methodology	1
1.0 Introduction	1
1.1 Research questions	1
1.2 The Positioning Paper	1
1.3 Research Procedures	4
1.4 Disability, Ageing and Carers (DAC) survey methodology	4
1.5 Key Player Interviews	5
1.6 Structure of the report	6
Chapter 2. Population Profiles and Housing and Service Use	7
2.0 Introduction	7
2.1 Data Definitions	7
2.2 Overview of people with disabilities	8
2.3 Accommodation and Living Arrangements	8
2.4 Predictors of access to housing and community services	20
Chapter 3. Key Players views on Long to Medium Term Policy Trends	23
3.0 Introduction	23
3.1 Deinstitutionalisation of younger people with disabilities	24
3.2 Ageing in Place with a disability	24
3.3 Recognition and support of carers	28
3.4 Rising expectations/consumer rights	30
3.5 Who pays?	30
3.6 Tensions between different players viewpoints	31
Chapter 4. Key Players Thoughts on Potential Government Action Areas	33
4.0 Introduction	33
4.1 Income Support	34
4.2 Housing Agreements	35
4.3 Disability Agreements	36
4.4 Community Care	37
4.5 Residential Care	39
4.6 Building and Land Regulation	39
4.7 Tensions between different players viewpoints	41

Chapter 5: Current Housing Models	42
5.0 Introduction	42
5.1 Formal Care Dominant models	42
5.2 Non Government Sector Care Enabling Models	43
5.3 Informal Care Dominant Models	44
5.4 Care Minimisation Enabling Housing Models	45
5.5 Conclusions	45
Chapter 6: Implications for Policy	46
6.0 Introduction	46
6.1 Policy Framework	46
6.2 Housing circumstances, needs and service use	47
6.3 Policy implications of interview findings	48
6.4 Exploration of current housing and care packaging models	52
6.5 Conclusions and Directions	53
References	55
Appendix A: List of User Group Participants	57
Appendix B: The Sampling Frame used for the Informant Interviews	58

LIST OF FIGURES

Figure 1-1: The intersection of accommodation, disability and care	2
Figure 2-1: Residence in Cared Accommodation by Severity of Disability for Younger and Older Adults with-Disabilities '	9
Figure 3-1: Number of informants who highlighted particular long to medium term policy trends	23

LIST OF TABLES

Table 1-1: Traditional continuum of housing options in terms of care availability	3
Table 2-1: Percentage of Adults with Disabilities by Housing Tenure, Age and Living Arrangement, Australia, 1998.	11
Table 2-3: Percentage of Adults with Disabilities by Disability Severity, Age and Living Arrangement, Australia, 1998.	12
Table 2-4: Percentage of Adults with Disabilities ' in Employment, by Age and Living Arrangement , Australia, 1998.	13
Table 2-5: Percentage of Adults with Disabilities on Low Incomes (less than \$240 per week) by Age, Living Arrangement, and Housing Tenure, Australia, 1998.	14
Table 2-6: Percentage of Adults with Disabilities by Extent of Needs Met, Age and Living Arrangement, Australia, 1998.	16
Table 2-7: Rank Ordering of Types of Assistance Needed for Adults with Disabilities by Age and Living Arrangement, Australia, 1998	17
Table 2-8: Rank Order of Types of Unmet Needs for Assistance for Adults with Disabilities ' by Age and Living Arrangement, Australia, 1998	18
Table 2-9: Percentage of Adults with Disabilities by Assistance Provider Type (Overall), Age and Living Arrangement, Australia, 1998	18
Table 2-10: Percentage of Adults with Disabilities ' Having Had Home Modification by Age, Living Arrangement, and Housing Tenure, Australia, 1998.	20

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 State 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 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: Sydney Research Centre, which examines the relationships between housing and care for younger and older adults with disabilities. Whilst disability, ageing, housing and care are important areas in themselves the real strength of this study is the provision of a national overview of housing as a key issue across and between these policy areas. The significance of the intersections between housing, and care is accentuated by population ageing, rising expectations amongst consumer groups, and constraints on government expenditure. Adults with disabilities often face multiple vulnerabilities, including limited incomes and social support, and therefore require integrated support delivered to a secure home base.

Project Aims

This project aims to inform pressing policy and program delivery issues associated with achieving the linkages, cooperation and efficiencies in housing, disability and care to create a 'whole of government' approach in three ways. Firstly, the project analyses the housing and care circumstances of older and younger adults with disabilities nationally. Secondly, it identifies systematic variation indicating differences in State/Territory policies concerning housing markets. Thirdly, it reviews and critically assesses policy and program approaches that enable better targeting of met and unmet need.

Structure of this report

The findings of this research study are presented in the following chapters; 2 covers national disability, ageing, housing and care analyses; 3 covers long to medium term policy trends; 4 covers potential government action areas and 5 covers current housing & care models. Chapter 1, sets the context by summarising relevant national and international academic literature as to what is known and what is still unclear whilst chapter 6 concludes the report with policy implications emerging from the work undertaken.

Research context

The Positioning Paper (see <http://www.ahuri.edu.au/research/summary/project19.html>), an early paper published at the start of the research journey, revealed that 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. Therefore, whilst Australian population patterns, theory, and practice concerning disability and ageing have been examined no previous study investigating differences between younger and older cohorts in terms of housing, disability and care relations had been carried out in Australia.

Housing and care have traditionally been linked for example, the same level of care can be provided in a private dwelling as in a nursing home. However, the in-home care option depends on accommodation security and the ongoing provision of quality care by informal caregivers. Consequently, people without accommodation or informal care support are far more likely to be placed in cared accommodation settings. Lack of accommodation and care choices for people with the highest levels of disability and the least informal support to draw on are compounded by unemployment. For most of this group, reliance on income support precludes purchase of accommodation from the private sector.

Previous research indicates that:

- Disability, housing and care are interdependent and complex. 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 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 risk for carers of acquiring disability themselves.

Policy Context

This report examines the Commonwealth/State policy context and maps some of the issues associated with coordination of policy initiatives. The current interest in linkages between housing, support and care arose in the early 1990's 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.

An analysis of current practice reveals that:

- The lack of knowledge about the relative effectiveness of different packages of income support, accommodation and care services means that further and ongoing research is urgently required.
- 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 accommodation market (hostels, nursing homes, boarding houses, rental properties and community housing) are compounded by the trend away from social housing and the move towards "self service" and "user pays" care packaging.
- 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 create fragmentation and inequalities. Additionally, the current national policy emphasis on home ownership fails to address disadvantage experienced by adults with disabilities who typically have less purchasing power and are further limited by insufficient affordable, adaptable and/or accessible properties to select from. This home purchase disadvantage when combined with decreasing Commonwealth support for public housing, limits community integration, especially flexibility of response to care needs which change over time. Furthermore, the generally low level of public input by younger and older adults with disabilities in the early stages of planning reform initiatives result in policy that fails to address consumer expectations and concerns.

Statistical Findings Summary

Secondary data analysis undertaken as a part of this research of the Confidential Unit Record Files (CURF) collected by the Australian Bureau of Statistics (ABS) for the 1998 Disability, Ageing and Care Survey (DACs) reveals that for adults (20 years of age and over) experiencing some difficulties with core activities (i.e. self-care, mobility and housing):

- Fully two-thirds reside in some form of cared accommodation settings, which are primarily aged care nursing homes.
- Younger persons with disabilities are much more likely to reside in private households in the community than older persons.
- Older persons with disabilities are much more likely to live alone (30% versus 15%), have a profound level of disability (30% versus 13%); and own their own homes (76% versus 62%).
- Public tenancies provide accommodation for approximately one fifth of those persons with disabilities residing in the community, both younger (18%) & older (21%).
- Fully two-thirds residing in the community have incomes less than \$240.00 per week - this is significant given full-time adult ordinary time earnings are reported as \$822.3 per week (Australian Bureau of Statistics, 2001)
- Fully 85% report some need for assistance, including property maintenance (60%), housework (46%), mobility & health care (44%), transport (42%), self-care (29%), meal preparation (18%) and communication (4%).
- Overall, half of the respondents identified needs in three or more areas whilst a quarter had needs in five or more areas.
- Fully three-quarters of those residing in the community rely on informal care whilst only 6% were entirely reliant on formal care services alone.
- Just under a fifth of persons residing in the community have already undertaken some home modifications. Owner occupants who live alone are most likely (34%) to choose to do this. This is considerably lower than in other countries such as England where over two-fifths of all disabled people surveyed have had adaptations made (McCafferty, 1994).
- Finally, any use of formal community services (both government and private) was best predicted by living alone, being male, being older and having a greater disposable income with which services could be purchased.

Policy implications Summary

In depth interviews with twenty-four 'key players' across Commonwealth and State governments and peak community organisations yielded views in terms of both medium to long-term policy trends and potential government action areas. The range of opinions sampled highlighted the following views regarding medium to long-term policy trends:

- The trend towards '*deinstitutionalisation*' recognises community care as being the preferred care context for younger adults with disabilities, however insufficient resources and shortage of suitable community housing has seen the cost of formal care erode flexibility and opportunities for participation and community inclusion.
- The trend towards '*ageing in place*' recognises community care as being the preferred care context for older adults with disabilities, highlighting the inappropriateness of much of existing Australian infrastructure for people with disabilities, particularly housing and transport. It has also highlighted age specific program policies as barriers, particularly those concerning employment and day care.

- The trend towards '*increasing expectations of carers*' has resulted from both '*ageing in place*' and '*deinstitutionalisation*' without which both would be infeasible. Concern exists over inadequate forward planning, lack of training and assistive devices, and the cost of caring. A number of interviews implicitly also raise issues about guardianship and the potential for a divergence of views between carer and client.
- The trend towards '*consumer rights*', reflects the fact that since the advent of the disability discrimination Act (1992) people with disabilities have had greater expectations of equal opportunity and inclusion. However, concern was raised because the rhetoric of discrimination legislation is not yet matched by the treatment currently accorded to people with disabilities. Additionally, rights based legislation such as tenancy legislation is still unclear about whose rights are paramount i.e. clients right to refuse service versus rights of other tenants and landlords. Implicitly this raises concern about the lack of ethical frameworks to guide achievement of a rights balance required for use in decision-making and outcome mediation.
- The trend towards '*user pays*' follows expectations that reduced government contributions and the devolution of cost responsibility through user charges will continue. Concern was expressed that home ownership opportunities were limited. There was also concern expressed over cost shifting between government departments like housing, disability and welfare given the cost of having a disability (McClure, 2000).
- The range of opinions sampled highlighted the following views regarding potential government action areas:
 - '*Income support*' was viewed as a key factor influencing activity and participation levels and underpinning ability to purchase housing and care services. Areas highlighted for action included the proportion of income expended on supported accommodation (up to 80%) and private rental; the need for more rental assistance and the equity benefits of capping public housing rental at 25% of income nationwide.
 - The '*Commonwealth/State Housing Agreement (CSHA)*' was viewed as essential particularly given the fact that there are increasing numbers of older disabled tenants living alone (30% as reported by Bishop, 2000a) whilst two-fifths of all public housing tenants are identified as having a disability (40% as reported by AIHW, 1999a). This increasing disability focus reflects a shift that has ramifications on property profiles, stock upgrading, housing allocation, staff training and linkages with support agencies. On a wider level, it also raises increasing concern about securing and maintaining affordable and appropriate housing and foreshadows continued growth in the community housing sector which was viewed as more flexible and locally responsive. However, concern was raised regarding viability, accountability and paucity of standards and procedures in the community-housing sector.
 - The '*Commonwealth/State Disability Agreement (CSDA)*' was viewed positively for its rights focus but was criticised for limitations surrounding overspending on group homes, its perceived inflexibility and gaps relating to children's and mental health services. It was noted that the CSHA and the CSDA operate under different principles and financial arrangements and that these are not currently complimentary. A greater emphasis on harmonisation and articulation of principles is required.
 - The '*Home and Community Care*' program was generally viewed favourably particularly regarding flexibility and local responsiveness but concerns were expressed about an ageing bias, regional inequity, particularly rurally, and funding formulas which severely limit capacity and capacity building. Community transport is viewed as fundamental to housing and care for both younger and older adults with disabilities.

The Commonwealth Department of Health and Aged Care has primary responsibility for funding and monitoring '*Residential Cared Accommodation Services*' for older persons and this option was generally viewed as a last resort for those who were unable to obtain the level of housing and/or support they required in their communities. Concern was raised regarding the eligibility for and role of Aged Care Assessment Teams (ACAT's) and about the considerable numbers of younger people who enter or remain in aged care facilities due to lack of appropriate alternatives. Conversion of a greater number of aged care beds into community aged care packages is urgently required to prevent younger disabled persons from inappropriate admission to aged care facilities.

- The pressure towards increasing '*building and land regulation*' results from increasing demand for community care as demonstrated by the trends toward both '*ageing in place*' and '*deinstitutionalisation*'. A predominantly community based care practice requires building and land infrastructure, particularly housing and transport planning, design and construction to better accommodate a wider range of human ability. Consequently, particular concerns were raised about discriminatory zoning practices and lack of motivation and knowledge particularly within the commercial housing sector. This is currently being compounded by lack of access to education, information and resources about better design options. Overall, the informants rated improved housing and land use regulation as being of the highest priority and considerable more attention needs to be directed towards it at national, State and local authority levels.
- Additionally a number of informants cautioned that a focus on any one-action area would be unlikely to be successful and that instead a '*Multifactorial, Integrated, Whole of Government*' approach, that was flexible enough to respond to individualised needs was instead required.

Housing and Care Models Summary

A critical research question developed and outlined in our Positioning Paper was the understanding, of what housing and care 'packages' have been explored in the Australian context. These follow four dominant themes with a primary focus on either formal care, privatisation of care, informal care or care minimisation. A summary of the models discussed follows:

- Those with a focus on formal care include '*Group homes*', '*cluster housing*' and '*Secure Accommodation Units*'.
- Those with a focus on non-government care include '*rooming houses, boarding houses and private hotels*', '*Singletons accommodation units*' and '*Aged Care units*'.
- Those with a focus on informal care include the '*Supported Living Model*', '*Community Disability Housing Program*' and '*Local Area Coordination (LAC)*' programs.
- Finally, the creation of '*Adaptable homes*' provides a focus on housing design, which maximises independence thus minimising care.

Conclusion

At the beginning of this study, it had been anticipated that housing tenure type i.e. difference between public and private tenancy might have a statistically significant impact on differential access to various forms of care. However, being a public or a private tenant does not appear to be a significant predictor of care need. Nevertheless, multivariate statistics suggest that the more advantaged forms of housing tenure such as home ownership are largely available to those who are relatively more advantaged in other aspects of their lives. Thus, it appears that the best predictors of access to formal care services are a higher discretionary income; less informal care availability;

being older; being male and having a secure home base. Furthermore, the primary national response for those with the highest levels of disability and the least access to informal care remains relocation to a cared accommodation setting.

There is currently, no national framework for the creation of a coordinated and flexible delivery of housing and support services for adults with disabilities. The existing divisions of responsibility and lack of harmonisation between Commonwealth and State programs, creates difficulties in efficient and equitable service provision. Linkages are still primarily based on informal cooperative efforts that vary in their effectiveness. Cost shifting and inefficiency arise because the lack of attention to cross-policy integration strategies has served to undermine linkages within health, housing and cared accommodation services irrespective of recent State trends towards departmental co-location. Consequently, Commonwealth/State agreements need to be strategically overviewed to ensure clear articulation of key principles and harmonisation of those principles across programs.

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 and the next logical step would appear to be a closer examination of various State based service delivery models.

CHAPTER 1: INTRODUCTION AND METHODOLOGY

1.0 Introduction

The 'Housing and Care for Younger and Older People with Disabilities' study addresses fundamental policy and program delivery issues. While ageing, disability, housing, and care policies are important areas in themselves, this study aims to provide an understanding of housing as a key issue across and between these policy areas. The project has a strong focus on the inter-related accommodation and other circumstances of vulnerable people, and on the linkages, cooperation and efficiencies across housing and care programs. The project findings aim to inform each of the housing and other policy areas in terms of their connections with each other. It also aims to contribute to the strategic development of 'whole of government' provision of comprehensive supports for vulnerable people.

This Final Report presents primary results from the two main data sources, namely the national policy interviews and the Disability, Ageing, and Carer (DAC) survey. This chapter outlines principal research questions, summarises the earlier Positioning Paper, and reviews the research methods and key tasks in the research.

1.1 Research questions

The research aimed to answer the following principal questions:

- What are the housing circumstances, vulnerabilities, resources, service use and perceived met and unmet needs amongst older and younger adults with disabilities? (1998, Disability, Ageing, and Carer survey)
- 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? (Developed from academic and policy review and key 'player' interviews)

The project conducted a limited analysis of State and Territory differences. While some State comparisons were drawn from publications from the DACS, the Australian Bureau of Statistics did not include State of residence as a variable in the data file analysed in this project. The policy interviews were national in coverage but in order to protect confidentiality of informants State-specific findings were limited.

1.2 The Positioning Paper

This paper (Bridge, Parsons, Quine, & Kendig, 2001) provides a broad context for the study. It showed that the significance of these issues is accentuated by population ageing, rising expectations amongst consumer groups, and constraints on government expenditure. People with disabilities often face multiple vulnerabilities, including limited incomes and social support, and therefore require integrated support delivered to a secure home base.

While there is a considerable body of academic research relating to housing, disability and care, the Positioning Paper showed that few studies have looked at policy linkages across all three areas and the combined impact of policies in meeting needs.

The research is framed around a conceptual understanding of how the intersection of accommodation, care and disability relates to met and unmet 'need'. Figure 1.1 illustrates how the intersection of accommodation and care raises issues of 'safety'; the intersection between disability and care relates to the continuum between independence and dependence; and the intersection of disability and accommodation raises issues of access to services and implicitly to premises. Levels

of access, safety and dependency frame the 'needs' and point to implications for disability, housing and care linkages.



Figure 1-1: The intersection of accommodation, disability and care

Following are key concepts for the project:

- 'Disability' traditionally implies deterioration not on the full spectrum of ability and/or enablement (Chiriboga, Ottenbacher, & Haber, 1999). Consensus has shifted to a more social model where disability is the result of the transaction between an individual and their environment (Ustan, 1997).
- 'Care' is defined as responsibility for provision of assistance to older and younger people with disabilities to ensure their health, safety and well-being.
- 'Accommodation' implies living-premises. 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. Homelessness is the result of failure to find secure accommodation
- 'Access' is being able to exercise the right to enter or use housing or care services, programs and facilities, irrespective of disabling restrictions, in such a way that is independent, equitable and dignified (Dunn, 1996).
- 'Dependency' implies the degree of control and reliance delegated to others to ensure health, safety and well being. It has been argued that all persons regardless of level of disability are in fact interdependent (Bould, 1990; Robertson, 1997).

