Final Report

Peer Reviewed

Moving to my home: housing aspirations, transitions and outcomes of people with disability

authored by

Ilan Wiesel, Carmel Laragy, Sandra Gendera, Karen R. Fisher, Samantha Jenkinson, Trish Hill, Kate Finch, Wendy Shaw and Catherine Bridge

for the

Australian Housing and Urban Research Institute

at The University of New South Wales
at RMIT University

August 2015

AHURi

Australian Housing
and Urban Research Institute

AHURI FINAL REPORT SERIES

AHURI Final Reports is a refereed series presenting the results of original research to a diverse readership of policy-makers, researchers and practitioners.

PEER REVIEW STATEMENT

An objective assessment of all reports published in the AHURI Final Report Series by carefully selected experts in the field ensures that material of the highest quality is published. The AHURI Final Report Series employs a double-blind peer review of the full Final Report where anonymity is strictly observed between authors and referees.

CONTENTS

LIST OF TABLES

LIST OF BOXES

ACRONYMS

ABS	Australian Bureau of Statistics
AHURI	Australian Housing and Urban Research Institute Limited
AIHW	Australian Institute of Health and Welfare
ANSA	Adults Needing Supported Accommodation
ATE	Alternatives to Employment
CDHP	Community Disability Housing Program
CHFA	Community Housing Federation Australia
CLF	Community Living Fund
CRA	Commonwealth Rent Assistance
DHASI	Disability Housing and Support Initiative
DSC	Disability Services Commission (WA)
DSP	Disability Support Pension
HASI	Housing and Accommodation Support Initiative
IASP	Individual Accommodation Support Package
ILC	Information, Linkages and Capacity Building
ILDIS	Independent Living Drop In Support
ILSI	Independent Living Skills Initiative
LCP	Leaving Care Program
LHA	Livable Housing Australia
LTCS	Life Time Care and Support
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDS	National Disability Services
NSW	New South Wales
OT	Occupational Therapist
PC	Productivity Commission
PJSHP	Port Jackson Support Housing Program
PWDA	People with Disability Australia
PWDWA	People with Disability Western Australia
SA	South Australia
SAIF	Supported Accommodation Innovation Fund
SDAC	Survey of Disability Ageing and Carers
SLF	Supported Living Fund
WA	Western Australia
YPRAC	Young People in Residential Aged Care

GLOSSARY

Disability—a social experience of disability based on bodily difference or impairment, including Intellectual, developmental, cognitive, physical, sensory, psychosocial and multiple.

Disability support—assistance provided to people with disability in daily tasks such as self-care, mobility, communication and building social connections.

Independent living—social relationships and informed decision-making to exercise choice and maximise autonomy about support arrangements and who to live with or alone.

Individualised funding package—funds allocated to a person to meet their disability support needs.

Informal support—unpaid disability support provided by family, friends or other significant people.

NDIS package—individualised funding package funded by the NDIS.

NDIS participants—recipients of individualised NDIS support packages.

EXECUTIVE SUMMARY

Many people with disability in Australia experience housing and living arrangements which are markedly different to the rest of the population. A large proportion of people over 25 years old live with parents, in group homes or in large congregate or institutional settings. People with disability are more likely to experience housing stress, are over-represented in housing assistance programs and in the homelessness population, and are under-represented in owner-occupation.

However, recent innovations and reforms in the disability sector are expected to have a major impact on housing for people with disability. Most importantly, the National Disability Insurance Scheme (NDIS)—to be gradually rolled out nationally by 2019—will transform the public funding system for disability services. Under the NDIS significantly more funding will be made available for disability services. Furthermore, most NDIS funding will be individualised, allocated to individuals rather than block funding for services. This will give people with disability more control over the use of their funding entitlements, and more people with disability will be able to access the support they need to live independently in the community. Yet, to achieve this, NDIS participants also need to secure affordable and suitable housing. The NDIS estimates an unmet need in affordable housing for 80 000–120 000 participants.

In this context, the study sought to identify the barriers but also the success factors that enable people with disability with individualised funding packages to move into housing which better suits their preferences and needs. The focus was on the aspirations and experiences of people with disability as consumers of housing. Findings from this analysis have implications for the finance, planning, design and management of housing supply, but a more systematic analysis of these issues was beyond the scope of the study.

The primary research questions addressed in this report are:

→ How do emergent practices in the funding and delivery of disability support services impact on housing demand among people with disability?

→ How do people with disability secure their preferred housing and living arrangements?

→ What are the shelter and non-shelter outcomes for people with disability who moved to their preferred housing and living arrangements?

A mixed method approach was taken to address the research questions, including analysis of the Australian Bureau of Statistics (ABS) Survey of Disability Ageing and Carers (SDAC) (ABS 2012) and Census of Population and Housing 2011 (ABS 2011); interviews with 13 frontline and managerial staff in disability and housing agencies; and, interviews with 51 people with disability—most with individualised funding packages—who moved, or planned to move, from congregate care, group homes, their parents' home or unstable housing to more independent and stable housing and living arrangements. Interviews were conducted in NSW, Victoria and WA, in major cities, regional NDIS launch sites and one remote area. The learnings from their experiences are valuable in highlighting some of the key factors underpinning successful housing transitions. Although the study focused on people with individualised funding, representing those who will receive NDIS support packages when the scheme is fully rolled-out, it has broader implications for the general population of people with disability, of whom a majority will not receive NDIS support packages.

How do innovations in the funding and delivery of disability support services impact on housing demand among people with disability?

Participants' motivations to move home varied, but common reasons were the aspiration to live independently in housing that meets their preferences in its design and location. The availability of flexible support funding arrangement enabled participants to pursue these

aspirations. This indicates the potential impact of the full national roll out of the NDIS on housing demand. High demand for affordable housing can be expected among over 51 000 people with severe or profound disability who are over 25 and still living with parents, and many others living in institutions, congregate housing, boarding houses or experiencing unstable housing (Chapter 2).

When and how do people with disability secure their preferred housing?

Access to housing is often difficult for people with disability, even if they have secured the support they need to live independently. Although specific barriers vary across housing tenures, ultimately they all derive from the shortfall in supply of affordable housing. Nevertheless, some people have been successful in overcoming these barriers, adopting various strategies and pathways to enter their preferred housing. Table 1 below summarises our key findings on both the barriers to, and enablers of, such transitions across housing tenures.

Table 1: Access to housing, barriers and enablers by tenure

Tenure	Barriers	Enablers
Social housing	People living with their parents or in group-homes low priority in housing allocations Shortfall in accessible or adaptable social housing stock	Nomination by support agencies Special programs (access outside general waitlist) Priority housing for those at risk of homelessness Transitional housing Purpose-built housing Home modifications
Private rental	Affordability Discrimination Lack of rental history and references Shortfall in accessible or adaptable private rental stock Shortfall in culturally appropriate housing for Indigenous people with disability	Established relationships with landlords Understanding landlords Low-value housing markets Sharing to reduce costs of housing
Home ownership	Affordability Difficulty accessing finance	Financial support from family Sharing Shared equity Trust ownership Home modifications

Source: authors

These factors are discussed and elaborated in Chapter 5.

What are the shelter and non-shelter outcomes for people with disability who moved to their preferred home?

People with disability in our study who moved to their preferred housing in a suitable location (e.g. close to their family, public transport and services), and with appropriate formal and informal support, experienced positive shelter and non-shelter outcomes. Most participants experienced a growing sense of independence, valued their privacy if they lived alone or valued having a choice of flatmates if they shared. Many participants noted improvements in

their physical and mental health following the move, as well as improved social participation, including new friendships and relationships.

Participants who moved to social housing experienced more secure and affordable tenancies, and most hoped to be able to remain in their new homes permanently. Participants who moved to their own homes (including shared equity arrangements) experienced pride and a sense of security. Participants who moved to private rental, in contrast, experienced less secure housing, as well as significant affordability stress.

For some participants stable housing provided a base from which to seek work, but overall there was little evidence in our study that housing moves impacted on employment outcomes for most people. Participants with mobility restrictions who managed to secure housing that met their accessibility needs experienced major benefits in terms of independence and social inclusion.

These and other outcomes of participants' housing transitions are elaborated in Chapter 6.

Policy implications

Detailed housing policies and strategies are necessary to prepare for the NDIS. Most NDIS participants will have low incomes, and private rental will not be affordable for many. Existing social housing stock falls far short of meeting existing levels of demand, let alone the growth in demand expected with the national rollout of the NDIS. Thus, new housing supply that is affordable and with good access to services, shops and public transport will be necessary to meet anticipated demand. Well-located housing can reduce ongoing costs of transport and support with substantial long-term savings for both the NDIS and its participants. Participants' desire to remain permanently in housing that is secure and meets their preferences also highlights the need for adaptable design to allow ageing in place even for those who do not currently have mobility restrictions. This could be achieved most effectively through legislative requirements for non-discriminatory access standards in new housing construction.

Some people will have more specific housing requirements, such as a higher level of accessibility or locations which are outside city or regional centres to be closer to their family and social networks in rural areas. The findings highlight the importance of conferring with prospective residents about the design of their home before it is built, to avoid the higher cost of further modifying an existing dwelling.

Home sharing will improve affordability outcomes for people with disability, enable the pooling of support funding, and improve overall utilisation of existing and new housing stock. Housing development and management strategies are necessary to ensure people with disability are able to choose their flatmates and share comfortably, for example through design that maximises privacy. Shared equity schemes were identified as a model that, if scaled up, can assist in both leverage of finance from families, and positive shelter and non-shelter outcomes for people with disability.

The findings demonstrate some of the positive housing outcomes associated with individualised and more flexible support funding. Sufficient support to make decisions about preferred housing arrangements, and to search, apply for and maintain housing, needs to be factored into NDIS participants' support plans. Independent advocacy, information and tenancy management services are needed to prepare and support people with disability before and through the planning process. NDIS funding—provided through the Information, Linkages and Capacity Building (ILC) program rather than individual funding packages—is also needed to build and strengthen capacity in participants' formal and informal support networks. Such capacity building support will ultimately increase housing opportunities for people with disability, for example by helping to connect potential flatmates or establish relationships with local real estate agents and social housing providers.

Policy implications are discussed further in Chapter 7.

1 INTRODUCTION

1.1 Background

Close to a fifth of the Australian population, 4.2 million people, had a disability in 2012. About a third of those, 1.4 million, had profound or severe core-activity limitation or restriction (ABS 2012). Many people with disability in Australia experience housing and living arrangements which are markedly different to the rest of the population (Bridge et al. 2003), including a large proportion of people with disability over 25 years old living with parents (Qu et al. 2012), in 'shared supported accommodation' facilities or in large congregate or institutional settings (AIHW 2013a). People with disability are more likely to experience housing stress (Beer & Faulkner 2008) and are over-represented in housing assistance programs (AIHW 2013b), reflecting their low income as well as other barriers in access to private housing (Franz et al. 2014). People with disability, particularly psycho-social disability, are overrepresented in the homeless population (Beer & Faulkner 2008).

The availability and nature of support services has limited the housing options available to people with disability to date. The short supply of funding for support has created considerable unmet need, forcing many adults with disability to continue to live with their parents, who are their primary carers (Qu et al. 2012). Furthermore, most existing support funding has been provided through 'shared supported accommodation' (AIHW 2012), where housing and support services are inseparable, restricting people's choice about where they live and with whom (Productivity Commission 2011; Wiesel 2011).

Recent innovations and reforms in the disability sector are expected to transform the housing landscape for people with disability. Such changes include innovative programs to facilitate independent living and stable housing for people with disability. The most notable innovation has been the introduction of individualised funding. Following international trends, individualised funding programs were introduced across Australia, particularly in Western Australia (WA) (Fisher et al. 2010). Individualised funding is also a centrepiece of the National Disability Insurance Scheme (NDIS), and at full national rollout of the Scheme in 2019 most disability support funding will shift from block funding to individualised funding. Furthermore, the NDIS will see a massive increase in the total amount of support funding distributed, from $7 billion in 2012–13 to $22.2 billion in 2019–20 (Productivity Commission 2011; Parliament of Australia 2013). It is estimated that NDIS funds will support approximately 10 per cent of people with disability, including people under 65-year old at the time of entering the scheme, with severe or profound core activity limitation. Other people will continue to arrange their support and housing through their own personal capacity, social connections or with other mainstream social services.

