

Research Paper



The housing careers of people with a disability and carers of people with a disability

authored by

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EXECUTIVE SUMMARY

This report considers the housing careers of persons affected by disability and those family members with significant care responsibilities. The report shows that the housing careers of persons with a disability are flatter and more restricted than those of the population overall. In addition, it is argued that the housing careers of carers and persons with a disability alike are changing in these first years of the 21st century. This change is a consequence of shifts in the ways support services are provided, because of impediments to movement through the housing market, because of reducing access to home purchase and as a result of trends in the incidence of disability.

The report considers the outcomes of both qualitative and quantitative data collection, with the research focused on three regions of Victoria – Darebin, Gippsland and Melton/Brimbank, as well as four disability groups – the cognitively disabled, the mobility impaired, persons with a psychiatric disability and persons with a sensory disability. This data collection took place in addition to the analysis of data on disability collected as part of the Housing 21 Survey – a national CATI survey of the Australian population. Our research found that when compared with the general population, households where one or more persons were affected by a disability were:

- Likely to report significantly lower incomes and were more likely to experience housing stress;
- Less likely to be home purchasers and more likely to be tenants, especially public tenants;
- Have lower stocks of assets (wealth);
- Have made housing decisions based on the needs associated with a family members disability or long term health condition; and,
- Less likely to live in a family household.

Detailed data collection was undertaken for each of the four disability groups and the research found that there was significant variation in the housing careers of each group. Importantly, the research also found that even within disability ‘types’ there is considerable variation in housing outcomes, based on the severity and source of the disability. This component of the research found that:

Psychiatric disability

- Persons with a psychiatric disability reported the lowest incomes and the greatest disadvantage of any group. Fully 71 per cent of this group were renting their homes – often from a social landlord;
- Thirty-nine per cent of respondents with a psychiatric disability indicated that their needs for assistance were only met in part and 5.6 per cent believed their needs for assistance were not met at all.
- Forty per cent of persons with a psychiatric disability lived by themselves and this is a very atypical household structure compared with the Australian population as a whole. Critically, 40 per cent of persons living in a household with at least one other person shared their living arrangements with another person with a disability.
- Very few persons with a psychiatric disability had full-time employment (31.1 per cent) with 35 per cent reporting that they were unable to work because of disability pension or WorkCover issues, and 15 per cent working part-time or casually.

Seventy-seven per cent of respondents received the Disability Support Pension, and a government pension or allowance was the major source of income for 94 per cent of households.

- Incomes for persons with a disability were very low, with 34.5 per cent of respondents with a psychiatric disability reporting a household income of less than \$12,999 and 90 per cent less than \$26,000.

Mobility impairment

- Persons with a mobility impairment were much under-represented in home purchase, with just 14 per cent buying a home, compared with 39 per cent outright owners and 37 per cent renting.
- Just 18 per cent of tenants with a mobility impairment rented from a real estate agent and 35 per cent of tenants with a mobility impairment had applied for public rental housing at some stage of their life. Thirty-two per cent of tenants with a mobility impairment had been owner occupants, and this finding is consistent with the discussion elsewhere in this report that the onset of disability frequently results in households 'falling out' of home ownership.
- Ninety per cent of tenants with a mobility impairment did not expect to enter home ownership in the next five years, and the contrast with the expectations of the general population of tenants is stark.
- Just over one quarter of respondents with a mobility impairment had undertaken major renovations of their home because 'the house was not appropriate to needs' (eight respondents), to 'avoid the costs of moving' (one) and 'to adjust the house for a person with a disability' (nine).
- Nineteen per cent of respondents with a mobility impairment believed that their home did not meet their needs well or at all.
- Respondents with a mobility impairment indicated that insufficient finances, the absence of continuing employment and the lack of suitable housing options prevented them from moving to more appropriate housing. Forty-two per cent of households affected by a mobility impairment had not moved dwelling in the decade to 2006, and 29 per cent had made only one move.

Sensory disability

- Nine of the 16 sensory disabled persons renting their housing had previously been owner occupants and 80 per cent of this group that had fallen out of home ownership had changed tenure because of the difficulty of affording mortgage repayments. Eighty-five per cent of this group did not expect to enter home purchase.
- Most persons with a sensory disability believed that their present home suited their needs well (38.8 per cent) or very well (57.1 per cent). They anticipated that their housing would continue to meet their needs over the next five years. That said, one quarter of respondents indicated that they would like to move to a different home, though few expected that this would happen. Finances and the lack of ongoing work were the major impediments to relocation.

Carers of people with a disability

- Carers were concentrated in owner occupation, with 65 per cent outright owners and 20 per cent purchasers. Thirteen per cent were tenants and 2 per cent lived rent free. This tenure distribution is consistent with the age distribution of the

carers included in the survey and highlights the fact that the provision of unpaid care is strongly associated with home ownership.

- Carers in rental housing most commonly leased their property from a real estate agent (40 per cent), followed by the Office of Housing (27 per cent) and other private landlords (13 per cent). Forty-four per cent of carers who were tenants had previously been owner occupants and, of those to fall out of owner occupation, two-thirds did so because of a relationship breakdown. A further 17 per cent fell out of this tenure because of the cost of providing care, and an equivalent percentage was forced to return to rental housing because of the loss of employment. Interestingly, no carers who were currently in the rental market expected to enter home ownership in the next five years.
- Only 10 per cent of carers participating in the disability survey were in full-time employment.

Conclusion

Finally the report concludes that that disability has a significant effect on housing careers and that the housing careers of persons with a disability are changing. The discussion highlights the significant differences in housing careers depending upon the source, type and severity of the disability. The housing careers of all household members are affected by disability. From a disability perspective and from an ageing perspective, health and wellbeing are now a significant influence on the housing transitions of many Australian households. Importantly, whereas the home was a place for the provision of care for children in the second half of the 20th century, in the 21st century it will take on a considerable role in the provision of care for adults.

From the literature, there does not appear to be a consensus on appropriate policy interventions, but this work has led to the call for new, more fine-grained, approaches to the provision of housing assistance and the potential re-ordering of priorities in the light of what we now know about 21st century housing transitions.

1 INTRODUCTION

1.1 Introduction

This report presents the findings of research into the housing careers of persons with a disability and family members with care responsibilities.¹ This research was conducted as part of a larger program of research, National Research Venture 2 of the AHURI Research Program, investigating 21st century Housing Careers and Australia's Housing Future. The overall aim of the research was to address the question:

How are housing careers for persons with a disability and their family members with care responsibilities changing in Australia and what are the implications of change for government provided housing assistance?

It is recognised that the housing careers of people with disabilities are shaped by the full range of factors of all participants in the housing system (family life stage, labour force participation, age, gender and so on) and that disability adds to this complexity, rather than being the sole driver of housing careers. As the term 'disability' encompasses a wide spectrum of conditions, housing needs and housing careers vary according to the type and severity of the disability. The housing decisions of persons with a disability, however, are often shaped by significant constraints.

This report examines the issues and processes that shape the housing careers of people with a disability including housing affordability, the accessibility and suitability of the housing stock, and the impact of government assistance. It identifies the lack of choice, and constraints upon choice with regard to housing and location outcomes, as well as choices, preferences and aspirations. The report also includes information on the housing careers of carers. The research recognises the important roles and responsibilities of carers and the influence that caring for a person with a disability can have on their own housing and locational outcomes.

As persons with a disability are now part of the general community, this research draws comparisons between the housing careers of the mainstream population and those of people affected by disability to raise awareness of the challenges to successful housing careers confronting persons with a disability and the challenges facing the policy community.

1.2 Background

The research was supported by the Helen McPherson Smith Trust and the Gandel Charitable Trust and was undertaken in Victoria. It focused on the housing careers of persons – and their carers – affected by four types of disability:

- Mobility impairment;
- Sensory impairment;
- Psychiatric disability;
- Cognitive disability.

The research was further focused on three regions within Victoria: Darebin as an example of an inner metropolitan region; Gippsland as an example of a non-metropolitan region; and Melton/Brimbank as an example of an outer metropolitan

¹ For the sake of brevity, family members with care responsibilities will be referred to as carers. This group does not include professional carers.

region. The research focused on three case study regions within different parts of the Victorian urban system because consultations undertaken at the commencement of the project highlighted the ways in which persons with a disability are confronted by different challenges in different locations. Darebin, Melton/Brimbank and Gippsland were recognized by informants from the disability sector as representative of experience in the inner suburbs, outer suburbs and non-metropolitan Victoria.

While the research presented here was undertaken in Victoria, the results are transferable to the other Australian States and Territories. The results are transferable because of the influence of Australian Government policies and programs on the delivery of services to persons with a disability and as a consequence of the similar policies employed by the States and Territories with respect to housing for persons with a disability. The Australian Government has a profound influence on how and where persons with a disability live through its funding of the Commonwealth State Territory Disability Agreement (CSDA) and this means that many aspects of their housing are broadly similar, regardless of the jurisdiction they live in. Secondly, a policy review paper undertaken as part of NRV2 (Tually 2007) demonstrated that across Australia's States and Territories the policy frameworks linking housing and disability are broadly similar. In all jurisdictions, publicly owned housing is seen as the primary vehicle for assisting persons with a disability with their housing. In addition, there is a strong focus on providing services that support individuals maintain as much independence as possible. The similarities in the policies adopted by the States/Territories and the unifying influence of Australian Government policies means that the results of research into housing and disability in Victoria are directly applicable in other parts of Australia.

The primary data collection instruments for this research included:

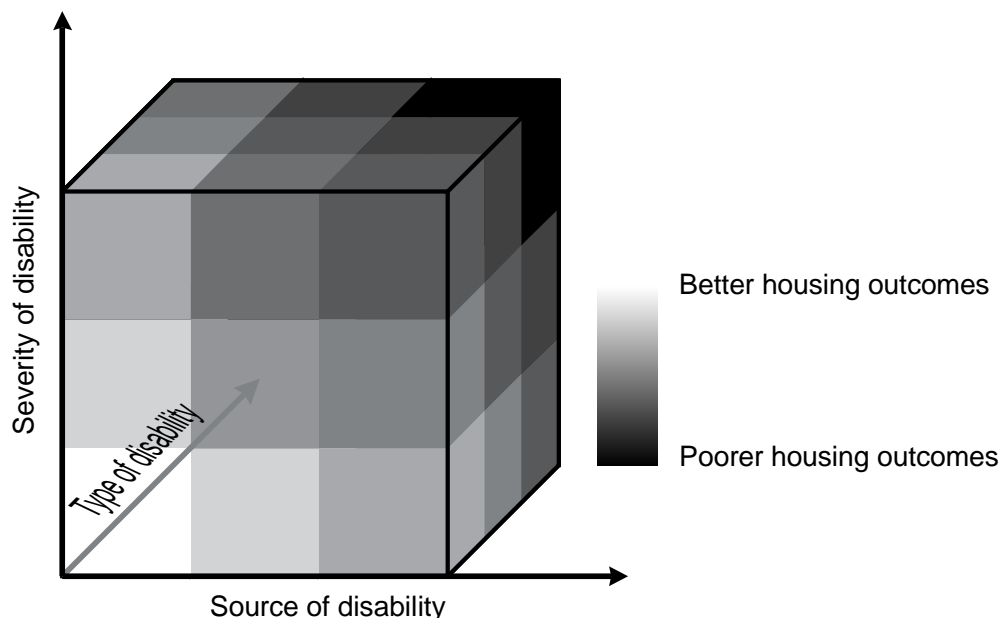
- Six focus groups undertaken in Melbourne, Morwell, and Sale (Project C of NRV 2). These included people with a sensory disability (deafness); persons with an acquired brain injury; persons with a mobility impairment; those with a psychiatric disability and their carers;
- The inclusion of disability and carer questions within the *Housing 21* survey in order to identify the incidence and impact of disability on the housing careers of the broader population;
- A specialist survey of persons with a disability and family members with care responsibilities, targeted to the three regions and four disability groups discussed above;
- In-depth qualitative interviews (Project E).

This paper draws upon all parts of the data collection – and the earlier review of literature (Beer, Faulkner and Gabriel 2006) and data sets (Wulff, Walter and Gabriel 2006) – to shed light on the 21st century housing careers of persons with a disability and family members with significant care responsibilities. In this instance the term 'significant care responsibilities' is taken to mean the provision of care and assistance to a degree that affects the day-to-day routines of the care provider and/or the capacity of that individual to engage in paid employment.

2 HOUSING CAREER AND DISABILITY: CONCEPTUALISING THE RELATIONSHIPS

In many ways, the concept of disability is problematic within the context of the discussion of housing careers. The term 'disability' implies a certain degree of uniform impact on housing career, with all persons affected by disability perhaps sharing a set of housing outcomes and affected by uniform processes. The reality is that disability is not uniform and the impacts upon housing career vary significantly according to its source, nature and severity. Each can be thought of as a significant determinant of housing career for persons with a disability (Figure 2.1) with an individual's position on each axis exerting a determinant influence on housing outcomes. A person with a mobility impairment acquired through an accident for which they can be compensated – for example, a work related injury or a car accident – will have a very different housing career when compared with someone who has had an identical mobility impairment – such as paraplegia – since birth. Moreover, the housing career impacts of the same type of disability can vary significantly according to the severity of the condition. To continue with the mobility impairment example, a person in a wheelchair may have a very different set of housing needs to a person who relies upon a walking frame. To further complicate matters, some disabilities – such as a mobility impairment associated with polio – worsen over the life course, such that potential and actual housing careers change over time. To further complicate the analysis, many persons have more than one condition. They may, for example, have both a hearing disability and an intellectual disability or they could have suffered a stroke and experience both the loss of mobility and cognitive function. Importantly, we have to acknowledge that housing careers vary considerably for persons with a disability, and that while there are common elements between and across disability groups, an individual's housing transitions will be determined by the nature, scale and source of the disability.

Figure 2.1: Conceptualising disability and its impact on housing career



Prior to considering the ways in which disability shapes housing careers in 21st century Australia, it is important to examine how households are affected by disability. The household rather than the individual is the primary unit of analysis in the

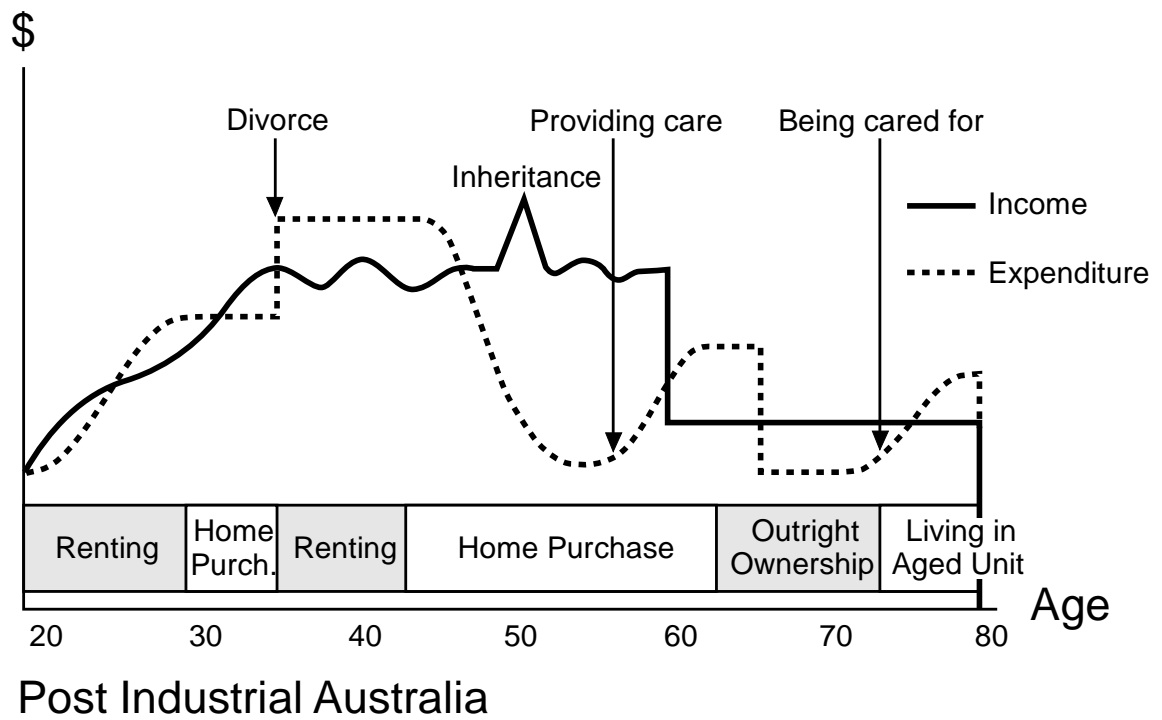
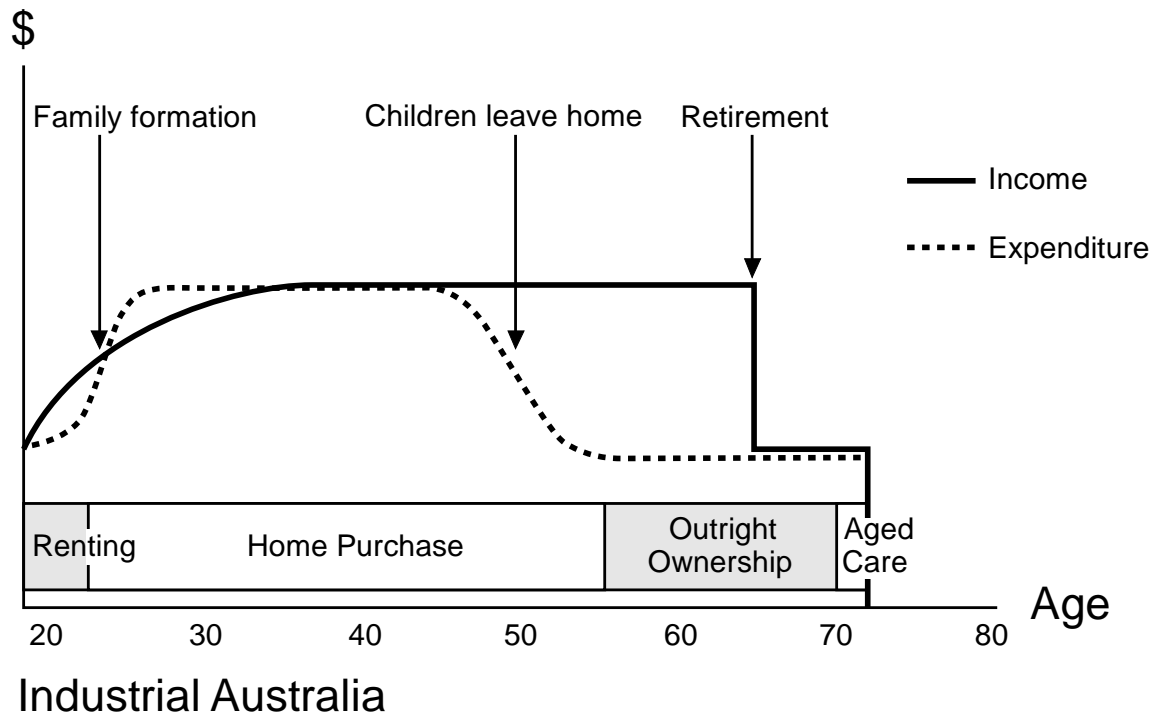
overwhelming majority of housing research because it is the household as a whole that occupies the dwelling, is affected by decisions to move or relocate and which jointly pays for accommodation. The review of the literature on disability and housing (Beer, Faulkner and Gabriel 2006) noted there was substantial discussion in the published research around the impact of disability on the housing careers of family members (Carers Australia 2003; Evandrou and Glaser 2003). Parents with care responsibilities may face higher housing costs and greater transport costs as a consequence of disability, and one parent is often unable to engage in paid work – thereby reducing household income – due to their care responsibilities. Lower household income reduces the level of choice within the housing market and may truncate housing careers. Importantly, we can conclude that it is the housing career of the household as a whole that is affected by the presence of a disability.