The traditional continuum of accommodation options in relation to the level of care provided is illustrated in Table 1-1. Firstly, independent accommodation is designed for those who are able to care for themselves. Secondly, there is low-level care with living arrangement provisions that cater for some having chronic limitations. Thirdly, high care accommodation provides more intense supervision, intermittent services and nursing care for those who require high support.

Table 1-1: 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)

Previous research indicated that:

- Disability, housing and care are interdependent and complex. Linkages between access, safety and dependency are not well understood particularly in the Australian context.
- Community care services can effectively supplement informal support but diversity, fragmentation, financial caps and lack of coordination result in settings that have consistently failed to adequately consider the needs of adults with disabilities, thereby increasing dependency and creating social exclusion.
- The capacity to ‘age in place’ depends heavily on the availability of informal care.

The Positioning Paper also examined the national policy context and some initiatives at State and Territory levels. Strong interest in linkages between housing, support and care emerged in the early 1990’s with the Mid Term Review of Aged Care and the National Housing Strategy. Over the last ten years legislative reform has impacted on policy at Commonwealth State/Territory and regional levels. There has been increasing emphasis on independence, customer satisfaction and service flexibility. At the same time, there has been increasing financial restraint, market driven competition, privatisation, outsourcing, and funder/provider accountability.

The policy analysis in the Positioning Paper revealed:

- There is a lack of knowledge about the relative effectiveness of different packages of income support, accommodation and care services and further and ongoing research is urgently required.
- The poor coordination, complexity and piecemeal nature of the current system are seriously impeding reform outcomes.
- Problems in regulating the private accommodation market (hostels, nursing homes, boarding houses, rental properties and community housing) are compounded by the trend away from social housing and the move towards “self service” and “user pays” care packaging.
- There is a plethora of bureaucracies and routes through which funding for housing and support is provided. Coordination difficulties create confusion and increase communication difficulties.
- Policy emphasis on home ownership fails to address disadvantage experienced by adults with disabilities who typically have less purchasing power and are further limited by insufficient affordable, adaptable and/or accessible properties to select from this in turn limits the potential for community inclusion as the primary care option particularly as care need tends to increase over time.

- Notwithstanding agreements between Commonwealth and State/Territory governments on reform and funding, the separate development of disability, ageing, housing and care programs creates fragmentation and inequalities.
- The generally low level of public input by younger and older adults with disabilities in the early stages of planning reform initiatives results in policy that fails to address consumer expectations and concerns.

The Positioning Paper concluded that there is no national framework for the coordinated and flexible delivery of accommodation and support services for younger and older adults with disabilities. Current federal policies are notably historically based, complex and mission focused. The division of responsibility creates inefficient and inequitable service provision and variable linkages between services. 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.

1.3 Research Procedures

The project has drawn on four main information sources:

- A comprehensive international literature review, was completed in January 2001 and was summarised in the Positioning Paper (Bridge, Parsons, et al, 2001).
- A review of key policy documents which was completed in January 2001 and was summarised in the Positioning Paper (Bridge, Parsons, et al, 2001).
- The Disability Ageing and Carers Survey (DACS) was analysed from January to May. Description of the methods and detailed data tables were provided in the Work in Progress report (Bridge, Quine, et al, 2001)
- Telephone interviews on key issues were conducted with leading 'players' from a range of States and interest areas. A report on the interviews that had been completed by April was provided in the Work in Progress report (Bridge, Quine, et al, 2001).

1.4 Disability, Ageing and Carers (DAC) survey methodology

The statistical information in this report is based on the 1998 Disability, Ageing and Carers (DAC) Survey conducted by the Australian Bureau of Statistics. The DACS provides an outstanding data bank that is representative of the population of all people with a disability, older people, and people who provide assistance to others because of their disabilities. It includes people in private households in the community as well as those in various forms of cared accommodation. The analyses in this report are based on the DACS confidential unit record file (CURF).

The DACS provides the basis for conducting integrated analyses, hitherto not possible in Australia, on the characteristics, needs, housing, and service use of these groups. While the DACS included people of all ages with a disability, the AHURI project focused on adults aged 20 years and older including only those with at least a mild disability. The foundations for community care are housing and living arrangements consequently; most analyses included only those in private households. By adopting these inclusion criteria, the responses for analysis were reduced from a total sample of 12,582 reported in the ABS survey to 2,830 reported in this AHURI project.

More information on the DAC's survey, analysis methods, and findings is provided in Chapter 2.

1.5 Key Player Interviews

The key 'player' interviews aimed to identify policy factors that facilitate or impede whole-of-government approaches to the accommodation and care of younger and older people with disabilities. The interviews were conducted by means of one-on-one telephone interviews that were open-ended and qualitative in nature. This assisted in exploring each key player's perspective and in identifying thematic issues. During the interviews, rough notes were taken by hand and these were later transcribed and sent back to the informants for verification.

The interviewing approach was developed over January and February and the fieldwork commenced in March 2001. As advised for qualitative interviewing (Strauss & Corbin, 1990) the semi-structured interview protocol was trialed with members of the user group and the results analysed before refining the approach. Informants were sent in advance an outline of the project and a request to consider priority long to medium term trends and potential government action areas. For many of them this was sufficient prompting but some preferred a more structured approach following through the previously identified priority trend and policy areas. In general, interviews ranged from forty minutes to approximately one hour and ten minutes.

In the two-phase interviewing process, many of our user group suggested other potential informants who were knowledgeable and who covered the program divisions within the scope of this study. However, following the first round of interviews (as reported in the Work in Progress paper), the information generated was found to be largely consistent. Consequently, prior to the second round of interviewing, a sampling frame was finalised to ensure that there would be systematic coverage. On this basis, the policy interviews achieved coverage of the following:

- Peak advocacy organisations: National Shelter, Physical Disability Council of Australia (PDCA); and the Australian Council for Rehabilitation of the Disabled (ACROD)
- Commonwealth policy areas: Commonwealth State Housing Agreement (CSHA); Commonwealth State Disability Agreement (CSDA); and the Commonwealth Department of Family and Community Services (FACS)
- Within each State (excluding the Territories) portfolio's covering: a Housing Authority; an Ageing and/or Disability authority; and a care/human services authority.

Sampling was complicated by the range of State government arrangements for human services, ageing, and disability and care portfolios. Additionally, the voluntary nature of participation for the in depth interviews meant that although we would have wished for the sample to have included informants from the Council on the Ageing (Australia) and the Commonwealth Home and Community Care Program this was not achievable within the research timeframe. Notwithstanding, the informant sample did reach 'saturation' in qualitative research terms, meaning that additional interviews were found not to yield any significantly new additional material. Consequently, after finalising interviews from 24 'key players' our focus became data analysis and interpretation.

1.6 Structure of the report

This Final Report provides a summary of key findings from the project and presents implications for policy. Chapter 2 draws from the DACS to present the population profiles, housing, resources and needs, and service use of the younger and older people with disabilities. Chapter 3 presents findings from the policy interviews on middle and longer-term trends. Chapter 4 presents findings on government action areas. Chapter 5 overviews current housing and care models. Lastly, chapter 6, discusses the policy implications of these findings and presents models of care that point to new directions for improved housing and care policies.

Project findings are also provided in the earlier Positioning Paper. In this report the emphasis is on interpretation thus our earlier 'Work In Progress', report provides the more detailed tables from the DACS secondary analysis. The Final Report of the project, summarises main findings and policy implications.

CHAPTER 2. POPULATION PROFILES AND HOUSING AND SERVICE USE

2.0 Introduction

This chapter provides an overview of the characteristics, housing, and service use of younger and older people with disabilities. The chapter begins with an overview of all people with disabilities and then moves into a more detailed analysis of those residing in cared accommodation and those living in the community. However, the main body of the chapter considers only those who live in the community, paying particular attention to differences of housing tenure and household composition. The later section describes expressed needs for and use of services, and describes the factors found to be the best predictors of needs regarding care and housing circumstances.

2.1 Data Definitions

The findings are based on unpublished data from the 1998 Disability, Ageing and Carers (DAC) Survey (see Chapter 1). The earlier Work in Progress report (Bridge, Quine et al., 2001) contains tables with more detail. In the 1998 DACS study, the Australian Bureau of Statistics (Australian Bureau of Statistics, 1998, pp. 3-4) followed an earlier World Health Organisation definition that defined people as having a disability if they had an impairment or long-term condition (six months or more) that restricted everyday activities. Consequently, the following definitions apply:

- The specific impairments or conditions include: sight, hearing and speech impairments; chronic pain; breathing difficulties; black-outs; learning difficulties; incomplete use of fingers or feet, arms or legs and difficulties gripping; nervous or emotional conditions; restrictions in physical activity or work; disfigurement or deformity; needing help or supervision because of a mental illness or condition; head injury, stroke, or other brain damage; and any other long term condition that restricts everyday activities.
- The restrictions of activities include core activities in self care (bathing or showering, dressing, eating, using the toilet and managing incontinence); mobility (moving around at home, getting into or out of a bed or chair; and using public transport); and/or communication (understanding and being understood by others including strangers, family, and friends). Activity restrictions also can include schooling or employment restrictions.
- The severity of disability is categorised in terms of the extent of core activity restrictions: profound (unable to perform a core activity or always needing assistance); severe (sometimes needing assistance to perform a core activity); moderate (not needing assistance but having difficulty performing a core activity); and mild (having no difficulty performing a core activity but using aids or equipment because of disability).

The overview profile in the next section includes all people with disabilities irrespective of their age or severity of disability. The rest of the chapter then goes on to focus on people aged 20 years and over having a significant disability (defined as including moderate, severe, or profound levels as per the above definitions). Those with a mild disability were excluded because few of them are at risk of living in cared accommodation or have significant needs for personal care or household support.

2.2 Overview of people with disabilities

Very large numbers of Australians - 3.6 million or 19% of the population - had at least a mild disability in 1998. These figures underscore the importance of housing and local environments that are supportive of people who have physical or *behavioural* disabilities. Most people will eventually experience some level of disability if they survive long enough. Further, increasing numbers of people who have disabilities at an early age are surviving through their adult years and reaching old age.

The ABS (1998) main report on the DACS findings stated that:

- Disability rates rise from 4% for children aged 0-4 years to 84% for adults aged 85 and over.
- Disability rates have been increasing steadily over the last two decades, mainly due to the ageing of the population, most recently, an increase of nearly two percent from the 1993 to 1998 surveys.
- Overall, there is a balance of men and women having disabilities, however more women than men live to the advanced ages where disability is most likely.
- Disability rates vary from as low as 13% in the Northern Territory to 22% in South Australia and Tasmania, mainly due to age differences between the States.

The ABS report shows that the vast majority of people with a disability (85%) have a main condition that is physical while 15% have a main condition that is mental or behavioural. Those with a mental or behavioural condition are much more likely to be profoundly or severely restricted (47 %) than are those with a physical condition (29%). These people are especially likely to require assistance in managing their accommodation and care. They can be very vulnerable living alone or negotiating in the private rental market and are particularly likely to live in an institution. They can have additional requirements for tenancy management in public housing and for case coordination in community services.

2.3 Accommodation and Living Arrangements

Accommodation arrangements are of over-riding importance for the quality of life of vulnerable individuals and for the provision and cost of care. In cared accommodation paid workers, oversee (monitor) residents, providing high and frequent levels of nursing and personal care, meals and household services, and of course accommodation. The benefits of residential care are of course offset by many factors including losses of control and privacy and separation from homes and communities.

2.3.1 Cared accommodation

The ABS defines 'cared accommodation' as inclusive of general and psychiatric hospitals, homes for the aged such as nursing homes and aged care hostels, components of retirement villages, and other 'homes' such as children's homes (Australian Bureau of Statistics, 1999). Consequently, comparison of DACS data over time indicates that the proportion of people with disabilities residing in cared accommodation has decreased. For instance, the Australian Institute of Health and Welfare report, (2000, p. 28) stated that "between 1981 and 1993 the number of people aged 5-64 years with a severe or profound handicap living in households rose from 244,100 to 349,100 while the numbers living in establishments (cared accommodation) fell from 27,000 to 19,200".

However, our analysis of the 1998 survey revealed that of all adults (aged 20+) with a significant disability, nearly two thirds (65%) continue to live in some form of cared accommodation. This single figure emphasizes how much having a *significant* disability increases the risk of institutionalisation. Severity of disability is the single greatest influence on the proportions of people living in cared accommodation. The proportion in cared accommodation ranges from nearly nine out of ten for those with a profound disability to little more than one out of twenty for those with only a moderate disability.

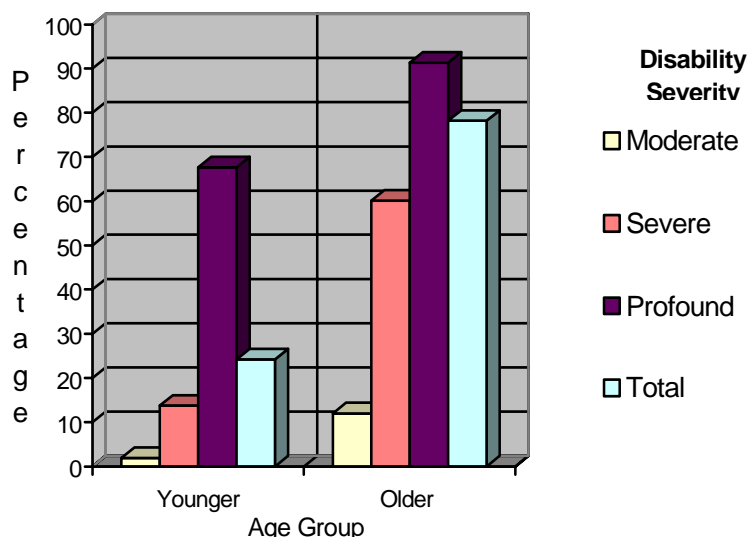


Figure 2-1: Residence in Cared Accommodation by Severity of Disability for Younger and Older Adults with Disabilities ¹.

Figure 2-1 shows that the proportions of people in care increases with severity of disability for both younger and older adults. However, for any given level of disability, those who are older are much more likely than their younger counterparts to be residing within a cared accommodation setting. The most notable age discrepancy is for those who have a severe disability: of these younger adults only 14 percent live in cared accommodation compared to fully 60 percent of the older adults. For those with a profound disability, the proportions in cared accommodation are high for both the younger adults (68 percent) and the older adults (91 percent). Older adults make up the vast majority of the disabled population and, relative to younger adults, they are more likely to have profound rather than moderate levels of disability. This largely explains their higher rates of living in cared accommodation.

Another major influence on residence in cared accommodation is the relatively limited informal support of older adults. Fully 86 percent of the many widows in the older disabled population live in cared accommodation and nearly all of the never married older men live in institutions. In sharp contrast, very few younger adults who have a disability and are married or in de facto relationships, live in cared accommodation. Indeed, 95% of younger people who have a disability and who are married are living in the community.

¹ Excludes people less than 20 years of age; younger adults are aged 20 to 59 years and older adults are aged 60 years or more. Also excludes people with mild disabilities.

The high proportion of older adults in cared accommodation extends well beyond the extent that would be expected based on their disability levels and available informal support. It would appear that cared accommodation is expected and available for a predominance of older adults with significant disabilities, but only for a minority of their younger counterparts. It is notable that the majority of older adults live in residential care where they receive Commonwealth subsidies that are largely unavailable for younger adults.

Older adults occupy more than ninety percent of the places in cared accommodation in Australia. This raises the question as to how much the balance of residential and community care results from the community expectations and available subsidies for the older and younger adults as compared to their relative needs, preferences, and informal support. Residence in the community - as discussed through the remainder of this chapter - is the overwhelming norm for younger disabled adults but residence in cared accommodation is the norm for most significantly disabled older adults.

2.3.2 Housing and living arrangements in the community

There is a nearly equal balance in the younger adults (52 %) and older adults (48 %) among people with a significant disability living in the community. While needs can often be similar irrespective of age, the life situations of the younger and older people, as shown below, can be quite different. The similarities and differences among age groups need to be appreciated fully in order to deliver appropriate accommodation and services to both groups.

The adults with significant disabilities in the community are comprised largely of those having moderate disabilities (45 % of the total). A smaller proportion has a severe disability (35 %) and an even smaller proportion has a profound disability (20 %). People with mild disabilities are excluded from the analysis but, to put the findings into perspective, their inclusion would have increased the numbers in the disabled adult population in the community by nearly 70 percent. The personal characteristics and housing circumstances of people with mild disabilities are generally similar to those of their age counterparts having moderate disabilities, but they do not have as much need for assistance and use fewer services.

The foundations for community care are housing and living arrangements. In addition to providing shelter and the psychological benefits of a home, housing is a major factor in the costs of living. Housing circumstances strongly influence service needs, such as with maintenance and gardening, and locations are crucial to access amenities, services, and public transportation. While non resident carers can provide a good deal of support, adults with disabilities who have co-residents have someone who potentially can share decision-making and costs of housing, provide over-sight if necessary, and also assist with personal care and household duties.

Overall, more than three quarters of people with significant disabilities live with other people if they are in the community, suggesting that those who do not have co-residents face more difficulties continuing to live in the community. A third of the older adults live alone as compared to only 15 percent of the younger adults. This indicates that the more limited availability of co-resident carers is a major factor in their higher risk of entering residential care. Among the older disabled adults who live alone, there are more than two women to every one man. Whether or not adults have co-residents, can be a critical influence on their service needs and manner of inter-relating informal and formal support.

The housing tenure of adults living with disabilities in the community is summarized in Table 2-1. Overall, nearly 70 percent of them - virtually the same proportion as for the general population - have the financial benefits and other security of owner occupied housing. Ten percent, much more than the general population, have the reduced costs and relative security of public housing. More than 20 percent are private tenants or are living in other forms of less secure accommodation. The high ownership rate of people with disabilities as a whole is explained by many of them having purchased a home prior to the onset of disability in older age or else living in homes purchased by others in the household.