Existing literature on individualised funding programs reports significant overall benefits for people with disability, associated with higher levels of satisfaction with the quality of service and perceptions of greater control over life decisions compared to more traditional models of funding (Fisher et al. 2010; Productivity Commission 2011). Individualised support funding also facilitates opportunities for people to receive support services wherever they live. This potentially widens the range of housing options for people with disability. Drawing on existing scattered and anecdotal evidence from Australian and international literature (LIME Management Group 2005; Poll et al. 2006; Head & Conroy 2005), three potential housing outcomes can be expected:

→ Transition of young adults with disability out of their family home to more independent living with appropriate support, on their own or sharing with others.

→ People with disability moving out of (or avoiding entry into) group homes or institutions.

→ More stable housing for people with disability with histories of unstable housing.

However, despite the availability and greater flexibility of support, people with disability will need to overcome persistent barriers to secure their preferred housing. These barriers include the shortfall in supply of affordable housing; discrimination or disadvantage in access to private rental; and, shortfall in the supply of accessible or adaptable housing for people with mobility restrictions (Beer & Faulkner 2008).

The NDIS is likely to be one of the most transformative social policy reforms in Australian history, and NDIS participants' access to housing will be a key to its success and an urgent policy priority. In addition to the majority of people with disability who will not use NDIS funds, the NDIS is expected to create unmet demand for affordable housing for 83 000–122 000 participants, who for the first time will be able to access the support they need to live independently in the community (Bonyhady 2014). This crude figure highlights the sheer scale of the problem, and also suggests a need for a deeper and more nuanced understanding of the Scheme's potential impact on its participants' housing aspirations and opportunities. Lessons from the NDIS trial sites and from past individualised funding schemes and other emergent models of support will therefore directly inform policy response in both the housing and disability sectors. An assessment of the shelter and non-shelter outcomes for people with disability who moved to different types of housing will inform policy debates and planning to enhance availability of housing that will achieve optimal outcomes for NDIS participants and meet policy objectives.

1.2   Research aims and questions

The study has two main aims.

1. To identify the factors enabling people with disability to transition into, and sustain, housing which suits their preferences and needs, in the context of individualised support funding and other innovative approaches to the delivery of disability support services.

2. To apply learnings from the NDIS trial sites and from past programs to inform current planning and policy in the housing and disability sectors in response to the NDIS reforms.

The primary research questions addressed in this report are:

→ How do emergent practices in the funding and delivery of disability support services—particularly individualised funding—impact on housing demand among people with disability?

→ How do people with disability secure their preferred housing?

→ What are the shelter and non-shelter outcomes for people with disability who have moved to their preferred home?

1.3   Disability and housing in Australia

1.3.1   Right to adequate housing

The right of people with disability to adequate housing has been increasingly recognised over recent years. The United Nations (2006) *Convention on the Rights of Persons with Disabilities* (CRPD) provided a watershed when it stated that people with disability have the right to an adequate standard of living with adequate food, clothing and housing and to the continuous improvement of living conditions (Article 28). The CRPD specifies that people with disability should have the opportunity to choose their place of residence; where and with whom they live on an equal basis with others (Article 19); and have access to public housing programs (Article 28). In the CRPD, the right to housing sits with people's other rights to independent living and full inclusion and participation in the community (Article 19).

In Australia, the Council of Australian Governments (COAG) initiated the National Disability Strategy (Australian Government 2011). This complied with the government obligations under the CRPD when stating that people with disability should have access to affordable and secure

housing across all tenures (Chapter 3). This right to housing was asserted within a broader context of maximising the potential of people with disability, and ensuring their participation as equal citizens in Australian society (Forward).

Despite these obligations, people with disability are disadvantaged in access to adequate housing. As discussed in the following sections, in recent decades housing affordability stress has affected an increasing number of Australians of all abilities. People with disability, in particular, have faced additional barriers in accessing affordable housing that is suitable for their needs.

1.3.2 Housing affordability in Australia

Housing affordability has become a key factor depressing home ownership rates and contributing to the financial stress experienced by low-income households renting privately. In the decade leading to 2011, house price rose by 69 per cent, rents have increased by 75.8 per cent for houses and 91.8 per cent for other dwellings (mostly flats/home units) across Australia's major cities while average earnings rose by only 57 per cent over the same period (NHSC 2013, p.7). This has created an affordability barrier for first time home buyers and consequently a decline in home ownership rates nationally. Between 1976 and 2011, home ownership rates declined from 60 to 45 per cent for households in the 25–34-year old age group. From 1986 to 2011, home ownership rates fell from 74 to 64 per cent for the 35–44-year old group (Yates 2011 pp.6–7). In the private rental sector, these decades have seen a rise in the overall proportion of renters, from 20.3 per cent of all households in 1981 to 23.4 per cent in 2011. Meanwhile, private rental affordability has been declining, with median rent to median income ratio rising from 19 per cent in 1981 to 26.9 per cent in 2011 (Stone 2015). A recent survey of 65 600 rental properties (Anglicare 2015) highlights the severe shortage of private rental stock that is affordable for low income households. The survey found that only 1 per cent of the surveyed properties would be affordable and suitable for a single income-support recipient; and, only 2.3 per cent would be affordable for a single person on minimum wage.

Multiple factors have contributed to the housing affordability problem. During the decade leading to 2010, the supply of housing has failed to keep pace with the growth in the number of households in Australia resulting in an estimated shortage of around 180 000 dwellings, contributing to house price inflation (NHSC 2010, p.71). Supply shortages were compounded by barriers to medium- and high-density infill housing development in existing residential areas, including: higher construction costs; difficulties aggregating land for construction; difficulties securing development finance; legal and urban planning constraints; and community opposition to higher density development. The affordability problem was further exacerbated by growing income gaps since the mid-1980s, with disproportionate household income growth at the top end of the income distribution leaving lower income households more vulnerable to house price inflation. Furthermore, a range of policies—including exemption on capital gains for owner-occupied homes, negative gearing for investors and non-means-tested first home buyers subsidies—have favoured higher-income owners and investors over lower-income households (Yates 2011).

The increase in housing affordability stress in the private sector has resulted in increased demand for social housing. However, the supply of social housing has failed to keep pace with levels of demand. Despite the one-off boost to supply through the Social Housing Initiative under the National Building Economic Stimulus Plan (NBESP), the longer term trend has seen social housing supply shrinking markedly. Overall, the proportion of social renters in the population fell from 5.8 per cent of households in 1998 to 3.9 per cent in 2010 (NHSC 2013).

In 2009 the National Rental Affordability Scheme (NRAS) was initiated by the Australian Government as a means to increase supply of affordable rental housing that is distinct from social housing in both its finance mechanism (a mix of government funding and private finance)

and it's more moderate discounts for renters. With the defunding of NRAS in the 2014 federal budget, funding sources for new affordable housing supply have virtually dried up.

1.3.3 Housing for people with disability

While housing affordability stress has affected low- and moderate-income Australians of all abilities, people with disability face additional barriers in accessing suitable housing. Poor housing outcomes for people with disability are associated with affordability barriers due to their low incomes, resulting from low rates of participation in paid employment. In 2012, labour force participation of Australians with disability aged 15 to 64 was 53 per cent, and for those with a profound or severe core activity limitation only 20 per cent and 36 per cent, respectively, compared to 83 per cent for those without disability (ABS 2012).

Poor housing outcomes for people with disability—primarily those with physical disability—are also compounded by poor domestic design that inhibits their movement into and around their own home or other people's homes (Imrie 2003). In Australia, although public spaces are now required to provide non-discriminatory access, there is no equivalent national requirement for housing design. Voluntary initiatives to increase supply of adaptable or accessible housing—such as the Livable Housing Australia (LHA) Guidelines—have been largely ineffective, and despite population ageing, demand for newly built accessible housing in the private market has remained low (Franz et al. 2014). Furthermore, it is currently impossible to establish either the existing supply of housing with accessibility features or functionalities because there are no central data repositories that are reliable and valid for all Australian states and territories (Bridge 2005). Housing design also affects people with non-physical disability, although there has been relatively little attention to the housing design requirements of people with cognitive or psycho-social disability in policy, practice, and research (Endeavour Foundation 2008).

People with disability are more severely disadvantaged than others by poorly located housing because of their relatively high reliance on public transport to access mainstream services, disability support services and their own families and informal support networks (Wiesel 2015). People with disability are also more severely disadvantaged by insecure housing, because of the high underlying risk of homelessness (Beer et al. 2012) and the difficulty to build and sustain long-term relationships with others in their community (Wiesel 2015).

Poor housing outcomes for many people with psycho-social or intellectual disability are affected by their segregation in institutional environments. As documented in numerous inquiries and studies (reviewed by Wiesel & Bigby 2015), such institutions were typically characterised by overcrowding, disease, neglect, a culture of resident abuse, regimentation of daily activity and restriction of individual freedoms. Since the 1980s, deinstitutionalisation programs have been implemented across Australia, significantly reducing the number of people with disability living in institutions. However, to date, the implementation of deinstitutionalisation has been slow, haphazard and incomplete (Wiesel & Bigby 2015). Although the research evidence demonstrates that smaller-scale, non-congregated housing in the community is a fundamental condition for social inclusion, self-determination, and wellbeing (Walsh et al. 2010; Kozma et al. 2009), close to 4000 people with disability in Australia remain living in institutions.

The closure of most large institutions led to the establishment of alternative models of housing and support, most notably the group home (shared supported accommodation), typically housing between four and six people with extensive paid staff support. There is evidence to suggest that group homes can offer more positive community participation and quality of life outcomes for residents compared to institutions. However, in Australia and elsewhere, outcomes for group home residents in terms of engagement, choice, and participation have been highly variable due to variation in the implementation of the model (Mansell et al. 2013). In terms of housing outcomes, key concern has been the limited choice available to group home residents about where and with whom they live. Other concerns related to the provision

of both housing and support by a single provider, reducing the choices available to residents to change their support provider while staying in their home, or vice versa (Wiesel & Fincher 2009).

As a result of these processes, the housing and living arrangements of many people with disability are markedly different to the rest of the population, with a large number of people with disability over 25 years old living with parents, in group households or in large congregate or institutional settings, and a high proportion of people with disability receiving housing assistance as summarised below:

→ While most young adults in Australia leave their parents' home by their mid-20s, people with disability are more likely to continue living with their parents many more years. Limited access to support for independent living has been the primary barrier preventing people with disability from leaving their parents' home. Using Survey of Disability Ageing and Carers (SDAC) 2012 data, Qu et al. (2012) identified more than 53 000 people with disability over 35 years living with parents (predominantly ageing parents), as were an additional 40 000 people with disability aged 25–34.

→ According to AIHW (2014, p.51), in 2012–13, 16 433 people with disability (most with intellectual disability) lived in over 4000 government funded group homes across Australia.

→ Despite four decades of deinstitutionalisation programs in Australia, in 2012–13, 3459 people with disability were still living in institutional accommodation, including large institutional facilities (over 20 people), small institutional facilities (7–20 people) and hostels (usually less than 20 people, but unlike other institutions hostels do not provide segregated specialist services) (AIHW 2014, p.51).

→ Home ownership rates among people with disability, particularly those with profound or severe disability, are significantly lower than the general population (Chapter 2).

→ People with disability are over-represented in housing assistance programs. At 2012, nearly 160 000 households with a member with disability lived in social housing, representing approximately 40 per cent of all households in social housing (ABS 2011). Approximately 250 000 people receiving a Disability Support Pension also received Commonwealth Rent Assistance (CRA), representing approximately 21 per cent of all CRA recipients (AIHW 2013b, p.40).

1.4 Innovations in disability services

Recent years have seen innovations in disability support programs that were expected, among other things, to create new housing opportunities for people with disability, including:

→ Individualised funding programs, where funding is allocated to individuals rather than services (e.g. NDIS; Support & choice; Supported Living Fund (SLF); Individual Accommodation Support Package (IASP)).

→ Programs involving close coordination between housing and disability service providers (e.g. Housing and Accommodation Support Initiative (HASI); Disability Housing and Support Initiative (DHASI)).

→ Programs designed to assist people with disability acquire the skills necessary for independent living (e.g. Independent Living Skills Initiative (ILSI), Independent Living Drop In Support (ILDIS)).

→ Programs designed to assist participants move out of shared supported accommodation or congregate care, including aged care, to more independent living in the community (e.g. Exits Program; YPRAC).

→ Programs to stimulate innovations in the design of housing for people with disability (e.g. the Supported Accommodation Innovations Fund (SAIF)).