2.1 Indicative housing careers by type of disability

Figure 2.2 provides an indicative housing career for the mainstream population while Figures 2.3 to 2.7 provide an indicative housing career of persons affected by disability. The figures draw upon the outcomes of focus groups undertaken as part of Project C (Kroehn et al. 2007) and are meant to illustrate outcomes rather than provide a definitive account. A more detailed discussion of housing career by type of disability will be provided later alongside an examination of the factors shaping housing careers for persons with a disability. Figures 2.3 to 2.7 have been drawn to mirror Figure 2.2 and thereby provide a point of contrast to the housing careers of the mainstream population. A line indicating Australian average earnings over the lifetime has been added to the figures in order to highlight the low incomes of people with a disability.

The housing career of a person affected by mobility impairment as a consequence of an accident is presented in Figure 2.3. The housing career is seen to track the trajectory for the mainstream population, after which income falls, expenditure falls and the individual maintains their position within the housing market through modification of the home they are purchasing – paid for by a compensating body such as a motor accident commission or work related insurance – and then remains in that dwelling through to old age. Implicit within the figure is a high degree of immobility because of the challenge of finding an accessible dwelling in combination with limited income.

Figure 2.2: Changed life histories and changing housing careers



Source: Adapted from Williams (2003, p. 166).

Figure 2.3: Indicative housing career for a person with mobility impairment acquired through injury

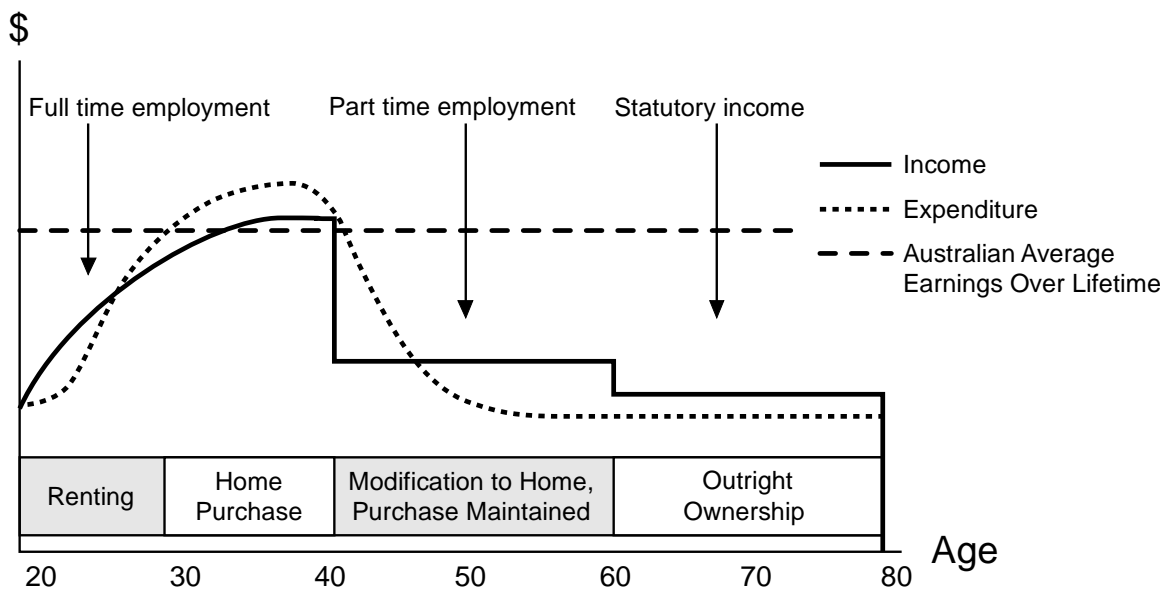


Figure 2.4 offers an indicative housing career for a person with a mobility impairment present since birth, and differs substantially from the previous figure even though the disability is the same. It highlights the potential significance of the source of disability, with both the end point and stages in the housing career varying significantly. Key issues include:

- Lower lifetime earnings because of an inability to secure well-paid employment and periods of un- or underemployment;
- A longer period living in the parental home;
- A return to the parental home in adult life due to the absence of appropriate and affordable alternatives;
- The impact of the death of parents, who have had substantial care responsibilities;
- A housing 'career' that terminates in public rental housing rather than owner occupation.

Figures 2.3 and 2.4, therefore, both emphasise how the source of disability can affect housing career and demonstrate the ways in which disability per se can be seen to shape housing outcomes through the life course. There is not a single housing career for persons affected by mobility disability, but there are common factors in terms of lower income and the need to live in an accessible dwelling that influences housing consumption.

Figure 2.4: Indicative housing career for a person with a mobility impairment present since birth

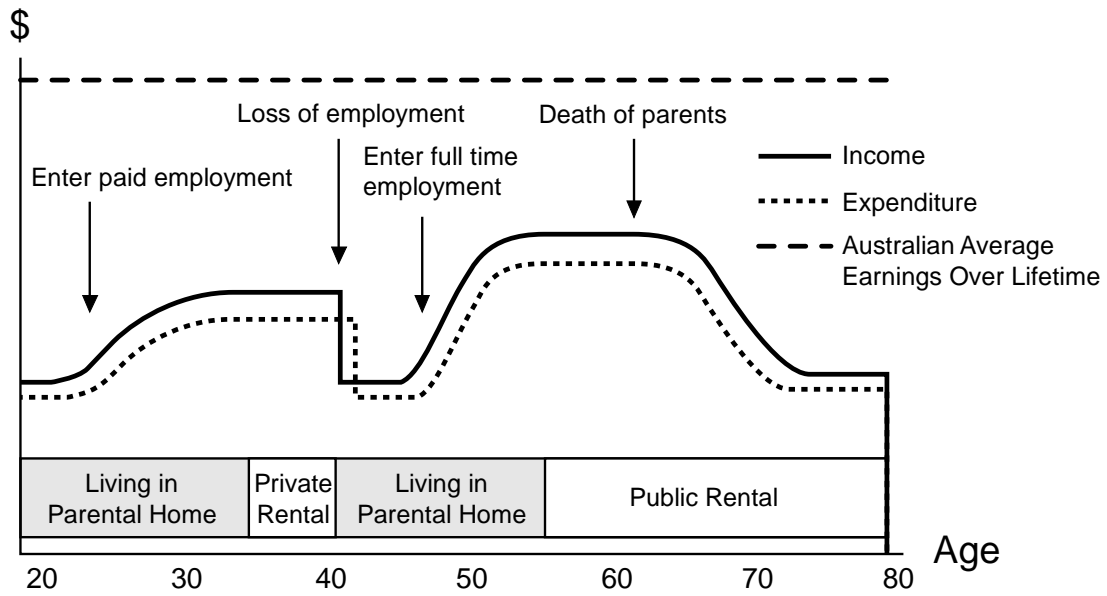
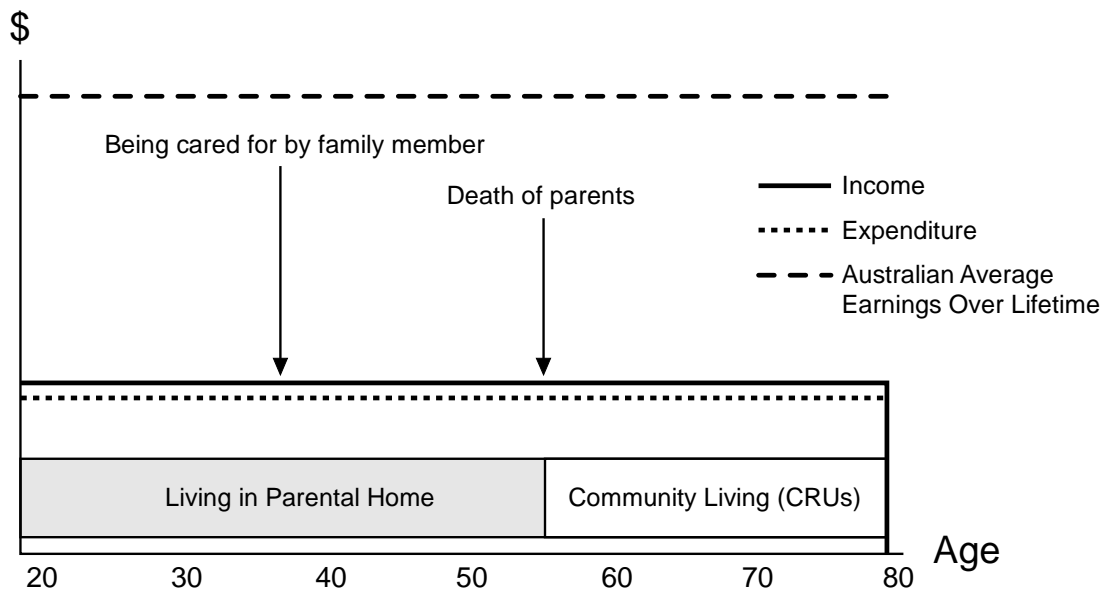


Figure 2.5 offers a different perspective on the housing careers of persons with a disability by focusing on those born with a cognitive impairment. In this instance, the individual has a flat employment and housing career: living with their parents until late middle age (when the parents either die or are too weak to continue to provide care) and then living in a community facility. The individual's income is low throughout their life, with employment provided through a specialist facility or activity centre. There is only the one significant transition through the housing market and it is precipitated by the demographic processes of the carers. This issue will be discussed in more detail later, but it highlights the considerable care responsibilities of many parents and siblings.

Figure 2.5: Indicative housing career for a person with a developmental disability



Persons with a psychiatric disability are likely to have a much more variable housing career than those affected by other disabilities (Figure 2.6). The episodic nature of much mental illness results in periods in and out of employment, as well as significant transitions through the housing market. Unlike the previously discussed disabilities, they are likely to report periods of homelessness and incidences of living in caravan parks or other insecure accommodation, with a high probability of eviction and ongoing transition from one tenure to the next. Figure 2.6 attempts to show how periods of mental illness have lag-effects that flow through to the transitions an individual makes in the housing market. Importantly, home ownership is not represented as the outcome of the housing 'career' for this group, instead public rental housing is suggested.

Finally, Figure 2.7 illustrates the likely housing career of a person affected by a sensory impairment and in this instance it draws upon the experiences of persons with a hearing impairment. They are represented as having both a stable housing career and stable employment, though the latter is not necessarily well paid. Persons born profoundly deaf often live within the private rental market because their disability is insufficient to secure public housing and they are unable for a range of reasons to easily enter home purchase. Those unable to hear have relatively few employment opportunities, which limits their income and therefore their capacity to repay a mortgage. In addition, they may not have access to information on how to purchase a home as they have limited access to English. Figure 2.7 suggests that home ownership is eventually achieved through the inheritance of a dwelling, as family members provide significant assistance throughout their lives, even though the hearing-impaired enjoy a high level of independence.

Figure 2.6: Indicative housing career for a person with a psychiatric disability

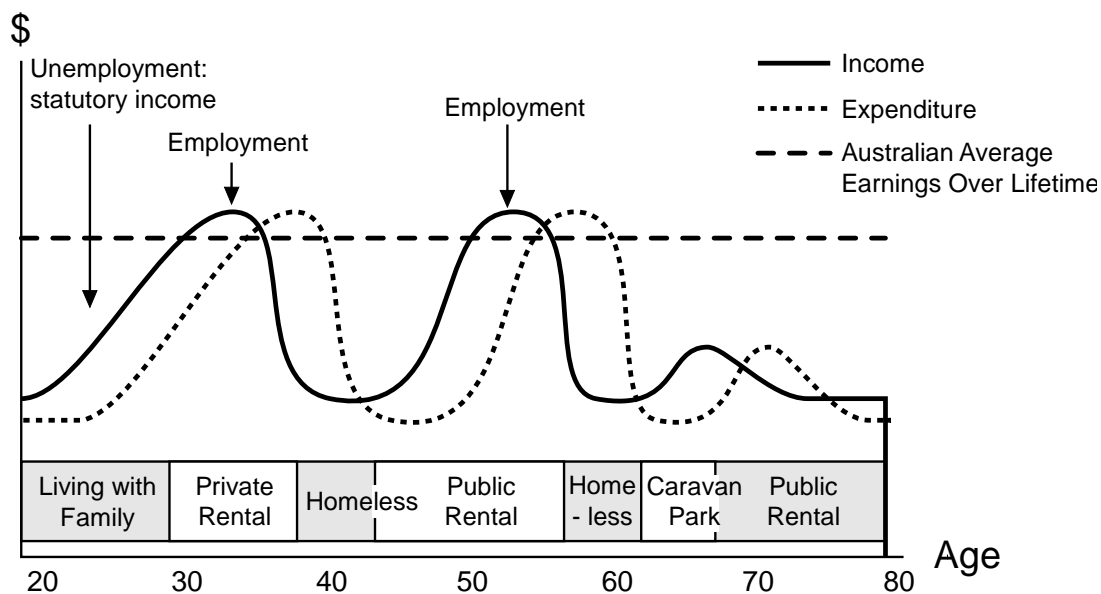
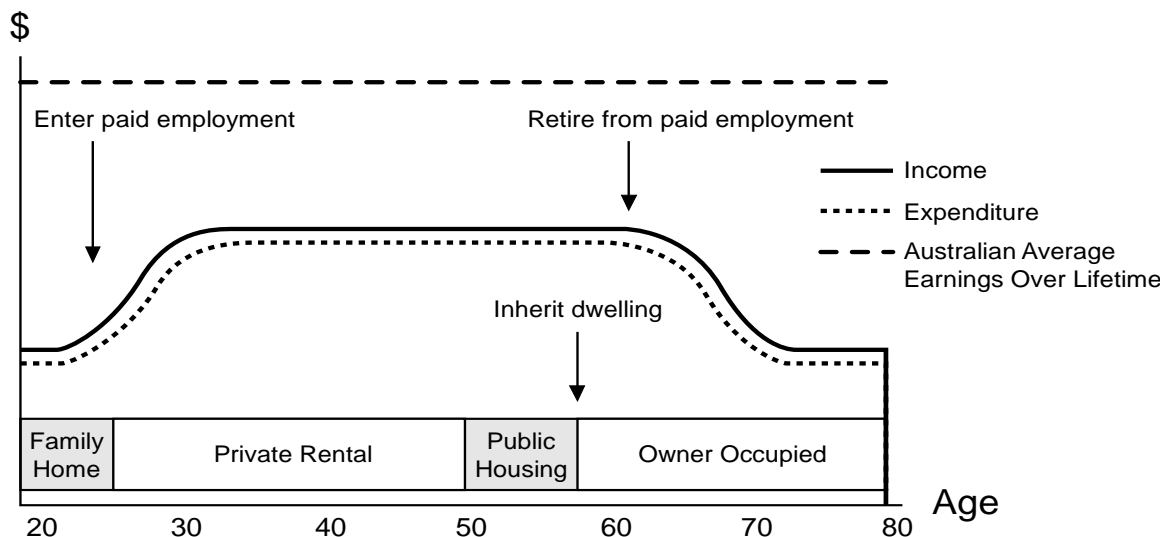


Figure 2.7: Indicative housing career for a person with a sensory impairment



The five figures present an abstract 'ideal type' based in large measure on the qualitative data collected as part of NRV2. The diagrams suggest both similarities and differences across circumstances, and also indicate drivers of housing careers for persons with a disability that are very different to those evident for the population as a whole. Key issues to consider include:

- In four of the five figures, persons with a disability are seen to have less variability in their housing careers than the population as a whole. This stability is a consequence of the limited options available to many persons with a disability and their limited capacity to express their housing needs as effective demand within the market. Low incomes and potentially truncated working careers result in little choice within the housing market. The absence of movement is significant because it may mean that persons have little opportunity to adjust their housing to meet their current needs as they pass through each stage of the lifecycle;

- How the disability is acquired can be highly significant. Commonly, disabilities acquired through injury are subject to compensation, for example, motor accidents or employment related incidents, and this group's subsequent housing careers may be very different to those of persons who have had a mobility impairment since birth or who acquired it through illness;
- Persons with a psychiatric disability can have complex housing careers that reflect episodes of psychiatric illness and associated difficulties in maintaining employment. Importantly, they are more likely than other groups to have periods of homelessness or inadequate housing as part of their housing career. This may, in part, reflect difficulties in staying in the family home or in sustaining relationships;
- Public housing is much more prominent in the housing careers of persons with a disability than for the general population and they are more likely to enter the tenure because of their considerable disadvantage, including low income, discrimination and higher living costs;
- Persons with a developmental disability may have a housing career that is largely determined by the housing opportunities that family members are able to provide. The inability of family members to continue to provide care, through death or their own ill-health, can force a transition in the housing of this group. Family members with care responsibilities are aware of the need to plan for the housing of their family member for when they are no longer able to care for them, but find it difficult because the alternatives are seen to be unattractive.

These figures do not offer a definitive account of the housing careers of persons with a disability, but they do suggest some themes that deserve exploration in the analysis of the quantitative data. They also raise issues of policy importance, as the stability of the housing circumstances of many persons with a disability suggests that it should be possible to engage in long-term planning for their needs. In addition, the figures emphasise the importance of integrating disability planning with planning for social housing.

3 THE IMPACT OF DISABILITY ON HOUSING CAREERS

The presence of a disability has the potential to affect housing careers in a number of ways. This section briefly considers the ways in which NRV2 has sought to develop a better understanding of the housing careers of persons affected by a disability before moving to consider the results of the analysis.

The inclusion of disability related questions in the *Housing 21* Survey was one of the most important ways that NRV2 sought information on the impact of disability on 21st century housing careers. The survey asked all respondents a suite of five questions that related to disability and the provision of care for persons with a disability.