Table 2-1: Percentage of Adults with Disabilities² by Housing Tenure, Age and Living Arrangement, Australia, 1998.

Housing Tenure	Age by Living Arrangement								
	Younger adults			Older adults			Total adults		
	Alone	With others	Total	Alone	With others	Total	Alone	With others	Total
Owner- Outright	24	30	29	68	66	66	53	45	46
Purchasers	17	35	32	4	13	10	9	26	22
Public Tenant	27	9	12	18	6	10	21	8	11
Private Tenant	25	14	15	5	4	4	12	9	10
Other ³	7	12	11	5	12	10	5	12	11
Total	%	100	100	100	100	100	100	100	100
(number)		(229)	(1249)	(1479)	(437)	(915)	(1352)	(666)	(2164)
									(2831)

Most of the older adults with disabilities acquired their conditions later in life after experiencing the employment and other economic advantages that had enable them to buy homes. Two thirds of them have paid off their mortgages. Even those who live alone (largely widows) are likely to still own outright the homes bought earlier in life. Among those who live alone one out of five, live in public housing.

Among the younger adults with disabilities, only 29 percent own a home with no mortgage and another third are paying off a mortgage. Having a significant disability before old age significantly reduces the likelihood that a person would ever have the financial means to buy a home. Those who live with others, however, have higher ownership rates, presumably because more of them would have become disabled after having bought homes. Of the younger adults with disabilities who live alone, a relatively high proportion (27%) live in public housing, thus providing a relatively secure financial base.

2.3.3 Resources and Vulnerabilities

2.3.3.1 Personal Resources

Nearly two-thirds of the younger adults with disabilities and more than half of the older adults have partners (Table 2-2). Notable areas of vulnerability include the 18% of younger adults who have never married and the 33% of older adults who are widowed - both groups are more likely to live alone. Further, especially among the older adults a number of the spouses also would have disabilities. Other figures calculated from the DACS data show that relatively more homeowners and public tenants are married, whereas private tenants were more likely to have never married.

² Excludes people with mild disabilities and those in cared accommodation

³ Includes renter other (31), boarder (123), rent free (122), other non specified (24)

Table 2-2: Percentage of Adults with Disabilities ⁴ by Marital Status, Age and Living Arrangement, Australia, 1998.

Marital Status	Age by Living Arrangement								
	Younger adults			Older adults			Total adults		
	Alone	With others	Total	Alone	With others	Total	Alone	With others	Total
Married-Defacto	2	76	65	3	81	55	2	78	60
Divorced-separated	49	9	16	18	2	7	29	7	12
Widowed	6	1	2	68	16	33	47	7	17
Never married	43	13	18	12	1	5	23	8	11
Total %	100	100	100	100	100	100	100	100	100
(number)	(229)	(1249)	(1478)	(437)	(915)	(1352)	(666)	(2164)	(2830)

The strong association between age and severity of disability, as noted above, is shown more specifically in Table 2-3. Older adults are more likely to have a profound disability (30%) whereas younger adults are more likely to have a severe disability (43%). Younger adults are more likely to have a behavioural or mental disability, whereas older adults are more likely to have a physical or sensory disability. Adults with only moderate disability are more likely to be living alone, whereas those with a profound disability are more likely to be living with others, presumably because many cannot stay in the community unless they have co-resident informal support.

Table 2-3: Percentage of Adults with Disabilities ⁵ by Disability Severity, Age and Living Arrangement, Australia, 1998.

Disability Severity	Age by Living Arrangement								
	Younger adults			Older adults			Total adults		
	Alone	With others	Total	Alone	With others	Total	Alone	With others	Total
Profound	6	13	12	28	31	30	20	20	20
Severe	36	44	43	24	28	27	28	37	35
Moderate	58	44	46	49	41	44	52	43	45
Total %	100	100	100	100	100	100	100	100	100
(number)	(229)	(1249)	(1478)	(437)	(915)	(1352)	(666)	(2164)	(2830)

Similar proportions of adults with profound disabilities are represented amongst outright owners, public tenant, and private tenant/other. This suggests that many of these people have been able to work and accumulate resources for home buying before being restricted by disabilities. There are smaller proportions with profound disabilities among owners with a mortgage, as most of the relatively younger adult homebuyers have to be able to work.

⁴ Excludes people with mild disabilities and those in cared accommodation.

⁵ Excludes people with mild or no disabilities and those in cared accommodation

2.3.3.2 Economic Resources

Nearly a quarter of the adults with significant disabilities in the community are employed either part or full-time (Table 2-4). A much higher proportion of the younger group are employed (40%) as compared to the older group (5%). Of the 77 percent of adults with significant disabilities who were unemployed or out of the workforce nearly half (46%) are over the age of 60 years and so might be considered to have retired from the labour force. The impact of disability on employment is shown by the proportions employed being notably higher for adults with mild disabilities: 57 percent for younger adults and 12 percent for older adults. The low employment rates of older adults with any level of disability, nearly all of who are retired may relate to the low public expectations for them to remain involved in the workforce.

The relationship between housing tenure and employment is most noticeable for the younger adults of whom more than half were found to be still purchasing their homes. Among these younger purchasers, 55 percent are employed, indicating the importance of work for securing income and housing. In sharp contrast, only 14 percent of the public tenants among the younger group are employed. Among those in the older age group, however, very few are employed irrespective of housing tenure. These findings underscore the importance of ensuring interconnections between housing, employment, and community service policies particularly for younger adults with disabilities.

Table 2-4: Percentage of Adults with Disabilities^{6,7} in Employment, by Age and Living Arrangement⁸, Australia, 1998.

Housing Tenure	Age by Living Arrangement								
	Younger adults			Older adults			Total adults		
	Alone	With others	Total	Alone	With others	Total	Alone	With others	Total
Owners-outright	21	39	37	4	7	6	7	19	16
Purchasers	50	56	55	0	10	8	35	46	45
Public tenant	8	17	14	1	0	1	4	12	8
Private tenant	35	36	36	2	2	2	22	25	25
Total %	27	42	40	3	6	5	11	27	23
(number)	(62)	(525)	(587)	(14)	(57)	(71)	(76)	(582)	(658)

The vast majority of adults with significant disabilities in the community understandably have low incomes given that relatively few have paid employment. Table 2-5 shows that more than two-thirds of them have personal weekly incomes of less than \$240 per week, which is not much more than the basic pension levels. Eight out of ten of the older adults with disabilities have low incomes as compared to six out of ten for the younger adults. This age difference is mainly due to the higher proportion of the younger group having jobs. However, in assessing financial means, account also needs to be taken of the transport and other costs incurred in working. [The impact of disability on income is indicated by the fact that less than half of younger adults with mild disabilities have low incomes].

⁶ A total of 2830 adults in the sample were known to have significant disabilities, live in the community, and be either employed, unemployed or out of the workforce.

⁷ In each cell, the top figure shows the percentage of the relevant group who are employed full or part time. For example, the upper left-hand cell shows that, 21 % of younger adults who own their own homes are employed.

⁸ Includes renter private, renter other, boarder, rent free, other non-specific.

Table 2-5: Percentage of Adults with Disabilities⁹ on Low Incomes (less than \$240 per week) by Age, Living Arrangement, and Housing Tenure, Australia, 1998.

Housing Tenure	Age by Living Arrangement								
	Younger adults			Older adults			Total adults		
	Alone	<i>With others</i>	Total	Alone	<i>With others</i>	Total	Alone	<i>With others</i>	Total
Owner- Outright	70	63	64	70	80	77	70	73	72
Purchasers	50	47	47	71	73	73	56	52	53
Public tenants	98	60	74	95	89	92	96	70	82
Private tenants ¹⁰	76	63	65	80	89	87	77	71	72
Total %	76	57	60	76	81	79	76	67	69
(number)	(169)	(683)	(852)	(312)	(697)	(1004)	(481)	(1379)	(1856)

Overall, most adults with disabilities have low incomes irrespective of their housing circumstances. Among the younger home purchasers, however, the majority have personal incomes well above the basic pension. At the other extreme, nearly all of the older and younger public tenants who live alone are on incomes close to the single pension level. For those on low incomes the main financial differences concern the housing costs of different housing tenures. The many pensioners among the outright homeowners are significantly advantaged by low housing outlays. The low incomes among public tenants are offset to a degree by policies that limit rents to approximately a fourth of their incomes. Private tenants generally pay far more than owners or public tenants for their housing notwithstanding Rent Assistance.

These income patterns have several major implications. First, only a minority of the adults with disabilities living in the community have incomes sufficient to pay much for private services. Indeed, only one out of five have incomes above \$16,000 a year, which is far below the minimum wage. The scope for many of them paying much for their own services is low. Such a policy direction would exacerbate the already powerful financial incentives for many of them (especially in the older age group) to enter cared accommodation.

Second, adults with disabilities in the community are likely to have a variety of forms of government assistance including pensions, housing subsidies, and community services. Each of these program areas has allocations and means testing that are administered separately. For vulnerable individuals the combined effects of means tests can have major impacts that are not anticipated nor alleviated very well across programs.

The financial position of people with disabilities is very different between community and residential care. In cared accommodation, they make contributions of their own resources but significant government subsidies comprehensively pay for accommodation and care as well as 'hotel services' of meals, laundry, and so on. Very few individuals with disabilities in the community would receive comparable financial support through income support, subsidized housing, and subsidized community services. While care arrangements depend on much more than financial incentive, it is clear that the primary costs fall on governments for residential care and for individuals in community care.

⁹ Excludes people with mild disabilities and those in cared accommodation.

¹⁰ Includes renter private, renter other, boarder, rent free, other non-specific.

2.3.4 Needs and Availability of Support

2.3.4.1 Met and Unmet Needs

Published results from the DAC survey (Australian Bureau of Statistics, 1998) show that just over half (57%) of the 3.6 million people with a disability living in households need assistance with some aspect of daily living. These figures are based on needs across eight areas: personal care (self care, mobility, health care, communication), household responsibilities (housework, meal preparation), and/or related tasks (property maintenance and transport). It is important to note that these figures are based on people at all levels of disability including those who have only mild disabilities.

Notwithstanding significant physical or mental limitations, the published results show that more than 40 percent of the people with disabilities remain substantially independent in the community. A major explanation is the inclusion of people with mild disabilities, who by definition do not have any needs for assistance in the core areas of self-care, mobility, and communication as per the definitions at the beginning of the chapter. Another explanation is that some vulnerable individuals can remain independent through adaptation of life styles (adjusting daily life to fit capacities) and/or the availability of supportive environments eg, (Davison, Kendig, Stephens, & Merrill, 1993).

The published DAC findings also show that most of those requiring assistance receive it: 64% have their needs fully met and 32% partly met, with only 4% reporting that their needs are not met at all. People with profound or severe disability who need assistance are more likely to receive it, but they are less likely to have their needs fully met. These generally positive findings need to be considered cautiously for two main reasons. First, people with high levels of unmet need are unlikely to have been able to remain in the community and they would have moved to cared accommodation. Second, the small proportions having unmet needs amount to large numbers of people: it is estimated that more than 600,000 people with disabilities in the community have their needs only partly met and nearly 80,000 have their needs not met at all.

The AHURI project analyses, as reported below, are based on the same areas of need, but with a smaller group of people, excluding those with mild disabilities and those who are under 20 years of age. Using this restricted definition, only 15 percent of the significantly disabled adults report that they have no needs. Virtually none of those with profound or severe disabilities reported having no-needs as compared to a third of those with moderate disabilities.

The findings also show the extensiveness of needs for these people with significant disabilities in the community. Half of them have needs in three or more areas and a quarter of them have needs in five or more of the eight areas. The intensity of needs is higher for the older group, with 59 percent having three or more, as compared to 45 percent for the younger group. For both age groups those who live with others tend to have more needs than do those who live alone. The younger adults who live alone have the lowest proportion (10 percent) with five or more needs areas.

As shown in Table 2-6, a third (32%) report that their needs are only partially met and a small minority (3%) report that their needs are not met at all. Of people with disabilities, younger rather than older adults are more likely to report not experiencing any needs (18% versus 12%). The more detailed analyses written up in the Work in Progress Paper (Bridge, Quine, et al, 2001) show that this age difference remains within the severe level of disability. This may suggest that old age is a compounding factor that heightens needs beyond those due to disability alone.

Table 2-6: Percentage of Adults with Disabilities ¹¹ by Extent of Needs Met, Age and Living Arrangement, Australia, 1998.

Extent of Needs Met	Age by Living Arrangement								
	Younger adults			Older adults			Total adults		
	Alone	With others	Total	Alone	With others	Total	Alone	With others	Total
No needs met	21	17	18	10	12	12	14	15	15
Fully met	31	51	48	49	56	54	42	53	51
Partially met	40	30	31	39	30	33	40	30	32
Not at all	9	3	4	2	2	2	4	2	3
Total %	100	100	100	100	100	100	100	100	100
(number)	(229)	(1249)	(1478)	(437)	(915)	(1352)	(666)	(2164)	(2830)

Living arrangements appear to be a modest but consistent factor in the extent to which people's needs are met. For both older and younger adults, those who live with others are more likely to have their needs fully met. Nevertheless, only among the younger adults do a significant proportion (9 percent) report needs not met at all. Housing tenure does not relate closely to needs being met, but those living in public or private rental are slightly more likely to report that their needs are not being met at all. The findings suggest that younger adults, those who live alone, and non-homeowners are target groups for service provision.

Overall, there does not appear to be a high intensity of unmet needs. Across the eight types of assistance 60 percent of the people report no unmet needs, 25 percent report one unmet need, 9 percent report two or more unmet needs, and only 6 percent report three or more unmet needs. The proportions having unmet needs is highest among younger adults living alone (62 percent) followed by older adults living alone (46 percent). Only a quarter of those who live with others report any unmet needs. The proportion having 3 or more unmet needs is notably higher among the adults living alone, particularly the younger ones.

2.3.5 Types of Assistance Needed

Following is an overview of the types of assistance needed by adults with significant disabilities in the community:

- 60 percent for property maintenance, which is understandable given the physical and financial demands of having this work done. Specific tasks include changing light bulbs and tap washers, minor house repairs, and gardening.
- 46 percent for housework including household chores of washing, vacuuming, and dusting.
- 44 percent for mobility with specific tasks including moving around at home or away from home; getting into or out of a bed or chair; and (by far the most common need) using public transport. This indicates that the trains and buses are largely inaccessible for independent use by many adults with substantial disabilities.
- 44 percent for health care with tasks including foot care, taking medications, dressing wounds, using medical machinery, and manipulating muscles or limbs.
- 42 percent for transport defined as getting to places away from the usual place of residence.

¹¹ This reports the self-rated degree of needs being met and refers to the eight needs areas reported in the text.

- 29 percent with self care including bathing or showering, dressing, eating, using the toilet, and managing incontinence.
- 18 percent with meals preparation including preparing ingredients and cooking food.
- 4 percent with communication including understanding and being understood by family, friends, and strangers.

The areas where need is less widespread tend to be the ones that are more critical to people being able to stay in the community with a reasonable quality of life.

After taking into account people's levels of disability and their age, there is relatively little variation of these findings across housing tenures or types of housing. However, needs for property maintenance is higher for homeowners and those in houses, although these needs also are found among public and private tenants and those in flats. Need for transport is higher for public and private tenants presumably because fewer of them can afford to pay for cars or taxis.

Table 2-7 shows that property maintenance is the type of assistance most frequently required for both younger and older adults irrespective of living arrangements. The older adults, with their higher rates of profound disability, have higher proportions requiring housing-related support such as property maintenance, housework, and transport and mobility. The needs for assistance with self-care, however, are relatively higher for those living with co-residents irrespective of age. This suggests that people who need these high levels of assistance find it difficult to live alone.

Table 2-7: Rank Ordering of Types of Assistance Needed for Adults with Disabilities¹², by Age and Living Arrangement, Australia, 1998

Age by Living Arrangement								
Rank	Younger adults				Older adults			
	Alone	%	With others	%	Alone	%	With others	%
1	Property Maintenance	49	Property Maintenance	57	Property Maintenance	68	Property Maintenance	63
2	Transport	35	Mobility	43	Housework	55	Health Care	54
3	Mobility	33	Housework	43	Transport	54	Housework	50
4	Health Care	29	Transport	37	Health Care	49	Mobility	44
5	Housework	28	Health Care	37	Mobility	44	Transport	47
6	Self Care	15	Self Care	32	Self Care	15	Self Care	34
7	Meal Preparation	8	Meal Preparation	16	Meal Preparation	14	Meal Preparation	23
8	Communication	0	Communication	4	Communication	0	Communication	5

The finding on unmet needs (including partly met needs) reinforces the priority to provide housing and local environments supportive for people with disabilities in the community. The most common areas of reported unmet needs are property maintenance (17 percent), housework (10 percent), transport (7 percent), and health care (7 percent). Less common areas of unmet needs are mobility (5 percent), self care (3 percent), meal preparation (2 percent), and communication (1 percent). Table 2-8 shows that these areas of unmet needs are broadly similar across the age and living arrangements groups, although the prevalence of unmet need tends to be higher for those who live alone.

¹² Excludes people with mild disabilities and those in cared accommodation

Table 2-8: Rank Order of Types of Unmet Needs for Assistance for Adults with Disabilities^{13,14} by Age and Living Arrangement, Australia, 1998

Rank	Age by Living Arrangement							
	Younger adults				Older adults			
	Alone	%	With Others	%	Alone	%	With Others	%
1	Property Maintenance	21	Property Maintenance	16	Property Maintenance	20	Property Maintenance	16
2	Transport	14	Housework	10	Housework	13	Health Care	8
3	Housework	13	Mobility	6	Transport	12	Housework	8
4	Health Care	4	Transport	5	Mobility	9	Mobility	7
5	Meal Preparation	3	Health Care	5	Health Care	7	Transport	6
6	Mobility	1	Self Care	3	Self Care	5	Self Care	3
7	Self Care	1	Meal Preparation	2	Meal Preparation	2	Meal Preparation	2
8	Communication	0	Communication	1	Communication	0	Communication	2

2.3.5.1 Providers of Assistance

It is widely recognised that informal support from family and friends is the primary source of assistance for people with disabilities. The AHURI project findings show that informal assistance in fact is received by more than three-fourths of the adults with significant disabilities living in the community. Forty percent of all of these adults, and more among those who live with others, rely entirely on informal assistance. A third of the respondents have assistance from both informal and formal sources. These findings underscore the importance of ensuring that accommodation and service provision takes close account of the interdependency of informal and formal assistance.