A small body of grey and scholarly literature examining the impact of such schemes is reviewed in Chapter 3. While being innovative and in some respects successful, such programs have been largely experimental and represented only a small fraction of the disability services industry. However, some of these innovations—most notably individualised funding—will become mainstream practice with the national rollout of the NDIS.

1.4.1 Transition to the NDIS

The rollout of the NDIS will transform the funding of disability services in Australia. An inquiry by the Productivity Commission into the existing disability services sector and its funding arrangements described these as extremely inadequate and placing an unacceptable burden on people with disability and their families. The major shortcomings of the service system were described by the Productivity Commission (Productivity Commission 2011, pp.5–10) as following:

→ A crisis driven approach which limits opportunities for early intervention.

→ Inequitable rationing of services.

→ Lack of choice for people with disability about how, when and where they receive services.

→ Lack of certainty for people with disability, families and support providers about the availability of funding for lifelong support, resulting in anxiety about the future and difficulties in planning ahead.

→ Prevalence of outdated models of support, including the continued operation of large congregate accommodation facilities and institutions.

To address these shortcomings, the Productivity Commission recommended and outlined the principles for the establishment of a new national scheme—the NDIS—to fund long-term support for people with significant disability (Productivity Commission 2011). The NDIS proposal received bi-partisan support, strong endorsement across the disability sector, and broad popular support demonstrated most notably through the 'Every Australian Counts' grassroots campaign launched in 2011. In March 2013 the NDIS Act 2013 was passed. Since July 2013 the scheme has been piloted in a number of launch sites across Australia and from 2016 to 2019 it is expected to be progressively rolled-out nationally.

In 2012–13, prior to the launch of the NDIS, government funding for disability services totalled $7 billion, including $4.7 billion by states and territories and $2.3 billion by the Commonwealth government (Parliament of Australia 2013). In 2019–20, the first year of full roll-out, total funding for the NDIS is expected to be $22.2 billion, of which $11.7 billion will be funded by the Commonwealth Government. The additional costs for government will be covered in part through an increase in the Medicare levy, from 1.5 to 2 per cent of taxable income. The change to the Medicare levy will raise around $3.3 billion in 2014–15, and $20.4 billion between 2014–15 and 2018–19, when the full scheme comes into place (Australian Government 2013).

The NDIS will not only increase the amount of funding available for disability services, but also differs from the existing system in its design. Three key differences are:

1. The scheme is overseen by a single National Disability Insurance Agency (NDIA) reporting to all Australian governments.

2. The NDIA is the assessor and funder of services, but not their provider. State governments, too, are expected to withdraw from direct provision of disability services.

3. Most NDIS funding is individualised (allocated to individuals rather than services) to give NDIS participants more choice and control over the support services they receive (see Section 2.3).

The NDIS is a tiered system. First, it is an insurance cover for all the Australian population. Second, the Information, Linkages and Capacity Building program (ILC) targets all people with

a disability (4 million) and their primary carers (800 000) providing information about, and referrals to mainstream services, as well as promoting community engagement. Third, the core business of the NDIS targets people aged under 65 years (when first accessing the scheme) with a significant and permanent disability (411 000), and funds a full range of long-term support. An individual support plan is developed with each participant, specifying which 'reasonable and necessary' support services will be funded by the NDIS to help the participant achieve their goals.

The first objective of the NDIS, as defined in the National Disability Insurance Scheme Act (2.3) is 'to give effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities' (CRPD). These obligations, as discussed in Section 1.3.1, include the right to adequate housing. Furthermore, the NDIS has an obligation to support people with disability to 'maximise independent lifestyles and full inclusion in the mainstream community' (Part 2.3 (g)) and to 'participate in and contribute to social and economic life to the extent of their ability' (Part 4.2). While in order to achieve these objectives and obligations, people with disability need adequate and appropriate housing, the NDIS legislation does not include housing as one of the NDIS's responsibilities. Nevertheless, the Productivity Commission (2011) costings for the NDIS scheme included 'user cost of capital' fund for participants with high support needs. Very little information has been made public to date about how these funds will be structured and allocated, and the details are still under negotiation between the NDIA and the Commonwealth and state governments. On 24 April 2015, the Council of Australian Governments (COAG 2015) announced that NDIS funds will be used to 'enable the market to generate and leverage new and innovative specialist disability housing' for 'people with disability requiring an integrated housing and support model'.

The transition to the NDIS, and concerns about its housing policy implications, are the key reasons for this study. However, the analysis of barriers and strategies in access to housing has implications for the much larger population of people with disability both with and without NDIS funding. The following section describes the methods undertaken in the study.

1.5   Method

A mixed method approach was taken to address the research questions, as detailed below. The research has been designed for consistency with the principles for disability research in the National Disability Research and Development Agenda (Disability Policy Research Working Group 2011), and incorporated disability inclusive research practice at all stages.

1.5.1   Quantitative analysis

Data from the ABS Survey of Disability, Ageing and Carers (SDAC) 2012 and the census was analysed to examine the current distribution of people with a severe or profound core activity limitation (as a proxy for the group of people most likely to be funded by the NDIS) by housing tenure and living arrangements, support arrangements and other demographic characteristics.

1.5.2   A review of past and current disability funding and support programs

The research team conducted a desk-based review of existing academic and grey literature on disability funding and support programs in Australia. The focus of this review was on evaluations of programs that have sought to facilitate transition of people with disability from congregate settings, group homes, family care and homelessness to more independent living in stable housing in the community. Findings from this review are presented in Chapter 3.

1.5.3   Interviews with disability services and housing providers

A cross-sector purposive sample of 13 people in frontline or managerial positions in disability and housing agencies in NSW, Victoria and Western Australia was identified, drawing on the research team's established contacts as well as advice from the research reference group. These participants were interviewed to gain background information on the design of programs

providing support or housing assistance for people with disability. Interviews were mostly face-to-face and semi-structured, with questions tailored to the specific expertise of each participant. These participants were also asked for advice and assistance in recruitment of people with disability who met our selection criteria (Section 1.5.4).

1.5.4 Interviews with people with disability

The core of the study involved a total of 51 in-depth interviews with people with disability who moved, or planned to move, from congregate care, group homes, their parents' home or unstable housing to more independent and stable housing and living arrangements. These were selected to represent the type of housing transitions that could potentially be facilitated by the NDIS. It was a purposive 'critical case' sample, and being targeted at those who were successful in moving home, it does not represent the majority of people with disability, or the majority of participants in the support programs studied. Nevertheless, the learnings from their experiences are valuable in highlighting some of the key factors underpinning successful housing transitions.

Participants were recruited in capital cities and NDIS trial sites in New South Wales (NSW), Victoria and Western Australia, including Sydney (11), Melbourne (8) and Perth (11), the Barwon region in Victoria (9) and the Hunter region in NSW (8). Additional interviews were conducted in the Pilbara region in Western Australia (WA) (4).

The participants were diverse in terms of their geographic location, disability types, gender, age group, Indigenous status, housing types and transition experiences and disability support funding arrangements (Table 2).

Table 2: Participant characteristics

Selection criteria	Sub-categories	Number (n=51)
Region	Sydney	11
	Melbourne	8
	Perth	11
	Barwon, Victoria	9
	Hunter, NSW	8
	Pilbara, WA	4
Disability	Intellectual, developmental, cognitive	24
	Physical, sensory	13
	Psychosocial	8
	Multiple	6
Gender	Male	28
	Female	23
Age group	18–20	2
	20–34	20
	35–44	19
	45–54	7
	55–64	3
Indigenous status	Aboriginal	6
Culturally and Linguistic Diversity	Born outside Australia	5
Housing before transition	Parent/s home	35
	Group home / Specialist housing	7
	Boarding house	1
	Unstable or inappropriate housing	8
Housing tenure after transition	Social housing	23
	Private rental	12
	Owner-occupation	3
	Shared-equity	2
	Not yet moved	11
Household arrangements after transition	Single person household	22
	Family (with partner and/or children)	4
	Sharing with others (including live in carer)	14
	Not yet moved	11
Disability support funding	NDIS	14
	Other	35
	None	2

Recruitment of participants with disability was carried out through initial contact with non-government housing and disability agencies, as well as contacts provided by the research partners People with Disability Australia (PWDA) and People with Disability Western Australia (PWDWA). The providers and research partners helped identify people with disability meeting the selection criteria, and passed on invitations to participate in the study. Those who accepted the invitation contacted the research team by email or phone to schedule an interview.

The interviews with participants were semi-structured and focused on several key themes:

→ Their housing histories.

→ Motivations to move home and housing preferences.

→ Experience of planning and executing their move to a new home.

→ Challenges and successful strategies in securing preferred housing.

→ Their disability and support needs.

→ Support funding and services they receive.

General information about participants' needs, preferences and outcomes in relation to the design of their homes was collected through the interviews. However, a more detailed architectural analysis of participants' homes was beyond the scope of the study.

Most interviews were conducted with only the person with disability who moved. In some cases—particularly for participants with intellectual disability—family members were also interviewed (separately or together, depending on the participant's preference) to gain additional contextual information about their housing move.

Most interviews were conducted as face-to-face verbal conversations, usually in the participant's home or another venue of their preference (e.g. a café near their home). Following inclusive research practices, some participants chose to participate in the study in non-verbal ways, such as taking the interviewer on a tour inside and around their house or showing pictures and visual diaries that conveyed their daily routines, friendships and various positive or negative aspects of their housing and living arrangements. One participant chose to be interviewed through an exchange of emails. Each participant received a $50 gift voucher. Interviews with people with disability took place between September 2014 and February 2015. Findings from these interviews are presented in Chapters 4–6.

1.5.5 Reference group

A reference group was established for the study consisting of key stakeholders in the disability sector and the housing sector. A teleconference was held with members of the research team and the reference group in June 2014. The project aims, questions and methods were discussed and advice was sought from the reference group on the selection of case study areas and recruitment of participants.

1.5.6 Policy workshop

Close to completion of the study, a policy workshop was held for the purpose of reviewing the research findings and discussing their policy implications with a range of knowledgeable stakeholders. Approximately 30 people participated in the workshop including staff in public and community housing, disability and human services government departments, disability support services, housing and disability industry peak bodies and advocacy agencies of people with disability across Australia.

Prior to the workshop, participants received a draft copy of the final report for review. The workshop included both plenary and small group discussions on key topics, including the overarching approach to housing policy that will be beneficial for people with disability,

strategies to replicate identified 'success factors', and challenges and strategies to achieving the necessary policy and private investment changes.

1.5.7 Analysis

A detailed case study summary was produced for each participant with disability, and these summaries were coded and analysed thematically using Nvivo software. Analysis of interviews with people with disability was framed around three broad themes, which correspond with three report chapters:

→ The stages of each participant's housing transition process, including the motivations for the move, its planning and access to formal and informal support to enable the move (Chapter 4).

→ Barriers, strategies and success factors in securing housing, addressing the distinctive challenges associated with different housing tenures—social housing, private rental and home ownership (Chapter 5).

→ The shelter and non-shelter outcomes (Bridge et al. 2003) for participants following the move to a new home (Chapter 6).

The interviews with people with disability—and in some cases their family members—formed the core of our analysis. Data obtained from interviews and policy workshop with key stakeholders in the housing and disability sectors was used to frame the wider policy implications of the research findings.

2 HOUSING TENURE AND LIVING ARRANGEMENTS OF PEOPLE WITH DISABILITY ELIGIBLE FOR NDIS PACKAGES

The data analysis in this chapter provides an indication of the current distribution of people with disability by housing tenure as context for the other components of the research. The data sets explored in this analysis include the 2012 Survey of Disability, Ageing and Carers (SDAC) (ABS 2012), and the 2011 Census of Population and Housing data (ABS 2011). The analysis first outlines the definitions of disability and housing types in each data source and then outlines the housing tenure of different socio-demographic and geographical population groups, as well as considering the household composition. The population under consideration for this analysis is those people with disability and a profound or severe core activity limitation aged 25–64 years, representing the group of people whose housing is most likely to be affected by their access to NDIS packages.