- How many people in the household have any long-term health condition, disability or impairment?
- Does this person/Do you need help or assistance with self-care, mobility or communication?
- Does anyone in this household provide care and assistance on a regular basis to any person who has a long-term health condition, is elderly or has a disability?
- Is this care or assistance given to someone living ... IN YOUR HOUSEHOLD
- Is this care or assistance given to someone living ... ELSEWHERE

Through these questions it is possible to identify all households where one or more persons has a disability or health condition, and where one or more household members provide care on an ongoing basis. It is important to acknowledge that these questions provide a relatively blunt instrument for the examination of the impact of disability on housing career because many of those who indicate they have a disability will have acquired it with older age, and the data collection did not include information on either the type of disability or its severity.²

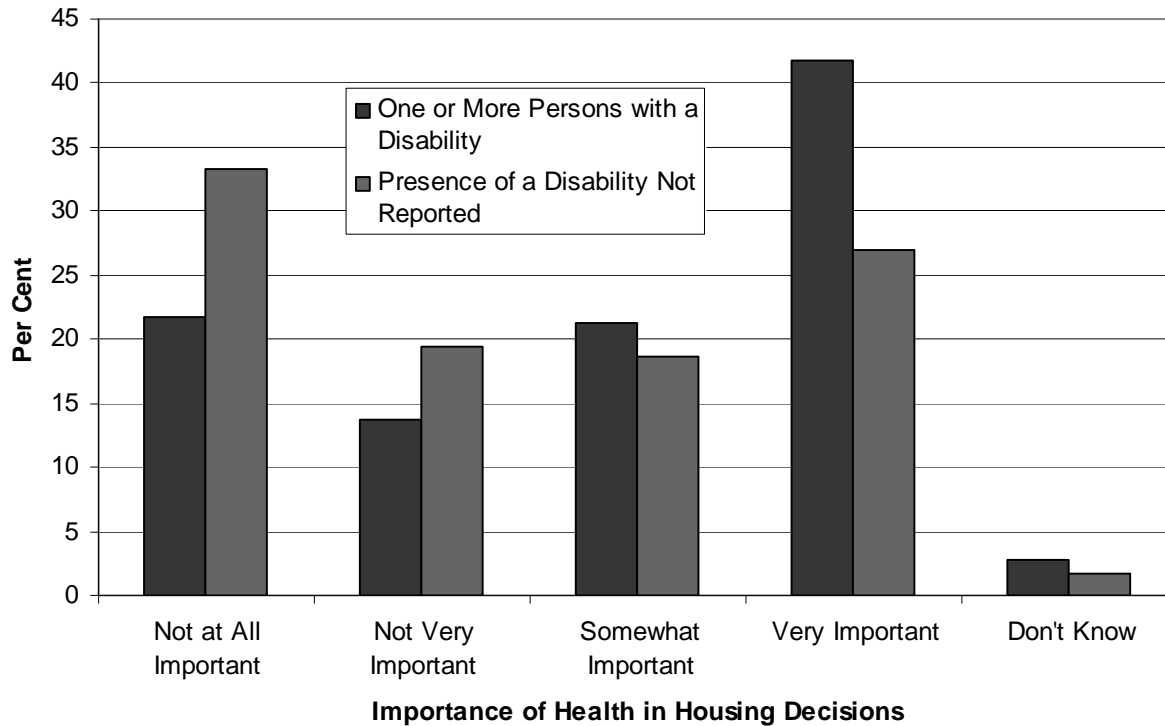
Of the 2,698 households who participated in the *Housing 21* Survey, 595 (22 per cent) reported that one or more household members had a long-term health condition, disability or impairment. This rate of self-reported disability is consistent with both the 2006 Census (Hugo 2007) and earlier Australian Bureau of Statistics data collections on the prevalence of disability. In most instances, only one household member had a disability, but in 74 cases two persons were reported as disabled and in three instances there were three people with a disability in the household. In 182 instances – 7 per cent of the total population and 30 per cent of households living with a disability – respondents reported that a household member needed assistance with self-care, mobility or communication. This figure is compatible with the AIHW's (2003) estimate of the incidence of persons affected by a disability to the extent that it represents a 'core activity limitation'.

It was reported by 381 respondents that they or a member of their household provided care and assistance to a person with a health condition or disability. Of this group, 53 per cent were assisting a person living within their household, while 54 per cent reported that a household member was assisting a person living outside their

² It was simply not practical to collect detailed information on the type or severity of a disability through a CATI survey directed to the general population.

household. In approximately 10 per cent of cases, household members were assisting both a person within their household and a person living elsewhere.

Figure 3.1: How important do you think your health has been in shaping your housing decisions? For households where respondent was under 65 years of age, by presence of a disability



Source: *Housing 21 Survey*

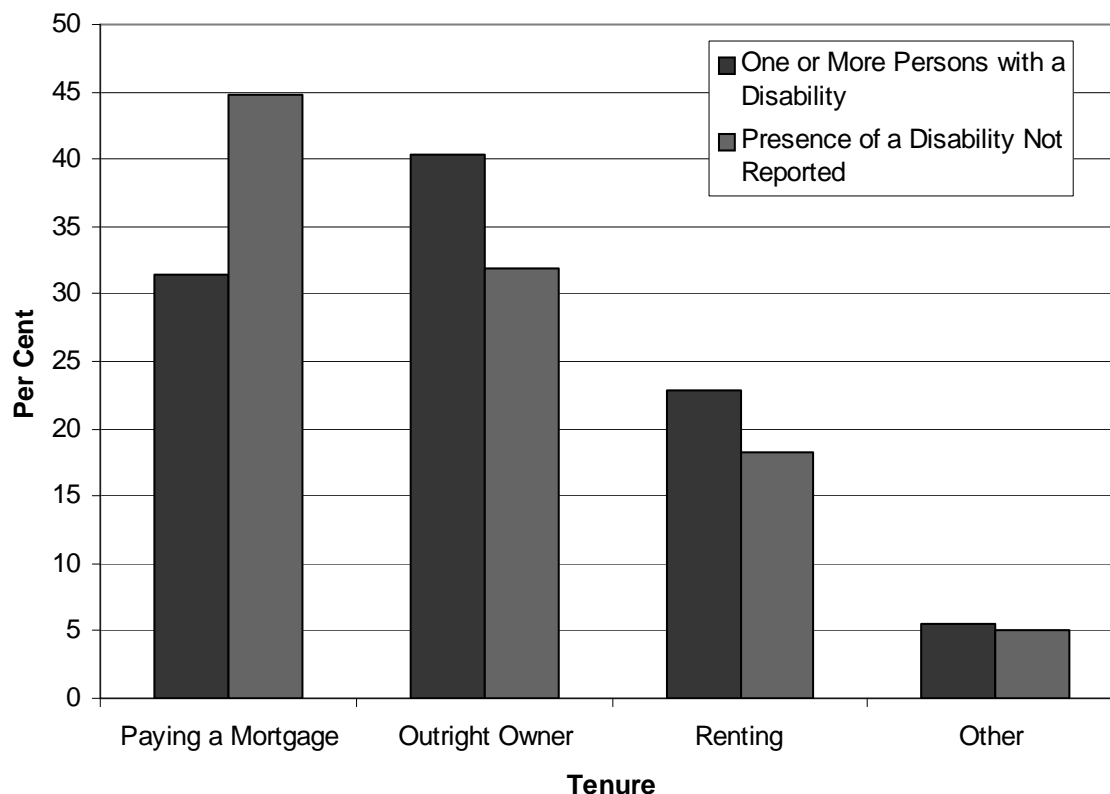
Potentially, the presence of a disability within a household can have a profound impact on housing career. The data presented in Figure 3.1 suggests that this potential impact has been realised, with over 40 per cent of households where one or more members has a long-term health condition or disability reporting that such factors have had a very important impact on their lifetime housing decisions. It is important to note that data is only presented for households where the respondent was under 65 years of age, as this partly controls for age related disabilities and health conditions. The figure also reflects all households to report the presence of a disability or long term health condition – or in other words, it is not limited to those persons whose disability or health condition is at the most extreme end of the spectrum. Clearly, households affected by disability believe their health or disability circumstances have affected their housing options and decisions – and therefore housing career – and how this finds expression in the housing market will be discussed in subsequent sections.

4 HOUSEHOLD TYPE, TENURE AND INCOME OF PERSONS WITH A DISABILITY

Household type, tenure and income are some of the critical dimensions of housing consumption for any group within the population and each is likely to be affected by the presence of disability within the household. Data from the *Housing 21* survey revealed that households where the respondent was aged under 65 and a disability was present were less likely to have children present than for the general population: 64.8 per cent of households in the economically active range where a disability was present did not report the presence of children, compared with 54 per cent of households where a disability was not reported and the respondent was less than 65 years of age. Overall, households where one or more persons had a disability tended to be smaller than households where no disability was present, with two person households accounting for 43.4 per cent of the total. The smaller number of conventional 'families' would account for this difference.

Analysis of the *Housing 21* data revealed significant variation between the tenure of households where the respondent was under 65 years of age and one or more persons had a disability, on the one hand, and the population of households where no member of the household reported a disability or long-term health condition, on the other (Figure 4.1). The former households were in percentage terms less likely to be home purchasers and more likely to be outright home owners. At the same time, households where a disability was present were more likely to be renting or paying board. Critically, households where one or more persons were affected by a disability were more likely to be home owners than home purchasers because high house prices over the last eight years have meant that they have been relatively immobile within the market, with relatively few able to enter occupation. Those in owner occupation are those who entered the tenure some time in the past and many have repaid their mortgage. In addition, some persons with more severe disabilities, continue to live in their parental home, well into their late 40s or 50s and their parents are likely to be home owners. Finally, it is important to acknowledge that while the data presented in Figure 4.1 are restricted to persons aged under 65 years of age, inevitably persons in their 50s and 60s are more likely to be affected by a disability and these are the age cohorts in which outright home ownership is concentrated.

Figure 4.1: Tenure, for households where respondent was under 65 years of age, by presence of a disability



Source: Housing 21 Survey

Importantly, the source of tenancy varied between households affected by disability and those where disability was not reported, and while 22 per cent of respondents to the *Housing 21* survey were tenants within the public rental sector, 39 per cent of households where a disability was present rented from a government agency, compared with 16.1 per cent of the population of households where disability was not recorded (Figure 4.2). This data is consistent with information on new housing allocation released by the Australian Institute of Health and Welfare (2007). Persons with a disability were also over-represented in community housing. Tually (2008, p. 9) commented that:

Acquiring a disability was also a key pathway out of homeownership for respondents and for many of the social housing tenants interviewed was the reason they were allocated their dwelling. Four of the social housing tenants who were interviewed were previous homeowners who had been forced to sell their home because of medical reasons and were granted a social housing dwelling as a medical necessity. That is, because they had to be near particular major medical facilities and because renting privately was affecting their health and wellbeing; mostly because their housing was insecure and unaffordable.

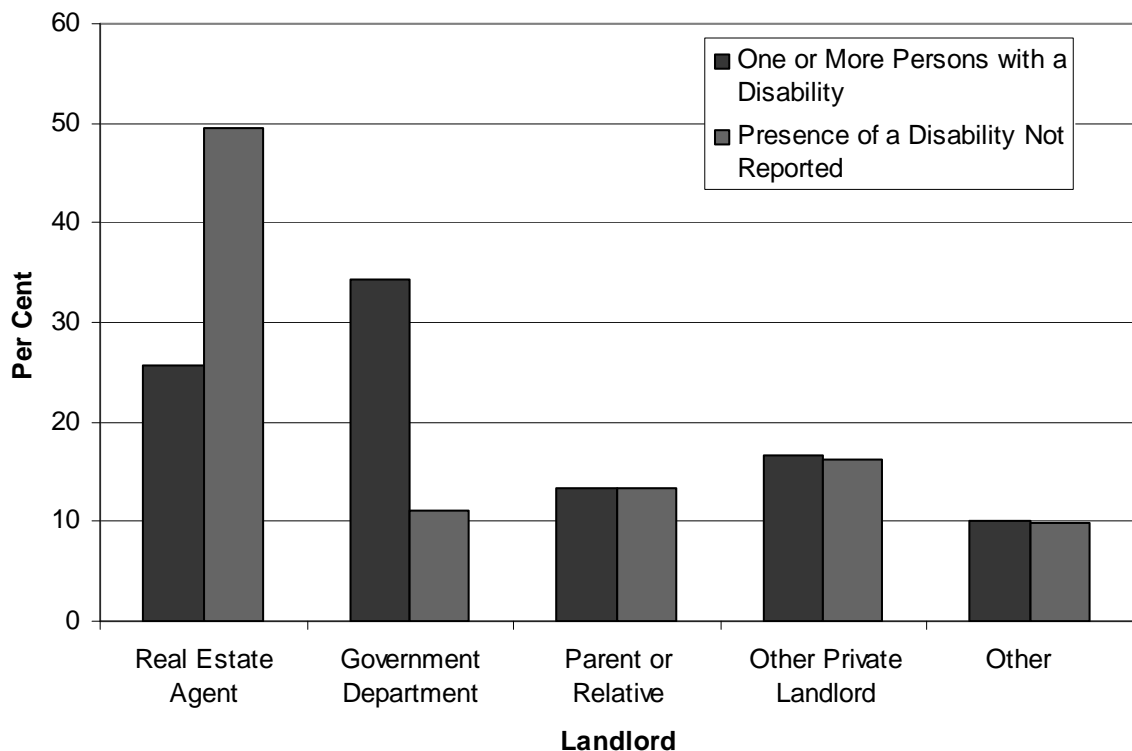
Tually's findings suggest that one of the reasons persons with a disability are under-represented amongst households purchasing their home is that they are unable to maintain their tenure. This conclusion underlines the vulnerability of this population within the housing market and reinforces their dependence on social housing.

Just under 50 per cent of tenants where a disability was not present in the household rented from a real estate agent, compared with 24 per cent of households where a

disability was present. Overall the tenure data suggest a significant concentration – and/or dependence – of households where one or more persons have a disability in the social housing sector. This outcome reflects contemporary allocation policies and the tight rationing of the social housing stock (Parkin and Hardcastle 2004).

The incidence and impact of discrimination was one of the unattractive aspects of rental accommodation for persons with a disability. A significant number of participants in the focus groups felt they had been discriminated against in the rental housing market because of their disability. This was seen to take a number of forms, including the landlord being unwilling to rent to a person with a disability, unfair treatment once the tenancy had commenced and a reluctance to agree to modest modifications in order to make the dwelling more appropriate to the person with a disability. Persons with a psychiatric disability felt especially vulnerable to discrimination but as one participant from Morwell said, *'It doesn't matter what disability you have, the landlords and the real estate agents treat you terribly'*.

Figure 4.2: Landlord type, for households where respondent was under 65 years of age, by presence of a disability



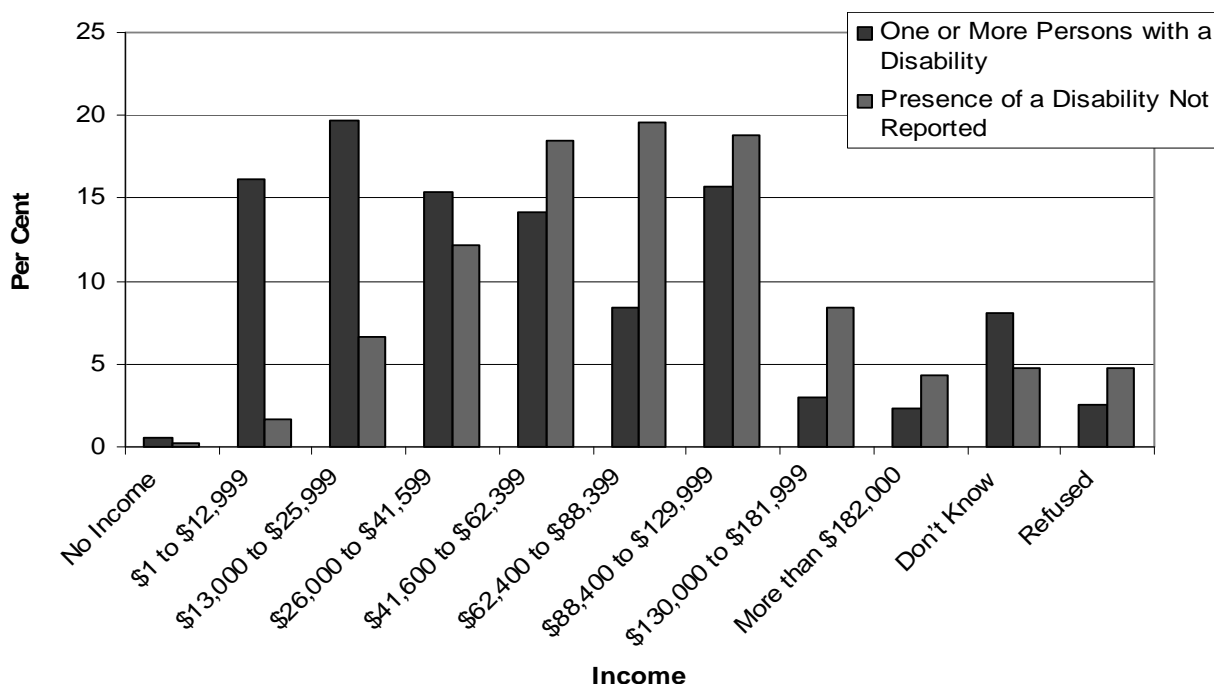
Source: *Housing 21 Survey*

5 HOUSING AFFORDABILITY AND ITS IMPACT ON HOUSING CAREERS

The affordability of housing is clearly an important determinant of housing careers and a factor likely to be affected by the presence of a disability within the household. Income data for households where the respondent was under 65 years of age is presented in Figure 5.1 which emphasises the significantly lower incomes of many households affected by disability. Thirty-five per cent had incomes of less than \$25,000 per year, compared with just 10 per cent of those where a disability was not reported. Clearly the capacity of these households to meet their housing needs within the market would be severely constrained. A measure of the impact disability has on earnings and housing careers was given by a wheelchair-bound participant in a focus group in Gippsland:

Before my disability I was earning \$40,000 plus and after the accident went down to a pension of \$11,000. This made my life and that of my family very uncertain and has had an immense emotional and financial impact on my whole family (Kroehn et al. 2007, p. 7).

Figure 5.1: Household income, for households where respondent was under 65 years of age, by presence of a disability

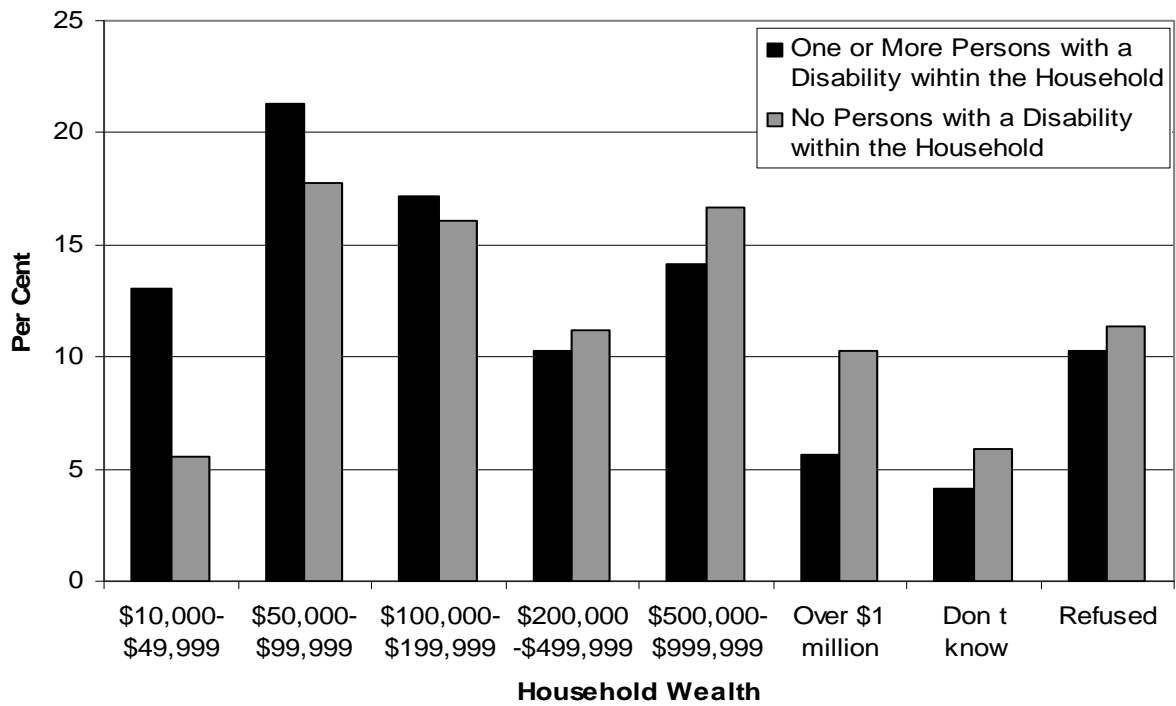


Source: Housing 21 Survey

The assets a household owns are an important economic resource, particularly in gaining access to home ownership. As Figure 5.2 shows, households in the *Housing 21* survey where one or more members had a disability or long-term illness had significantly fewer assets than the general population. This estimate of gross household assets includes the value of the family home and it is important to reflect on the fact that households where a disability is present are more likely to be outright owners than home purchasers. This suggests that they will have fewer liabilities against their gross wealth holdings and that housing may be a more significant part of their 'asset mix' than for the population as a whole. In other words, the labour market and tenure characteristics of this group means that they are more likely to own

housing assets than the general community, but less likely to hold superannuation, shares or other assets. The substantial concentration of households affected by disability in public rental housing – and the limited engagement with the formal labour market – would assist in explaining the high proportions of households affected by disability with no, or very limited, assets. From a housing career perspective, low wealth – both with respect to housing and more liquid assets – narrows the range of housing available to any group in the future.