Table 2-9: Percentage of Adults with Disabilities¹⁵ by Assistance Provider Type (Overall), Age and Living Arrangement, Australia, 1998

Assistance Provider Type	Age by Living Arrangement									
	Younger adults			Older adults			Total adults			
	Alone	With others	Total	Alone	With others	Total	Alone	With others	Total	
No assistance	9	3	4	2	2	2	4	2	3	
Informal	31	50	47	16	42	34	21	46	40	
Formal	14	2	4	20	4	9	17	3	6	
Formal & Informal	26	29	28	52	41	44	43	34	36	
Not needed	21	16	17	10	12	12	14	15	15	
Total	%			%			%			
(number)		(229)	(1249)	(1478)	(437)	(915)	(1352)	(666)	(2164)	(2830)

¹³ Excludes people with mild disabilities and those in cared accommodation.

¹⁴ Unmet needs includes partially met as well as not met at all.

¹⁵ As for footnote 14.

Formal providers are defined by the DACS to include government, private non-profit, and private for profit services. Formal services are received by 42 percent of the adults with significant disabilities in the community. In many cases, these are privately provided services of a kind that also are used as a convenience by many people who do not have any disability, for example, taxis, gardeners, and housekeepers. Only 6 percent of these adults rely entirely on formal services for support. The proportions relying only on formal services are much higher for the older adults who live alone and, less so, for the younger adults who live alone. Thirty six percent of adults receive both formal and informal services. The findings suggest that formal services mainly augment informal support but occasionally provide an alternative. They indicate some of the reasons why older people who are not married reside disproportionately in cared accommodation (see Table 2-9).

After taking into account age and living arrangements, there are only few and small variations in sources of assistance by housing tenure. However, use of any formal services was lower for private tenants (38 percent) than for public tenants (43 percent) or owner occupants (48 percent). The main explanation appears to be the reduced capacities of tenants to buy private services.

2.3.6 Home Modifications

A supportive home and neighbourhood environment provides one of the most desirable ways of overcoming disabilities. Although environmental supports cannot meet all needs, they are desirable wherever possible because they enable people to remain independent. However, the DAC survey had relatively little information on environmental supports, partly because it was designed after an earlier WHO concept of disability that focused almost entirely on the limitations of individuals rather than those of their environments.

The DACS measure concerning the environment was a question that asked if people with disabilities have had any modifications to their property because of their disability. These modifications comprised structural changes, ramp, toilet/bath/laundry modification, door widening, handrails, remote controls, new or changed heating, air-conditioning, home automation system, telemonitoring system, other not elsewhere specified. Table 2-10 shows that fewer than one out of five adults (18%) with significant disabilities live in a home that has had modifications to assist with their disabilities. Overall, owners are most likely to have modifications, presumably because they have the necessary resources and control and face more barriers in moving to more supportive accommodation. Slightly more public tenants than private tenants have had home modifications.

Table 2-10: Percentage of Adults with Disabilities ^{16,17} Having Had Home Modification by Age, Living Arrangement, and Housing Tenure, Australia, 1998.

Housing Tenure	Age by Living Arrangement								
	Younger adults			Older adults			Total adults		
	Alone	With others	Total	Alone	With others	Total	Alone	With others	Total
Owner-outright	18	16	16	34	25	28	31	22	24
Purchaser	18	9	10	28	17	19	21	11	12
Public tenant	7	13	11	21	28	24	15	18	16
Private Tenant ¹⁸	8	8	8	9	22	19	9	13	12
Total %	12	11	11	29	24	26	23	17	18
(number)	(27)	(138)	(165)	(126)	(220)	(346)	(153)	(358)	(511)

The proportions having had a home modification range from as low as 7 percent, for younger public tenants living alone, to a high of 34 percent of the older adults who live alone in owner occupied homes. Among the latter group, the proportions having modifications rises even higher among those who live in houses rather than flats.

2.4 Predictors of access to housing and community services

The purpose so far in this chapter has been to describe the characteristics and circumstances of the people with significant disabilities in the community. This analysis has been limited, however, because the cross tabulations do not provide a very good indication of the central factors that explain variation in the findings. For this purpose, it is necessary to employ multivariate statistical methods.

2.4.1 Description of Logistic Regression Methodology Employed

For this Final Report we present only a written account of the main findings. However, the full technical information (including the predictive power of the models and the levels of significance for variables) is available from the authors.

Unless otherwise noted the following nine variables were examined as possible predictors of each outcome:

- age (older versus younger adult);
- sex (male versus female);
- disability severity (severe/profound versus moderate);
- disability type (physical versus behavioural);
- living arrangements (living with others versus living alone);
- labour forces status (unemployed or not in the workforce versus employed);
- weekly income (lower/less than \$240 versus higher/more than \$240);
- housing tenure (renter versus owner); and
- dwelling structure (flat versus house).

¹⁶ Excludes people with mild disabilities and those in cared accommodation. A total of 2830 adults with disabilities in the sample were known to either have had or not had home modifications in their current home.

¹⁷ The table shows the percentage of people in each group who have had home modifications, for example, the upper left hand cell shows that, of the younger men with disabilities who live alone in owner occupied housing, 18% have had home modifications.

¹⁸ Includes renter private, renter other, boarder, rent free, other non-specific

2.4.2 Access to housing tenure

The primary predictors of home ownership (with or without a mortgage) as compared with renters (public and private) are being older, living in a house, living with others, being employed and having a disability, which is physical rather than behavioural. Higher weekly income is a weak predictor of home ownership. Sex and severity of disability are not predictors of home ownership.

Public housing tenants have a very different profile when compared with home owners or private renters. They are more likely to be young, living in flats, living alone, on low incomes, and be unemployed or not in the workforce. While severity of disability is not a predictor, the type of main disability is. Public housing tenants are more likely to have a main disability that is behavioural rather than physical. As was found for home ownership, sex is not a predictor of public housing tenure.

2.4.3 Needs Met or Unmet

The most significant factors in having needs being fully met (including those with no needs) compared with adults whose needs are only partially met or not met at all, are living with others and having only a moderate disability; other significant factors are being older, male, and employed. Home ownership, dwelling structure, disability type, and income are not significant predictors.

A further analysis distinguished between predictors of needs being fully rather than partially met. Older adults, living with others and having only a moderate disability are more likely to have their needs fully met. Sex, dwelling structure, housing tenure, weekly income, labour force status and main disability are not significant predictors.

2.4.4 Specific assistance needs

It is important to understand the different factors influencing whether or not each kind of needs are met. As shown below predictors of needs for assistance vary considerably depending on the particular assistance required.

With self-care, the main predictors of need are living with others; having greater severity of disability, and having a physical rather than a behavioural main disability. Age, sex, dwelling structure, housing tenure, weekly income and employment status are not predictors of this need.

With transport the main predictors of need are being older, being unemployed or not in the workforce, having greater disability severity, living alone and living in a house. Being a renter is a weak predictor. Weekly income, sex or main disabilities are not predictors of this need.

With property maintenance, the strongest predictors of need are being female, having greater disability severity, having a physical disability, living in a house, and being an owner. Those most likely to have this need are those who are unemployed or not in the workforce. But those on higher incomes also are more likely to require assistance, which may be associated with living in houses and owning homes, where there is greater responsibility for maintenance. Living arrangement is a weak predictor. Only age is not a predictor of this need.

With housework the main predictors of need are disability severity, having a physical main disability, being unemployed or not in the workforce, being older and female. Living alone is a weak predictor, while dwelling structure, housing tenure and weekly income are not predictors of this need.

2.4.5 Predictors of use of formal services (overall)

The analyses here examine use of any formal services including those from the government, non profit, and for profit, sectors across any of the eight needs areas, described earlier in this chapter. The most significant predictor is living alone. Other predictors are being older, male, having a moderate disability and being on a higher income, the latter possibly reflecting the ability to pay for such services. Being unemployed or not in the workforce is a weak predictor. Housing tenure, dwelling structure and main disability are not predictors of use of formal services.

2.4.6 Public versus Private Tenancy as a Predictor

In order to identify whether the results differed when only renters were considered, the analyses was re-run to exclude homeowners. Responses from public housing tenants were compared with those of private housing tenants to identify predictors of public housing tenure versus private rental tenure. Public housing tenants are much more likely to be unemployed or not in the workforce than private renters, and are more likely to be living alone and come from the older age category. Sex, dwelling structure, weekly income, severity of disability and main type of disability did not appear to be predictive factors.

For needs fully met overall, or no needs, living with others and having only a moderate disability are the main predictors, and older age is a weak predictor. While being male is a significant predictor for adults in all forms of housing tenure, it is not a significant predictor when only renters are considered. Housing tenure (public versus private renter) is not a predictive factor, and neither are other factors like dwelling structure, weekly income, labour force status or main type of disability.

Indicators of overall needs for assistance are being female, having greater disability severity and being older. Lower income and having a behavioural main disability are weak predictors. Housing tenure, dwelling structure, living arrangement, and labour force status are not predictors.

For specific assistance needs some similarities and differences were noted between the predictors for renters only and those for all forms of tenure. In some instances, differences between public and private renters were evident and are reported elsewhere.

With self-care for renters, as for all forms of tenure, living with others and having a physical disability are predictors, but in addition being on a lower income is also a weak predictor. Severity of disability is not a predictor of this need for renters. Age, sex, dwelling structure, housing tenure and labour force status are also not predictors. With transport, the main predictor is severity of disability. Being older, unemployed or not in the workforce are also predictors. Also of significance is the finding, that transport assistance needs were greater for public renters than private renters.

With property maintenance the main predictors are being female, having a physical main disability, having a greater severity of disability, being unemployed or not in the workforce, living with others and living in a house. The need for property maintenance was somewhat more likely to be noted by Public tenants than by private renters. Age is not a predictor, and neither is weekly income.

With housework, the main predictors are being older, female, living with others, being on a lower income, having greater disability severity and having a physical main disability. Dwelling structure, housing tenure and labour force status are not predictors.

For use of formal services only older age and living alone are predictors for renters, whereas the findings for adults in all forms of housing tenure identified these two predictors but also being male, having a moderate disability and a higher income.

CHAPTER 3. KEY PLAYERS VIEWS ON LONG TO MEDIUM TERM POLICY TRENDS

3.0 Introduction

This chapter outlines the results of analysing the data obtained by interviewing 'key' player informants. Thus, the focus within the chapter includes aspects of long to medium term policy trends that pose specific challenges for housing, disability and care services. The focus is on comments by participants from the key 'player' interviews but references to particular policy, legislation and programs are interwoven with the comments as appropriate.

The pilot interview phase confirmed that the approach and key themes identified from the research framework were those of the most concern to key players. The final analysis of common themes is illustrated in Figure 3.1.

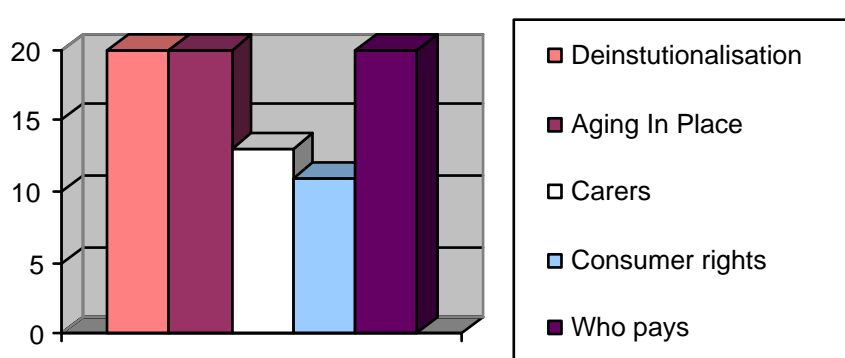


Figure 3-1: Number of informants who highlighted particular long to medium term policy trends

The focus of informants within the interviews on these areas differs from the pilot analysis, in that emphasis ranges more widely. For instance, the pilot phase identified the issue of 'who pays' as the most common theme but the final analysis indicates that '*deinstitutionalisation*', '*ageing in place*' and '*who pays*' were all of equal concern. The flattening out of the data is to be expected with a much larger pool of informants and clearly indicates the interaction of policy implementation to the emergent financial concern raised by increasing expectations regarding high-level care provision for individuals within their homes.

'*Deinstitutionalisation*' concerns mostly younger people with disabilities whilst '*ageing in place*' concerns older people and as such challenges community care resources for the most vulnerable. Ageing in place challenges services because of the increasing and compound demands produced by early onset ageing of the deinstitutionalised population in combination with general population ageing. A more detailed sub-thematic breakdown and analysis of all five long to medium term themes, including illustration of sub-themes using actual interview excerpts, follows.

3.1 Deinstitutionalisation of younger people with disabilities

The rate of 'deinstitutionalisation' varies between States¹⁹ with some of the larger States actually choosing to keep some of the larger institutions providing primary care for intellectually and mentally impaired younger adults open albeit with no admittance policies in place. For instance, larger States like NSW, Victoria and Queensland are still running and maintaining the older style large institutions.

"[there are] still three large government institutions (approximately 610 beds in total) however these currently all have a no admissions policy."

Whereas, smaller States like Tasmania and South Australia that only had a small number of institutions have been able to move much more rapidly to close them.

"..[this was a] process that occurred over a very short period of time (1988-1999). All care for clients with intellectual and mental health problems are now community based."

All informants regardless of the rate of institutional closure within their State believed that 'deinstitutionalisation' was desirable in theory. However, many questioned the practice, in terms of unanticipated side effects and failure to deliver the outcomes anticipated. The greatest concerns raised were those of waning political will because of carer backlash, the high cost of care and the unanticipated squeeze placed on public resources resulting from the failure to adequately resource accommodation, care and infrastructure. There is a clear sense that although many large institutions have been effectively closed that 'deinstitutionalisation' is now going backwards. Many informants for instance reported difficulties finding accommodation for younger people with disabilities and therefore many are ending up in residential care, albeit primarily aged care.

The process of 'deinstitutionalisation' has been dependant on the availability of social housing and the engineering of partnerships between government and non-profit community agencies in terms of accommodation and support packaging. However, there is a strong perception amongst informants that this has not produced the desired flexibility or even a range of accommodation options. Instead, the predominant model appears to have been group homes or 'Community Residential Units' (CRU's). The group home model became the predominant model because it enabled closure of institutions in a timely manner by reducing both cost of in-home supervision and waiting lists more effectively than other more individualised accommodation options as the following excerpts highlight.

"in the past the implementation of 'deinstitutionalisation' and closure of institutions meant that the transition to a CRU has been the only option. For instance, the trend has been to build and then staff a CRU" and "Group homes were a practical approach to 'deinstitutionalisation' but we need to look at other options. For example many group homes are really just mini institutions."

Additionally, a focus on institutional closure without provision of a range of accommodation alternatives has had some serious ramifications as the following interview transcript illustrates.

"Because of the absence of secure accommodation facilities some clients are now appearing in hospital or prisons. For example a young person set fire to his group home on three occasions and as a result because there were no alternative secure options ended up being charged and going to jail."

Of particular concern, is the fact that failure to adequately provide for a range of accommodation and support needs means that the criminal justice system is often the only alternative for those with severe behaviour problems as the following excerpt illustrates.

"An alternative to aged care beds in terms of secure accommodation is the (18 bed) secure accommodation facility provided by the criminal justice system."

¹⁹ Other AHURI projects like the final report of the "Deinstitutionalisation and housing futures study" (Bostock, L., Gleeson, B., McPherson, A. & L. Pang, 2001) provide more detail. For more information about this research project, see www.ahuri.edu.au/research/summary/project15.html.

Just moving adults with disabilities from large-scale institutions to group homes located within the community has not achieved the community integration, increased choices and inclusion that were anticipated and which had been hard fought for by the disability community. The following transcript excerpt illustrates that considerable community disillusion exists about the process.

"outcomes put up to the public about 'deinstitutionalisation' are not coming true (industry report). The isolation from the community is intense"

Disillusion about *'deinstitutionalisation'* stems not just from failure to achieve social inclusion via relocation alone but also from the additional pressures being experienced by informal carers as the following excerpt illustrates.

"Deinstitutionalisation has increased the pressure on the rest of the family, which in turn has increased the likelihood of family breakdown"

The process of *'deinstitutionalisation'* appears to have shifted the burden of care from the health system back onto the community sector and informal carers. However, informal care and support systems are not the only systems adversely affected. The other sector in many States that has had significant additional demands made on it because of *'deinstitutionalisation'* is the social housing sector as the following excerpt illustrates.

"Deinstitutionalisation is also squeezing housing because as people who were previously in cared accommodation move into low cost public housing this displaces others."

Thus, social housing availability has become a major pressure point in many Australian States. In some States like South Australia, "there is a grave risk of running out of housing stock". The decreasing availability of social housing stocks in all States combined with the closure or reduction of boarding houses and a failure of the private housing market to respond to the issues of affordability or accessibility has resulted in a changing focus from predominantly low income housing to disability housing. This shift in focus concerns housing providers who believe that higher concentrations of people with disabilities increases marginalisation and social isolation whilst reinforcing a reliance on formal care services because available accommodation is often at a geographical distance from established informal support systems.

3.1.1 Community participation as a concept

For the majority of informants, *'deinstitutionalisation'* was viewed as being time limited, in other words a trend having a ten to twenty year history. For instance, the term *"post-deinstitutionalisation"* was employed by some, whilst for many there was a clear notion that the game has shifted focus with the emphasis now being on achieving community living and participation as a means of preventing institutionalisation.

Under the subtheme of community participation, a number of other themes emerge such as the 'meaning' of home and community. Firstly, community participation does not necessarily result from placement of accommodation within a community context.

"Being in a CRU does not mean community inclusion, despite appropriate accommodation, support and networks. the largest barrier is still community attitudes." and *"For example is it really desirable to have one person in a group home with a ten-foot high fence all around because of behavioural problems."* and *"boarding houses, hostels etc. are unrecognised institutions in many ways."*

Secondly, there is lack of clarity about the distinction between a 'home' versus an 'institution'. Homes are typically distinguished from institutions not just by size, but more importantly, by individuation and opportunities for personal expression. A home provides more than just shelter, it also provides a living space that reflects individual aspirations, providing emotional as well as physical security.