2.1 Data and definitions of housing types

2.1.1 ABS Survey of Disability, Ageing and Carers

The Survey of Disability Ageing and Carers (ABS 2012) is the most recent in a series of comprehensive surveys of people with disability living in both households and cared accommodation (ABS 2012). As outlined in Table 3, the SDAC Confidentialised Unit Record File (CURF) in 2012 has a total sample size of 67 208 individuals living in households, and within this sample 36 073 individuals are aged between 25–64 years. Among this age group, 1385 people have a disability and are profoundly or severely limited in core activities. This represents a weighted population estimate of 465 165 people with a profound or severe core activity limitation (3.8% of this age group) (a weighted estimate of 163 349 with a profound core activity limitation and 301 816 with a severe core activity limitation). The ABS provides the following definition for these categories:

→ Profound core activity limitation: where a person is unable to do, or always needs help with, a core-activity task (communication, mobility or self-care).

→ Severe core activity limitation: where a person sometimes needs help with a core-activity and/or; has difficulty understanding or being understood by family or friends; or can communicate more easily using sign language or other non-spoken forms of communication (ABS 2013).

The estimate of 465 165 people with disability and a profound and severe core activity limitation is slightly more than the Productivity Commission (2011) estimate that 411 000 people would be eligible for NDIS funded packages. The Productivity Commission argued that the profound and severe categories were too broad as a category for their purposes, as some people may only need assistance sometimes and would not require ongoing funded support. The Productivity Commission modelling is based on estimating the numbers of people who would need 'funded support' where their disability is, or is likely to be, permanent. The definition of 'permanence' would include people with long-term functional limitations who may only need episodic support. In addition, people would have to meet at least one of the following conditions. They would:

→ have significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support (330 000); or

→ be in an 'early intervention' group (80 000) for whom interventions would improve functioning (as in autism, acquired brain injury, cerebral palsy and sensory impairments) or delay or lessen a decline in functioning. This might include people with newly diagnosed

degenerative diseases, such as Multiple Sclerosis and Parkinson's disease (Productivity Commission 2001, p.157).

The analysis in this chapter reviews the housing status for people who have a profound or severe need for assistance with core activities as defined in both the SDAC and the Census data.

While the SDAC is a comprehensive survey, that data is limited in that the CURF does not provide a variable indicating Aboriginal or Torres Strait Islander status. It should also be noted that the housing tenure variable in the SDAC refers to the household the person is living in and does not necessarily refer to the individual's own personal housing status.

Table 3: SDAC CURF sample aged 25–64 years, living in households by disability status

	Sample size	Sample %	Weighted population Estimate	Weighted population %
Profound limitation	467	1.3	163,349	1.4
Severe limitation	918	2.5	301,816	2.5
Moderate limitation	1074	3.0	340,242	2.8
Mild limitation	1880	5.2	618,644	5.2
School or employment restriction	692	1.9	233,862	2.0
Has disability but no limitation in core activities or schooling or employment	832	2.3	270,411	2.3
Long-term health condition without disability	8942	24.8	2,891,861	24.1
No long-term health condition or disability	21,268	59.0	7,178,849	59.8
Total	36,073	100	11,999,033	100

Source: ABS 2012, authors' analysis of CURF data. The SDAC CURF population estimates will not exactly replicate the ABS published estimates or the estimates produced form Tablebuilder due to confidentialising of the CURF sample by the ABS and the limitations on categories available.

The data on housing tenure and landlord type have been used in this analysis to provide the following housing types outlined in Table 4 for the whole sample of interest for this analysis. The definitions of the less common forms of housing tenure are outlined below. As the sample size is relatively small for the last three housing tenure types they have been joined together in an 'other' category in some tables.

Overall, around one quarter (23%) of the people with a profound or severe core activity limitation lived in a house that was owned outright without a mortgage while nearly a further one quarter (24%) lived in a household that had a mortgage. One-fifth lived in private rental and 14 per cent in public rental accommodation. Seventeen per cent lived in some other tenure and a small group, nearly 3 per cent, lived in a form of special dwelling as defined below.

Table 4: People with disability and profound or severe core activity limitation aged 25–64 years by housing tenure, SDAC 2012

Housing tenure	Weighted population estimate	Weighted population %	Sample size
Owner without a mortgage	107,360	23.1	340
Owner with a mortgage	109,889	23.6	332
Renter—private	94,272	20.3	273
Renter—public	62,799	13.5	203
Renter—other	41,275	8.9	115
Rent—not applicable	33,428	7.2	80
Other	4,266[#]	0.9[#]	10
Special dwelling—other	11,876	2.6	32
Total	*465,164*	*100.0*	*1,385*

Source: ABS 2012, authors' analysis of SDAC CURF data.

Notes: # denotes estimate is likely to be unreliable due to small sample size and should be interpreted with caution. Housing tenure refers to the household in which the person lives and may not refer to the individual's own housing status.

Definitions of additional housing tenure terms in SDAC are based on combining the household tenure, landlord type and dwelling type variables:

→ Renter—other: people who are paying rent to housing co-ops, paying rent/board to someone living in the same dwelling and people paying rent to other people or organisations not elsewhere classified.

→ Rent—not applicable: rent free, life tenure.

→ Special dwelling: institutions or group homes; accommodation for the homeless, night shelter or refuge, hotel, motel or other short term accommodation, retired or aged accommodation, religious and education institution, staff quarters, guest house, boarding house or other long-term accommodation, Aboriginal settlement, short-term caravan park, youth camp or camping grounds, other special dwelling.

→ Other: participants in rent/buy or shared equity schemes, and other housing arrangements not elsewhere classified.

Table 5 outlines the housing tenure arrangements for the population aged 25–64 years with and without a profound or severe core activity limitation. One quarter (24%) of people in this age group with a profound or severe core activity limitation lived in homes with a mortgage compared to 42 per cent of those without a profound or severe core activity limitation. Fourteen per cent of people with a profound or severe core activity limitation lived in public rental accommodation compared to 2 per cent of those without.

Table 5: Housing tenure by core activity limitation, people aged 25–64 years, SDAC 2012

	No profound or severe limitation	With profound or severe core activity limitation	Total	No profound or severe limitation %	With profound or severe core activity limitation %
Home owner	2,375,841	107,360	2,483,201	20.6	23.1
Mortgage	4,866,852	109,889	4,976,741	42.2	23.6
Renter—private	2,862,537	94,272	2,956,809	24.8	20.3
Renter—public	272,000	62,799	334,798	2.4	13.5
Renter—other	496,229	41,275	537,504	4.3	8.9
Rent free	554,653	33,428	588,081	4.8	7.2
Other	62,256	4,266	66,522	0.5	0.9
Special dwelling other	43,500	11,876	55,376	0.4	2.6
Total	*11,533,868*	*465,165*	*11,999,032*	*100.0*	*100.0*

Source: ABS 2012, authors' analysis of SDAC CURF data. Housing tenure refers to the household in which the person lives and may not refer to the individual's own housing status.

2.1.2 ABS Census of Population and Housing

The ABS Census of Population and Housing 2011 is a survey of the Australian population, which includes a series of self-completion questions on whether a person has a need for assistance with core activities and the duration of that need. The questions were designed to identify the group as people with a profound or severe disability, defined as:

> Those people needing help or assistance in one or more of the three core activity areas of self-care, mobility and communication, because of a disability, long-term health condition (lasting six months or more) or old age. (ABS 2011)

The Census identifies around 330 000 people with a profound or severe disability aged 25–64 years. The numbers estimated in the Census are lower than the ABS SDAC, which is likely to be due to differences in the data collection methods, as the Census relies on self-reporting, whereas the ABS SDAC data is collected in an interview and is based on a comprehensive module for identifying disability. Thus the population identified in the Census may be different from that identified in SDAC and may lead to differing findings with respect to the composition of the population and housing tenure. The Census data has the advantage of being a survey of the whole population and provides more reliable estimates of small population groups, such as Aboriginal and Torres Strait Islander communities and geographically based data.

The Census provides the following data outlined in Table 6 on the housing arrangements of people with a profound and severe disability. Table 5 shows that for around 7000 people, housing tenure was 'not stated' and 22 600 people were in the 'not applicable' category. This latter category includes people living in non-private dwellings. When we focus on the groups living in private dwellings only, nearly one-third are living in a home that is owned outright, one quarter live in a house with a mortgage, 14 per cent are renting privately and 16 per cent are renting in a state or territory housing authority.

Table 6: People with a need for core activity assistance aged 25–64 years: housing tenure, Census 2011

	Population numbers	Percentages	Population numbers	Percentages (excluding not stated and not applicable)
Owned outright	98,145	29.7	98,145	32.7
Owned with a mortgage	76,097	23.0	76,097	25.3
Rented: real estate agent	41,368	12.5	41,368	13.8
Rented: state or territory housing authority	49,077	14.9	49,077	16.3
Rented: person not in same household	20,564	6.2	20,564	6.8
Rented: housing co-operative, community or church group	5,201	1.6	5,201	1.7
Rented: other landlord type	4,486	1.4	4,486	1.5
Rented: landlord type not stated	2,286	0.7	2,286	0.8
Other tenure type	3,353	1.0	3,353	1.1
Tenure type not stated	7,141	2.2	-	-
Tenure type not applicable	22,612	6.8	-	-
Total	*330,330*	*100.0*	-	-

Source: Census of Population and Housing (ABS 2011), authors' analysis of customised data request, based on place of enumeration. Housing type refers to the household in which the person lives and may not refer to the individual's own housing status.

Table 7 provides the comparison in housing tenure status in the Census data between people with disability and with a severe and profound core activity limitation and those who do not have a need for assistance with core activities for the 25–64 years age group. Overall, as noted above in the SDAC data, people with disability are less likely to be living in a home with a mortgage (23% compared to 44%) and more likely to be living in a home that is owned outright or rented from state or territory authority or in the not applicable category which includes special dwellings.

Table 7: Housing tenure by need for core activity assistance aged 25–64 years, Census 2011

	Has need for core activity assistance		Does not have need for core activity assistance	
	Population Numbers	**Percentages**	**Population numbers**	**Percentages**
Owned outright	98,145	29.7	2,515,861	23.9
Owned with a mortgage	76,097	23.0	4,651,351	44.2
Rented: real estate agent	41,368	12.5	1,741,594	16.6
Rented: state or territory housing authority	49,077	14.9	276,330	2.6
Rented: person not in same household	20,564	6.2	662,020	6.3
Rented: housing co-operative, community or church group	5,201	1.6	42,773	0.4
Rented: other landlord type	4,486	1.4	161,667	1.5
Rented: landlord type not stated	2,286	0.7	54,902	0.5
Other tenure type	3,353	1.0	47,913	0.5
Tenure type not stated	7,141	2.2	137,558	1.3
Tenure type not applicable	22,612	6.8	225,610	2.1
Total	*330,330*	*100.0*	*10,517,579*	*100.0*

Source: Census of Population and Housing (ABS 2011), authors' analysis of customised data request, based on place of enumeration. Housing tenure refers to the household in which the person lives and may not refer to the individual's own housing status

As the SDAC data provides a more comprehensive assessment of disability the SDAC data will be used in many of the tables below except when sample size constrains the data availability.

2.2 Housing tenure by socio–demographic characteristics

2.2.1 Gender

Women (57%) comprise a greater proportion of the population of people with disability and a profound or severe core activity limitation in the 25–64-year age group than men (43%). The housing tenure profiles of men and women in this group are fairly similar (Table 8).

Table 8: Housing tenure by gender, people with disability and profound or severe core activity limitation, aged 25–64 years, SDAC 2012

	Weighted population estimates			Weighted population %	
	Male	Female	Total	Male	Female
Owner without a mortgage	43,424	63,936	107,360	21.8	24.0
Owner with a mortgage	43,656	66,233	109,889	21.9	24.9
Renter—private	38,948	55,324	94,272	19.6	20.8
Renter—public	22,838	39,961	62,799	11.5	15.0
Renter—other	22,683	18,593	41,275	11.4	7.0
Rent—not applicable	19,685	13,744	33,428	9.9	5.2
Other	2,627[#]	1,639[#]	4,266	1.3[#]	0.6[#]
Special dwelling—other	5,153[#]	6,723[#]	11,876	2.6[#]	2.5[#]
Total	199,014	266,150	465,164	100.0	100.0
Total per cent	42.8	57.2	100.0		

Source: Survey of Disability Ageing and Carers (ABS 2012), authors' analysis of CURF data.

Notes: # denotes estimate is likely to be unreliable due to small sample size and should be interpreted with caution. Housing tenure refers to the household in which the person lives and may not refer to the individual's own housing status

2.2.2 Age

Around two-thirds (67%) of people with disability and a profound or severe core activity limitation are aged between 45–64 years. The older age group are more likely than the younger age group to be living in a home that is owned outright without a mortgage (33% vs 7%) and less likely to be renting (Table 9).