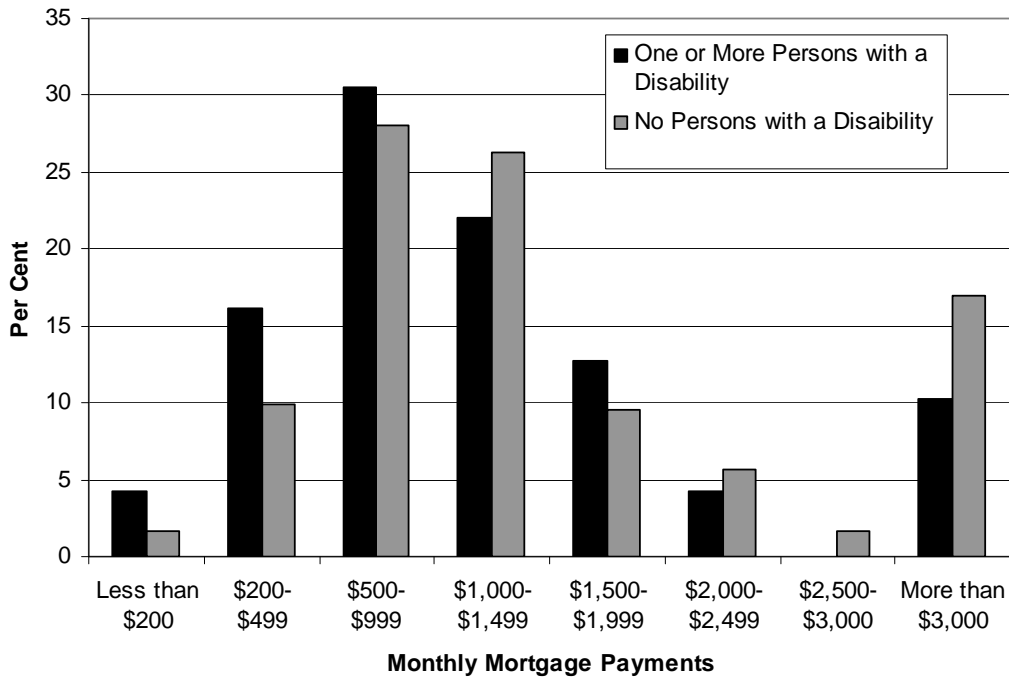
Figure 5.2: Estimated gross household assets, for households where respondent was under 65 years of age, by presence of a disability



Source: *Housing 21 Survey*

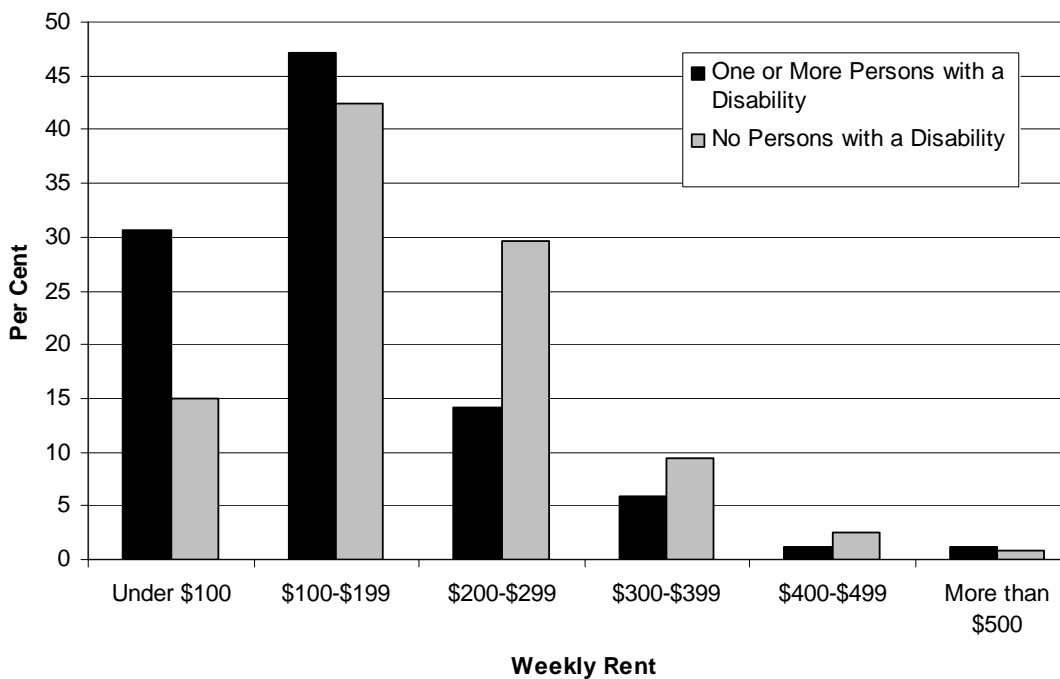
Households where one or more persons are affected by a disability tend to have both lower mortgage payments and lower weekly rents than the general population (Figures 5.3 and 5.4). While the lower rents reflect the more modest cost of housing in public rental compared with private rental, mortgage payments clearly do not. Households where one or more persons have a disability or long-term health condition must engage in one or more behaviours that limit their mortgage liabilities.

Figure 5.3: Monthly mortgage payment, for households where respondent was under 65 years of age, by presence of a disability



Source: *Housing 21 Survey*

Figure 5.4: Weekly rent, for households where respondent was under 65 years of age, by presence of a disability



Source: *Housing 21 Survey*

It is important to acknowledge that lower incomes than the general population and lower housing costs may, or may not, result in a greater incidence of affordability problems for households affected by disability. The data presented in Figures 5.5 and 5.6 suggests that housing affordability is a major challenge for households affected by

disability, especially within rental housing. Just under 15 per cent of households where one or more persons were affected by a disability or long-term health condition who were renting paid more than 60 per cent of their gross income for their housing.³ Thirty-six per cent of households affected by disability and accommodated within rental housing (including public rental housing which is capped at approximately 25 per cent of household income) paid more than 30 per cent of their income for their housing.

Those households affected by disability purchasing their home are less likely to be confronted by unaffordable housing and this reflects both their higher household incomes relative to tenants and the impact of historical rather than current housing costs, as most have been home purchasers for a considerable period of time. This said, home purchasing households affected by disability were more likely than the general population of home owners to be paying more than 30 per cent of income on housing, with 27 per cent paying more than 30 per cent, compared with 13 per cent for the general population of purchasers.

Clearly, the private rental market presents significant challenges for persons with a disability and their family members. The difficulty of sustaining private rental accommodation is highlighted by the experience of a male participant with a psychiatric disorder:

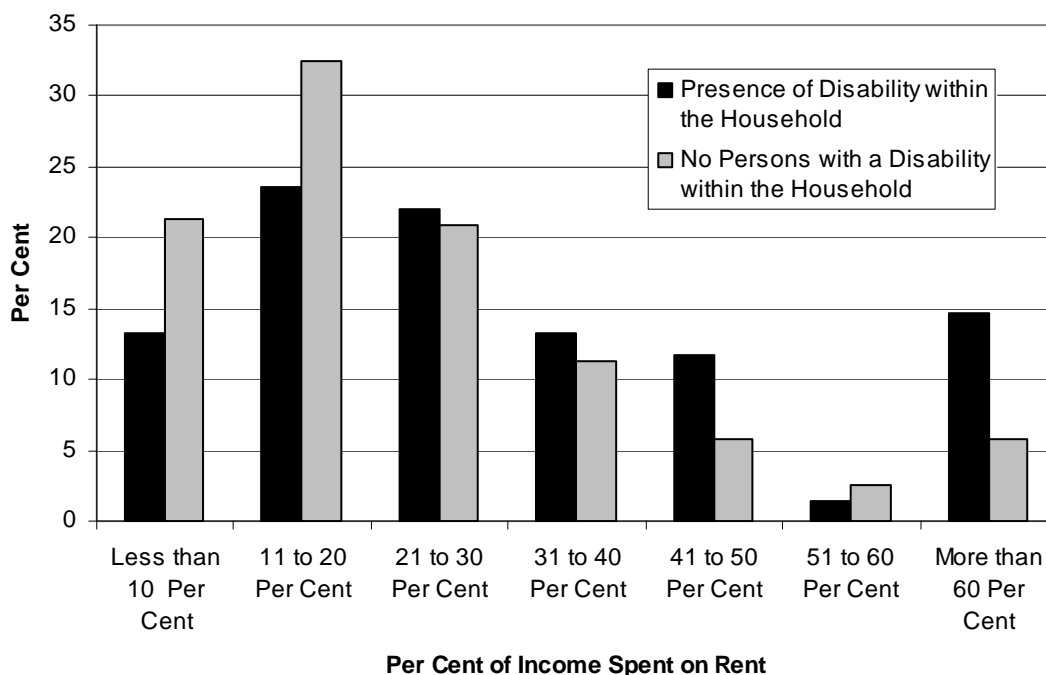
I tried private rental in [north-western suburb] and living on a pension and paying private rental ... It was extremely hard. I was evicted ... I couldn't maintain the rent, yeah ... It was a friend that I played cricket with, it was one of his properties. He sort of said, yeah, that's fine, as long as you maintain the rent then we'll have no problem. But yeah, I fell behind (Saugeres 2008, p. 21).

Other people had to compromise on the quality of their accommodation in order to afford to rent privately.

The insights offered by the *Housing 21* survey are entirely consistent with the findings of the qualitative research. Many of those who participated in the qualitative research voiced the view that the combination of high house prices and low incomes meant that persons not already owner occupants would find entry to the tenure difficult. A group from Sale in Gippsland who were already owner occupiers were thankful that they had their own places as they believed '*it would be impossible to enter the housing market due to rising prices*' and '*securing a loan on part-time or casual work was difficult*' (Kroehn et al. 2007, p. 20). One participant in a Morwell focus group explicitly acknowledged the importance of receiving an insurance settlement for his disability – and by implication the source of his disability – noting that '*Being paid out made buying a home and modifying it possible to do. I don't know where I would be without the payout*'.

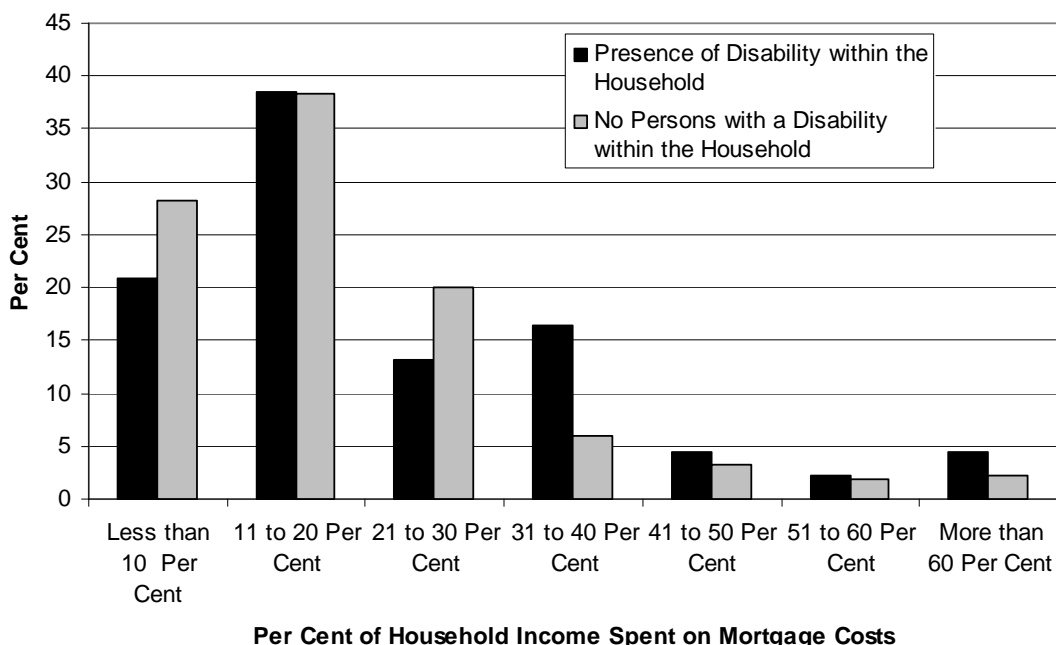
³ It is important to discount the argument that those paying 60 per cent or more of their income in housing were living in an institutional or community care setting where living costs and housing are provided as a bundle. In common with other CATI surveys, such living arrangements were under-represented in the Housing 21 survey.

Figure 5.5: Housing affordability for tenants aged under 65 years, by presence of a disability



Source: *Housing 21 Survey*

Figure 5.6: Housing affordability for home purchasers aged under 65 years, by presence of a disability



Source: *Housing 21 Survey*

Tenants, by contrast, noted that finding appropriate accommodation was difficult and diminished greatly the options for where they lived, even within an affordable housing market such as Morwell. Participants in a focus group in Melbourne affected by a mobility impairment felt that the city's housing market had either failed them or was

not relevant to them. Only one was an owner occupier and no-one rented privately. At least one participant and one carer had rented privately in the past, but the private rental market was seen to be difficult because of the inaccessibility of the housing stock, high rents and the inability to find and sustain work.

Respondents reported that while work is available for them, it is often short-term, part-time and not especially rewarding financially. Those who could find work part-time often struggled financially as the income earned was little more than what was available through the Disability Support Pension (DSP). In addition, the fact that the DSP is income tested could be a disincentive to finding full-time employment, particularly as the health of many of these people is unstable and reliance on this pension is anticipated to be long-term. A young respondent in the qualitative interviews expressed this concern about what would happen if she lost her DSP due to gaining full-time employment:

I'm a bit concerned about that, yes. If I earn too much money I will lose my disability pension and there goes, you know, I won't be able to see a doctor, I'll have to pay and things like that ... I am a bit concerned about that because it is a bit of a security net, you know? ... Like I only get my granny flat because I have a disability pension ... So I might lose my granny flat as well. So I don't really want to do that (Saugeres 2008, p. 22).

6 THE ACCESSIBILITY AND SUITABILITY OF THE HOUSING STOCK

The accessibility of the housing stock was a major issue for many people with a disability, as many participants in the qualitative data collections reported that much housing was not suitable for them because of the limitations imposed by their disability. The type and severity of disability has a clear impact on the need for housing that is appropriate to their condition. While there is a general perception that individuals with a mobility impairment, and in particular those in a wheelchair, are most affected, people in a variety of circumstances need to modify their dwelling and/or find appropriate accommodation condition. The deaf, for example, may need a range of modifications including flashing alarms and telephones and access to a computer. Concerns about the suitability of the stock, therefore, are not limited to one type of disability or set of circumstances.

Owner occupiers who participated in the focus groups believed that they were fortunate that they were able to live in their own homes because they were not confronted by the stress of uncertainty over their future living arrangements. Home owners were seen to be better off because they could undertake modifications to their dwelling, while tenants were confronted by housing that was unsuitable in many instances and landlords were often unwilling to sanction modifications. Even when changes were approved, tenants could not be secure in their tenure and might lose the benefit of such changes when the lease expired. Modifications were a significant challenge for private tenants for two reasons:

- It was financially impossible to carry out modifications on premises that were not ideally suited to the modifications required. As one renter stated, 'different disabilities require different housing modifications';
- Landlords were not receptive to modifications being carried out. One participant had undertaken modifications to their bathroom and considered these to be very minor. However, they reported that they were harassed by the landlord over this matter.

Owner occupiers also voiced their concern at the expense of modifications. One person had door handles lowered, light switches lowered and remote controlled doors installed and this cost approximately \$50,000. Many home purchasers could not afford both the cost of their loan repayment and the modifications. The absence of some modifications adversely affected these people. Most prominent among the desired modifications was the provision of access for wheelchairs and this usually involved ramps and doorway widening. Other frequently sought changes were-repositioning of door handles, easier access to light switches, bathroom modifications, installation of grab handles and removal of carpet.

A group of carers in Sale noted that each had put substantial effort into modifying their home to meet the needs of a wheelchair-bound relative. Two had spent several thousand dollars adding handrails, removing steps and grading paths to link outside areas to doorways. One, a former builder, had completely rebuilt their home to meet his wife's needs:

We had a nice old house, but after the accident my wife was in the chair. So we bulldozed the old house and built a new one. I like it because of the garden and it's suitable for my wife. During her rehab I gained a good understanding into what wheelchairs require. So it all came together.

Tenants in public rental housing had a generally positive attitude to the Office of Housing and it was praised for keeping maintenance up to date and for making minor amendments to the housing stock, such as the addition of grab rails and ramps. However, tenants were concerned that the Office would not consider more substantial modifications. For example, a couple who had a house built for them by the Office of Housing at Broadmeadows asked for kitchen benches at wheelchair height. This was refused on the basis that it might reduce the future capacity to let the dwelling to other tenants. From the qualitative in-depth interviews conducted by Saugeres (2008) as part of NRV2, one woman aged 60 described her difficulty in trying to get more suitable accommodation for her disabled grandson. Only by contacting her MP was she finally able to get the accommodation that allowed her to continue to provide care:

I needed a house with no steps because I had to open big double gates because the ramp was at the back of the house. That meant in winter he was getting soaking wet before he could get into the house. I needed a big bathroom, where the one we had, I couldn't put his wheelchair in. I needed a hoist on the ceiling because the hoist I was using, if you put him in a manual hoist it swings, the sling will swing like a swing. Now I can't push a manual hoist and hold him at the same time – it's impossible. I needed a safety door where he couldn't get into the kitchen when I was cooking, I didn't have that (Saugeres 2008, p. 12).

Carers of persons with a disability in Gippsland who were renting from the Office of Housing appreciated their tenure but felt that the stock was not always suitable. They noted that funding for the remodelling of public housing is available but *'you can wait a long time'* and *'everything is a compromise'*. One explained how she liked a bath but had to move from a house with a bath to a home with a bathroom more accommodating of her partner's disability. In addition, they had to relocate from Morwell to Traralgon to enter public housing and to be closer to services, and this meant moving away from family and familiar schools.

6.1 Housing and transport

Discussion of the suitability and accessibility of the housing stock inevitably results in consideration of access to transport and especially public transport. Many people with a disability rely upon public transport because they do not hold a licence or cannot drive. Focus group participants in Melbourne reported that while they frequently used taxis, these were often seen to be unreliable, especially for persons in wheelchairs, as access cabs prefer customers whose transport needs can be dealt with more quickly and simply. They generally reported a very high level of public transport use and a generally good quality of service. Not all regions were equally served, however, with some people noting the challenges of finding housing that was both close to public transport and affordable. For many of those with a disability, there is a very sharp trade-off between house prices and access to public transport that has shaped their housing decisions.

As would be expected, people in rural areas reported much poorer access to public transport. The focus group participants in Sale who were carers stressed the importance of transport:

You can't talk about housing without talking about transport. It's quite easy for transport in general. But there is only one bus. If you live in a country town with a disability, life is dramatically different if you can't drive.