3.2 Ageing in Place with a disability

'Ageing in place' has become a major issue as the Australian population ages and this is evident from informants across all States. There are attitudinal, cultural and policy changes needed if institutionalisation is to be prevented. 'Deinstitutionalisation' has been accepted because current values recognise the growth and development capacity of youth but age-related conditions are problematic as older people are not as valued. Medical advances over the last 50 years or so have enabled a growing proportion of seniors with disabilities to survive, with major economic and social consequences. Furthermore, people with longstanding disabilities may actually experience, premature ageing and require access to services well before reaching the age of 65. Older women can also be considered another subgroup, as they are more likely to live alone, be in greater need of community-based care, and be at greater risk of admission to residential care.

Consequently, a critical issue that concerned the majority of informants was the inflexibility of boundaries between employment and accommodation support. Employment impacts on economic well-being, socialisation and formal care provision for those in supported accommodation settings. Furthermore, implementing the notion of 'ageing in place' challenges the concept of retirement as a chronological age transition point as this excerpt illustrates:

"[there is] a problem with enabling older people with disabilities to retire." and "loss of a job means loss of friends, loss of accommodation etc."

Consequently, retirement for people with disabilities raises issues associated with Commonwealth/State divisions of responsibilities. The Commonwealth funds employment/day care whilst the State funds accommodation related support with the resultant lack of access to formal day support within the home a common problem as the following excerpt illustrates.

"day care is not covered (they are not funded for staffing between the hours of 9-3 p.m.) and so the expectation is that residents will not be home during the day. For instance clients who are now 60-75 years have increasing problems with sickness."

This situation is compounded in some States by a Disability Act, which stipulates that no-one service provider can have total control of a persons welfare. Whilst building in multiple service providers may have benefits, it also potentially creates artificial boundary issues because funding is linked to service provision programs and not to the individual in need of support. Therefore, there is a strong sense that additional resources are required to address the growing concerns surrounding obtaining, maintaining and increasing support within a secure community based accommodation setting. Failure to adequately resource this increases the vulnerability experienced by adults with disabilities (particularly those without informal supports) and effectively prevents them from being able to 'age in place'.

"'Ageing in place' for people with disabilities requires more funding resources and is hit and miss at present. People are at risk in terms of health, personal safety and in losing access to food and shelter."

Furthermore, additional resources are required to adapt homes to better respond to the changes in functional ability or health status of their occupants. This means that challenging environments particularly home ones with multiple changes in level, steps or lack of circulation spaces require inspection, maintenance and modifications in order for the occupants to remain at home.

"As people age and disability increases it is inevitable in social housing models that the need to make adjustments also increases." and "If there is a physical component, modifications will be required. It is now pretty simple to do this and flexibility is also possible but it is difficult to modify existing dwellings"

In social housing models, this may mean a major reconfiguration of existing housing stock, which is likely to impact on budget management and internal prioritisation. Additionally, there is a belief that appropriate knowledge exists but that this is not reflected in current practice and that increased funding will be required in order to make the needed changes.

"We have the knowledge (but not the practice) to support people to 'age in place'. Increased funding leads to better practice."

There was also a strong belief that the issues raised by 'ageing in place' are complex and reflect ethical values within Australian society, including a general lack of respect for older persons.

"Ageing in place', is not a simple issue because older people are the least valued in our society and they are the lowest priority...and our current work practices make assisting (supporting elders) a devalued task."

The devaluing of informal care and the continued focus on individual employment related achievement means that recruiting and keeping informal carers will become more difficult as the population in general ages and the support base for older people decreases. 'Ageing in place' also raises issues associated with dying at home, which can be both a stressful and expensive activity.

"in assisting an older person to die at home it cost \$10,000 a month and took six weeks. This was only achieved because of personal wealth and there is no way that other older people could afford this. At the moment there is no governmental assistance apart from palliative care and people without personal resources have to go to hospital."

It was evident from the pilot interviews that 'ageing in place' impacts urban planning, particularly so in terms of how quickly the Australian planning and regulatory system are able to respond to changes in social policy. Both positive and negative comments about planning changes were evident. Planning was raised as significant because of the time lag between planning and development and the long-term and cost intensive nature of the issues associated with a mismatch between planning instruments and actual housing infrastructure outcomes. For instance, the following excerpt illustrates both that fact the predicted transition to smaller or retirement housing by older persons has been considerably less than anticipated whilst the changes in planning legislation enacted to facilitate the provision of informal care have been taken up by developers and home owners alike.

"People are staying in the one home longer and there has been a growth of dual occupancy, granny flats etc." and "we need more 'granny flats."

Additionally, planning instruments such as development control plans enacted by States have the ability to either facilitate social policy or effectively impede it. There is an inherent tension between the desire to maximise space from a cost perspective and the result in terms of social policy outcomes for older persons and those with disabilities. For instance, the following excerpts highlight potential issues related to planning measures currently being proposed.

"the model Development Control Plan (DCP) [under development in NSW], effectively draws down the size of a bedroom to 3.2 m. This is not a good footprint and implementing this will create problems with useable circulation space and impact on the achievement of the option to 'age in place' into the future." and "At the moment Aged Care Units going up don't have to be accessible"

3.2.1 Variability of need based on disability type

Older people and people with disabilities are not a homogeneous group and there is considerable variation in their health and related care needs. As with any group, there are internal differences and subgroups so that the disability experience can differ for individuals depending on their age, gender, nature and extent of disability, ethnicity, socio-economic status and geographic location. For example, someone ageing with a long-standing disability such as cerebral palsy or Down's syndrome will have an entirely different experience of ageing than someone who is relatively fit and well.

Consequently, amongst informants interviewed, there is a clear desire to develop more individualised and flexible support and accommodation options. This is in part predicated on the fact that the needs of people with disabilities varies widely and that changes in health care practices and general well being mean that this is not static over time. For instance, a number of participants singled out clients with intellectual disability, mental health problems, age-related dementia and acquired brain injury as the most problematic groups to service. Moreover, informants commented on significant differences between these groups in terms of assessment policy and ability of services to respond with the consequence that some groups were more likely to be placed in residential care.

"An emerging issue is providing for the complex care needs of those with Acquired Brain Injury (ABI) as separate from Intellectual Disability...As a result young people with ABI end up inappropriately placed in nursing home accommodation" and "Aged related dementia is also an increasing issue." and "Some systemic issues surround assessment and communication failures and this is worse for particular groups and their needs. For instance, visual impairment is currently not well accommodated."

Furthermore, patterns of disability will continue to change as technological, sociological and cultural change impact on society. Consequently, policies and practices will need to remain flexible enough to respond to this.

"[In the future] genetic or developmental disabilities like Downs Syndrome, Spina Bifida etc won't be seen." and "[Acquired Brain Injury] is a growing trend as a result of petrol sniffing, heroin and alcohol."

Lastly, concerns were expressed about service inequalities between age-banded cohorts. It would appear from the observations of a number of informants that the experience of age cohorts varies, with the younger cohort receiving significantly less service despite similar levels of need as the following excerpts illustrate.

"[There is an] access trough coming up behind the current baby boomer's...[This group] is getting a lower level of service provision." and "the baby boomer's [are] looking good, but generation x, are not looking so good"

3.3 Recognition and support of carers

As already mentioned both *'deinstitutionalisation'* and *'ageing in place'* are predicated on primary community care being cheaply available. This raises issues of culture and gender based roles expectations and inequalities with consequent impacts on financial well-being, employment opportunities and child rearing. As the following excerpt illustrates most of the burden of care traditionally falls to women.

" [this amounts to] exploitation of the unpaid work of women ... Adult children's participation in the labour market and child rearing are affected by the expectation that they provide informal care."

Consequently, increased support and recognition of community carers underpins and sustains the ability to implement social policy objectives such as *'ageing in place'* and *'deinstitutionalisation'*. Whilst informants acknowledge, that over the past ten years both State and Commonwealth governments have been active in allocating additional resources to carer needs, there was still a strong perception that lack of co-ordination and fragmentation of carer support have seriously hampered outcomes.

"Because of increasing expectations there has been more dollars directed to needs of carers but support is fragmented and uncoordinated and requires an articulate person to negotiate system."

The central role of informal caregivers in maintaining people with disabilities within their local communities means that particular care needs to be taken to provide appropriate support to carers. However, the importance of negotiating partnerships and the difficulties in achieving this were a central theme.

"There is a need for respective partnerships, partnerships however can be difficult. Services need to work to enable informal carers and need to respect and honour the care provided."

Given that the transition to cared accommodation usually follows a crisis of some sort, some key 'players', believe that improved long-term planning, legal and lifestyle advice may deliver more individualised and cost effective long-term care alternatives.

"Where carers are supporting an individual they need to be supported to continue this. They require security and this can be best achieved by better long term planning." and "good support to families and assistance with legal issues and social support should enable at least 20% of this group to 'age in place' more cost efficiently."

Caring is challenging and carers require support and a break. Consequently, lack of access to both advice and respite has already become acute in rural and regional communities where populations are shrinking and younger people are relocating to urban areas to obtain employment.

"Carers have increasing expectations ... and a desire for more support services particularly in regional areas where support staff cannot be gotten."

Moreover, this has created a situation of increasing tension for carers as lack of appropriate support combined with increasing social pressure to provide quality informal care services has been linked to family breakdown.

"Respite remains insufficient although clients in community organizations can get respite. However, it has been found that the community sector places people into respite and then won't take them back which means that the department of housing has to provide accommodation to prevent blockage of respite beds."

The fear of family breakdown and insecurities and tensions associated with caring for a relative have directly led to carers becoming more politically active and vocal about their needs.

"As a result there has been a carer backlash" and "Carers do not want respite and support as carers but want viable community options for their loved ones. In the past this has been taboo but increasingly numbers of people are saying they have a right to live too, without being accused of saying that they are not loving or caring for their family member."

Another common theme concerned the lack of training and support systems for both formal and informal care. Lack of appropriate training has been linked to increased incidence of secondary disability and or crisis interventions by formal services.

"[behavioural problems result from the] system using unskilled or entry level workforce [staff] to provide support for people with complex needs. There is a desperate need to better skill this workforce."

One informant talked about the financial impact on services of rising insurance premiums and increasing occupational health and safety claims as the following excerpt illustrates.

"There is an issue around training carers. Occupational health and safety issues are up and insurance premiums have doubled to as high as 15% with an average of 7-8% whereas only a few years ago costs were as low as 2%."

Additionally, the whole issue of poor or inadequate training when combined with lack of availability of appropriate assistive technologies becomes compounded. Informants referred to the need to increase funding to the national Program of Aids for Disabled People (PADP) scheme as failure to utilise assistive devices because of affordability appears to be a significant factor in well being and in injury prevention.

"The government also needs to properly fund PADP, because the absence of appropriately funded programs means that people with disabilities are unnecessarily dependent and or suffer economic disadvantage. Lack of provision of equipment can lead to a higher incidence of injury to carers both paid and unpaid."

Furthermore, there is an inherent tension between rights and perspectives of carers and consumers. In some States, lobbying by carers has directly impacted on both increasing demands on social housing and the decision in some States like Victoria and Queensland to keep some of the large residential institutions open. A number of informants stressed the need for subsidy and support whilst questioning the ability of carers to act as advocates.

"a subsidy issue [exists] because of lost income and opportunities [for carers] but ... focus should be on clients not on carers." and "Thirty to forty family groups can influence a decision about closure of institutions and if the person with a disability doesn't have advocates their voice is never heard."

3.4 Rising expectations/consumer rights

Because of the widespread adoption of rights based ideologies within all facets of legislation, both carers and adults with disabilities are more aware of and more vocal about both their rights, particularly in terms of needs and choices. However, despite rights based legislation, people with disabilities are generally less articulate than advocates or carers. This silence increases their vulnerability, and may in part be attributed to disability barriers and to a failure of more direct consultative processes.

"We haven't done well in engaging people with disabilities in our customer participation process. This needs to be looked at by factoring in better access and use of alternative formats. It is easier to deal with advocacy groups."

Informants mentioned two sub-themes within this section, one primarily concerning policy discrepancies and other primarily about the tension between individual rights and rights of others. Firstly, current policy reflects varying degrees of emphasis on consumer rights.

"This is patchy across sectors. SAAP has a rights focus, housing less so."

Secondly, some rights based Acts, such as the Residential Tenancy Act in South Australia, tend to work against people with disabilities and consideration has to be given to finding an acceptable balance between the rights of the individual with a disability and those around them.

"Residential Tenancy Act (Cl. 90) allows neighbours to complain about a person. This is most likely to have a big impact on people with disabilities, because it makes it easier for landlords to evict people." and "[Care] might break down and other tenants may take on the support roles. [which raises the question,] what are tenants rights? ... Some [of the issues raised are] tenancy management stuff and the need for closer links with support agencies. It is not black or white."

Community living highlights inherent tensions surrounding relationships with others. This sort of tension can be particularly problematic for community tenancies where consumers' rights to refuse support and their inherent right to privacy and confidentiality might lead to negative outcomes. Negative outcomes like eviction are most likely when policy and practice surrounding informed consent and duty of care are unclear or where consumers choices conflict with service provider goals. An example of this conflict in terms of tenancy legislation and housing policy is evident in the following excerpt.

"tenancy legislation is rights based and provides clients with greater control and independence but also gives them the right to refuse support...with eviction often being the only recourse." and "There is a tension between expectations and rights. There are ethical issues...For instance, if the right to privacy is dominant then people will end up in jail etc...We can't afford as a field to see rights as the only issue, we also have a collective responsibility to keep people safe."

3.5 Who pays (user; which level of government or government department's responsibility)?

As the graph at the beginning of the thematic analysis indicates, nearly all informants considered the issue of 'who pays' a significant theme. The inherent themes being one of cost shifting and within this there were two sub-themes, firstly, shift in cost between sectors and secondly, shift in cost to users. Some informants mentioned the significance of the shift in resources resulting from State based departmental strategic planning and restructuring. For instance, the State based trend towards amalgamation of previously separate human services and housing departments. Furthermore, significant shifts in resources between departments in some States impacts sometimes positively and sometimes negatively on availability of social housing.

"The broader health/human services shift has caused a shift in cost between sectors. This has been positive between health and housing." versus "[Health and Welfare departments] are moving money out of housing and the only government department left in the game with their hand up is social housing. There needs to be greater recognition of this in terms of funding and support especially in crisis/illness where a quick response is essential because without this the housing system is unsustainable."

Current national policy rhetoric concerning a “user pays’ mentality reflects the notion that high dependency community care can be shifted back to individuals. However, many informants believed that this was just playing with words, as the majority of adults with disabilities were for the greater part dependent on welfare because of premature retirement and long-term unemployment. The cost of having a disability combined with significant gaps in superannuation and other retirement income sources makes user payment impracticable.

“User pays is a furphy particularly for people with disabilities because they are dependent on financial support from government anyway because of lack of employment opportunities. Given dependence on income support this is simply just shifting money around.”

3.5.1 Provider roles and relationships

Of equal significance to consideration of the financing of housing and care were the issues that related to partnerships between agencies, and the negotiation, clarification and prioritisation of provider roles and responsibilities that underpin the success of this. It is pleasing to note that many informants’ comments reflect significant improvements in this area.

“Public housing is working closely with both health and community services” and “This has started in the area of mental health, it is not perfect but gives a framework.”

However, informants also stated that overlap, funding boundaries, skill and knowledge continue to present barriers to achieving an integrated approach.

“There are different mindsets within agencies partly because of business/service focus and also because of funding models. Overlap is a big challenge.” and “when hospitalisation occurs in response to health crises, the hospitals are demanding as a prerequisite for treatment that [clients with high care needs receive] 24-hour disability support.”

Some informants felt that more formalised memoranda of understandings or legal agreements were required in order to ensure that roles and responsibilities were clearly understood and adequately negotiated between all key players.

“Agreements across governments (i.e. State and Commonwealth) and between departments.” and “Particularly at a State level there needs to be more formalised agreements between housing and support providers about what ‘social housing’ really means i.e. independence, social success, community living.”

Lastly, a number of informants stressed that the development of a culture and practice that valued sharing, listening and learning would be critical in achieving the whole of government directions needed to improve coordination and linkages.

“better planning and increased sharing of information between agencies.” and “Service organizations need to be learning and listening organizations.”

3.6 Tensions between different players viewpoints

The trend towards ‘deinstitutionalisation’ and ‘ageing in place’ raise a number of particular tensions between viewpoints where ideologies or accepted cultural practice clashed. For instance, the desire of people to remain in a familiar environment impacts on both younger people with disabilities who do not want ‘deinstitutionalisation’ and older people with disabilities who seek to remain in the community despite high support needs. Some informants commented on the desires expressed by those living in institutions to remain there but this view of ‘ageing in place’ contrasts quite strongly with the view that transitions are ‘normal’ and inevitable for older persons with high care needs. Evidence of two contrasting viewpoints is illustrated in the two excerpts following:

“There is a desire expressed by people still in specialised settings (i.e. institutions) which have been their home for most of their life, to not want to move” versus “What is wanted is exactly the same as the general community, i.e., if they cannot cope at home then they move to an elderly care facility.”

These two opposing viewpoints highlight some of the lack of clarity about fundamental principles and imply that there may be other issues at work such as the cost and responsibility for care provision plus the value placed on community participation as a right by older persons. Another significant difference of opinion between informants that appeared in the transcripts was primarily about ethical frameworks and responsibilities.

With increasing litigation against disability services it is not surprising that informants who were government employees or service providers were more likely to raise issues relating to their ability to fulfil their 'duty of care' as a concern. However, this goal contrasts with the views of those coming from a more consumer perspective that expressed a belief that individuals have the right to make choices even if this placed them at risk. The following excerpt illustrates this tension.

"the right to take risks and live in the community raises tensions with duty of care to care. i.e. privacy versus safety."

CHAPTER 4. KEY PLAYERS THOUGHTS ON POTENTIAL GOVERNMENT ACTION AREAS

4.0 Introduction

This chapter outlines the results of analysing the suggested government action areas or potential interventions that might go some way to resolving particular problems resulting from the impact of current long to medium term trends. Thus, this chapter focuses on aspects of current policy that pose specific solutions and that were isolated for specific comment by participants from the key ‘player’ interviews.

As in the previous chapter, the pilot interview phase confirmed that the approach and key themes identified from the research framework were those of the most concern to key players. The final analysis of common themes for all the informants sampled is illustrated in Figure 4-1.