Table 9: Housing tenure by age, people with disability and a profound or severe core activity limitation, aged 25–64 years, SDAC 2012

	Weighted population estimates			Weighted population %	
	25–44 years	45–64 years	Total	25–44 years	45–64 years
Owner without a mortgage	9,475	97,885	107,360	6.7	32.6
Owner with a mortgage	33,357	76,532	109,889	24.7	23.7
Renter—private	38,926	55,346	94,272	24.9	17.4
Renter—public	18,001	44,797	62,799	14.0	15.0
Renter—other	24,618	16,657	41,275	15.1	5.2
Rent—not applicable	20,310	13,119	33,428	10.2	3.8
Other	2,803[#]	1,463[#]	4,266	1.6[#]	0.3[#]
Special dwelling—other	5,564[#]	6,312[#]	11,876	2.8[#]	2.1[#]
Total	153,054	312,111	465,164	100.0	100.0
Total per cent	32.9	67.1	100.0		

Source: Survey of Disability Ageing and Carers ABS 2012, authors' analysis of CURF data.

Notes: # denotes estimate is likely to be unreliable due to small sample size and should be interpreted with caution.

2.2.3 Disability group

The SDAC collects information on a range of disability groups including sensory, intellectual, physical, psychological, head injury, stroke and brain damage and 'other', which includes 'receiving treatment or medication for any other long-term conditions or ailments and still restricted in everyday activities and any other long-term conditions resulting in a restriction in everyday activities' (ABS 2013, Appendix 2). Individuals can report more than one disability group and a high proportion of the sample do so. For the purpose of this analysis, the disability groups have been aggregated into three groups in Table 10 below. People classified into the 'intellectual' disability group report that disability but may also report other disabilities. People classified in the 'physical' disability group do not report an intellectual disability but have a physical disability and may report other disabilities in addition. People in the 'other' group have neither an intellectual nor physical disability but may have any combination of the other disability groups. Overall, just over one-fifth (22%) of people in this group reported an intellectual disability, two–thirds (67%) had a physical disability and 12 per cent were in the 'other' group. These proportions are substantially different to the profile of existing service users, where a majority are people with intellectual or learning disability (AIHW 2014b, p.13).

Thirteen per cent of people with intellectual disabilities lived in homes owned outright compared to around one quarter of those with physical or other disabilities. Over one quarter (28%) of the people with intellectual disabilities lived in household in the 'other' category, which includes rent free, life tenure, rent/buy or shared equity schemes and special dwellings. This compares with only 6–8 per cent of people with physical or other disabilities.

Table 10: Housing tenure by disability group, people with disability and profound or severe core activity limitation, aged 25–64 years, SDAC 2012

	Weighted population estimates				Weighted population %		
	Intellectual	Physical	Other	Total	Intellectual	Physical	Other
Home owner	12,476	82,230	12,654	107,360	12.5	26.5	23.1
Mortgage	6,669[#]	88,654	14,565	109,889	6.7[#]	28.6	26.5
Renter—private	16,080	65,317	12,875	94,272	16.1	21.1	23.5
Renter—public	17,401	40,509	4,888[#]	62,799	17.4	13.1	8.9[#]
Renter—other	19,705	15,752	5,818[#]	41,275	19.7	5.1	10.6[#]
Other	27,664	17,801	4,105	49,570	27.7	5.7	7.5
Total	99,995	310,263	54,906	465,164	100.0	100.0	100.0
Total per cent	21.5	66.7	11.8	100			

Source: Survey of Disability Ageing and Carers (ABS 2012), authors' analysis of CURF data.

Notes: # denotes estimate is likely to be unreliable due to small sample size and should be interpreted with caution. Housing tenure refers to the household in which the person lives and may not refer to the individual's own housing status.

2.2.4 Income levels

Around one-third of people with disability and a profound or severe core activity limitation reported gross personal incomes of less than $320 per week, another third had gross personal incomes between $321 and $580 per week, while just under one-fifth had incomes over $581 per week (thus falling outside the income threshold for social housing eligibility). This data reports on individual income rather than household income, which may also have a big impact on housing tenure options. Nonetheless, it is evident that a 40 per cent of people in the highest income bracket are living in a home that is being purchased compared to 12 per cent of people in the middle income bracket and 15 per cent of people in the lower income bracket. Over a

quarter (27%) of the group in the higher income bracket are renting in the private rental market compared with 17 per cent of those in the lowest income bracket (Table 11).

Table 11: Housing tenure by individual income, people with disability and a profound or severe core activity limitation, aged 25–64 years, SDAC 2012

	Weighted population estimates					Weighted population %			
	Not known, not applicable	less than $320	$321–580	$581 or more	Total	Not known, not applicable	less than $320	$321–580	$581 or more
Home owner	17,487	41,680	27,275	20,919	107,360	26.8	27.7	16.6	24.7
Mortgage	16,811	38,058	20,204	34,816	109,889	25.8	25.3	12.3	41.0
Renter—private	8,259[#]	25,489	37,520	23,003	94,272	12.7[#]	17.0	22.8	27.1
Renter—public	6,451[#]	23,887	30,061	2,399[#]	62,799	9.9[#]	15.9	18.3	2.8[#]
Renter—other	7,326[#]	8,666[#]	22,597	2,687[#]	41,275	11.3[#]	5.8[#]	13.7	3.2[#]
Other	8,807[#]	12,637	27,089	1,037[#]	49,570	13.5[#]	8.4	16.4	1.2[#]
Total	65,141	150,417	164,746	84,861	465,164	100.0	100.0	100.0	100.0
Total per cent	14	32.3	35.4	18.2	100				

Source: Survey of Disability Ageing and Carers (ABS 2012), authors' analysis of CURF data.

Notes: # denotes estimate is likely to be unreliable due to small sample size and should be interpreted with caution Housing tenure refers to the household in which the person lives and may not refer to the individual's own housing status.

2.2.5 Household type

Eighty-one per cent of people with disability and a profound or severe core activity limitation live with others while around 17 per cent live alone (the other 3% are living in special dwellings). Among people living alone 31 per cent lived in private rental and a further 31 per cent lived in public rental housing. Only 12 per cent of the people living alone lived in a house being purchased compared to 27 per cent of those living with others (Table 12).

Table 12: Housing tenure by household type, people with disability and a profound or severe core activity limitation, aged 25–64 years, SDAC 2012

	Weighted population estimates			Weighted population %	
	Lives with others	Lives alone	Total	Lives with others	Alone
Home owner	92,265	15,095	107,360	24.6	19.4
Mortgage	100,358	9,531	109,889	26.7	12.3
Renter—private	70,442	23,831	94,272	18.8	30.6
Renter—public	38,645	24,154	62,799	10.3	31.0
Renter—other	38,089	3,187[#]	41,275	10.1	4.1[#]
Rent free	31,397	2,031[#]	33,428	8.4	2.6[#]
Other	4,266[#]	n.a	4,266[#]	1.1[#]	n.a
Total	375,462	77,827	453,289	100.0	100.0
Total per cent	80.7	16.7			

Source: Survey of Disability Ageing and Carers (ABS 2012), authors' analysis of CURF data.

Notes: Special dwellings do not have a household type and so are not included in this table. # denotes estimate is likely to be unreliable due to small sample size and should be interpreted with caution. Housing tenure refers to the household in which the person lives and may not refer to the individual's own housing status.

2.2.6 Relationship in household and household type

Almost 50 per cent of people with profound and severe core activity limitation (around 230 000) lived with a partner, a further 10 per cent were lone parents. Eleven per cent (over 51 000) were adults living with their parents, representing one of the key focus groups for this study, because of the potential demand for housing to facilitate transition to independent living. Seventeen per cent lived in lone person households and around 5 per cent in group households. Around one-third (34%) of people living with a partner lived in a home without a mortgage, while another one-third (37%) lived in a home with a mortgage, and 18 per cent lived in private rental accommodation. The majority (64%) of lone parents lived in rental accommodation, with one-third (32%) in private rental and another quarter (24%) renting from a public authority. Around half (48%) of the adults living with parents lived in the 'other' housing category, which includes rent free, life tenure, special dwellings and other categories. In the lone person category, 31 per cent were living in private rental accommodation and another 31 per cent were in public rental accommodation. People living in group households were most likely to live in rented accommodation, either private (34%), other (25%), or public (17%) (Tables 13 and 14).

Table 13: Housing tenure by relationship and household type, people with disability and profound or severe core activity limitation, aged 25–64 years, SDAC 2012, weighted population estimates

	Living with partner	Lone parent living with children	Adult living with parents	Other	Lone person household	Group household	Total
Owner without a mortgage	78,542	5,760[#]	3,191[#]	3,558[#]	15,095	1,214[#]	107,360
Owner with a mortgage	85,315	10,149	n.a.	2,523[#]	9,531	1,877[#]	109,889
Renter—private	41,727	14,255	n.a.	4,762[#]	23,831	7,303[#]	94,272
Renter—public	17,573	10,422	2,494[#]	4,407[#]	24,154	3,749[#]	62,799
Renter—other	4,561[#]	n.a	18,576	5,975[#]	3,187[#]	5,261[#]	41,275
Other	3,950[#]	n.a	24,568	4,959[#]	2,031[#]	2,104[#]	49,570
Total	231,668	44,382	51,719	26,185	77,827	21,508	465,164

Source: Survey of Disability Ageing and Carers (ABS 2012), authors' analysis of CURF data.

Notes: # denotes estimate is likely to be unreliable due to small sample size and should be interpreted with caution
Housing tenure refers to the household in which the person lives and may not refer to the individual's own housing status.

Table 14: Housing tenure by relationship and household type, people with disability and profound or severe core activity limitation, aged 25–64 years, SDAC 2012, percentages

	Living with partner	Lone parent living with children	Adult living with parents	Other	Lone person household	Group household	Total
Owner without a mortgage	33.9	13.0[#]	6.2[#]	13.6[#]	19.4	5.6[#]	23.1
Owner with a mortgage	36.8	22.9	n.a.	9.6[#]	12.3	8.7[#]	23.6
Renter—private	18.0	32.1	n.a.	18.2[#]	30.6	34.0	20.3
Renter—public	7.6	23.5	4.8[#]	16.8[#]	31.0	17.4[#]	13.5
Renter—other	2.0[#]	n.a	35.9	22.8[#]	4.1[#]	24.5[#]	8.9
Other	1.7[#]	n.a	47.5	18.9[#]	2.6[#]	9.8[#]	10.7
Total	100.0	91.5	94.4	100.0	100.0	100.0	100.0
Total per cent	49.8	9.5	11.1	5.6	16.7	4.6	

Source: Survey of Disability Ageing and Carers (ABS 2012), authors' analysis of CURF data.

Notes: # denotes estimate is likely to be unreliable due to small sample size and should be interpreted with caution
Housing tenure refers to the household in which the person lives and may not refer to the individual's own housing status.

2.2.7 Indigenous status

Nearly 15 000 people with a profound or severe core activity limitation in the Census identified as Aboriginal and/or Torres Strait Islander in the Census, representing 4.6 per cent of this population (excluding those whose Indigenous status was 'not stated'). Just over one-third (35%) of Indigenous people with disability lived in housing rented from the state and territory

housing authority, while a further one quarter (27%) lived in another form of rental accommodation. Twelve per cent lived in a home owned outright and 13 per cent in a home with a mortgage (Table 15).

Table 15: Housing tenure by Indigenous status, people with a need for core activity assistance, aged 25–64 years, Census 2011

	Population numbers		Percentages	
	Indigenous	Non-Indigenous	Indigenous	Non-Indigenous
Owned outright	1,779	95,069	11.9	30.6
Owned with a mortgage	1,945	73,272	13.0	23.6
Rented: real estate agent	1,870	38,977	12.5	12.6
Rented: state or territory housing authority	5,198	43,048	34.8	13.9
Rented: person not in same household	872	19,416	5.8	6.3
Rented: housing co-operative, community or church group	974	4,172	6.5	1.3
Rented: other landlord type	250	4,143	1.7	1.3
Rented: landlord type not stated	133	2,085	0.9	0.7
Other tenure type	173	3,057	1.2	1.0
Tenure type not stated	503	6,236	3.4	2.0
Tenure type not applicable	1,229	20,838	8.2	6.7
Total	14,926	310,313	100.0	100.0

Source: Census of Population and Housing (ABS 2011), authors' analysis of customised data request, based on place of enumeration. ('Not stated' responses excluded from the denominator). Housing tenure refers to the household in which the person lives and may not refer to the individual's own housing status.