Most relied upon cars as there is little public transport. They used trains to get into Melbourne when required to travel to medical appointments or attend family events.

All the participants in the focus group drove a car, and the person they cared for was reliant on them for their mobility and access to services, socialisation and shopping needs. When asked what they liked or disliked about their current housing and where they lived, they all generally liked the structural form of their housing but disliked the location relative to suitable transport. Access to services, principally transport, was a major concern, and the low level of train services to Melbourne made getting to medical specialists a very substantial logistical exercise:

Travelling to appointments and accessing various services was all the more difficult if you could not drive and it was a big effort to get to Melbourne to doctors and required a 5.30 start in the morning and getting home at 10.30 or 11.00 o'clock at night.

Participants were unanimous that the scheduling of rail services to larger centres from Sale and Bairnsdale was poor and that this should be improved as there were no buses. Those with a disability who lived with these carers also believed that inadequate public transport was a major impediment to achieving independence in their lives. Many would like to move and the main reasons were the lack of public transport and the limited opportunities and activities in Sale. One said he would like to move to Melbourne as the younger have better options and access to a broader range of activities: *'Spare parts [for wheelchair] are also more accessible and I don't have to wait 2 to 3 weeks as I do now'*.

Overall, the accessibility and unsuitability of much of the Australian housing stock is a major impediment for many persons with a disability and their carers. Tenants reported having a limited number of dwellings they could move into because they simply could not live in many of the dwellings available in the market. Properties need to be accessible to public transport and have a physical structure that facilitates independence within the dwelling and property. Owner occupants were also affected by the dual concern about access to transport and the suitability of the stock because while some funding is available in Victoria from the Department of Human Services to modify the family home, it is a modest amount and would quickly be eroded by extensive renovations to a property.

6.2 Access to services, social and support networks

The lack of available transport and the need to be closer to services can be a significant driver of changes in housing for households with persons affected by a disability, while the need to find suitable housing can distance households from their social networks. A number of interviewees had moved from the country or the outer suburbs of Melbourne to be nearer to services such as special schools, support services and programs. For example, a male sole parent aged 60 with an intellectually-disabled child moved from his home and place of work as a town planner in rural Victoria to a home he owned in Melbourne for the sake of his son:

I decided for his future it would be best for him to be in the city ... just better services ... support agencies and all that sort of thing. I had been trying to work and I had a job that required me to go to lots of meetings at night and so on, while I was there, and some of these would be called at fairly short notice, so I was always having problems trying to find someone to look after him while I was at meetings and things. So anyway, I'd taken a redundancy payment, so I was able to come back to the city (Saugeres 2008, p. 12).

Some people with a disability reported that they were not happy with their living arrangements because they lived with their families (in their parents' home) or rented a dwelling from the Office of Housing that was distant from family, friends or support

services. For example, a wheelchair-bound woman aged 52 lived in a house in Darebin with her son that she rented from a housing association. She would have preferred a home in a suburb closer to the CBD where she had family and friends. She would have liked to be closer to the city, primarily for her son's sake: *'All his friends were around Carlton and Brunswick. I thought, for his sake, and again most of my friends'*, but believed that *'if I didn't take this place I could have been sent even further out'* (Saugeres 2008, p. 18).

Another participant who was wheelchair-bound and living with his parents was unhappy with their move from the inner city to an outer western suburb:

I don't like the location, Richmond was a lot better, more central to everything, everything like was around the corner. Now, yeah, if I wanted to go to the shops it's sort of a lot more harder for me now and I'm further away from things ... Like work and, you know, some friends and stuff like that ... If it was my choice I would've stayed in Richmond, because I know the community, I know the neighbours (Saugeres 2008, p. 18).

Clearly, trying to balance the need for suitable and appropriate accommodation and the need for access to services, social networks and transport is very difficult and highlights the limits on choice available to many households.

6.3 Need for care and assistance

The need for care and assistance from others, particularly from the informal sector, that is, family and friends, often has a significant bearing on the housing choices and housing outcomes of people with a disability. Many need care on either a part-time or full-time basis. While some are able to manage to live independently with the help of professional carers, most are reliant on a family member living close by or they need to live with family members as there are few acceptable alternatives. One parent (aged 63) with a son with MS was concerned about what would happen if the son's current live-in care ceased, as he was ageing and felt it would become too difficult to provide for his son. He was willing to use his own money with the assistance of agencies to set up a house where a number of people with a disability could receive care for an extended period of time:

My dream with this thing was to build a complex, if you like, that would have something like 14 or 15 young physically disabled people in it at different levels of disability. We might have, say, four single bedroom units for people who just need a little bit of supervision or a little bit of help or a little bit of guidance, so they're pretty good, they can live in there, almost no care. Then we would have people that, say, where Jade is now where they need help for, you know, four or five hours a day. They need help in the morning, they need help with their meals and medication and so forth. And then you would have another four or five people who need 24/7. Which means that these people can move in here and say, gee, I can stay here for life, right? (Saugeres 2008, p. 30).

While this parent had received support from the Victorian government's Affordable Housing Unit, complications had delayed the project for over two years.

The lack of supported accommodation suitable to the needs of people with different types of disability not only severely restricts the options and choices available to them, but caring for someone with a disability can place limitations on the opportunities, expectations and housing outcomes of carers.

7 THE ROLE OF CARERS AND THE IMPACT OF CARE RESPONSIBILITIES ON HOUSING CAREERS

Family members take on a very considerable workload and care responsibilities in providing assistance for their relatives with a disability. Amongst the focus group participants there was a view that providing care was more than a full-time occupation: that they were on call 24 hours a day, seven days a week. It was seen to dominate all other aspects of life such as ability to find employment and time to pursue social activities. There was a general consensus that there was no time for anything else – *‘there is no other life’*. From a housing career perspective, this means that one or more adults within the household are unable to engage in full-time work, thereby lowering household income, while the disability itself has the potential to add to medical and other costs. For example, none of the carers in the Sale focus group worked due to their status as full-time carers and the associated burden on their time. The financial impact of this was a major theme. As one woman said:

X was born with a disability. It is a huge financial adjustment to live with a person with a disability and support a person with a disability. This is before any costs related to modifications of the house come into it.

Carers commonly rely upon either the carers allowance or the carers pension, the later of which is more generous – equivalent to the age pension – but means tested. Three of the four carers in the Sale focus group received the carers allowance and only one received the carers pension. The lower disposable income available to households where someone is providing care to a person with a disability limits their available choices in the housing market. The financial burden is clearly portrayed by the plight of one family interviewed for Project E (Saugeres 2008). Sole reliance on the carers pension and the need to provide care 24 hours a day to twin daughters with severe disabilities, as well as providing for the needs of a son with attention deficit hyperactivity disorder, has left one couple unable to meet their expenses, forcing them to place their adaptable mortgaged house on the market. This has serious consequences for the care of their twin girls:

Housing is always a problem, if I had to go into a rental now, and it is a big possibility still at this stage. But if I went into rental, there is nowhere available that would cater for my girls ... which basically means that I would have to give up the girls and I would have to put the girls in permanent care. Which is dumb. Because the government has got nowhere where they can put them ... the chances are, my girls would be split up, which is not fair on them either ... There is not enough out there. Kids like ours, there is a fair chance my girls would end up in somewhere like a nursing home, if they were put into permanent care, because there is nowhere else to put them. And that is not right (Saugeres 2008, p. 24).

Many respondents believed the carers pension and carers allowance did not reflect the amount of work or the costs associated with caring for someone with a disability.

Some people with a disability receive care assistance provided by the state government, and in Victoria this is provided by the Department of Human Services. The level of assistance is determined on the basis of need. For family members who provide care, this external assistance is an important form of respite. For example, the mother of the daughter with an acquired brain injury felt she (and her daughter) were very fortunate to receive around 30 hours a week of care (five hours a day, six days a week). This care included housework, shopping and taking her daughter out into the community. This released the carer to go away at times and to do voluntary work for

disability organisations such as Headway Victoria (an advocacy and information service for people with acquired brain injuries). Respite was an important issue for many carers who felt that their responsibilities limited their involvement with sporting, social and other groups, as caring is a '24/7' responsibility. They noted that providing care is both mentally and physically tiring and, to a certain extent, socially isolating. One carer in Gippsland commented on the partial nature of any release from care responsibilities:

My husband usually tells me when I should shower him. When I get help they shower him and I get a break and get to read the newspaper. It's the frustration and it is mentally tiring. When a carer gives you time off, you can't really leave the house, you have to see them in. You get to read the newspaper and have a coffee, that's about it.

It is important to acknowledge that, in the overwhelming majority of instances, care paid for by governments is supplementary to that received from family members. One focus group participant received two or so hours per fortnight of paid care with assistance provided in cleaning the house, others had three to four hours per week, seven hours per week, ten hours per week and one had more than ten hours. All strongly emphasised that family and friends contributed large amounts of time to their care and in nearly all cases this was unpaid. Any paid care to family members was minimal and the focus group participants felt this needed to be addressed. One expressed their dissatisfaction at the poor level of funding available to family carers:

I would love someone from government to come along and experience our lives for a couple of days as they would soon realise the difficulties we face.

Many carers recognised that they in turn would benefit if the person they cared for had a wider range of housing options available to them, including a capacity to live with a greater degree of independence. The ability of a younger person with a disability to move out of the family home would open up housing opportunities for their parents:

At this stage of our life we all deserve a better lifestyle. Quality of life, safety, how can we guarantee this for her? We can't think about pensions or retirement because of the need to provide for her and ensure she has a future.

People of a similar age who are not carers of someone with a disability have greater choices. Preparing for life after being a carer (if that happens at all) is put on hold due to the drain on finances and time:

We have to replace the car, the daughter wants to leave home, these costs are huge. My husband is four years from 60 and wants to stop working someday!

For carers and persons with a disability alike, the prospect of carers no longer being able to provide support is challenging because they can see few attractive alternatives. For example, one older person in a Morwell focus group summed up their resignation at not knowing what will happen in the event of losing their spouse by saying *'I will get a spot outside the cemetery and wait'*. Carers, especially older ones looking after their now adult children, expressed similar sentiments as they were all well aware of their inability to maintain their responsibilities indefinitely. Such concerns may not directly affect the housing careers of persons with a disability and their carers, but they do raise significant issues of public policy as de facto disability policy in Australia relies heavily upon family members to provide care. Shifts in attitudes towards the provision of care would have a significant impact on the demand for more formal assistance, which in turn would affect public sector outlays. Policies and programs that could assist carers in providing support for their family members for

longer, and which offer the prospect of an attractive alternative in the foreseeable future, could both improve the quality of life for carers and persons with a disability, as well as limiting demands on public outlays.

8 HOUSING CAREERS BY TYPE OF DISABILITY AND HOUSING CAREERS OF CARERS

As discussed previously, the type of disability, and when and how it was acquired, can significantly affect a household's housing career. This section examines the variability in the housing careers of people with a mobility impairment, developmental disability, psychiatric disability and sensory disability. As Figure 2.1 indicates, how disability affects the housing transitions of an individual or household varies considerably according to the nature of the disability, the severity of the disability and the way in which the disability was acquired. The *Housing 21* survey provides some indications of the way in which disability shapes housing outcomes, but it provides no indication on any of these three dimensions. To overcome this gap, a specialised disability survey was undertaken in Victoria, focused on three regions: Gippsland as an example of a non-metropolitan region; the region in and around Darebin, an inner metropolitan area; and Melton/Brimbank as an example of an outer metropolitan region. Data collection was further focused on four disability groups and associated family members with care responsibilities: persons with a mobility impairment, persons with a sensory impairment, persons with a psychiatric disability, and persons with a cognitive impairment. In all instances a modified version of the *Housing 21* survey was applied, in order to facilitate comparison with that national data collection instrument. The survey instrument had to be truncated considerably for application to persons with a cognitive disability, and in other instances it was modified to reflect the potential impact of disability on housing career.

In total, the disability focused survey set out to complete 600 interviews, with participants recruited through advertisements in newsletters (e.g. Wheelchair Sports Association of Victoria), email lists (e.g. Victorian Women with a Disability Network, Blind Citizens Australia, InfoXchange), snowball recruitment, through the assistance of non-government organisations (e.g. Carers Australia) and through the efforts of rural access workers in Gippsland. Data collection for this phase of the project commenced in November 2006 and continued until November 2007.

The survey instrument used in this research was a modified version of the *Housing 21* questionnaire. In large measure the *Housing 21* survey was maintained in order to ensure comparability between these findings and those for the Australian population as a whole. However, some changes were necessary in order to gain information on key aspects of the housing of persons with a disability and carers. In addition, the survey instrument administered to persons affected by an intellectual disability was substantially shortened – from approximately 40 minutes to 10 minutes.

Table 8.1 presents data on the number of surveys completed. In total, 281 interviews were completed with persons affected by disability, and 137 with family members with care responsibilities. Several factors contributed to our inability to achieve our targets for the data collection exercise for persons with a disability:

- The targeting of regions and disability groups limited the potential pool of respondents, thereby complicating the data collection process and ruling out some data collection strategies;
- In some cases, organisations believed they had the capacity to assist us in completing large numbers of surveys but found that they could not deliver against this expectation;
- Some members of target groups refused to participate because they did not believe they had a disability;

- The concept of a ‘carer’ does not have validity with some disability groups. For example, the focus group with persons with a disability highlighted the way in which few lived with a person who could be considered a ‘carer’;
- There is some evidence that the population affected by disability is over-studied, with potential respondents ‘burnt out’ from repeated exposure to data collection;
- The use of the general questionnaire from the *Housing 21* survey – an explicit component of the study in order to deliver data that is comparable between the mainstream and disability affected populations – discouraged some respondents who found the questionnaire too long and not relevant to their circumstances;
- Some organised events did not have the expected number of participants and this contributed to either under- or over-sampling of a particular group;
- Finally, it is important to acknowledge that we did not anticipate the complexity of the lives of some households affected by disability, with some affected by multiple disabilities.

Despite these failings, substantial data was collected and this represents an important breakthrough in research on housing and disability in Australia. The results of the analysis of this survey will complement the data collected through the *Housing 21* survey and provide a more detailed understanding of the housing circumstances of persons affected by substantial disability. The questionnaires were completed through a range of methods: in some instances telephone interviews were undertaken by members of the research team; some questionnaires were completed via face-to-face interviews at the premises of service providers, others were administered by service providers on behalf of the research team and a substantial number were completed by VisionAustralia via telephone interview. Overall, the use of a flexible, mix methods approach to data collection ensured an adequate number of responses and an appropriate spread of data collection across target groups and regions.

Table 8.1: Achieved data collection framework for disability focused research

	<i>Gippsland</i>	<i>Inner Melbourne</i>	<i>Outer Melbourne</i>
Sensory disability	32	17	7
Carers of persons with a sensory disability	9	8	1
Mobility impairment	21	7	22
Carers of persons with a mobility impairment	4	2	16
Psychiatric disability	27	19	41
Carers of persons with a psychiatric disability	1	24	3
Cognitive impairment	25	10	9
Carers of persons with a cognitive impairment	14	23	15
Other/multiple disability	25	10	9
Carers of other/multiple disability	1	2	14
Total	159	122	137

8.1 Psychiatric disability

The qualitative research of Kroehn et al. (2007) and Saugeres (2008) undertaken as part of NRV2 clearly highlights the disruptive effect of a psychiatric disability not only on housing careers but on every aspect of a person’s life. The episodic nature of the illness, resulting in high levels of unemployment, reliance and dependency on the DSP, and consequently low incomes, restricts choices within the housing system. For

these people, moving house is often a recent and recurrent phenomenon through the private and public rental systems.

Many of these people are single as they find it difficult to maintain good relationships with others, including family, and as a consequence they do not have strong networks of support from family and friends as is the case for other disability types. Whereas people affected by other disabilities are often highly dependent on the support provided by family, Saugeres (2008) for example found many with a psychiatric disability could not turn to their families for support (even though some did against their better judgement in times of crisis) because the families could no longer deal with their circumstances, or the person had been abused by one or more family members earlier in life.

The lack of interaction with family and friends, poor engagement with social welfare and other support agencies, and inability of some persons with a psychiatric disability to make responsible decisions, makes this group particularly vulnerable to social isolation and poor housing outcomes. This has the capacity to heighten the impact of their illness. Unsuitable and inappropriate housing outcomes include boarding houses, caravans and ultimately homelessness. Their lack of financial and human resources makes them particularly vulnerable to living in situations of risk involving abuse, drugs and alcohol.

Housing assistance is essential to the maintenance of stability in these people's lives and, though many who were interviewed were currently living in public housing, for some this had taken several years to access. Many do not find stable housing until assisted and supported by case workers or agencies such as Alcohol Related Brain Injury Australian Services (ARBIAS). This support in many cases needs to be ongoing, because persons with a psychiatric illness may make poor decisions, including choosing to not take medication. Such behaviour increases the risk of psychotic episodes and hospitalisation, or threatens their housing situation by increasing the risk of eviction (Saugeres 2008; Reynolds, Inglis and O'Brien 2002).

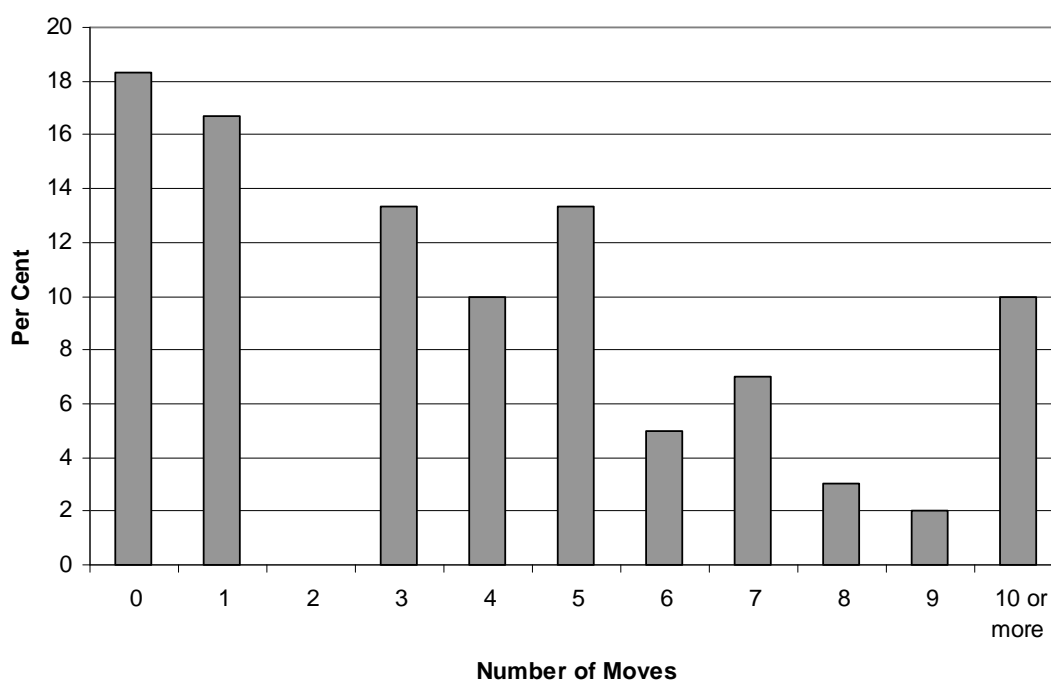
Seventy-seven persons with a psychiatric disability responded to the specialist survey of persons with a disability, with most aged 25 to 55 years. Fifty-five per cent lived by themselves and 31 per cent lived in a household with just one other person. Half lived in a flat, unit or caravan park, while 39 per cent lived in a separate house. Seventy-one per cent were renting. This outcome is partly a function of the way in which participants were recruited for this part of the study, with accommodation and service providers collecting the data on our behalf, but it is also likely to reflect a more general trend. Sixty-one per cent of tenants (and 42 per cent of all respondents) rented from the Office of Housing, with a further 22 per cent renting from real estate agents and 5.6 per cent from a parent or other relative. Over 27 per cent of respondents had applied for public housing at some stage and 13 per cent were currently on the waiting list. Over 55 per cent of tenants reported that they rented because they couldn't afford mortgage payments. Only 8 per cent of our respondents were home owners and 9 per cent were paying off a mortgage.