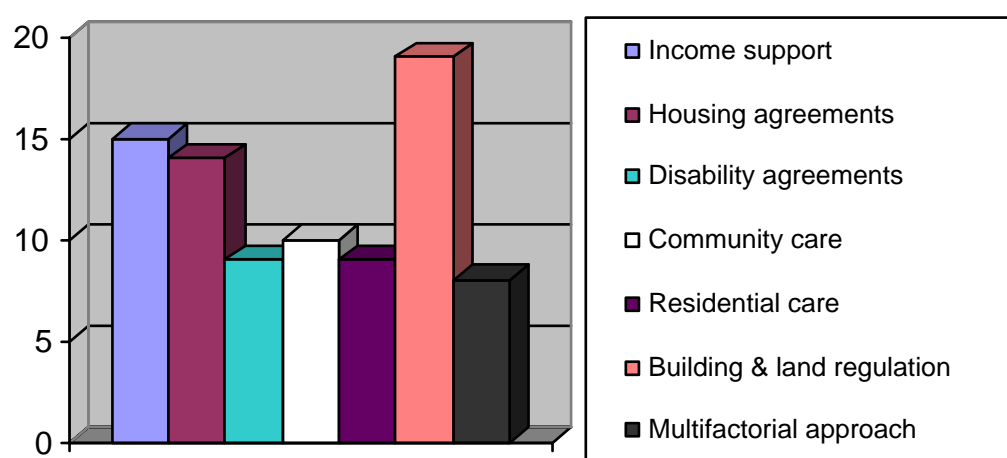


Figure 4-1: Number of informants who highlighted specific government action areas

The focus of informants within the interviews on these areas differs from the pilot analysis published in our ‘work in progress’ paper, in that ‘community care’ is no longer the most commonly mentioned theme and the area of ‘building and land regulation’ instead has now taken central place, followed by income support and housing agreements. However, many of the informants cautioned that any approach that was solely focused on any one area was bound to fail; instead, a multifactorial approach was advocated.

The fact that ‘building and land regulation’ was such a central theme should fail to surprise, given the current lack of incentives for adaptable and accessible accommodation across all Australian States. Inconsistencies in legislation, zoning and current construction practices work to effectively restrict the range of accommodation options available, particularly those in the private market the result of which is to increase both housing and care costs. A more detailed sub-thematic breakdown and analysis of all seven potential government action areas, including illustration of sub-themes using actual interview excerpts, follows.

4.1 Income Support

Income support concerns the degree of activity restriction resulting from disability severity in conjunction with financial status, this in turn influences available housing and care options. For this reason advocacy for greater levels of income support, appears to be a predominant theme amongst informants. Increased personal income enables choice and creates more private market purchase possibilities. At present, there is huge variance in the costs of housing and care options and relatively little choice for some persons with disabilities. Up to 80% of personal income can go towards supported accommodation. Whilst this offsets care costs in the short term, people provided for in this manner are unlikely to ever be in a position to use their money in a discretionary manner. The following excerpt illustrates the enormous variance in accommodation costs faced by people with disabilities depending on how their accommodation is packaged.

"Charges vary depending on the type of disability and the type of accommodation. For instance, a range of money goes on housing rental anything from 20-32%, whereas other forms of supported accommodation may charge anything up to 80%."

People with disabilities who are ageing are particularly vulnerable as the impact of long-term unemployment and or premature retirement may result in higher health and care related costs whilst securing and maintaining affordable housing becomes increasingly difficult. The following excerpt illustrates the flow on impacts of financial insecurity for people with disabilities and comments on how critical a secure and adequate income is to securing and maintaining community based accommodation.

"For instance, a community housing agency provides accommodation for someone with an intellectual disability, they pay rental from their 'Newstart' allowance but if they breach their conditions their income is at risk as is their accommodation. People not on disability support are even more vulnerable."

The sheer number of people with disabilities who rely on incomes well below the minimum wage may explain why so many of the informants expressed a belief that increased income for people who depend on disability benefits and other entitlements would increase both choice and flexibility.

"One of the McLure reports main points is about enabling more individualised service delivery. Supplementary payments to cover additional costs of disability such as home modifications, specialised equipment etc are needed. This has proved too difficult so it keeps getting put aside but it could be done with political will"

The Commonwealth's failure to top up income support for younger people with disabilities was compared unfavourably with the treatment of seniors. Informants clearly believed that double disadvantage occurs for those whose low income becomes compounded by the cost of having a disability as the following excerpt illustrates.

"People with disabilities did not get the \$1,000 grant that Seniors got, and now everything has gone up for them, since introduction of the GST. This is not solely GST, but the HACC 'user pay's' system, plus having to pay for taxi vouchers etc." and "User pays is the way that things are going, however, the pension is going to be insufficient in the future."

The fact that many people with disabilities are reliant on government support raises issues when operating with an expectation that users contribute to care costs as a medium to long-term policy trend. Failure to attend to economic comfort and security amongst users with disabilities increases the risks associated with morbidity, homelessness and social exclusion.

"From a client perspective the most critical [aspect] is income support, this allows them to pay rent, purchase food and is adequate but there are no monies to spare."

A belief was also expressed that the Federal government's current emphasis on rental support as a means of addressing issues related to income and security of tenure was failing because of the inherent lack of interest from and within the private housing sector.

"Increase disability income as increasing rental assistance won't work because the private sector is not interested."

Lastly, given the importance placed by informants on the need to improve disability income support there was a sub theme that related to how this might be achieved. One view was that in the longer term a rationalisation of the newly introduced Goods and Services Tax (GST) might create income supplementation opportunities. However, the GST was also singled out for negative comment because of its impact on construction costs.

“the introduction of the GST has substantially increased ... per square metre building costs. This has meant redesign across all buildings and this has resulted in decreasing the size of buildings.”

4.2 Housing Agreements

The role of housing agreements was considered particularly significant by informants, given that it remains significant implies the degree of concern surrounding the ‘scaling back or potential cancellation’ of Commonwealth/State Housing Agreement (CSHA) funding. This uncertainty is compounded by the squeeze currently being experienced in obtaining affordable housing across Australia making housing agreements of great concern. This also reflects the concerns surrounding the reform directions more recently outlined under the CSHA. Informants made a number of specific comments surrounding the insecurity of CSHA continuation and current limitations experienced by the social housing sector.

“The downscaling of public housing program is a backward step...We need to be committed to redesigning infrastructure within a good social housing paradigm that welcomes all people.” and *“Without the CSHA any accommodation progress could be halted, because if the CSHA was not continued the State would not pick it up”* and *“At present we can sustain management but not stock so we need a targeted capital injection so our assets retain relevance and grow.”*

Comments also concerned principles that informants believed were desirable or that were expressed within the CSHA but that created tensions, as the following excerpts illustrate.

“The bilateral CSHA is about creating a sustainable community. Creating sustainable tenancies can be competing interests...For instance it can create dysfunctional communities and there can be difficulties associated with reconfiguration of housing stocks.” and *“People with disabilities and older people need equitable access to regular housing programs, ordinary first...i.e. home modifications within public housing.”*

Additionally, as was discussed in the previous section on income support, the fact that State housing authorities have narrowed targeting to people whose needs cannot be met adequately within the private market creates concern about social housing’s ability to sustain quality services in the future as the following two excerpts illustrate.

“Unfortunately public housing is fast becoming a disability service, this is problematic because it will lead to it being further undermined. A safeguard at the moment is that there is a much larger group of people who are a political force to demand services.” and *“People with disabilities lacking informal [care] alternatives creates problems in a system, which was originally meant to be about low cost housing.”*

Furthermore, the increasing predominance of people with high support and disability related need within the social housing sector has placed an additional skill and management burden on housing providers as the following excerpt illustrates.

“complex specialised need provision has placed a number of additional pressures on the system (i.e. having to understand disability, mental health, drugs etc).” and *“Housing is a large scale operation which can’t intensively assess everybody’s need. Therefore [we] require triggers to prompt further investigation, ... [however, this requires] client consent.”*

Moreover, the increasing numbers of older disabled persons living alone has led to State Housing Authorities having to readjust housing stock in response, further reducing the availability and choice of available housing stock. Overloaded public housing authorities are thus increasingly looking to community housing associations to create more affordable housing options for private renters. Informants in particular expressed concern that this trend was increasing and would become a major issue.

“Availability of low cost housing will become a major issue. There is a huge waiting list (especially in cities) for affordable accommodation near employment opportunities.”

Furthermore, there was considerable concern expressed about the process of obtaining and maintaining adequate support for those persons either on public housing waiting lists or already in public housings as the following excerpts illustrate.

“The future requires integration of support for high care and housing with public housing and community choice. For instance, creating a segregated waiting list for public housing priority for people with disabilities if they have an appropriate care package.” and “Giving people housing choices is tied to department of housing policy, which won’t allocate accommodation without support systems in place. Thus some people are not identifying as having support needs which leads to eviction when tenancy arrangements break down.”

Lastly, there were comments from some housing informants about the importance of maintaining a bigger picture view. Firstly, reliance on the CSHA varies significantly across States with small states such as Tasmania who have had less of a State commitment to social housing being particularly vulnerable. However, there are substantial variances between States regarding their reliance on the Commonwealth and State Housing Agreement for social housing resources. For instance, informants indicated that historically the Ministry of Housing WA has always raised its own funds and the CSHA has only contributed 11% of the money to their budget. Secondly, bigger picture means thinking beyond the overall proportion of monies going to social housing via the CSHA, because as the following excerpt illustrates the goal for people with disabilities has to be much broader than social housing alone.

“Social housing represents a small sector 10% at most, probably some improvements that can be made in terms of response to people with disabilities but other issues concern balance and other types of housing i.e. home ownership (70%) ought to be on the agenda”

4.3 Disability Agreements

The history of the Commonwealth State Disability Agreement has evolved around intellectual disability and institutionalisation. Consequently, both the agreement and it’s focus reflect this history. The CSDA provides a tool to ensure that all State based legislation compliments the Commonwealth Disability Services Act. As one informant involved in Commonwealth/State negotiations pointed out, the CSDA is intended to be very general and is more a tool to encourage collaboration than a means of prescribing outcomes.

“The CSDA is a very general agreement, it is not descriptive because of historical problems in the past. As a spin off there has been collaboration by working together in the past bilaterally. The CSDA funding agreement grew out of the need to rationalize and bond respectively”

Informants considered the role and performance of disability and housing agreements equally significant. Nevertheless, some States appear to view accommodation as the most crucial whilst others appear to view support as being of a higher priority. A few informants were also quick to point out that in some States the CSDA has not been the sole source of funding for State based disability services.

“[In Tasmania] \$46 million to disability is provided over and above the monies available under the CSDA”

This is of interest if we reflect back to similar comments in the previous section about the CSHA. Furthermore, it implies that historically differences between States reflect a difference in how disability and accommodation support are balanced.

Additionally, the actual focus of the CSDA, concerned a number of the informants. The CSDA was perceived to be particularly limited, inflexible and exclusive of particular disability groups.

“The CSDA needs to be more flexible around both housing and employment...[For instance], care funding [needs to be] linked to the individual not to the care program.” and “A significant problem in accessing services and in reducing flexibility is the prevailing view that disability and ageing are exclusive... For example, the ACAT program is restricted to older people and people with disabilities are ineligible. Packages need to be designed irrespective of age.”

Overall the CSDA was generally compared unfavourably with other Commonwealth disability initiatives like the Home and Community Care Program, which were perceived to be considerably more flexible.

"The CSDA's over expenditure on housing because of group homes divorces people from their families and informal supports altogether but HACC monies assist informal care providers." and "HACC provides a level of choice that allows for increased flexibility at the local level."

4.4 Community Care

Informant's discussion around community care centred on both general issues such as having an inclusive and welcoming community and the type and flexibility of support services available. As a counterpoint to the social isolation identified as problematic for many adults with disabilities particularly those living alone or living some distance from informal care, informants raised issues related to developing and maintaining inclusive communities. Informants singled out lack of community education and planning as a significant issue in terms of developing and maintaining infrastructure. The fact that despite legislative changes much of the shopping and transport services available across Australia remain non-inclusive presents significant barriers to 'ageing in place' and the notion of normalisation that underpins 'deinstitutionalisation'.

"buses are too fast, there are no seats in shops, older people can't get things delivered etc." and "implementation of accessible transport has to be a significant part of the future thing in planning for housing... For instance, siting adaptable/accessible housing 4-5 kilometres from a regional centre is not OK...[we need better ways of] looking at concentrations of housing for older people."

Another important sub theme was insufficient early intervention and monitoring services for informal carers.

"[We] Need earlier support and intervention for informal carers within communities at community health and local council levels."

Another significant theme was the unpacking of assumptions that predicated the design of housing and care packaging. In securing supportive environments for people to live, a number of informants stated that assessment of informal and formal care support prior to examination of accommodation solutions was a prerequisite for continuation of community living.

"This means they require appropriate personal support then housing" and "those with appropriate support should be able to choose accommodation based on a secure personal support package"

Issues with community-based assessment and reassessment continue to be critical issues. Currently across most States in Australia assessment practices tend to focus on the person with a disability and fail to adequately harness or prioritise information required for establishing and maintaining partnership with those providing informal care. Additionally, the current system has multiple entry points and inconsistencies in data gathering and prioritisation with the majority of services currently prioritising those in crisis rather than being resourced sufficiently to prevent this occurring.

"What we haven't yet come to terms with is a community based, individual response that is collaborative." and "There is a need to look at preventative measures. For instance, in the past we haven't been very good at looking at the son/daughter in early teenage/adult years where parents have money to purchase a home. In past this couldn't be done because of issues related to queue jumping etc. But if parents say they can't cope then crisis accommodation must be found."

Existing, community care services that were singled out by informants included 'Home and Community Care (HACC) and Homecare support services. In general, Home Care services were considered central to enabling community living for adults with disabilities. However, some services were perceived of as either currently inequitable or insufficient. For instance, one informant stressed the need to increase the resources to enable more comprehensive home modification services.

The lack of flexibility and comprehensiveness of community-based services continues to be a problem for many Australian States. However, the following excerpt highlights how some states like NSW have moved decisively over the last couple of years to close this gap and improve portability and equity of support services.

"NSW is unique in that Homecare is provided comprehensively across the State...Over the last couple of years Homecare has created a high needs virtual pool, which has facilitated greater service portability (i.e. head office approval is not required if relocating to an area with a different branch office. Thus it is now easier to relocate than it was 5 years ago."

4.4.1 Economics of care

One of the most significant emergent themes was the underlying issue of the economics of care. Despite much of the rhetoric surrounding policy trends such as 'ageing in place' and 'deinstitutionalisation' providing formal individualised care and accommodation support services is a costly business. Thus, there appears to be a strong perception amongst informants that the available resources are inadequate and consequently a climate of rationing exists. This insufficiency appears to be most acute around salaries and capital expenditure. Thus, it is not surprising that concern was raised around the issue of staff salaries, as these represent the largest recurrent cost for any service organization. That this is already a major concern is illustrated in the following excerpt.

"Because of tight funding constraints the disability organizations are insufficiently resourced to provide individualised care." and "To what level do we support the individual with behavioural problems. For instance it may cost \$190,000 to support one individual versus a group home which supports five for \$43,000 annually."

Additionally, the pressure to increase remuneration in accord with more professional qualifications has become a significant issue for a number of support agencies.

"[An] insufficient level of remuneration raises issues around retention of staff." and "The increasing professionalisation of staff means increasing costs."

Of particular concern from a service provider viewpoint is a funding allocation system that enables purchase of capital equipment but fails to factor in upkeep and maintenance.

"[There are] no funds for turnover of cars or buses, as a result the equipment supplied on establishment of [accommodation] facilities is ageing and there is no funding allocated to update or maintain this type of infrastructure."

Nevertheless, as one informant pointed out the amount of money invested in capital infrastructure such as housing, represents a considerable part of many State departmental budgets. In this sense, the economics of care issue means that cost efficiencies are most achievable when utilising individuals personal resources or capitalising on existing public housing and transport infrastructures.

"funding directed towards housing and support is quite significant as it represents 40% of expenditure and sometimes only targets 5% of clientele...People want to contribute to their own care but we haven't [yet] set up systems to support this. This has contributed to the increasing burden placed on the present system."

Lastly, comment was made on the failure of philanthropy to adequately supplement the formal housing and care system. This is particularly problematic for smaller states like Tasmania as the following excerpt illustrates.

"Private sector involvement in housing and support for people with disabilities has been zilch...For instance, the multiple sclerosis association ran a raffle in Tasmania for a car and were unable to even cover the costs of the raffle."

4.5 Residential Care

Most of the informants in the phase one sample believed in community service provision, which implies that although residential care was not top on the list for government action that action was needed. It was the clear view of all informants that raised it as a theme for potential action that residential care was the place of last resort for those who were unable to obtain the level of support and accommodation they required elsewhere. Concern was particularly acute for younger people with disabilities who ended up in residential care, in part, because they are more visible. As the following excerpt illustrates whilst the Commonwealth covers accommodation and care costs for those in residential care, younger persons with disabilities are excluded from additional funding under disability services and so in effect are disadvantaged.

"[NCOSS] found that while nursing homes receive Commonwealth funding, they were not specifically covered under disability legislation for services to young people with disabilities."

Consequently, there were three key themes within this section. Firstly, there were a number of comments about the role of Aged Care Assessment Teams (ACAT's). Comments about ACAT services centred on lack of training, insufficient knowledge of disability support options and in their perceived willingness to admit people with high care needs to residential care.

"ACAT teams are remarkably good at assessing people and then placing them into nursing homes. For instance, people with disabilities with high physical support needs or dementia."

Secondly, informants commented on the potential for the redirection of Aged Care funding to maintain people with high support needs within their local communities. Redirection of Aged Care Packages remains a viable alternative to nursing home admission.

"Nursing Home funding can be converted to Aged Care Package, which means a disability provider, can get accreditation under the Aged Care Act." and "[The Stanton report recommended devolution of] beds out of aged care facilities"

Thirdly, there were concerns raised about residential care standards and safeguards. Given the fact that those most likely to be admitted to residential care are those with the highest support needs such as those with dementia, the vulnerability of this population raised concern about the current insufficiency of safeguards. Furthermore, the notion of private for profit services being able to ensure high quality services was questioned.

"[There have been] several deaths in government accommodation. This has raised a number of issues ... [related to] Amount of staff and adequacy of staff/client ratios, staff training, staff support..[and the] need for quality controls in the system" and "Nursing homes and hostels are run by private industry for profit and there are insufficient safeguards."