2.3 Housing tenure by geographical region

2.3.1 State

Tables 16 and 17 report the housing profiles of the group across geographical region of states and territories based on the data from SDAC, while Tables 18 and 19 report the same data from the Census. Small sample sizes mean that most, or all, of the data for South Australia, Western Australia, Tasmania, Northern Territory and the Australian Capital Territory in SDAC is unreliable. Both data sources show that around one-third of people with a profound or severe core activity limitation lived in New South Wales, one quarter in Victoria and one-fifth in Queensland.

In the Census data, Victoria and Tasmania have the highest rate of home ownership (33% and 31% respectively). In all states/territories, except for the Northern Territory, between 21–25 per cent of the group are purchasing a home. NSW and Queensland have the highest rate of private rental at 14–16 per cent. Northern Territory and ACT have the highest rates of public rentals at around 29–32 per cent.

Table 16: Housing tenure by state/territory, people with disability and a profound or severe core activity limitation, aged 25–64 years, SDAC 2012, weighted population estimates

	New South Wales	Victoria	Queensland	South Australia[#]	Western Australia[#]	Tasmania[#]	Northern Territory	Australian Capital Territory
Owner without a mortgage	33,837	34,953	14,195	11,038	7,450	3,655	230	2,002
Owner with a mortgage	32,503	31,872	24,068	10,536	5,942	3,042	582	1,344
Renter—private	29,783	22,711	26,638	4,760	6,000	3,236	353	792
Renter—public	27,627	12,593	8,475	5,811	4,240	2,553	417	1,084
Renter—other	11,748	11,374	9,028	3,489	3,063	1,903	n.a	500
Other	21,863	10,770	9,746	2,272	3,718	593	n.a	537
Total	157,361	124,273	92,149	37,905	30,413	14,982	1,822	6,259
Total per cent	33.8	26.7	19.8	8.2	6.5	3.2	0.4	1.4

Source: Survey of Disability Ageing and Carers (ABS 2012), authors' analysis of CURF data.

Notes: # denotes estimate is likely to be unreliable due to small sample size and should be interpreted with caution. Housing tenure refers to the household in which the person lives and may not refer to the individual's own housing status.

Table 17: Housing tenure by state/territory, people with disability and a profound or severe core activity limitation, aged 25–64 years, SDAC 2012, weighted percentages

	New South Wales	Victoria	Queensland	South Australia[#]	Western Australia[#]	Tasmania[#]	Northern Territory[#]	Australian Capital Territory[#]
Owner without a mortgage	21.5	28.1	15.4	29.1	24.5	24.4	12.6	32.0
Owner with a mortgage	20.7	25.7	26.1	27.8	19.5	20.3	32.0	21.5
Renter—private	18.9	18.3	28.9	12.6	19.7	21.6	19.4	12.7
Renter—public	17.6	10.1	9.2	15.3	13.9	17.0	22.9	17.3
Renter—other	7.5	9.2	9.8	9.2	10.1	12.7	n.a	8.0
Other	13.9	8.7	10.6	6.0	12.2	4.0	n.a	8.6
	100	100	100	100	100	100	86.8	100

Source: Survey of Disability Ageing and Carers (ABS 2012), authors' analysis of CURF data.

Notes: # denotes estimate is likely to be unreliable due to small sample size and should be interpreted with caution. Housing tenure refers to the household in which the person lives and may not refer to the individual's own housing status.

Table 18: Housing tenure by state/territory, people with a core activity need for assistance, aged 25–64 years, Census 2011, population estimate

	New South Wales	Victoria	Queensland	South Australia	Western Australia	Tasmania	Northern Territory	Australian Capital Territory	Total
Owned outright	32,951	26,007	19,405	7,573	7,345	3,335	508	1,021	98,145
Owned with a mortgage	23,313	20,146	15,607	6,817	6,199	2,588	410	1,017	76,097
Rented: real estate agent	15,666	9,393	10,723	2,282	2,059	891	132	222	41,368
Rented: state or territory housing authority	17,488	9,065	8,548	5,727	4,361	1,788	929	1,171	49,077
Rented: person not in same household	5,937	4,352	5,397	1,828	1,836	900	138	176	20,564
Rented: housing co-operative, community or church group	1,873	871	874	779	445	102	203	54	5,201
Rented: other landlord type	1,416	899	1,154	356	411	121	97	32	4,486
Rented: landlord type not stated	741	550	510	202	174	67	28	14	2,286
Other tenure type	1,191	797	634	312	277	91	26	25	3,353
Tenure type not stated	2,426	1,887	1,265	586	554	233	135	55	7,141
Tenure type not applicable	7,197	6,084	4,286	1,988	1,757	676	323	301	22,612
Total	110,199	80,051	68,403	28,450	25,418	10,792	2,929	4,088	330,330

Source: Census of Population and Housing (ABS 2011), authors' analysis of customised data request, based on place of enumeration. Housing tenure refers to the household in which the person lives and may not refer to the individual's own housing status.

Table 19: Housing tenure by state/territory, people with a need for core activity assistance, aged 25–64 years, Census 2011, population percentages

	New South Wales	Victoria	Queensland	South Australia	Western Australia	Tasmania	Northern Territory	Australian Capital Territory	Total
Owned outright	29.9	32.5	28.4	26.6	28.9	30.9	17.3	25.0	29.7
Owned with a mortgage	21.2	25.2	22.8	24.0	24.4	24.0	14.0	24.9	23.0
Rented: real estate agent	14.2	11.7	15.7	8.0	8.1	8.3	4.5	5.4	12.5
Rented: state or territory housing authority	15.9	11.3	12.5	20.1	17.2	16.6	31.7	28.6	14.9
Rented: person not in same household	5.4	5.4	7.9	6.4	7.2	8.3	4.7	4.3	6.2
Rented: housing co-operative, community or church group	1.7	1.1	1.3	2.7	1.8	0.9	6.9	1.3	1.6
Rented: other landlord type	1.3	1.1	1.7	1.3	1.6	1.1	3.3	0.8	1.4
Rented: landlord type not stated	0.7	0.7	0.7	0.7	0.7	0.6	1.0	0.3	0.7
Other tenure type	1.1	1.0	0.9	1.1	1.1	0.8	0.9	0.6	1.0
Tenure type not stated	2.2	2.4	1.8	2.1	2.2	2.2	4.6	1.3	2.2
Tenure type not applicable	6.5	7.6	6.3	7.0	6.9	6.3	11.0	7.4	6.8
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Source: Census of Population and Housing (ABS 2011), authors' analysis of customised data request, based on place of enumeration. Housing tenure refers to the household in which the person lives and may not refer to the individual's own housing status.

2.3.2 Region

The majority (58%) of people with disability and a profound or severe core activity limitation lived in capital cities while 42 per cent lived in the rest of the state or territory. Housing profiles by region were fairly similar (Table 20).

Table 20: Housing tenure by region, people with disability and profound or severe core activity limitation, aged 25–64 years, SDAC 2012

	Capital city	Balance of state/territory	Total	Capital city	Balance of state/territory
Owner without a mortgage	60,995	46,365	107,360	22.5	24.0
Owner with a mortgage	68,790	41,099	109,889	25.3	21.2
Renter—private	52,032	42,240	94,272	19.2	21.8
Renter—public	34,879	27,920	62,799	12.8	14.4
Renter—other	26,784	14,492	41,275	9.9	7.5
Other	28,152	21,418	49,570	10.4	11.1
Total	271,631	193,533	465,165	100.0	100.0
Total per cent	58.4	41.6			

Source: Survey of Disability Aging and Carers (ABS 2012), authors' analysis of CURF data. Housing tenure refers to the household in which the person lives and may not refer to the individual's own housing status.

2.3.3 Remoteness

Nearly two-thirds (65%) of people with disability and a profound or severe core activity limitation lived in major cities as classified by the ARIA remoteness index and a further quarter (23%) lived in the inner regional areas. In the major cities, around one-fifth (21%) lived in homes that were owned outright compared with nearly one-third (31%) of those living in the 'other areas' (Table 21).

Table 21: Housing tenure by geographic area, people with disability and profound or severe core activity limitation, aged 25–64 years, SDAC 2012

	Major cities	Inner regional	Other areas	Total	Major cities	Inner regional	Other areas
Owner without a mortgage	64,718	25,341	17,301	107,360	21.4	23.7	31.3
Owner with a mortgage	77,460	23,359	9,070	109,889	25.6	21.9	16.4[#]
Renter—private	55,788	26,267	12,218	94,272	18.4	24.6	22.1
Renter—public	42,922	11,545	8,332[#]	62,799	14.2	10.8	15.1[#]
Renter—other	27,783	9,332[#]	4,160[#]	41,275	9.2	8.7[#]	7.5[#]
Other	34,443	10,997	4,131[#]	49,570	11.4	10.3	7.5
Total	303,113	106,841	55,210	465,165	100.0	100.0	100.0
Total per cent	65.2	23.0	11.9	100.0			

Source: Survey of Disability Ageing and Carers (ABS 2012), authors' analysis of CURF data.

Notes: # denotes estimate is likely to be unreliable due to small sample size and should be interpreted with caution. Housing tenure refers to the household in which the person lives and may not refer to the individual's own housing status.

2.4   Chapter conclusions

The housing and living arrangements of people who are most likely to be supported with an NDIS package (25–64 years old with a severe or profound disability) are markedly different to those of the rest of the population.

A majority of people in the group (79%) were on low or very-low income, highlighting the need for affordable housing. However, only 13.5 per cent were public renters. Thus, although significantly over-represented in this housing tenure (compared to 2.5% of people with no severe or profound disability), only a small minority of people with severe or profound disability benefit from the relative affordability and security of tenure in social housing.

The proportion of people living in owner-occupied housing (46%) is significantly smaller than the general population (70%). Home ownership rates were particularly low among people with intellectual disability, with a relatively high proportion of people from this group in supported accommodation and public housing. The proportion of people with disability renting privately was lower—though not drastically—from the general proportion of private renters in the population. Only 2.6 per cent of people in the target group live in 'special dwellings', including group homes.

Over 51 000 people with severe or profound disability who are 25–64 years old are living with their parents. With the NDIS national rollout, many in this group will be able to access, for the first time, the support they need to live independently and will require affordable housing that meets their locational and design needs and preferences. The proportion of people living alone (17%) is slightly lower than the proportion of lone person households with people aged 35–64 years in the general population (20%). However, as more people with disability move out of their parents' home or group housing, the proportion of single person households is likely to increase significantly.

Differences in housing tenure between capital cities and other regions (inner-regional and remote) were apparent, but perhaps less striking than could be expected given substantial housing cost differences. This suggests that barriers other than the costs of housing affect the housing tenure outcomes for people with severe and profound disability.

3 EMERGENT DISABILITY FUNDING AND SUPPORT PROGRAMS: DESK-BASED REVIEW

A literature review was conducted to learn from past disability funding and support programs across Australia and identify lessons to inform housing policy responses to the NDIS. The review covered existing academic and grey literature on such programs to examine the extent to which they have facilitated housing transitions, and the associated challenges, practices and outcomes for participants.

Following an overview of the review method and programs covered, we discuss in turn: the housing-related objectives of these programs; the forms of support provided to achieve desired outcomes; and, the housing outcomes for participants in such programs.

3.1 Review method

Various starting points were used to identify reviews and information about existing programs including individualised funding, independent living schemes, and housing programs for people with disability. The focus was on programs in which facilitating housing transitions for participants was an explicit or implicit aim. The search included academic databases (e.g. Google Scholar), disability studies journals and websites of government departments, organisations and peak bodies.

An open google search was conducted using the following search terms and semi-phrases: consumer directed; choice; direct payments; self-determination; self-managed care; cash-for-care; social care; individualised funding; independent living; housing transitions; innovative housing.

When the search resulted in a relevant study or program, further information was sought through browsing these organisations or programs' websites, and google searches using the program's name as the keyword. This investigative review method was used, rather than a more systematic academic review, because much of the material about recent programs was only available in grey literature.

A detailed summary was compiled for each relevant program or study identified, focusing on the housing related information provided.

3.2 Overview of programs covered in the review

The review focused on programs across Australia that, among other things, enabled participants with disability to experience transitions from family, group homes or institutional care to independent living. While the review encompassed a far wider range of programs, Table 22 below lists those few programs for which we were able to obtain studies or evaluation reports with relevant information about housing transitions.