Persons with a psychiatric disability were relatively satisfied with their dwelling with respect to both their current needs and their needs in five years time. Unlike the mobility impaired (discussed elsewhere in this report), they do not require physical modification of the dwelling stock and are therefore more likely to report satisfaction with the dwelling. Access to support services, however, presents different challenges and is an important reason why 49 per cent indicated that they would like to move. In large measure they indicated that they wished to move for personal reasons (including disability and health), in order to live by themselves and to improve access to family and other social contacts. Importantly, as Figure 8.1 demonstrates, persons with a

psychiatric disability tend to be very mobile through the housing market as they struggle to maintain stable housing. Forty per cent of respondents had moved five times or more over the past decade.

Of the 77 persons affected by a psychiatric disability within the specialist survey, 47 per cent reported that their disability had been present throughout their life, with the remainder indicating that it was more recently acquired. Fifty per cent of persons with a psychiatric disability reported that living close to services and support was a very important part of their lifetime housing goals and a further 36 per cent said it was an important component.

Figure 8.1: Number of times persons with a psychiatric disability have moved, 1996-2006



Source: *Housing 21 Survey*

In common with some other disability groups, the location of the home was either very important (50 per cent) or important (40 per cent) to persons with a psychiatric disability, and this finding is consistent with the qualitative material collected as part of Project C (Kroehn et al. 2007). The investment dimensions of housing were relatively unimportant (with 30 per cent saying it was unimportant), as was proximity to employment and family.

Forty-two per cent of respondents recognised that their disability had been important in shaping their lifetime housing goals and almost 80 per cent felt that they had been very successful or somewhat successful in achieving these goals. Sixty-seven per cent acknowledged that their health had been a very important influence on their housing decisions across the life course.

Unlike some other groups, few persons with a psychiatric disability reported that they needed assistance with self-care, though 18 per cent reported that they required help with caring for their health and 43 per cent needed assistance with communication. Over half relied upon others to assist them with transportation and 40 per cent needed assistance with property maintenance. Thirty-nine per cent of respondents with a psychiatric disability indicated that their needs for assistance were only met in part

and 5.6 per cent believed their needs for assistance were not met at all. Assistance was provided from diverse sources, including partners (13 per cent), parents (26 per cent), children (10 per cent) and other relatives (8.6 per cent). Government (14.3 per cent) and non-government organisations (14.3 per cent) were also important sources of help and are far more prominent in the pattern of care-giving than for other disability groups. Importantly, then, one of the determinants of difference in housing transitions between disability groups is the varying patterns of assistance each receives.

Twenty per cent of persons affected by a psychiatric disability who responded to the survey lived with at least one other person with a disability. However, 40 per cent lived by themselves and this is a very atypical household structure compared with the Australian population as a whole. Forty-seven per cent had never married or formed a permanent relationship, 13 per cent were separated from their partner, and 19.5 per cent were divorced. Only 16 per cent were currently married and 4 per cent were living in a de facto relationship. This is a very distinctive household structure which inevitably generates housing careers that are not shared with the broader community. Critically, 40 per cent of persons living in a household with at least one other person shared their living arrangements with another person with a disability.

Very few persons with a psychiatric disability had full-time employment (31.1 per cent) with 35 per cent reporting that they were unable to work because of disability pension or WorkCover issues, and 15 per cent working part-time or casually. Seventy-seven per cent of respondents received the DSP, and a government pension or allowance was the major source of income for 94 per cent of households. Incomes for this group were very low, with 34.5 per cent of respondents with a psychiatric disability reporting a household income of less than \$12,999 and 90 per cent less than \$26,000.

8.2 Mobility impairment

The housing circumstances of people with a mobility impairment vary depending on whether the disability is a lifelong condition or more recently acquired as the result of an accident or medical condition in adulthood.

The housing careers of people affected by long-term mobility issues differ substantially from that described above for people with a psychiatric disability. Some had moved a number of times through the rental system, often to seek independence and then often returning to the family home for long-term stability and support. One of the most significant differences between this group and those affected by a psychiatric illness is that most are helped by family members with their housing, either financially or by being able to continue living with the family in adulthood. This places a considerable burden on many families as modifications are needed to the home to accommodate the disability, and care is generally required on a daily basis. While people with a long-term mobility impairment may have periods of employment, the nature of their disability and changes in their health levels over time mean many are unable to sustain long productive periods in the work force, limiting their access to home ownership. Some households are able to afford home ownership through assistance from family or partners but many are reliant on the public rental system.

The housing career of a person affected by mobility impairment later in life is generally much more stable as these people often owned or had substantially paid off their mortgage at the time of becoming disabled. While other forms of accommodation may be necessary while the family home undergoes modifications, most return to the family home but now require support and assistance from partners and family members. Being able to sustain home ownership in the event of an accident, however, is difficult for some. One focus group participant who had acquired his disability in the last five years had lost his job and as a consequence could no longer

afford the mortgage payments, selling the home and moving into rental accommodation. This was very disheartening as they now lived in an area determined by the availability of rental properties. It was not where they would like to live and the uncertainty of the rental market affected them in a negative way. The participant had to accept rental accommodation in areas where there was easy access to services. The rentals that met this criterion did not offer accommodation to suit their needs (Kroehn et al. 2007). The provision of care and support is vital to the stability of housing for people with a mobility impairment.

Data collected through the disability focused survey provides quantitative insights into the housing transitions with a mobility impairment. Forty-nine valid survey responses were analysed for this group, with most respondents aged 45 to 54 years. Two-thirds lived in a separate house, with a further 20 per cent in a flat, unit or apartment and 10 per cent in a semi-detached home. Forty-five per cent lived in family households, 25 per cent in single person households and another 25 per cent in couple only households. Five per cent lived in a group household of unrelated people. Approximately half the respondents had a mobility impairment for all or most of their lives, with the remainder acquiring an impairment in adulthood.

Persons with a mobility impairment were much under-represented in home purchase, with just 14 per cent buying a home, compared with 39 per cent outright owners and 37 per cent renting. Four per cent lived rent free and a further 4 per cent lived as a dependent with their parents. Fifty-six per cent of tenants with a mobility impairment rented from a State Housing Authority and a further 6 per cent rented from a co-operative or equivalent organisation. Just 18 per cent of tenants with a mobility impairment rented from a real estate agent and 35 per cent of tenants with a mobility impairment had applied for public rental housing at some stage of their life. Thirty-two per cent of tenants with a mobility impairment had been owner occupants, and this finding is consistent with the discussion elsewhere in this report that the onset of disability frequently results in households 'falling out' of home ownership. Just under half of tenants with a mobility impairment reported that owning their home one day was important or very important to them, but 20 per cent said it was unimportant. However, 90 per cent of tenants with a mobility impairment did not expect to enter home ownership in the next five years, and the contrast with the expectations of the general population of tenants is stark.

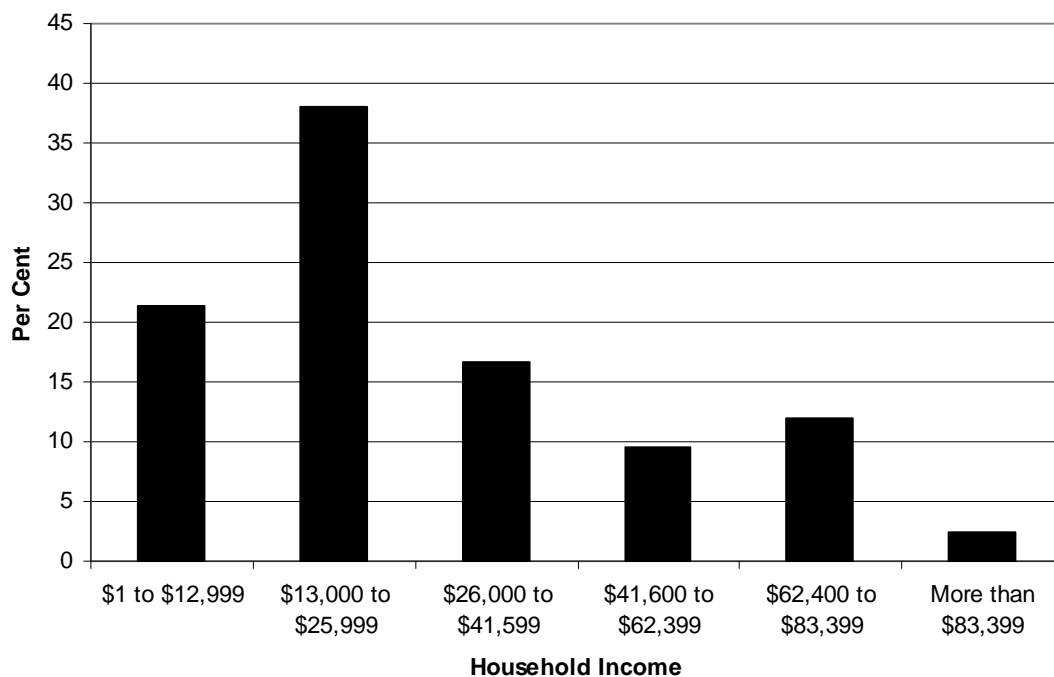
Just over one quarter of respondents with a mobility impairment had undertaken major renovations of their home because 'the house was not appropriate to needs' (eight respondents), to 'avoid the costs of moving' (one) and 'to adjust the house for a person with a disability' (nine). Clearly, the challenges of living in the housing stock drive many households affected by a mobility impairment to modify their dwellings. Half the respondents reported that their current dwelling fits their needs very well, and a further 28 per cent said it met their needs well. However, 19 per cent believed that their home did not meet their needs well at all. Participants in the survey were more concerned about how well their present home will meet their needs into the future, with 19 per cent indicating that they did not believe their home would meet their needs very well in five years and 9 per cent indicating that their home would not meet their needs at all. Respondents indicated that insufficient finances, the absence of continuing employment and the lack of suitable housing options prevented them from moving to more appropriate housing. Forty-two per cent of households affected by a mobility disability had not moved dwelling in the decade to 2006, and 29 per cent had made only one move. This data reinforces the argument that households where a mobility impairment is present have a limited capacity to move through the housing market and secure housing that better meets their needs.

Mobility impaired respondents to our survey reported attitudes to housing through their life course that differed from the general population: they were less likely to attach value to the material/asset dimension of housing, but were more likely to value highly the physical environment of the dwelling and the access it offered to services. Only 31 per cent rated as very important the capacity to live close to work, but 63 per cent considered living close to services and support a very important feature of housing. In addition, 78 per cent acknowledged that their disability had been a very important determinant of their lifetime housing goals and 66 per cent felt that their health had been very important in shaping their housing decisions.

Most respondents (98 per cent) with a mobility impairment needed some assistance or care and while 54 per cent said their needs were fully met, 43 per cent said their needs were only met in part. Partners (58 per cent), parents (12.5 per cent) and children (4.2 per cent) were very important sources of assistance, with government provided care of first order importance for 10 per cent. The provision of care is a significant issue, especially given that 30 per cent of respondents reported that at least one other member of the household had a disability.

Relatively few respondents with a mobility impairment were engaged with the labour market, with 6 per cent in full-time employment, 31 per cent in part-time or casual employment, 12 per cent unemployed, 20 per cent retired or engaged in home duties, and 26.5 per cent unable to work because of WorkCover compensation arrangements. Two-thirds of respondents received the DSP and that was the major source of household income for 57 per cent of households and this in turn contributed to low household incomes: 21 per cent had a household income of less than \$13,000, 60 per cent less than \$26,000 and 76 per cent less than \$42,000 (Figure 8.2).

Figure 8.2: Household income for persons with a mobility impairment



Source: *Housing 21* survey

8.3 Cognitive impairment

Twenty-nine persons with a cognitive disability participated in the disability survey and they ranged in age from 22 to 61 years, with a mean age of 40 years. It is important to

note that all members of this group had a developmental disability, rather than a cognitive impairment acquired later in life. Twelve of the respondents were male and 17 were female. Just under half lived in a house and 16 per cent lived in a flat, unit or apartment. Twenty per cent lived in a community residential unit and 7 per cent lived in other supported accommodation. Forty per cent of respondents lived with their family, 20 per cent with friends and a further 20 per cent with other unrelated adults. Only 13 per cent lived by themselves.

Seventy per cent of the respondents affected by a cognitive impairment paid rent or board and many reported very stable housing careers: only 22 per cent had lived in their current dwelling for less than five years and 6 per cent had lived in the same dwelling all their life. Just over 55 per cent had not moved at all within the last ten years, and 41 per cent had moved up to three times. This data supports the argument that this population group typically experiences a very stable or 'flat' housing career.

Respondents reported very favourable attitudes to their current housing, with few looking to move and most valuing their home for the people and relationships embedded in that place. Only 12 respondents worked, mostly one or two days a week. Family members were nominated as the most important care givers in their life, with staff from support organisations the second most important source of care and assistance. Cooking, assistance with transport and help with craft activities were the main forms of assistance reported.

8.4 Sensory impairment

The housing careers of people with a sensory impairment such as a hearing or vision impairment can vary considerably depending on whether they have partners and are able to participate in the workforce. Fifty-two persons with a sensory disability participated in the focused survey, with almost 90 per cent of interviews completed via telephone interview conducted by Vision Australia. The results, therefore, provide a snapshot of the vision-impaired population rather than persons with a hearing disability. The population interviewed was an older group, with 47 per cent aged over 75 years and 72 per cent aged over 54 years. Sixty per cent had had their disability for their entire lives and 34 per cent were married, 19 per cent widowed, 15 per cent divorced and 23 per cent had never married. As would be anticipated given the age distribution, 43 per cent lived by themselves and 38 per cent lived with one other person. Fifty-eight per cent lived in a separate house and 30 per cent lived in a flat, unit or terrace house. Single person households dominated at 38 per cent of the total, followed by couple households (32 per cent) and family households (23.6 per cent).

Outright home ownership was the largest single tenure amongst the sensory impaired, accounting for 47 per cent of the total, followed by 33 per cent in rental housing and 11 per cent paying off a mortgage. Another 5.5 per cent had been given life tenure of their property by a relative and 3.6 per cent were living rent free. No other disability group reported similar levels of direct family assistance with housing. Only a small percentage had renovated their property or intended to do so in the foreseeable future.

Exactly half the persons in this category who were renting their property rented from the Victorian Office of Housing, with 25 per cent renting from a private real estate agent, 18 per cent from a relative and 6 per cent from a community housing group. Nine of the 16 sensory impaired persons renting their housing had previously been owner occupants and 80 per cent of this group that had fallen out of home ownership had changed tenure because of the difficulty of affording mortgage repayments. Eighty-five per cent of this group did not expect to enter home purchase in the next five years.

Most persons with a sensory disability believed that their present home suited their needs well (38.8 per cent) or very well (57.1 per cent). They anticipated that their housing would continue to meet their needs over the next five years. That said, one quarter of respondents indicated that they would like to move to a different home, though few expected that this would happen. Finances and the lack of ongoing work were the major impediments to relocation. Overall, the sensory impaired – consistent with their age profile – were a stable population, with 61 per cent not moving at all over the previous decade and 24 per cent moving once only.

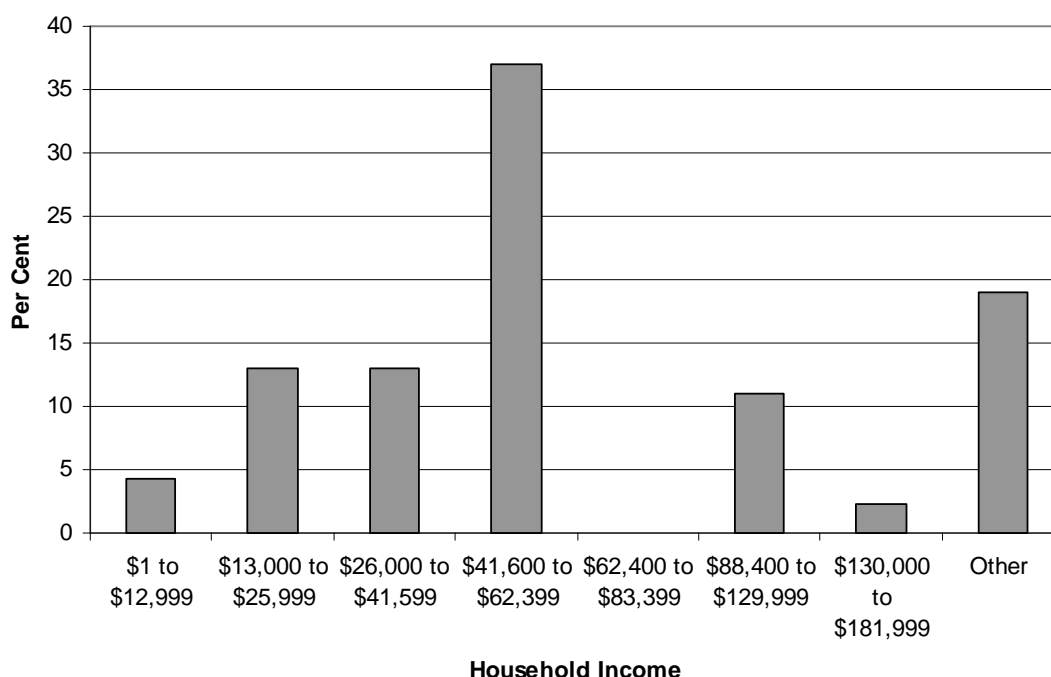
In common with the other disability groups discussed, persons with a sensory disability placed a great emphasis on the location and/or environment of their housing. Forty-one per cent considered location had been very important in shaping their lifetime housing goals and 34 per cent believed it had been important. Just under 50 per cent indicated that being close to amenities had been a very important influence in shaping their lifetime housing goals and 30 per cent said it was an important influence. Similarly, 44 per cent rated living close to services as an important influence on lifetime housing decisions and 20 per cent considered it important. Clearly, for all disability groups, the ability to gain ready access to services is one of the key drivers of their lifetime housing decisions. Persons with a sensory disability also recognised that their impairment had shaped their lifetime housing goals, with 39 per cent assessing it as very important and 32 per cent as important. Seventy-three per cent believed they had been very successful or successful in achieving these goals.

The respondents with a sensory disability required less care and assistance than some of the other groups covered in the disability focus survey. Only 25 per cent needed assistance with self-care and 26 per cent needed help with health care. Just over one-third needed assistance with the preparation of meals and one quarter needed help with communication. Twelve per cent needed assistance with mobility, though 57 per cent needed help with property maintenance and 30 per cent with housework. While 70 per cent needed assistance with transport, the need for assistance with routine tasks appears limited, emphasising the relative independence of this group. Sixty per cent of respondents believed their care needs were fully met, while 32 per cent indicated that their needs were partially met and the remainder reported that they had no need for care. The provision of care largely fell to partners (40 per cent), parents (25 per cent), other relatives (10.4 per cent) and children (8.4 per cent). Government providers were nominated as the most important care givers in 8.3 per cent of cases.