4.6 Building and Land Regulation

Building and land regulation issues were singled out as the most commented on potential action area. This is not surprising given the 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. Informants raised issues surrounding planning processes, lack of an agreed universal design footprint and failure to impact on home purchases and the private rental market as amongst the most significant issues.

Firstly, a number of informants believed that urban planning outcomes were consistently poor for people with disabilities. Consideration of the needs of people with disabilities appears to be either lacking or ad hoc in approach. Consequently, a number of informants believed that additional incentives such as tax breaks; changes to housing awards and targeted funding injections were required to lift the game nationally as the following excerpts illustrate.

“Don’t plan well enough to provide adequate access for people with disabilities. So funding and awards being used to encourage the provision of better access” and “Housing award competitions must develop a category for adaptable design. Even if not the whole house, elements of the house could be a part of the award process. For instance accessible door handles or door openers.”

Secondly, in all Australian States, three levels of government are involved in planning and this in itself presents barriers to appropriate distribution, design and regulation of residential housing suitable for people with disabilities. A number of informants commented on residential zoning barriers, which effectively discriminate against community accommodation for people with disabilities. The interpretation of zoning regulations also influences the concentration of housing within geographic areas as the following excerpt illustrates.

“Some councils are easier to work with than others and this leads to greater number of houses in certain localities...Rezoning to allow housing for people with disabilities is needed” and “Land regulation is a real issue. For instance zoning and segregation of land disempower communities.”

Thirdly, contributory factors to poor planning outcomes were identified as failure to coordinate affordable, adaptable and energy efficient design principles with the result that tensions exist between often competing agendas. Additionally, poor coordination is compounded by lack of any credible Australian research into the anthropometrics of disability.

“There needs to be a universal design footprint for unit development that increases the proportion of accessible/adaptable units within multistorey developments. This is critical as 30% or more construction will fall into this category over the next few years.”

Lastly, a number of informants believed that both State and Commonwealth levels of government needed to move towards enacting additional legislation in order to facilitate the development of adaptable housing in Australia. This is particularly critical in terms of ensuring a range of accommodation options from home purchase through to enabling rental from within the community housing and private sector markets. The following excerpts highlight the importance of legislative reform in this area.

“[There is a need to] Create adaptable housing requirements within the private sector” and “The way to move forward at a higher level is to legislate for visitability and universal design.”

Another critical sub theme was the need to inform both the public and building and construction professionals of adaptable and cost effective design possibilities. Informants indicated gaps were evident in both knowledge and practice. A sample of some informant’s comments relevant to this theme follows.

“We need project homes that demonstrate adaptability i.e. the ‘Masterton ranch house’ in adaptable form and then we need to look at the cost differentials. ” and “a lot of money could be saved if housing providers used better construction techniques. For example when hallways are constructed if they are widened to 1400 mm then 400-600 mm could be used for prefabricated storage/cupboard space.”

Whilst most of the comments from informants centred on the need to improve residential design and planning, some informants were also concerned about the design of residential and age related congregate infrastructures. Indeed, the more adaptable and accessible the newer residential facilities are, the better placed they will be to respond to changing needs in the future.

“with accreditation and building of intermix facilities (Nursing home and hostel) there has been a change in standards and we still need to pick up adaptable housing principles for retirement villages.”

4.6.1 Multifactorial approach

A number of informants stated that because of the inherent complexities in housing and care provision for adults with disabilities that a focus on any one government action area was bound to fail. Instead, the common theme here was the need for a multifactorial integrated and individualised whole of government approach.

“I don’t know that it can be said that one is more important than the other, instead an integrated approach is needed.” and “[What is required is] Increased individualised and personalized support, stable accommodation and community integration. Can’t separate them out.”

4.7 Tensions between different players viewpoints

Commonwealth players identified the potential of the community-housing sector as a more locally responsive and flexible alternative to public housing. Thus, it follows that the current trend towards building the community-housing sector up to increase its future viability will likely continue.

"The community housing area still exists as undeveloped potential and we are assuming that a lot more could be made of this model in the future."

However, consumer informants in particular expressed concern about increasing reliance on the community-housing sector as a public housing alternative because they perceived there to be poor lines of accountability, lack of standards and procedures and a shift of resources away from public housing.

"[There is a] sort of competition between public housing and community housing...The competition is a furphy because both are publicly funded...when [the Commonwealth] favours community housing to house homeless, single parents and people with disabilities it is in effect, undercutting tenants rights...There is a whole dynamic of devolving responsibility to someone else with taxpayers money."

Another theme with inherent tensions concerns the partitioning of disability and aged services, both of which construe a narrow specialist focus. Lastly, tensions surround the balancing of ideological approaches to services. For instance, some informants believe that services should be mainstream, whereas others advocate for specialist services. A middle position might mean a commitment to positive discrimination for people with disabilities within mainstream services. The following excerpt illustrates this approach as a potential solution.

"there is a clamour of different need, so still need disability policy areas as advocates to impact and modify broad stream broad brush policy"

CHAPTER 5: CURRENT HOUSING MODELS

5.0 Introduction

A critical research question developed and outlined in our Positioning Paper was the understanding within the past decade, of what strategies had been trialed in Australia for enabling a secure home for adults with disabilities and for ensuring that support for community participation was provided. The models identified from the transcripts can be grouped according to their implicit but predominate orientation into four sub-groupings as follows:

- Formal Care Enabling
- Non Government Sector Care Enabling
- Informal Care Enabling
- Care Minimisation Enabling

The development of various packaging of housing and support depends on what perspective predominates. In this sense, the perspective reflects policy directions and initiator and funder perspectives. Greater detail about the models and their perceived effectiveness follows.

5.1 Formal Care Dominant models

5.1.1 Group homes

Group homes are clearly the predominate housing option for younger adults with disabilities who are unable to be cared for within the family home. This form of accommodation typically involves purchase or construction of a six-bed domestic home designed to accommodate 4-5 residents with a live in carer. It has been the norm for people with disabilities being deinstitutionalised of both older and younger years (Intellectual Disability Services, 1995; McGuire, 1991). The reason the group home model has been so popular as the following excerpt illustrates is its relative cost effectiveness in combination with its efficiency in enabling relatively rapid relocation from larger institutional care.

"The reason we have gone down the group home model is primarily because it is reasonably cost effective and quickly eliminates waiting list. i.e., if everyone wanted to live alone the system would be unable to sustain this."

However, in a primarily post-deinstitutional environment matching and selecting compatible people with similar support needs can be difficult. Whilst the smaller size facilitates personalisation, the inflexibility of the accommodation and support packaging makes this unsuitable for some. The following excerpt highlights these tensions.

"A group home environment gets adapted to an individual but if an individual leaves [the same level of] support might not follow. The advantage is security or a housing and care package guarantee."

5.1.2 Cluster housing

Some States such as Victoria, Queensland and NSW are moving towards clustering group homes to better achieve economies in care, whilst retaining a local community focus. In this model, 30-40 adults may be accommodated. This model appears to work best for those with similar age and or disability requirements. The preference for this type of accommodation by some disability groups is highlighted in the excerpt below.

"... [we have been] approached by particular disability groups (i.e. deaf/blind) requesting that they be housed together in a congregate bed-sitter facility because of communication difficulties with the rest of the community. This opens up opportunities but also opens up a can of worms with the Disability Services Act, which is about rights etc. However this model has been successful overseas i.e. in Canada." and "A subset program is an independent living program for people with mental health. People who can live independently with some support are now moving to small group homes and clustered housing."

This model has been particularly successful in other OECD countries like Canada in the bigger cities such as Toronto (McCrudden, 1998).

5.1.3 Secure accommodation units

Given that challenging behaviours are so costly to manage in the community, it is not surprising that a recent trend has been towards the construction of specially designed and staffed secure accommodation units for those individuals who are at risk of harming themselves or others. Unfortunately this type of unit is all too often located either within a criminal or a medical facility i.e. prison or hospital. Neither of which are primarily intended for habilitation or permanence. So, this trend presents particular issues around life skills training and 'ageing in place'. This trend is illustrated in the following excerpt.

"An alternative to aged care beds in terms of secure accommodation is the (18 bed) secure accommodation facility provided by the criminal justice system."

5.2 Non Government Sector Care Enabling Models

5.2.1 Boarding/rooming and private hotel type accommodation

A large number of people with disabilities particularly those with mental health, intellectual disability and alcoholics tend to reside in rooming houses, boarding houses and private hotels. Whilst there is some consensus that because of the economics of care, shared facilities and shared options need further exploration, the boarding house market segment is currently not well addressed. Boarding houses were predominantly private sector supplied and run but this has had a bad history. Complaints from consumers, services and other key stakeholders across a number of States (Tait, 2001) have led to many States currently reviewing or having reviewed this form of accommodation with the view to reaccommodating those most in need of support elsewhere. The following excerpt highlights some of the issues inherent in managing this type of accommodation profitably.

"Boarding houses have gone out of business because of the expense of retro fitting for fire ramps. ...because provider agencies are dealing with properties that are ageing, the expenses involved make it unprofitable to continue to operate and maintain property appropriately."

Despite the notion of break even or profit making driven accommodation having a poor reputation, there are instances of innovative and successful implementations. Sharing of communal facilities and close proximity of peers and carers can be effective in both facilitating care support and in restraining costs.

"The 'Winteringham' model in Victoria appears to be quite good, it provides secure accommodation and support in the context of controlled drinking."

5.2.2 Singletons accommodation

Another model that is more innovative in terms of partnerships with non government providers that was highlighted by an informant was the 'Singletons' housing model, which appears to have been quite successful in Victoria. The Singletons community accommodation model provides clustered single apartments dwellings that enable sharing of communal facilities and care. Nevertheless, the following excerpt illustrates some of the unanticipated public cost burden involved.

"Particularly difficult to get complex care needs adequately met by the private sector. For instance, 'Singletons' housing provides [the accommodation] component but the department had to put in fire safety. To access these accommodations [clients] have had to buy an interest in the company."

5.2.3 Aged Care units

Units that are age specifically targeted 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 an onus of responsibility off family whilst retaining a level of independence of the older persons themselves. However, unit design rarely caters for functional decrement and the standard inclusion of steps, hobs in conjunction with insufficient storage and circulation space can force those residents with balance, reach and sensory problems or who require assistive devices to have to relocate to higher level care facilities.

"Units [are constructed especially] for older people but these are not suitable for wheelchair or frames"

5.3 Informal Care Dominant Models

5.3.1 The supported living model

The supported living model appears to have developed in Western Australia, where it was supported by a grant from the lotteries association. This model enables families to form a company to receive money directly to provide care for their sons and daughters. The model appears to provide a considerable degree of flexibility and control to families in the running and maintenance of supported accommodation and so is very popular with carers. Whilst this sort of approach is not popular with the Unions, presumably because it potentially impacts employment opportunities and worker entitlements it might also have potential for being widened out to include retirement housing for people with disability. The following excerpt illustrates the key ideas inherent within the supported living model.

"[There are] Two models that are similar, one is more in house and the other is setup like a large residential place, i.e., parents are directors and employ staff." and "The families determined arrangements, roster, backup care, training, and wills"

Similar models have also been implemented in NSW and Tasmania where disability services have privately funded groups of families to house their sons and daughters. The primary difference between these implementations and the original model as developed in Western Australia is the requirement that a lawyer or accountant be included in the financial management. This is an important difference because although a variant on this model appears to be particularly useful in rural and regional areas where other options are limited it is potentially open to financial abuse. The following excerpts illustrate the basic concept behind the Western Australian implementation.

" In this model, Homes West provided the housing for groups of 5 people, parents and a lawyer/accountant actually run the housing. Parents can hire and fire staff and having an account/lawyer as part of the group avoids problems with budgets."

5.3.2 Local Area Coordination

Local Area Coordination (LAC) programs were piloted and developed in Western Australia where they have been so successful they are now being implemented in other OECD countries and in other Australian States. The LAC program provides a bridge between families and assists them to 'age in place' by coordinating support and information services at a grassroots level.

"The Local Area Coordination program in WA is an effective means of better targeting this issue."

5.3.3 Community Disability Housing Program

The Community Disability Housing Program is another newer and more innovative initiative, which involves partnerships between local community auspices, disability and housing support. It has many of the advantages of the supported accommodation model but is less flexible in operation and provides families with less direct control of household running. The following excerpt illustrates the basic principles.

“Community Disability Housing Program this is where a community agency leases houses and applies to the disability services commission for support, for particular individuals, then the Ministry of Housing provides the house.”

5.4 Care Minimisation Enabling Housing Models

5.4.1 Singles Units

There is an increasing push towards one home per person and singles units, which have a bedroom, bathroom and kitchenette are increasingly popular as the following excerpt illustrates.

“Part of the push is towards single units”

Singles units cater well for the increasing numbers of younger and older people with disabilities who lives alone. This model potentially has the advantage of reducing the need for housework and property maintenance services for owners whilst preserving privacy and independence. However the effectiveness of this model depends on design and construction techniques that maximise accessibility and facilitate community inclusion.

5.4.2 Adaptable homes

Adaptable homes are a form of private dwelling that can be constructed in the form of a house, unit, flat, townhouse or villa. They can be rented or purchased and are intended to grow or change as the occupants needs change. For instance, the Adaptable Housing Standard (AS4299) was written to provide guidelines for adaptable construction. Key principles of adaptable design are level entry, accessible sanitary facilities, wider corridors and hob free showers (Standards Australia, 1995). Adaptable housing as a concept has been advocated widely both here in Australia and overseas (Frain, 1996; Kahler, 1998; Alzheimer’s Association Australia, 2000; Hill PDA, 1999). However, whilst public housing has moved to incorporate adaptable principles into new construction the private sector has been slow to take this up. The following excerpt illustrates the key ideas.

“when a house is built it should be accessible to people of all ages. This means user-friendly living space, not just for people with disabilities but for kids.”

5.5 Conclusions

None of the housing and support models overviewed are mutually exclusive but given the long to medium term trends identified in chapter three, it would appear that those models which are the most enabling of informal supports and which work to reduce the experience of disability by good design will prove to be the most desirable and cost effective.

It is also clear that the housing and support models so far explored within the private sector in Australia have consistently failed to incorporate adequate fire protection, circulation space, no step entries and accessible bath and kitchen facilities without governmental subsidy. Given the emphasis on government action highlighted in chapter four, it would appear to be vastly more cost effective in the longer term to move some of the more universally applicable provisions into the mainstream by regulation or legislation. Whilst encouraging the incorporation of more specialised and individualised design features in purpose built housing (i.e. cluster housing or aged care units) by providing special tax incentives or rebates.

CHAPTER 6: IMPLICATIONS FOR POLICY

6.0 Introduction

This final chapter attempts to explore some of the policy implications arising out of the research findings previously presented. The strength of these findings is the national overview of the policy and legislative framework provided. After reviewing the policy framework, this chapter addresses the three key research questions outlined in chapter 1 and in our Positioning Paper.

These are:

- Housing circumstances and service use amongst older and younger adults with disabilities;
- Viewpoints of policymakers and service providers; and
- Australian housing and care 'packages'.

The chapter concludes with a summary statement on future directions.

6.1 Policy Framework

The complexity of disability, ageing, health, housing and care programs means that funding and management is divided between Commonwealth and State/Territory levels. The devolvement of program responsibility to non-government and private sector organisations further complicates matters (Kalish, 2000). The division of responsibilities, and the piecemeal and historical base for them, underscores the need to consider their joint impact on individuals whose complex needs may require provision across a number of service areas. A number of policy reviews, such as the recent National Strategy for an Ageing Australia (Bishop, 2000), have presented the case for more comprehensive and strategic development of policies and programs. However, the division of management and funding responsibilities, together with a narrow focus on accountability for outputs and costs within each of the program areas does not provide a sound base for provision of integrated accommodation and care.

All States/Territories have their own Acts and legislative frameworks that have major impacts on people with disabilities. Many State and Territory governments are trying to fill perceived gaps in national legislation and programs. Crucial areas of state action include disability rights legislation and policy frameworks, property-related tenancy and other Consumer Protection legislation aimed at private dwellings and cared accommodation policies (including regulation of retirement villages). Most states are aiming to overcome some of the policy divides across housing, care, and ageing/disability areas by establishing larger operational departments with a wider range of responsibilities.

A number of policy and service documents, reviewed in our Positioning Paper, provide critical comment on the difficulties of existing 'systems'. An example of these difficulties is provided in the case of Commonwealth-State contests in the area of community care (Burbidge, 1996). On the one hand, the Commonwealth's responsibility for residential care services for older persons provides an incentive to cap these costs and divert people in need to community care. On the other hand, State/Territories' responsibility for hospital care provides an equally strong financial imperative to discharge people early to their homes and care from community services.

6.2 Housing circumstances, needs and service use

The 1998 DACS provides a valuable population perspective on the circumstances of people including those who are not directly known to service systems. Chapter 2 in this report and the Work in Progress Report provide a full account of the findings. In this section, we consider some of the policy implications of the population findings.

The fact that fully two-thirds of persons with at least moderate levels of disability reside in some form of cared accommodation implies that the primary government policy response remains support of the Residential Care industry. There is of course, far more Commonwealth funding available for residential care for older people than there is State funding for cared accommodation for younger people. Consequently, some younger people with high needs may find it difficult to access residential care while older people with similar needs may find it difficult to avoid entry to residential care.

People in the community with at least moderate disabilities are nearly equally divided between those in the younger and older age groups indicating that policies concerning equity of access to community based services need to be addressed. Three quarters of persons with significant disabilities living in the community receive informal support, reinforcing the significance of policies related to maintaining and enabling continuance of informal care.

One in ten community-based respondents indicated that housework needs were unmet implying that, this type of service should be a higher priority for Homecare. Additionally substantial levels of unmet need for property maintenance and transport services imply that neither of these receives sufficient attention in either Commonwealth or State policies. People who live alone and non-homeowners are especially likely to report having unmet needs, suggesting that they are important priority groups for service delivery.

Furthermore, half of the respondents indicated needs in more than three areas whilst a quarter had needs in more than five areas. Multiple need underscores the inter-related nature and indicates that improved coordination and integration across services is critical. However, the scope for 'user pays' approaches to services remains limited for both age groups, particularly as strong financial incentives to enter residential care exist. Overall, the findings suggest that policies need to be flexible enough to meet high levels of needs among adults in a wide variety of economic, personal and housing circumstances.