Table 22: Key programs and sources reviewed that included housing transition information

State	Program	Sources of data
NSW	Younger People in Residential Aged Care NSW (YPRAC NSW)	Health Outcomes International (2011)
	Independent Living Skills Initiative (ILSI) Independent Living Drop In Support (ILDIS) Supported Living Fund (SLF) Individual Accommodation Support Package (IASP)	Purcal et al. (2014)
	Housing and Accommodation Support Initiative (HASI)	Bruce et al. (2012)
	Leaving Care Program (LCP)	Goldblatt et al. (2010)
	Life Time Care and Support (LTCS)	NSW Parliament (2011)
Victoria	Support & Choice	Lime Management Group (2005)
	Marrilac KeyRing	Fyffe & Bigby (2008)
Tasmania	Disability Gateway	DHHS (2013)
South Australia (SA)	Younger People in Residential Aged Care SA (YPRAC SA)	Slowinski et al. (2012)

3.3 Program aims and housing transitions

Most programs had overarching aims to support people with disability to achieve outcomes defined in very general terms—independence, community participation, self-directed support and maintaining existing formal and informal support networks.

Some of these programs had more explicit aims in terms of specific types of housing sought for participants, including: to sustain their existing housing (Disability Gateway); to live in their own homes in ordinary neighbourhoods (KeyRing); to create living arrangements that suit the person's life and preferences (SLF); to sustain stable housing (HASI).

Some programs sought to facilitate housing transitions out of inappropriate housing and living arrangements, without specifying the desired alternative. For example, transitions out of shared supported accommodation (Support & Choice), or out of residential aged care (YPRAC NSW & SA).

A few programs specified the housing transitions they aimed to facilitate. The ILDIS program in NSW aimed to support transition of people from group homes to more independent living arrangements. Likewise, the primary objective of the LCP was to support young people with disability to transition from the Parental Responsibility of the Minister for the NSW Family and Community Services (FACS), to live as independently as possible and be part of their local community once they turned 18 years of age.

Housing was not an explicit aim of some programs, yet was identified as a major challenge to achieving other aims. For example, the Lifetime Care and Support (LTCS) scheme in NSW was established to provide for the treatment and care of people who have been catastrophically injured as a result of a motor accident, irrespective of who was at fault. A parliamentary report on the program highlighted the significance of housing in achieving the program's aims (NSW Parliament 2011).

3.4 Types and models of support to facilitate housing transitions

Whether individualised or not, funding programs can facilitate independent living by providing people with disability with in-home support to assist with personal care and with everyday tasks

in the home and relating to home, wherever they live. Funds for such support were typically the single largest category of support funded by the programs evaluated (e.g. 49% of all support funded by Support & Choice, Victoria; Lime Management 2005, p.16). In some of the programs, support delivered to a participant was based on a plan taking into account his or her goals, skills, experience and needs. Funded support was also used to assist participants in planning their transition into independent living, and in securing a rental tenancy or even purchase their own home by providing administrative and practical assistance in the process (e.g. Marillac KeyRing). In addition to this support, it was reported that real estate agents were in some cases more willing to let properties to people with disability who had regular support, and some of their initial concerns were allayed by the knowledge that there was somebody to contact in addition to the tenant (West et al. 2013, p.30).

The support can be provided by a paid worker; in some programs participants could use their individualised packages to pay for 'good neighbour support'; Individualised funds could also be used to plan and facilitate rosters of informal (unpaid) support. For example, a paid support worker was hired to facilitate peer-support in a 'KeyRing' model[1] , and to help manage a persons' 'circle of support'[2] (Taleporos et al. 2013).

Some programs facilitated independent living by providing funds for home-modification or assistive technologies such as emergency assistance systems, automated timers and doors and others (Taleporos et al. 2013). In addition to home modifications, some programs provided home maintenance and improvement funds to enable participants to move into, or sustain, housing. In one case, in the Disability Gateway program, such funds were used for intensive cleaning to make a family home 'fit for occupancy' according to the local council standards, to prevent a person with disability and their family from being evicted (DHHS 2013, p.51). In another program, Support & Choice, funds were used to replace flooring to complement an existing home extension (Lime Management 2005, p.69). Since home modification and improvement funds can improve the physical standards of dwellings, they can also serve as incentives for housing providers—such as community housing organisations—to take on tenants with a disability in the case of LCT, NSW (Goldblatt et al. 2010, pp.46–47).

Some programs included funding to train people with disability to live independently, and provide increased hours of support at the transition stage. The primary focus of the ILSI program, for example, was on skills development and support during the transition stage.

Programs to assist people with disability who are homeless or at risk of becoming homeless may include brokerage funds to purchase personal care and emergency accommodation when out of home respite is at capacity (Disability Gateway). The HASI program in NSW enables participants' access to stable housing through partnership with social housing providers, as well as—in some cases—provision of temporary accommodation for participants waiting for a social housing vacancy.

An advantage of individualised funding, which is portable and can be transferred across providers, is that participants can have greater control over the nature of support that is provided to them. Other advantages are the relative flexibility of how funds can be used, including for example the option to 'bank' support funds to enable management of future unplanned contingencies, purchase a piece of equipment that saves ongoing costs, etc. (Taleporos et al. 2013, p.46). There are nevertheless some new risks from individualised

---

[1] Key Ring models involve a small number of people (typically up to 10) who live close (e.g. in the same neighbourhood) to each other and to a paid supporter. The housing may be owned by a disability service provider or be mainstream housing. (Taleporos et al. 2013)

[2] Circles of Support and Microboards are a group of committed, unpaid individuals who oversee the living arrangement and other aspects of the person's life in partnership with a person with a disability. Circles of Support are usually less formal and Microboards are typically an incorporated entity and more formalised (e.g. Vela Microboards, Western Australia). (Taleporos et al. 2013)

funding not associated with block-funded housing. Housing arrangements that rely on the pooling together of funds, such as home sharing or the KeyRing housing, can be destabilised when people want to change their housing. If one member chooses to leave, the remaining pooled funds may not be sufficient to sustain these living arrangements for other participants (Wiesel & Fincher 2009). However, in some programs the flexibility to pool together the individualised funds of two or more people with disability was found to be a key factor underpinning successful housing transitions (LIME Management 2005).

Some programs provided direct rent/bond assistance, but this seems to have occurred in unique circumstances (2% of funds provided in Support & Choice, Vic, were for rent/bond; LIME Management 2005, p.16).

Some of the reports highlight the inadequacy of support funding provided by programs. This included complaints by participants about insufficient funds allocated to them, and by service providers who were asked to deliver services at rates that were not sustainable (Disability Gateway). In some cases, participants were deemed to have support needs too high for moving to housing in the community, therefore remaining in congregate aged care (YPRAC SA). Other barriers reported were the difficulties developing informal support from other members of the community or family. Most service providers have limited skills at facilitating informal support, despite policy that clearly states that the sustainability of formal services is premised on supplementing informal support (Taleporos et al. 2013, p.37).

The challenges of coordinating housing and support—both tightly rationed—produced additional complexities. The process of applying for housing is separate from the process of applying for support, yet some services cannot provide support before housing has been secured. Likewise, some housing schemes will not accept tenants without guaranteed support (HASI). One solution for participants with approved support but no long-term housing was to move into transitional accommodation (LTCS). Transitional accommodation, however, can in some circumstances increase the risk of homelessness. For example, people discharged from hospital to transitional accommodation could be left without accommodation should the arrangements for interim accommodation expire prior to long-term accommodation having been found. This risk can be reduced through interim accommodation that expires only once a long-term solution is found, but the outcomes for participants who remain for long periods in transitional accommodation can be problematic (NSW Parliament 2011, p.79).

Successful coordination of housing and support relied to a large extent on the relationship between the providers of both types of services. Whilst collaboration was effective in some programs and areas, in others it was poor (Purcal et al. 2014). When successful, formal and informal partnerships between housing and service providers delivered results in the form of suitable housing options for participants. From the perspective of housing providers—especially community housing providers and private real estate agents, the guarantee of support reduced concerns about taking on tenants with a disability (West et al. 2013). However, in the evaluations of YPRAC NSW it was reported that the state housing authority had no direct involvement in the program, an 'unacceptable situation' given the emphasis on increasing housing options for participants (Health Outcomes International 2011, p.48). Compared to community housing, coordination with public housing was at times more problematic due to policies to only accept tenants who are able to sustain a tenancy without support, thus excluding even those who had support packages in place (Goldblatt et al. 2010, p.41).

Successful coordination of housing and support to enable transition into independent living requires intensive preparation, including a comprehensive person centred planning process to identify both support and accommodation needs and preferences. The transition process was particularly time-consuming and expensive when it involved development of purpose-built accommodation based on the needs of an individual or a group, as reported in the case of YPRAC NSW (Health Outcomes International 2011).

3.5 Housing outcomes

Overall, existing literature suggests some programs have had success in achieving their aims related to housing. Most participants in most programs reviewed (HASI, LCP, Support & Choice, ILSI, ILDIS, SLF, IASP) were satisfied with their housing and support arrangements. Only a few respondents reported being unhappy with the place they were living or the people they were living with. However, some of the evaluations acknowledged that it was too early to assess long-term housing outcomes for participants. Generally speaking, positive outcomes were associated with programs facilitating transitions to less congregated housing, enabling individual choice about housing and providing housing stability.

3.5.1 Stable housing

As discussed above, reducing homelessness and facilitating more stable housing for participants were key aims in some of the programs reviewed (Disability Gateway, HASI, LCP). Evaluations of these programs reported successful outcomes for participants.

The HASI program was found to have achieved its aim of stable housing for most participants. Most participants entered the program with a history (including in many instances just before entering the program) of unstable housing, including accommodation in hospital, prison, living with friends or family, living in a boarding house as well as primary homelessness. Since joining the program, most HASI consumers obtained suitable long-term housing and were supported to successfully maintain their tenancies. The success of the program was attributed to the effective mechanisms of coordination to achieve integrated response to participants' needs, from tenancy management, through clinical support, to housing provision (Bruce et al. 2012, p.9).

Similarly, an evaluation of the LCP program found that overall the program appears to have been effective preventing homelessness and facilitating stable appropriate housing for its participants. The program's key strengths, contributing to these outcomes, were its flexible approach to meeting diverse individual needs, being well resourced, highly structured and positive inter-agency relationships (Goldblatt et al. 2010, pp.vii–viii).

In Tasmania, the Disability Gateway review reported interventions in the form of brokerage support to assist people with disability in crisis and risk of homelessness. These interventions were found to be effective by creating a 'space in which more appropriate longer term planning can take place' (DHHS 2013, p.49). There were, however, concerns that such crisis driven interventions were concealing service gaps such as a lack of emergency accommodation, limited funding for in home support and respite, and a lack of suitable long-term accommodation (DHHS 2013, p.49).

3.5.2 Avoiding or moving out of congregate or group care

Reducing numbers of people with disability in institutional or congregate care, through prevention of admission or rehousing for those already accommodated in such facilities, were the major aims of several programs (YPRAC NSW & SA).

In NSW, the rehousing ('move out') component of the YPRAC program saw 48 young people move out of residential aged care to alternative housing by 2009–10. Overall, the number of residents aged less than 50 years old living in RACFs in NSW, declined from 382 in December 2006, to 285 in October 2010 (25% decrease). This was achieved primarily through substantial investment in new purpose-built facilities for YPRAC clients. The review of the YPRAC NSW program criticised its focus on rehousing at the expense of prevention of admission into residential aged care (YPRAC NSW). Reliance on purpose built group housing also lacks flexibility for subsequent mobility and alternative housing arrangements.

Positive outcomes were reported for participants who moved out of aged care to the family home, a purpose built group home or independent living in mainstream housing. However, two

of three participants who moved to group homes viewed this option as an interim arrangement, due to distance from family and desire to live independently.

Similarly, in SA, most participants in the evaluation of YPRAC have moved to purpose-built group or cluster housing in the community. Only one participant of 24 moved to live on their own with a YPRAC funded support package. This participant took a risk by moving from full-time support to only eight hours of support a day. Modifications to a rental property, assistive technology, and flexible care arrangements made this move possible, and the participant reported being happier and healthier three and a half years after the transition. This approach is similar to other high needs attendant care packages to support people to live independently (Fisher & Campbell-McLean 2008).