Just over half the population with a sensory disability were employed part-time or casually and 14 per cent were employed full-time. Intriguingly, the rate of employment was the highest of the four disability groups considered in this report, despite their elevated age profile. Sixty per cent received the DSP and 17 per cent received the age or widow's pension, and for 78 per cent of households a government pension was the major source of income.

Persons with a sensory disability (Figure 8.3) reported the highest household income of any of the disability groups, although their incomes were still modest relative to the total population.

Figure 8.3: Household income for respondents with a sensory disability

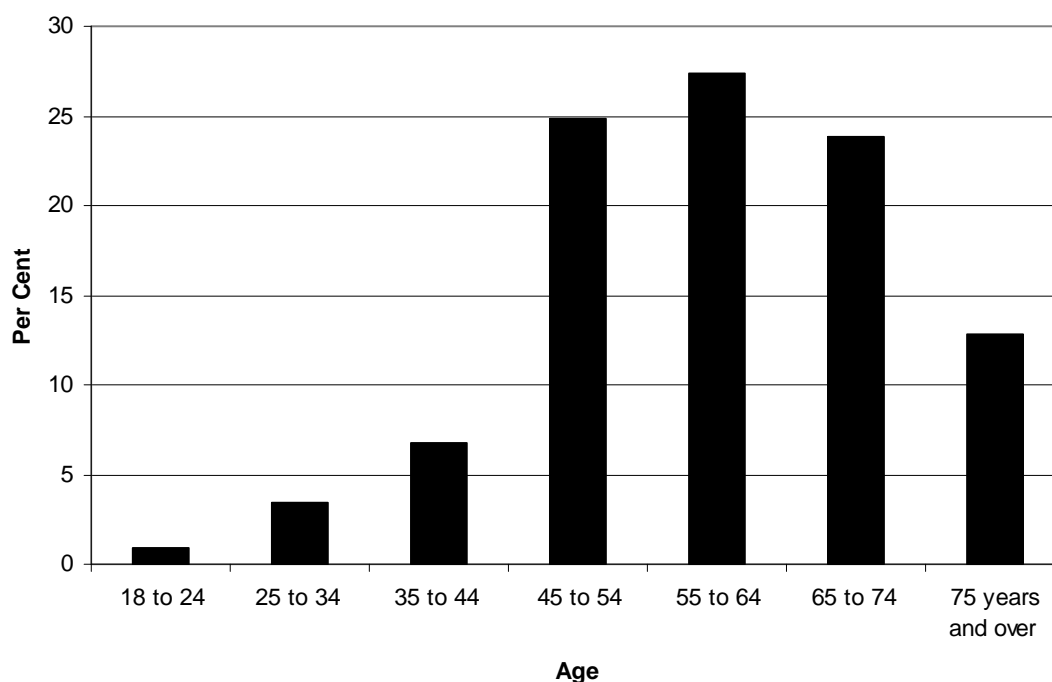


Source: *Housing 21* survey

8.5 Carers

Family members who provide support for people with a disability have housing careers shaped by their care responsibilities. Providing care can have a significant impact on families and individuals with respect to their social networks and mental health (Edwards, Higgins and Zmijewski 2007), financial resources (Hughes 2007) and other relationships (Spicer 2007). Carers participated in the disability focused survey and 80 per cent of the respondents were female. This gender imbalance reflects the unequal distribution of care responsibilities, with women much more likely to take on the role of unpaid carer than men. The carers had an elevated age profile (Figure 8.4), with three-quarters aged between 45 and 74. Most lived in households of two or three people, and 22 per cent reported the presence of children under the age of 18 in their home. Seventy-four per cent described their household as a family, but 14 per cent were sole parent households and this reflects the relatively high rate of relationship breakdown amongst households where a disability is present. Couple only households accounted for 9 per cent of the total, and lone person households for 2.5 per cent. Twenty-four per cent of respondents provided care to their partners, but children were the greatest recipients of care, with 36 per cent providing care for a son or sons and 31 per cent caring for one or more daughters. Only 4 per cent of respondents cared for their mother, and two provided care for a brother.

Figure 8.4: Age of carers participating in the disability focused survey



Source: *Housing 21* survey

Carers were concentrated in owner occupation, with 65 per cent outright owners and 20 per cent purchasers. Thirteen per cent were tenants and 2 per cent lived rent free. This tenure distribution is consistent with the age distribution of the carers included in the survey and highlights the fact that the provision of unpaid care is strongly associated with home ownership. It is interesting to speculate whether a decline in the home ownership rate has the potential to trigger a fall in the rate at which family members are willing and able to provide unpaid care for their relatives or partners. Just under 15 per cent of carers received assistance with the purchase of their home and, while 6 per cent of carers received government assistance, 7.6 per cent received assistance from family with the purchase of the home. A loan from a parent or other relative was the most common form of assistance received, but other forms included loan guarantees, gifts from parents and the inheritance of a house. Clearly, family assistance is an important part of the housing career of family members with care responsibilities in Australia.

Carers in rental housing most commonly leased their property from a real estate agent (40 per cent), followed by the Office of Housing (27 per cent) and other private landlords (13 per cent). Forty-four per cent of carers who were tenants had previously been owner occupants and, of those to fall out of owner occupation, two-thirds did so because of a relationship breakdown. A further 17 per cent fell out of this tenure because of the cost of providing care, and an equivalent percentage was forced to return to rental housing because of the loss of employment. Interestingly, no carers who were currently in the rental market expected to enter home ownership in the next five years.

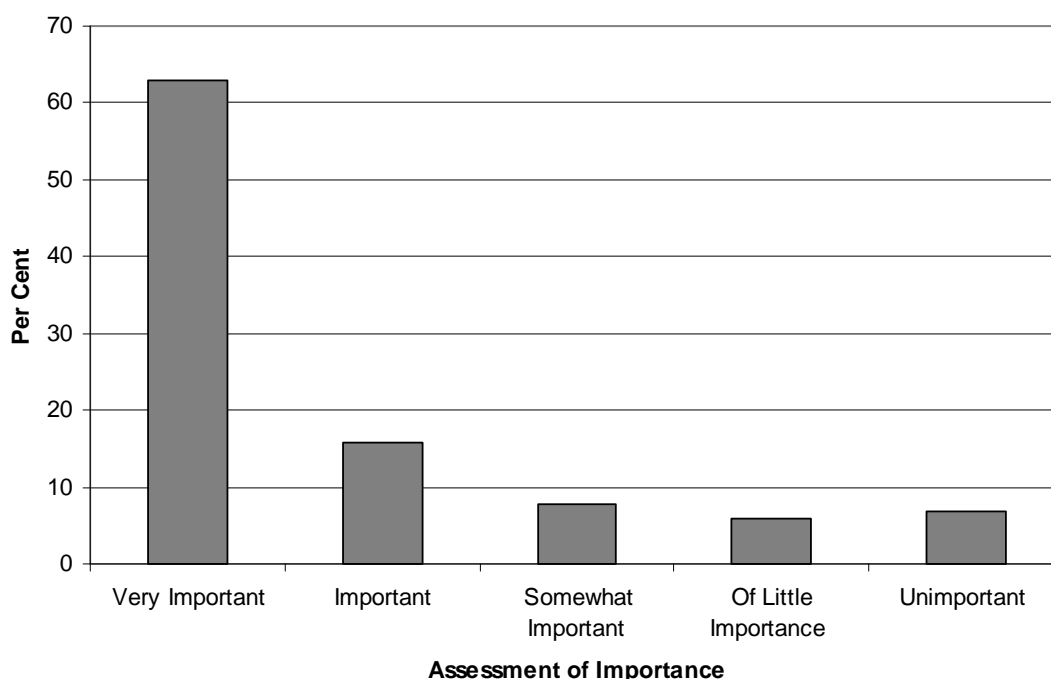
Slightly more than one-third of carers had renovated the property they lived in, with 53 per cent doing so because it did not meet the household's needs. Respondents suggested a number of ways in which their housing choices had been shaped by the care and disability needs of their family member:

The suburb they live in is dictated by need to be close to services;

Doorways had to be wider;
 Moved from country to city for child;
 Would have moved to another suburb/area if did not need to care for person with a disability;
 Two storey house but live on the ground floor;
 Loss of independence. Because have to care full-time, time is not their own;
 Bought house before they knew they would have to care for disabled family members. Now need to modify and restructure.

In common with persons affected by the disability and the respondents to the *Housing 21* survey, carers were asked a battery of attitudinal questions that related to the values and needs that had shaped housing decisions across the life course. Many of their responses mirrored those of the population affected by disability, with participants in the survey placing a premium on the environment in which they live and their ability to gain access to services. Respondents were also asked, 'How important has caring for a person with a disability been in shaping your lifetime housing goals?'. As Figure 8.5 demonstrates, care responsibilities have exerted an overwhelming impact on the housing aspirations of the carers who participated in the survey. Ninety per cent believed they had been successful or very successful in achieving their lifetime housing goals, and a substantial majority placed considerable value on housing for its capacity to serve as an investment and the ability of home owners to choose how they live. It is important to acknowledge that these values reflect both the status of the respondents as carers and their position as an older, home owning, group.

Figure 8.5: Assessment of the impact of caring responsibilities on lifetime housing goals



Source: *Housing 21* survey

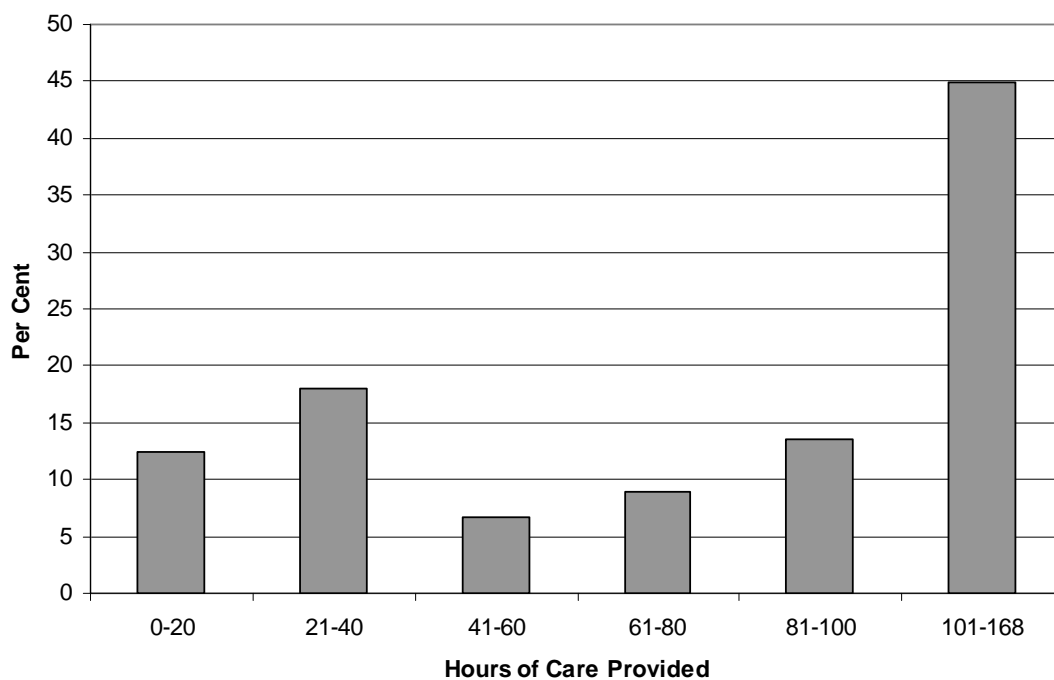
The impact of care responsibilities on the lives of family members providing care is reflected in Figure 8.6 with fewer than 30 per cent of respondents indicating that they

provide under 40 hours of care per week. Forty-five per cent indicated that they provided more than 100 hours of care per week and the single biggest response to 'How many hours of care do you provide each week?' was 168 hours, that is, '24/7'.

A reduced capacity to engage in paid employment is one impact of the substantial care responsibilities many individuals bear. Only 10 per cent of carers participating in the disability survey were in full-time employment, while 22 per cent were employed part-time. Twenty-eight per cent had retired from the formal labour market while 21 per cent nominated 'home duties' as their current work status. Fourteen per cent were full-time carers while 2.5 per cent were not in paid employment because of their own disability. One-third of those in paid employment worked fewer than 24 hours per week.

Household incomes for carers participating in the disability survey were low, with 7 per cent reporting an annual household income of less than \$13,000, 30 per cent between \$13,000 and \$26,000, and a further 30 per cent between \$26,000 and \$41,600. Forty-four per cent received the carers allowance or payment, 27 per cent received the age or widow's pension, and 12 per cent received a disability pension. Fifty-three per cent of carers reported that a government pension or benefit was the household's main source of income.

Figure 8.6: Estimate of the hours of support provided by carers



Source: *Housing 21* survey

Finally, carers were asked to nominate those aspects of the place in which they live that makes housing difficult. Many indicated that transport was a major concern:

- No transport where they live and don't know what they will do when they can't drive;
- Travelling time/distance from country to Melbourne for health care;
- Lack of suitable public transport.

Others noted that the cost and availability of professional carers affected their quality of life:

- Cost of carers;
- Living rural makes it difficult to get paid carers to travel to home, especially with fuel costs so high.

The physical quality of the housing stock and the urban environment challenged other carers:

- Uneven footpaths make pushing a wheelchair difficult;
- Very hard for disabled persons to enter or leave the house.

For others, social factors were more important:

- Lack of emotional understanding and support – feeling isolated because of the stigma of mental illness.

Overall it is worth noting that carers reported the challenges facing those they supported – accessibility, social attitudes etc. – as affecting them, reflecting their very substantial link to the wellbeing of the family member to whom they provide care.

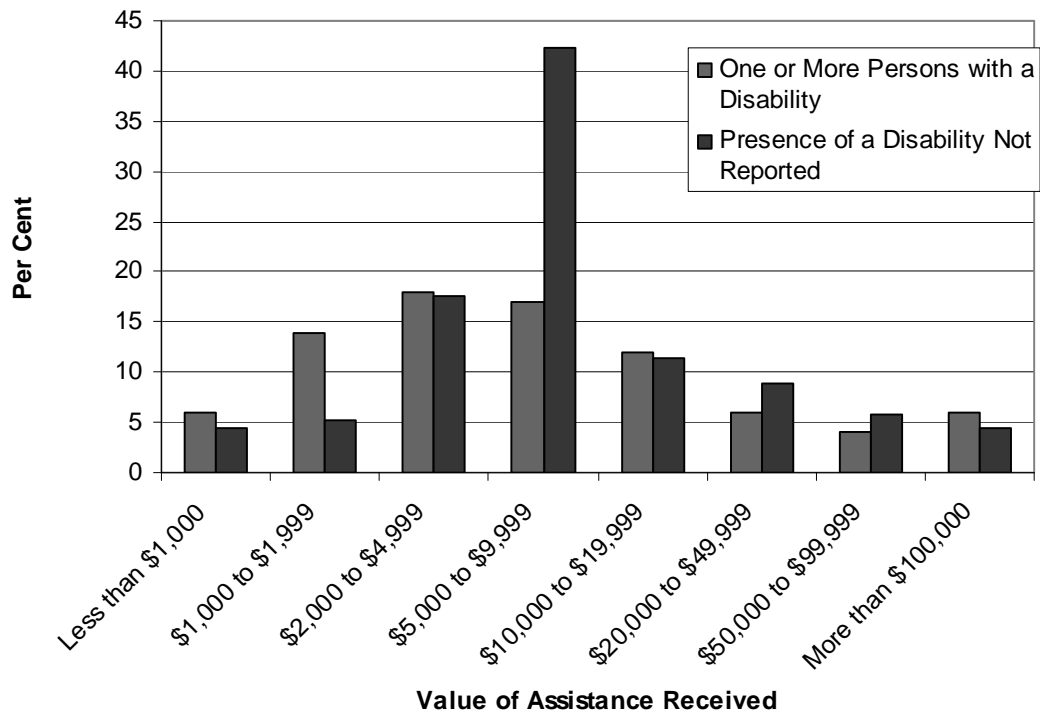
9 THE IMPACT OF GOVERNMENT HOUSING ASSISTANCE ON PERSONS WITH A DISABILITY

Assistance from governments is an important component of the lives of persons with a disability and family members with care responsibilities. This takes a number of forms, including the provision of income support, through to funding professional care, access to public housing and the ability to benefit from other mainstream housing programs. The provision of care is one of the important ways in which governments provide specialist disability support that assists people with their housing. It makes it possible for some people to live independently when otherwise they could not. For others it reduces the burden placed on family members who provide full-time care, helping them stay in that setting. Information collected through the focus groups undertaken in Project C of NRV2 suggests that there is a widely held view that help and assistance (support packages) are relatively difficult to obtain and that they are more easily secured by persons with a physical disability: *'If you can't see a disability, then you haven't got one'*. Even though there is a policy of individualised service, some participants in the focus groups felt the structured selection criteria for assistance excluded some categories of people or made it very difficult for them to secure help.

Access to public housing is one of the most significant forms of housing assistance provided to persons with a disability. As the Australian Institute of Health and Welfare (2001) has shown, over the last decade approximately 40 per cent of all new entrants to public housing have a disability of some type, and this pattern has been reflected in the tenure data for households affected by disability discussed above. At a qualitative level, focus group participants were concerned that governments appeared to no longer build public housing on any scale and that while the Victorian Office of Housing has a building program to meet the needs of persons on the waiting list, the program was slow to provide housing relative to demand. They believed that persons with a disability did not get priority with respect to the waiting list. In addition, they did not believe that the Office of Housing provided housing in all parts of the metropolitan area and that public housing for disabled people *'was really only available in outer suburbs that were flatter'*.

One of the most important forms of government assistance with entry into home ownership is the First Home Owner Grant (cash assistance to the value of \$7,000), with approximately \$1.6 billion spent on this annually (Yates 2007). However, Figure 9.1 suggests that while this form of assistance is significant for the general population, households where one or more persons are affected by a disability have taken up this program to a very limited degree.

Figure 9.1: Value of assistance to purchase a home for households where respondent was under 65 years of age by presence of a disability



Source: *Housing 21 Survey*

The relative unimportance of the First Home Owner Grant for households affected by disability reflects the lower rate of home purchase within this group, their lower household incomes and their relative inactivity within the housing market over the last decade. Figure 9.1 raises an important issue of public policy because it illustrates the way in which a mainstream policy measure has had little or no take-up amongst that section of the population affected by disability. Our analysis would suggest that a more targeted measure is needed to specifically assist low income households affected by disability to enter and sustain home purchase.

10 CONCLUSION: DISABILITY AND 21ST CENTURY HOUSING CAREERS

This report has considered the 21st century housing careers of persons with a disability and carers from a number of viewpoints. The discussion has drawn upon the data from the *Housing 21* survey, the specialist survey of persons with a disability and carers, and the qualitative data collection processes instituted as part of NRV2. In many ways it has been a wide-ranging discussion because many of the issues affecting the housing careers of those with a disability and their carers are unique. It has been important to understand the nature of those issues in order to comprehend their potential and actual impact on housing careers. The discussion has highlighted the significant differences in housing career depending upon the source, type and severity of the disability and how the housing career of all household members is affected by disability. While it is, perhaps, dangerous to extrapolate across disability types, the available evidence suggests that in the 21st century the housing careers of households affected by disability are flatter, more focused on the public rental sector, affected by health and disability concerns to a considerable degree, and less likely to be driven by consumption aspirations when compared with the broader population.