Multivariate statistics also suggest specific ways in which policies can improve targeting of services to expressed need:

- Homeowners generally are older, living in a house, living with others, employed, and have only a moderate and/or physical disability. This suggests that the most advantaged housing tenure is largely available to those who have relatively more advantage in other aspects of their lives.
- Public tenants are more likely to be young, living alone, on low incomes, and unemployed. This finding suggests considerable effectiveness in directing these public resources to those who have higher levels of need.
- The most significant factors in having some unmet needs are living alone, having more disability, being younger, being female, and not being employed. In other words, each of these characteristics can be considered as a risk factor that needs to be addressed in improving the targeting of formal services.
- Predictors of needs for self-care are living alone and having a greater degree of disability.
- Predictors of needs for transport assistance are being older, living alone, not being employed, and having a greater degree of disability.

- Predictors of needs for property maintenance are disability severity (particularly of a physical nature), living in a house, and being a homeowner.
- Predictors of needs for housework are disability severity, physical disability, being unemployed, and being older and/or female.
- Finally, any use of formal services was best predicted by living alone, being male, older, and on a higher income, with the latter probably indicating a greater capacity to buy private for profit services. Public and private tenants do not appear to have differential access to various forms of services.

6.3 Policy implications of interview findings

The analysis of key informants' perspectives provides a sound basis to assess priorities for whole-of-government actions across levels of government and policy areas. As detailed earlier in the report, the policy interviews yielded views in terms of both middle terms trends and specific policy actions. These views are particularly significant given that 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 providing institutional care has been estimated to be \$30,000 annually for each nursing home bed provided (Australian Institute of Health and Welfare (AIHW), 1999b).

6.3.1 Middle to longer term trends

Over recent years there has been a significant shift in community expectations about the creation of more equal opportunities. Non-discriminatory access to housing and care services has increased the pressure on Australian governments to implement a restructured human service delivery 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 with good quality of life as an alternative to institutional care but this adds to the demand on already strained public resources.

The trend towards '*deinstitutionalisation*' and '*ageing in place*' demonstrates that community care is becoming the primary and preferred context of care for younger and older people with disabilities. They also raise a number of particular tensions between viewpoints where ideologies or accepted cultural practice clash. For instance, the desire of people to remain in a familiar environment impacts on both younger people with disabilities who do not want '*deinstitutionalisation*' and older people with disabilities who seek to remain in the community despite high support needs. Some informants commented on the desires expressed by those living in institutions to remain there but this view of '*ageing in place*' contrasts quite strongly with the view that transitions are 'normal' and inevitable for older persons with high care needs.

The trend towards '*deinstitutionalisation*', raises a number of consequences that require attention. Notable among these are:

- A lack of sufficient resources following moves of people from institutions to the community, shifting costs on to the community and public housing sectors.
- A shortage of community housing and over-reliance on a single model of care, namely the 'Community Residential Units' (CRU's) that can be 'mini' institutions. The result can be limited access to the community inclusiveness that is central the rights promulgated by the Disability Services Act.
- State-based agreements across departments of health, disability, housing, and care are needed to facilitate integration of service delivery.

The trend towards '*ageing in place*' is seen as closely accompanying the massive population ageing anticipated as the baby boom cohort reaches old age over the next two decades. Over the next decade, the growth in the numbers of people with disabilities is anticipated to be overwhelmingly in the 50 to 64 year age group (Australian Institute of Health and Welfare, 2000). This is partly due to acquired disabilities with the ageing of the baby boom but also due to the increased survival of younger people with disabilities. This changing demographic pattern is already challenging assumptions as to younger people with disabilities having notably different needs from their older counterparts and increases the case for more integrated treatment of people with disabilities irrespective of age.

A number of additional issues arise from '*ageing in place*' including:

- Changed care arrangements as younger people with disabilities reach retirement age and require more resources and different mixes of services.
- The inappropriateness of much of the existing private stock of residential housing given that their residents will grow older and their chance of having a disabilities will increase.
- The wide variation of needs within the population of people with disabilities due to specific main conditions such as Acquired Brain Injury Syndrome.

'*Deinstitutionalisation*' and '*ageing in place*' are virtually impossible without major contributions by informal carers. Overall, it does not appear that the availability of carers will be decreasing over the coming decade, notwithstanding the demands of providing this assistance (ibid, 2000). While support for carers has increased considerably over recent years, there is a strong perception that carer support is relatively uncoordinated, fragmented, and difficult to access.

Particular concerns raised by the interviewees about carers included:

- The need for security among caregivers and information important for long term planning.
- Carers and community workers require training, to better manage behavioural problems and to prevent occupational health and safety problems.
- Aids and assistive devices need to be provided for carers as well as for people with disabilities.
- The heavy financial costs of caregiving, both directly and in lost earnings, including restrictions on carers pensions.
- Concerns related to guardianship and issues when carers and clients views and interests may diverge.

The expectations of people with disabilities are rising and there is an increasing consumer rights focus. The rights focus now enshrined in disability legislation is increasingly found among older as well as younger people. However, the rhetoric of legislation is not yet matched by the treatment accorded to people with disabilities by staff in many services. Tenancy legislation is raising new issues concerning the rights of people with disability to not accept recommended services and the rights of neighbours or landlords to complain about people with *behavioural* or other difficulties that can reduce amenities.

The last of the major trends addressed by the policymakers concerned increasing contention in terms of 'who pays' for accommodation and services. At one level there is the expected continuation of trends towards reduced government contributions and increased devolution of cost responsibility through user charges. There also is widespread concern that government funding for housing has been falling disproportionately and that people with disabilities have decreasing access to home purchase. Ways need to be found for services to have joint responsibility, for example for people with mental health difficulties in public housing, rather than for services to shift costs onto each other.

6.3.2 Government Action Areas

Income support influences activity and participation levels of people with disabilities and influences their capacities to purchase accommodation and services. Specific concerns of the interviewees included the following income-related issues:

- The high proportions of income paid by people with disabilities especially for supported accommodation (up to 80 percent) and private rentals; the need for higher rent assistance; and the benefits of capping rents in public housing at 25 percent of income nationwide.
- The low levels of disability pensions thus limiting capacities to buy services, and the increased benefits recently provided to older people but not to younger people on disability pensions.
- The need for social security reform such as the provision of supplementary payments in recognition of the higher costs of living for people with disabilities as was previously recommended within the McLure (2000) report.

The Commonwealth State Housing Agreement attracted extensive discussion whilst having broad support for continuance. Public housing is coping with increasing numbers of older disabled persons living alone 30 percent (Bishop, 2000a) whilst up to 40 percent of all public tenants are now identified as having a disability (Australian Institute of Health and Welfare, 1999). Additional concerns arise given the high proportions of residents who have mental health difficulties. The downscaling of government investment in public housing is viewed as a serious concern because it leads to less accommodation for vulnerable people and leads to their increasing social segregation from the mainstream.

Overloaded public housing authorities are increasingly looking to community housing associations to create more affordable housing options for private renters. Commonwealth players view the community-housing sector as more locally responsive and flexible alternative to public housing. Thus, it follows that the trend towards building this area up to increase its viability will continue.

However, consumers are concerned about poor lines of accountability, lack of standards and procedures, and they see a shift in focus away from public housing.

Coordinating linkages between public housing and between various community and health services is seen as a major problem. More formalised agreements could assist in reaching common understandings of the principles of 'social housing' by better defining concepts such as independence, social success, community living, and related concepts.

A number of concerns arise concerning the partitioning and ideologies inherent in disability and aged care services, both of which can construe a narrow specialist focus. For instance, some informants believed that services should be mainstream, whereas others advocated instead for specialist services. A middle position is a commitment to positive discrimination for people with disabilities within mainstream services.

Widespread support exists for the principles of the Commonwealth State Disability Act (CSDA) particularly for its rights emphases. However, some viewed the CSDA as placing too much emphasis on group homes and leaving major gaps through not covering children's or mental health services. It was noted that the CSDA and the Commonwealth State Housing Agreement operate under different principles and financial relationships that are not always complementary. The CSDA has greatest value when health, housing, and care agencies delineate and coordinate key roles and responsibilities and set consistent priorities.

The Home and Community Care (HACC) program is viewed as a major landmark providing the opportunity for a locally based more flexible community care delivery system. Whilst the HACC program has had funding increases (Australian Institute of

Health and Welfare (AIHW), 1999a), services are still below what consumers are demanding. Consequently, a reform framework for the HACC sector is being undertaken to enhance integration and reduce duplication whilst introducing economies of scale. New HACC agreements reflect a move towards a more contestable environment. For instance, the new funding arrangements enable purchase outside the traditional community sector agencies (Bishop, 2000a).

Commonwealth and State governments have recognised to some extent, 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).

Additional issues arose in the policy interviews concerning the following aspects of HACC:

- The importance of capacity building, for example, in generating priority services hitherto unavailable.
- The high value placed on the flexibility of HACC funding compared to CSDA funds.
- The need for more individualised responses and preventative measures where possible.
- Property maintenance and home modification assistance currently available for adults with disabilities is insufficient to meet demand.
- Transportation infrastructure needs to be improved including replacement funding for buses and cars as necessary.

The Commonwealth Department of Health and Aged Care has primary responsibility for funding and monitoring residential care for older people. Recent restructuring has resulted in community and private sector organizations 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 (AIHW), 1999b). The previous distinction between nursing homes and hostels created a dual system that did not recognise that many clients progress through a continuum of care needs. However, in an 'intermix' model with no identifiable 'nursing home' or 'hostel', consumer representatives are concerned that the conglomeration of older people at various levels and kinds of frailty in the same facility may impact adversely on the lifestyle of other residents and compromise the desired 'home-like environment'.

Specific issues raised in the policy interviews included the following:

- Problems of younger people with disabilities entering inappropriate aged care accommodation due to a lack of alternatives.
- Lack of appropriate community based assessment and rehabilitation services for younger people with disabilities.
- The potential benefits for younger people with disabilities, of converting a greater number of residential care places into community care packages.

Building and land regulations can ensure that new residential and commercial buildings provide supportive environments that facilitate independence for all Australians throughout their life course. The ability of future cohorts to '*age in place*' also relies on housing design and construction that can be adapted to better support the occupant (Bishop, 2000a). Legislation relevant to housing construction includes the Disability Discrimination Act (DDA), the Building Code of Australia (BCA) and relevant Australian Standards. However, there is no national framework for

regulating the implementation of adaptable housing standards for new building construction. While the Australian Urban and Regional Development Review identified principles of accessible design and Standards Australia produces standards to create a framework for better designs, neither are implemented in other than an ad hoc and piecemeal manner without political will. (Kendig, 2000). Land use controls and public transport systems also have a critical bearing on people with disabilities.

Specific concerns of policymakers include the following:

- Notwithstanding their potential importance, building and land use controls take relatively little account of the needs of people with disabilities.
- Some Councils have zoning that effectively excludes housing for people with disabilities.
- The need for demonstration homes to show the way with better design.

Overall, the policymakers rated improved land use and housing regulations as among the highest priorities but there appears to be relatively little government attention to the needs of people with disabilities particularly in State and Council planning.

6.4 Exploration of current housing and care packaging models

A critical research question concerned community housing and care 'packages' being provided for adults with disabilities in the Australian context. In understanding the development of various packaging of housing and support it is important to determine what perspective predominates. In this sense, the perspective chosen results from the policy drivers, reflecting priorities and impacting policy directions either furthering or hindering them. The models identified from the policy interviews can be grouped according to their implicit but predominate orientation into four themes with a focus on formal care, privatisation of care, informal care or care minimisation.

The policy implications of housing models with a formal care focus including '*Group homes*', '*cluster housing*' and '*secure accommodation units*' concern the apparent preference for this model within government action areas such as the CSDA. This model relies on housing or land purchase coupled to formal care packaging. State-housing authorities under the CSHA are often expected to provide the accommodation component. In terms of housing, there are considerable infrastructure costs including purchase, design and construction and/or adaptation of existing older housing stock. There are also ongoing maintenance and infrastructure expense which are either overlooked or dealt with by cost shifting between agencies. Nevertheless, care costs are the most significant in the middle to longer term.

This model is strongly linked to deinstitutionalisation trends. However, in a post-deinstitutional environment, where the primary objective of rapid deinstitutionalisation has already been met, continued preference for this model may conflict with other trend areas like 'Ageing in place'. This is significant when considered in conjunction with the increasing importance being placed on informal care, consumer rights and cost recovery. Consequently, while this model provides security and relieves families of the onus of responsibility, the distance from and lack of input by informal caregivers tends to disenfranchise informal care giving and carer and resident autonomy.

The policy implications that flow from models that focus on non-government care such as '*rooming houses*', '*boarding houses* and '*private hotels*' centre on the issues of building and land regulation and income support. Consumer rights and balancing out 'who pays' are also of significant concern and consequently warrant further attention. These models tend to offer less security and safeguards but there are instances of innovative and successful implementations. Private sector involvement in care provision, for those who can pay for it, ensures greater choice and flexibility in the

medium to longer term particularly in supply of accommodation options suitable for those living on their own. Enabling sharing of facilities and/or support can reduce costs associated with provision. However, further subsidy or tax incentives for training, education and housing fitouts need to be considered to encourage greater participation and to ensure compliance with regulations and standards in line with increasing consumer expectations.

The models that focus on informal care like the '*Supported Living Model*', '*Community Disability Housing*' and the '*Local Area Coordination (LAC)*' programs have had considerable success in increasing the degree of flexibility and control of family caregivers. By enabling the continued involvement by caregivers, 'Ageing in place' is enabled whilst formal care costs and burdens are lowered. These models have particular significance in that they demonstrate that coordination, support and information services provided at a grassroots level can positively impact on carers and consumers.

Models with a care minimisation focus like '*Adaptable homes*' have the potential to enable both 'Ageing in place' and 'Deinstitutionalisation' by providing a home environment that can be adapted over the lifespan and is inclusive of a much wider range of human ability. Uptake and implementation of this model outside of accommodation being built by State housing authorities requires public education and policy initiatives in the building and land regulation and income support areas to have a maximally beneficial effect. Policies initiatives that encourage adaptable design, construction and purchase can reduce formal care costs and the necessity for housing relocation whilst maintaining individual autonomy. Finally yet importantly, government policies that facilitate a combination of private sector involvement and adaptable design whilst facilitating continuance of involvement by carers are the most likely to be effective in enabling community based care.

6.5 Conclusions and Directions

This chapter reviewed policy implications from this study and their relationship to services, housing and care. It underscores the need for more flexible thinking and some fundamental changes in the priorities and delivery systems of health, housing, urban planning and local government.

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 expected quality of life are resulting in pressure for further change. These changes need to target the following four areas:

Firstly, resources need to be allocated to ensure the harmonisation and articulation of principles both within Commonwealth/State agreements and within State based policy and programs across the broad areas of urban planning, housing, social welfare, health, and disability support.

Secondly, there is an urgent need to create supportive and enabling community residential environments. As in the UK, the introduction of adaptable and visitable housing would increase the housing options within the wider mainstream marketplace. Housing options need to be diversified to increase opportunities for people with disabilities to build, adapt and buy their own homes. Speedy action is required to forestall losing momentum regarding the ability to sustain '*deinstitutionalisation*' and enable '*ageing in place*' outside the social housing sector particularly given the very high unmet needs by adults with disabilities in securing a home and maintaining it. This will require re-examination of zoning, land use provisions, and building regulations.

Thirdly, there is an urgent need to invest more in community based support and training. Findings from this study indicate that both property maintenance and transport are insufficiently served and are crucial to the ability to '*age in place*'. The lack of previous recognition of the value of these factors may relate to the fact that they relate to long-term ability to meet one's needs within the community rather than to reduce transitions to institutional care per se.

Fourthly, social housing for adults with disabilities needs to be maintained and diversified. Adults can '*age in place*' within their local community only if they have a secure home base into which support can be brought.

Finally, research on housing, ageing, disability and care policy futures remains limited. In many ways, the findings of this research, like most research studies, raise more questions. Obviously, further research would assist in better understanding how a whole of government perspective might be achieved. For instance, an examination of comparative patterns of expenditure at a State level related to need indicators might assist in assessing implications of particular housing and support models. In addition, examination of more detailed State related policy differences (legislation and organisational) might promote greater insights into the impacts of common and divergent approaches across Australia. Alternatively, more qualitative approaches such as State based focus groups with key regional service providers, might shed more light on issues surrounding behavioural and mental health care. These studies if undertaken, would enrich the understanding of what housing and support models work best.

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APPENDIX A: LIST OF USER GROUP PARTICIPANTS

Department	State	Person	Position
Commonwealth Department of Family & Community Services (FACS)	NSW	Annette Donohoe	Senior Policy Advisor
Ageing & Disability Department	NSW	Pat Occelli	Senior Policy Advisor
Department of Human Services	VIC	Arthur Rogers	Assistant Director
Council on the Ageing	VIC	Kath Bruster	Advocate
Department of Health & Human Services	TAS	Malcolm Downie	Director of Housing
Physical Disability Council of Australia	NSW	Mark Relf	Advocate
Department of Housing	NSW	Andrew Wood Cappie-	Director General
Department of Housing	QLD	Margaret Ward	Senior Policy Advisor

APPENDIX B: THE SAMPLING FRAME USED FOR THE INFORMANT INTERVIEWS

	Housing	Ageing/Disability	Care
Peak	National Shelter	PDCA/COTA	ACROD
Commonwealth	CSHA	CSDA	HACC
NSW	Department of Housing NSW	ADD-NSW	FACS-NSW
VIC	Housing Victoria (Department of Human Services)	Disability Program (Department of Human Services)	Policy and Services Branch (Department of Human Services)
QLD	Housing Queensland	Disability Services	Community Resource Unit
TAS	Housing Tasmania (Department of Health & Human Services)	Disability Program (Department of Health & Human Services)	Aged, Rural & Community Health Program (Department of Health & Human Services)
SA	SA Housing Trust	Human Services SA	FACS-SA
WA	Ministry of Housing	Disability Services Commission	FACS-WA

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Affiliates

Ecumenical Housing Inc
Northern Territory University
National Centre for Social and Economic Modelling



Australian Housing and Urban Research Institute
Level 7 20 Queen Street, Melbourne Victoria 3000
Phone +61 3 9629 5033 Fax +61 3 9629 8536
Email information@ahuri.edu.au Web www.ahuri.edu.au