The 21st century housing careers of households affected by disability are also substantially different from those evident in the latter part of the 20th century. This change reflects shifts in support services, the nature of the housing market, the prospects for persons affected by disability and trends in access to differing tenures.

Support services. In many respects the housing careers of persons affected by disability are significantly different from those evident in the latter part of the 20th century when support for independent living was largely unknown and institutional forms of accommodation were common across a range of disabilities (Quibell 2004). It could be argued that there has been policy innovation in bringing the population of persons with a disability into the mainstream of society, but this transition has not translated into opportunities to participate fully in the housing market. Markers of the partial success of this change include the relative immobility of this group over the last decade; the incidence of housing stress amongst households affected by disability; and the fact that a majority of households report that their housing decisions have been very much influenced by their disability. In other words, they have had to moderate their engagement with the market to reflect their disability status. This change has also had profound implications for the housing transitions of carers who are now more likely to be providing substantial care than in the past and do so for extended periods. Care responsibilities clearly shape the housing careers of a significant group within the Australian population. Policy transformations that increase the level of care provided by family members simultaneously reshapes their housing needs, opportunities and transitions. Importantly, they receive no capital compensation or housing allowance for the services they provide to their family member, and by extension, the community as a whole.

Change in the housing market. House price inflation since the year 2000 and a tightening of the rental market has limited the housing careers of persons with a disability. As both the qualitative and quantitative data has shown, households affected by a disability are less mobile within the market than the population overall and less able to have their needs met through the market. The cost of housing is a significant barrier to movement and escalating land and house values have meant that many of these households have not been able to relocate as they otherwise would. In addition, a tightening rental market makes households more vulnerable to

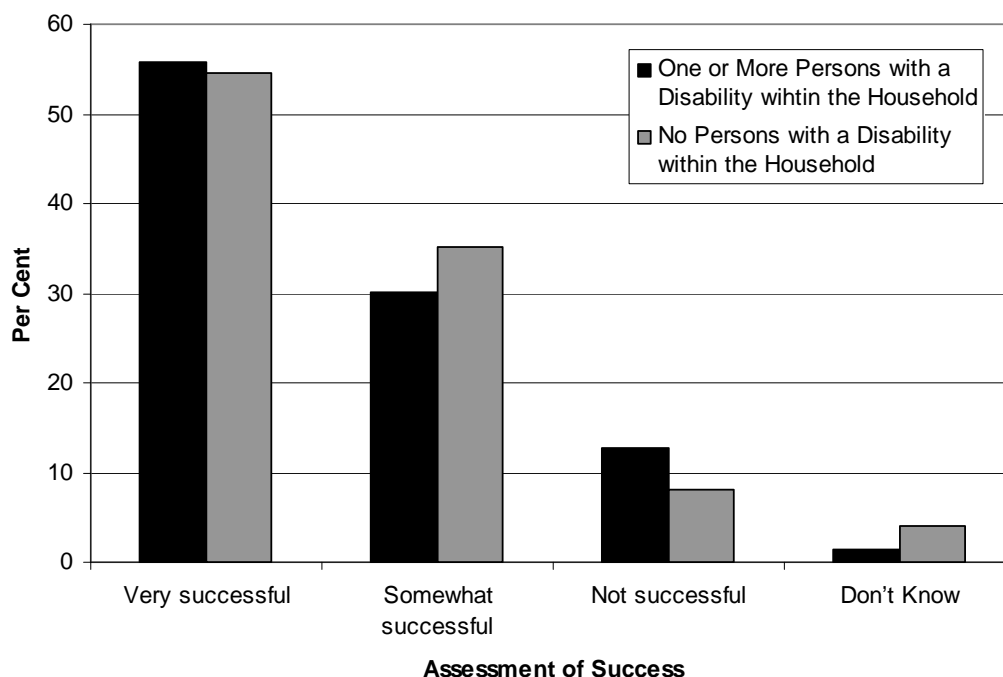
discrimination by landlords or real estate agents, thereby reducing the opportunities available to households affected by disability.

Trends in disability. One of the fundamental ways in which the housing careers of persons affected by disability are changing is through shifts in the incidence and impact of these conditions. Research by the AIHW (2003; 2007) notes that there has been change in the rate of disability amongst the non-aged population and that persons affected by disability have increasing life expectancies. There is now a significant population of persons affected by disability who are in old age or about to enter old age. This trend can be expected to continue through the 21st century and in so doing it will fundamentally reconfigure the housing careers of this group. In addition, there has been growth in the number and percentage of households affected by particular disabilities – especially psychiatric disability. As noted above, this group is one of the most marginalized within the housing market and has some of the most challenging housing careers of any disability population. A growth in the number of persons affected by this type of disability will reshape the housing careers of the disabled population overall, and inevitably generate policy reform.

Declining access to home purchase. The data presented in this report has shown that access to home purchase has become more difficult for households where one or more persons has a disability since the year 2000 when house prices began a long upward trend. This has meant that fewer households affected by disability have been able to buy a home when compared with the latter part of the 20th century and a greater percentage has had to rely upon the private or public rental sectors. Significantly then, the housing careers of this group have been reshaped away from the dominant housing tenure and towards the more marginalized tenures with the Australian housing market.

The available evidence does not suggest that households affected by disability feel a greater level of frustration in their housing careers than the population overall (Figure 10.1). However, as the discussion above has shown, there are limited housing options for this group, there is considerable pressure on carers, access to home ownership is problematic and there are already substantial expectations on the public housing system to deliver accommodation for this group. Looking forward to Australia's housing future, we would conclude that these pressures are likely to increase as we move into the second decade of the 21st century. There is therefore an increasing imperative for appropriate policy initiatives.

**Figure 10.1: How successful have you been in reaching your housing goals?
Respondents aged under 65, by presence of a disability in the household**

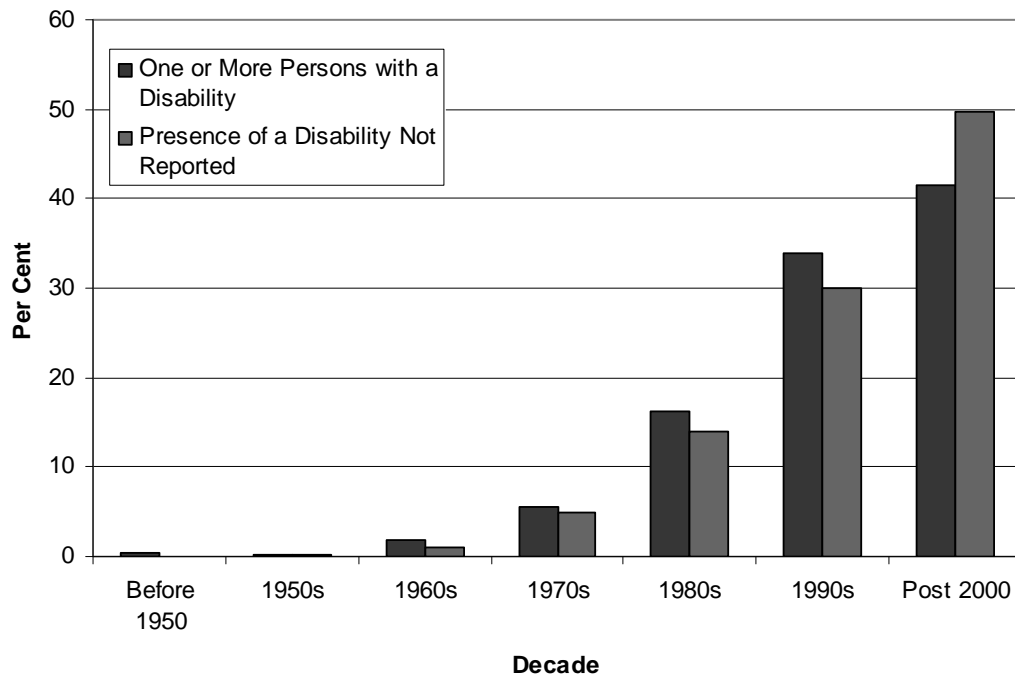


Source: *Housing 21 Survey*

The 'flatter' housing careers of households affected by disability are significant. As Figure 10.2 shows, households where one or more persons were affected by a disability were less likely to have moved in the previous seven years, the period when house prices in Australia escalated. More broadly, they made fewer moves through the housing market over the period 1996 to 2006 (Figure 10.3), with 40 per cent not moving or only moving once, compared with 30 per cent of households unaffected by disability. In combination, this data is strongly suggestive of households affected by disability being priced out of the housing market and this interpretation is, in part, supported by the qualitative insights generated through Projects C and E. Kroehn et al. (2007, p. 6) reported that there was:

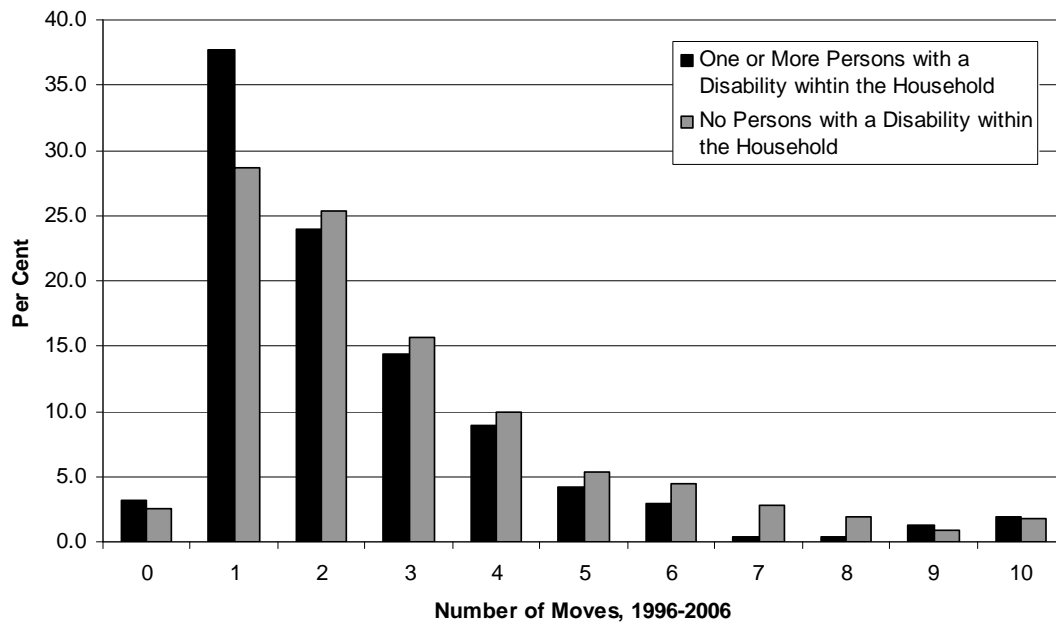
A general consensus within the group was that there was a major disincentive to sell their current home and try to find something more appropriate structurally or that was in a better location. This solely reflected the costs of buying and selling a home. Some participants said this forced them to make modifications to homes that were not ideally suited to the required modifications and were poorly located with respect to their future needs. There were also 'sunk costs' incurred in modifying current homes not ideally suited to the required modifications and this expenditure would be lost in any move.

Figure 10.2: Decade moved into current home, for households where respondent was under 65 years of age, by presence of a disability



Source: *Housing 21 Survey*

Figure 10.3: Number of times moved, by presence of a disability, all households, 1996-2006



Source: *Housing 21 Survey*

Movement through the housing market was seen to be inhibited by both dwelling and locational factors. For example, one woman living in Darebin who was interviewed as part of the specialist disability survey noted that her current dwelling did not meet her aspirations or those of her partner. However, she was reluctant to move because she did not believe she could find a dwelling in a more attractive neighbourhood that was affordable, offered access to public transport that was equal to that available from her

current home, and was accessible for a person in a wheelchair. She also noted that she had modified her current home to make it appropriate for her disability when she first moved in. Any relocation would require an equivalent additional investment in the new dwelling and she expected that would be beyond her means. Similar sentiments were expressed by carers in Sale who noted that the city and its region were seen to offer superior services and closer contact with relatives than would be possible in Melbourne. There was strong emphasis on the available services provided, personal contact and relationships with the relevant groups (e.g. council social workers and disability access workers), and the investment already made in home modification and renovation. As one participant commented:

We have done renovations. We own our own home and we have built and lived in three homes. The need for equipment is significant. I have created more space, accessible space, extra room out of colonial solid timber, and we put in two double doors. We graded the driveway onto the carport. We have roll-in showers, double barn doors.

Finally it is worth recognising that the relative immobility of households affected by disability should be a matter of policy concern because, as Baker (2007) notes, residential relocation is one of the most important ways in which a population adjusts its housing to better meet its needs, including its health needs. A population unable to move through the market because of unaffordable housing may be trapped in accommodation that does not meet its needs or adversely affects its health.

Through analysis of the *Housing 21* survey, health and disability issues have emerged as an important driver of housing careers in 21st century Australia. Twenty-two per cent of households included in the *Housing 21* survey, and 19 per cent of those where the respondent was aged under 65, had one or more household members affected by a disability or long-term health condition. Thirty-six per cent of respondents reported that health or disability concerns had shaped their lifetime housing decisions. One of the challenges for governments and policy makers is to better integrate accommodation requirements for persons with a disability and other forms of assistance, including care or assistance packages.

The housing policy environment for disability has now moved beyond a stage where the processes of deinstitutionalisation are unfolding (Quibell 2004), and the challenge over the next decade is to develop and implement programs that meet the needs of a disability-affected population that lives within the broader community. The research undertaken by Tually (2008) as part of NRV2 showed that, in all states and territories, governments view public rental housing as the most appropriate vehicle for responding to the housing needs of those affected by disability. However, as the Allen Consulting Group (ACG) (2007) has recently noted, the stock of public housing in Australia has fallen, with the Australian Institute of Health and Welfare (2007, p. 103) noting that the number of public housing dwellings declined from 359,000 in 2001 to 341,500 in 2006. Moreover, the impacts of a tightening supply of public rental housing are exacerbated by other factors, including the difficulties people with a disability have in finding accessible and appropriate public housing and 'the fact that their rents are not adjusted to reflect the higher costs of tailoring their homes to their particular needs' (ACG 2007, p. 12). The AIHW (2007) concluded from their study of met and unmet needs in the disability sector that accommodation and respite services were one of the greatest areas of unmet need, while the Steering Committee for the Review of Government Service Provision (2007) noted that government expenditure on accommodation support for persons with a disability has risen in all states and territories. Clearly there are significant policy challenges at the intersection of housing and disability services. Bridge et al. (2003) noted that there has not been the

establishment of effective linkages between housing and other services for people with a disability. The ACG (2007, p. 10) observed that:

This lack of co-ordination is partly a function of the involvement of different levels of government. Commonwealth programs provide some services, while others are funded and provided at the state level. This can lead to a fragmented service offering where either people with a disability or their families must acquaint themselves intimately with the details of both state and Commonwealth government policy arrangements. This fragmentation can, as Bridge et al. (2000, p. 3) observe, 'hinder efficient and fair service delivery'.

As Bridge et al. (2003) also note, the lack of integration evident in this approach also imposes inefficiencies on service providers and government departments. By failing to link public housing with support services, policy makers may not be extracting the public value that would accrue from closer integration between health, disability, accommodation and care services.

Ultimately, however, the failure to link support and housing effectively limits the scope of people to with a disability to live independently. Regardless of the direction of public policy towards encouraging independent living, if support does not allow people to take up the opportunity to live independently, then policy will not succeed.

This highlights the multiple policy challenges that need to be overcome to produce more effective housing outcomes for persons with a disability. For many people affected by disability, it is not simply a matter of state or territory support relative to Australian government programs, or even housing programs relative to support services; instead, the capacity to secure appropriate housing lies at the intersection of all these elements. This complexity becomes more acute when we recognise the need to integrate policies on ageing also. The impacts of structural ageing within the population have to be seen to be part of the policy mix, as persons with a disability age and many persons acquire a disability later in life.

10.1 Developing a more appropriate social housing supply for persons affected by disability

As discussed by Tually (2007), current policy frameworks view public rental housing as the most appropriate mechanism for directly assisting persons affected by disability with their housing need. This has contributed to a concentration of persons with a disability in the public housing stock, with 40 per cent of new entrants being disabled (AIHW 2003). However, as the discussion in the section above has shown, much of this stock is seen to be physically inappropriate for persons with a disability because of the design of the dwelling, distance from public transport, poor quality maintenance etc. It is also appropriate to question whether the systems of public housing management are appropriately focused on the needs of persons with a disability, given the current and growing demand from this group.

International experience can suggest ways in which social housing can become better focused on the housing needs of a population with disabilities. UK experience suggests that housing will need to change with respect to allocation processes and the quality and design of the stock. In their work on medical priority rehousing in England, Smith, Alexander and Easterlow (1997) emphasised the positive impact of housing on the wellbeing of persons relocated for medical or disability related reasons, including psychiatric disability. This stock is of a high quality, has been designed for persons with a disability, is often clustered into groups and includes contact with a warden who can assist with a range of needs. Such a model appears to

better recognise the circumstances of persons with a chronic health condition or disability who need assistance. Such models could be trialled in Australia.

At an institutional level, a number of jurisdictions have investigated new models for the supply of social housing for persons affected by disability. The Disability Housing Trust (DHT) was established by the Victorian government 'to promote and develop new housing options and encourage new investment in housing for people with disabilities' (ACG 2007, p. v). This initiative was established in June 2006 and is still within the early stages of implementation, but it is expected that the DHT will build and let social housing units for persons with a disability, and also encourage the development of new vehicles for private investment – including family members – in disability housing. Other policy options include the use of government home lending agencies to support access to home ownership for people with a disability. Both Keystart in Western Australia (ACG 2007) and HomeStart in South Australia have specialist packages for persons with a disability.

10.2 The adoption of universal design principles in new housing and renovations

The adoption of universal design principles into the Building Code of Australia would result in a more accessible housing stock for persons affected by disability and their households. Many of the physical attributes of the Australian housing stock make it difficult, if not impossible, for persons affected by mobility or other disabilities to occupy those dwellings. Persons affected by disability report that government programs to modify the housing stock are inadequately funded relative to need, and the more holistic approach would be to build and renovate dwellings such that all members of Australian society can gain access to them into the future. Such an initiative is entirely consistent with the planning that is needed, and should be in place, not only for people with disabilities but for an ageing population.

10.3 Conclusion

This part of NRV2 was established to address the question: How are housing careers for persons with a disability and their family members with care responsibilities changing in Australia and what are the implications of change for government provided housing assistance? This question was answered in the context of examining how housing careers for the total population have changed in Australia.

It is clear from the evidence presented here that disability has a significant effect on housing careers. The discussion overall has highlighted the significant differences in housing careers depending upon the source, type and severity of the disability and how the housing careers of all household members are affected by disability. From a disability perspective and from an ageing perspective, health and wellbeing are now a significant influence on the housing transitions of many Australian households. Importantly, whereas the home was a place for the provision of care for children in the second half of the 20th century, in the 21st century it will take on a considerable role in the provision of care for adults.

There does not appear to be a consensus on appropriate policy interventions, but this work has led to the call for new, more fine-grained, approaches to the provision of housing assistance and the potential re-ordering of priorities in the light of what we know about 21st century housing transitions. Home ownership remains a priority of all tiers of government and both Labor and Coalition parties. Shifts in the relationship between individuals and governments have had an appreciable impact on housing transitions and the need for government assistance. This change is seen most clearly in the areas of housing for older Australians and persons with a disability where

established, largely institutionally-based, policy interventions have been abandoned in favour of greater integration with the broader community. This shift has generated new demands for housing assistance and support with independent living, and it is likely that this will be an area of considerable program development over the next two decades.

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