The Victorian Support & Choice program, in its first year, facilitated the exit of 41 participants from group homes. Positive outcomes were also found for Support & Choice participants who moved out of group homes, and these moves were described as being 'on the whole extremely successful', due to the level of self-determination afforded through the planning process (Lime Management 2005, p.57). However, the evaluation notes that many of the people who moved out of group homes would have done so regardless of Support & Choice, and in fact some had already moved or were in the planning process before joining the program (Lime Management 2005, p.14).

3.5.3 Housing and living arrangements of participants

Several of the studies reviewed provided information about the post-transition housing and living arrangements of participants. In the HASI program, most participants moved into social housing, and while some participants moved into private rental—with some assistance from Housing NSW—data on the size of this cohort was not available (Bruce et al. 2010, p.117).

In the YPRAC NSW program, purpose-built specialist housing was planned for 'move out' participants, including villas, group homes and co-located units. Of the 121 places planned, only eight included 'flexible packages' (individualised support for independent living in mainstream housing).

The most detailed data was provided by the evaluation of Support & Choice in Victoria, which detailed the housing tenures and living arrangements of those participants who moved out of Shared Supported Accommodation (SSA). Public housing (36%) was the most common housing tenure. Only 19 per cent moved into private rental, and a similar proportion moved back to their family home. Other exits from SSA moved into other forms of accommodation such as aged care and KeyRing housing (26%). The proportion of participants who moved into sharing arrangements (45%) was almost double those who moved alone (23%), although the report does not explain whether this was due to affordability constraints, the need to pool together support funding, or other considerations, such as preferences (Lime Management 2005, p.14).

A survey of the living arrangements of 58 LCP participants found that nine moved to independent living on their own, whereas most others moved to foster family (17), a relative's home (5) or a group home (26). Indigenous respondents were much more likely to live independently in a flat or home compared with non-Indigenous respondents, who were more likely to be in a group home (Goldblatt et al. 2010, p.18).

Some reports commented on participants making gradual housing transitions. This included, for example self-contained accommodation attached to the family home or even a group home (e.g. a granny flat) (Purcal et al. 2014; Taleporos et al. 2013, p.35; Lime Management 2005, p.58), as a transitory step before moving into more independent living.

While the data on distribution of housing tenures and arrangements is an important indicator of the potential housing outcomes of future programs (i.e. the NDIS), very little is known about the

processes through which housing arrangements were planned and secured, and the factors contributing to different housing outcomes for different participants within and across programs.

3.5.4   Choice and control in housing-related decisions

The extent of participants' choices in housing varied significantly across programs. In some programs, participants' choices were relatively limited. The LCP review found that participants were evenly split between those who felt they had choice about where they lived and those who did not (Goldblatt et al. 2010, p.18). In the evaluation of the YPRAC program in SA, concerns were raised that the self-determination of participants in decision making can be easily undermined (Slowinski et al. 2012, p.30).

More personalised funding programs with flexible funding criteria such as Support & Choice, ILSI, ILDIS, SLF and IASP, were found to offer participants more choice about their housing and support (Lime Management 2005, p.57; Purcal et al. 2014).

3.5.5   Social inclusion and interpersonal relationships

The housing transitions facilitated by the programs were found to generally improve social inclusion and interpersonal relationships for participants. These improvements were associated with moving to more independent and more stable housing and living arrangements.

Moving out of group homes—as in the case of Support & Choice participants—was associated with improved family relationships, and greater community membership (Lime Management 2005, p.66). Moving out of residential aged care also increased social inclusion for some participants (YPRAC SA: p.25f).

Individual support packages or drop-in support options were generally associated with increased social inclusion, including frequent community activities and social connections in participants' local community (Purcal et al. 2014, pp.16–17). This was related to the flexible nature of individualised support and also to the location of participants' housing—living close to public transport and local shopping areas, and living within a supportive local community.

Stable housing was also associated with greater social inclusion, and most HASI participants— over 80 per cent—had some form of regular social contact (daily or weekly) with a family member, friend, spouse or partner, and were participating in at least one kind of community activity (Bruce et al. 2012, p.108).

At the same time, it was noted that social participation and inclusion requires on-going attention—as moving from residential care to a community setting 'does not automatically reduce social isolation and create community connections' (YPRAC SA, p.30).

Loneliness was reported as an issue for some participants who moved into independent living on their own (Lime Management 2005, p.62; Bruce et al. 2010, p.68). The HASI evaluation reported that 14 per cent of program participants—mostly men with higher support needs— only had contact with paid staff and did not have any regular contact with other people, such as a family member, friend or partner.

3.5.6   Location of housing

The location of housing determines to a large extent people's access to family and friends, transport, mainstream and specialist services and recreational facilities. Analysis of the locational outcomes for participants was lacking in most studies reviewed, though anecdotal references are made to problematic outcomes for participants resulting from housing in unsuitable locations. This included examples where participants were dissatisfied with their housing due to unsafe locations, limited access to public transport and recreational activities and living at a distance from family and friends (Goldblatt et al. 2010, p.30; Health Outcomes International 2012, p.38).

Location was noted as a major factor in YPRAC participants' housing decisions, including cases where participants turned down offers of housing that were too far away from their preferred location (Slowinski et al. 2012, p.18). In HASI, the desire to move out of a location in some cases resulted in the person exiting from the program (Bruce et al. 2012, pp.21, 83), highlighting the risk of homelessness associated with unsuitable housing locations.

In some reports, although the importance of location was mentioned, no specific reference was made to the locational outcomes for participants (Lime Management 2005; Purcal et al. 2014). However, it seems likely that participants' increased control and choice over housing decisions in more individualised programs such as Support & Choice, ILSI, ILDIS, SLF and IASP, enabled them to move into housing in locations that suit their preferences and needs.

3.5.7 Housing affordability

Despite the relatively high proportion of participants who moved into private rental, most reports said little—if anything—about the rental affordability stress for these participants following the transition. In addition to low-income, people with disability often have significant expenses related to their impairment, which add to the levels of financial stress. A survey conducted by NDS (2014) found that 31 per cent of respondents with disability spent more than 60 per cent of their income on housing. Taleporos et al. (2013, p.32) described cases of people with disability who moved to independent living, but were forced to return to living with their parents due to the costs of housing.

3.5.8 Unsuccessful housing transitions

Some of the studies report on planned or desired housing transitions which—at the time of the research—had not yet eventuated. In Support & Choice, this occurred due to delays in approval of plans, as well as lack of suitable accommodation. Participants experiencing such delays 'spoke of feelings of powerlessness and frustration in the waiting' (Lime Management 2005, p.58). Similar delays, due to shortage of affordable housing in required locations, were reported in the HASI program (Bruce et al. 2012, p.107).

In some cases, housing transitions that did take place eventually proved unsuccessful, requiring rehousing of participants. For example a young person in the LCP who moved into public housing only to realise he was not yet ready for independent living in the community (or did not have sufficient support to do so), and another LCP participant who moved into public housing and experienced harassment. In both cases, participants were able to move to alternative housing—in one case with a family member and in another case through a transfer to another public housing tenancy (Goldblatt et al. 2010). Such experiences highlight the importance of risk management plans to avoid and address unsuccessful housing transitions.

3.5.9 Cost benefits

Costs associated with housing for people with disability include the housing itself; assistive technology and equipment; support to find the housing and manage the transition; modifications for accessibility; and support to live there (Fisher et al. 2010). Although most studies provide details on the average costs per individual in different programs and housing, these are difficult to compare due to insufficient comparable data about the level and type of needs of participants. Exceptions include Fisher and Purcal (2010), who examined the cost-benefit of different types of accommodation options for people with disability, and consistent with international literature, found that compared to group homes, personalised approaches to disability housing support offer better outcomes for service users, at costs that are similar or lower, depending on the person's support needs.

While at the housing transition stage participants may require a higher level of funding, evidence suggests that over time after they have settled into suitable housing with an appropriate mix of formal and informal support, the level of funding can stabilise. Funding can then be redirected to more meaningful activity, such as community and economic participation

(Bruce et al. 2012). Funding levels sometimes even reduce as in some of the Western Australia (WA) cases (Fisher et al. 2010). Other studies reviewed provide only anecdotal evidence of such cases (e.g. Taleporos et al. 2013, p.45).

3.6 Chapter conclusions

The chapter reviewed existing literature on Australian disability funding and support programs that sought to facilitate participants' transitions into stable, more independent, less congregated housing that met their preferences.

The programs examined assisted such transitions by supporting participants in the preparation and planning for the transition, including assistance in securing housing; and, by providing participants with in-home support following the transition, including ongoing support as well as funds for home-modification or assistive technologies. These forms of assistance are likely to continue to be funded by the NDIS.

Key factors undermining positive outcomes in some cases were the inadequacy of support funding provided by programs; the challenge of securing affordable, suitable long-term housing in suitable locations; and the challenge of coordinating housing and support.

Despite these challenges the programs reviewed have had considerable success in achieving their aims related to housing. Some programs successfully provided stable housing for most participants, including those with high risk of homelessness (HASI, LCP). Other programs succeeded in facilitating transitions out of congregate or group care into independent living (YPRAC, Support & Choice), and such moves were generally associated with outcomes such as improved satisfaction and social inclusion. Programs were most successful in achieving these aims when they were well resourced; when inter-agency relations worked well, especially between housing and support providers; and, when a flexible approach was taken to supporting individual needs.

While the review highlights the overall positive outcomes for most participants who experienced housing transition, there are some obvious knowledge gaps. These include insufficient information about affordability and the financial circumstances of participants; lack of information about the factors determining housing tenures and living arrangements for participants; limited data to assess the relationship between specific housing types and other housing and non-housing outcomes for participants; lack of evidence on the important question of how different housing and living arrangements impact on participants' support needs over time; and, more generally, the absence of a longer-term perspective on the outcomes for participants.

Importantly, some of the programs reviewed included specific objectives and targets in terms of the housing transitions they sought to facilitate, and were designed and delivered accordingly. The aims of the NDIS are more generic in nature, and to date no targets have been specified in terms of the desired nature and volume of housing transitions facilitated by the NDIS.

4 TRANSITION PROCESS

Participants' housing transitions were shaped by a variety of housing and non-housing factors. In this chapter we focus on the latter, examining the staging of participants' housing transition, including the motivations for the move, its planning and execution, and the role of formal and informal support in enabling these transitions.

4.1 Motivations

Participants in the study (and their families and supporters) described a wide range of motivations for moving, reflecting their current housing circumstances, housing and lifestyle preferences as well as their experience of living with disability. Most participants cited more than one motivation for the move.

Some motivations to move were described in positive terms. Most notably, the aspiration for greater independence and choice was the most frequently cited motivation to move. For most participants the desire to move was associated with an aspiration for greater independence in their daily routines and more choice about where and with whom they live. This was a particularly strong reason for people with intellectual disability, and people leaving group homes (who were also mostly people with intellectual disability).

> Since I've been 19 years old I wanted to find a place and live on my own, to move out. (Lucas)

Parents and family members often strongly encouraged participants to become more independent and to move out. Often parents' encouragement was underpinned by concerns about their own ageing.

Other common motivations to move related to locational preferences and access to family, friends, social activities, a day program or a job. Opportunities from individualised funding programs and policies designed to encourage independent living had stimulated some participants to examine housing options. Others, however, pursued plans to move prior to the availability of individualised funding or independent living programs.

Other motivations for housing transition were described in negative terms, such as a desire to move away from housing, neighbourhood and living arrangements that had adversely impacted on participants' health and wellbeing. Unsafe neighbourhoods and unsafe or unstable housing were the primary motivation to move for some participants who had previously lived in public as well as private housing. For example, Barbara's (40-50, Barwon, intellectual disability) experience of unstable and unaffordable housing was the underlying motivation for her transition into social housing:

> I had been in insecure housing for over 20 years prior to that. The most recent was in private rental, a small run down unit, with holes in the roof, the landlord never did repairs and the rent was excessive. It was in a very dangerous and loud neighbourhood and I hated it. I have been in and out of refuges and other … funding housing programs, as well as a number of private rental properties. All have been horrible, and unbearable … the need for stable and affordable housing was a big motivator, along with not being able to afford a property to meet my disability related needs in the private rental market. (Barbara)

Some participants who lived in shared supported accommodation, at the time or prior to the interview, were dissatisfied with these living arrangements. Common reasons for dissatisfaction included: incompatibility with other residents due to personal, age or other differences; or a lack of privacy and safety (particularly for those in larger congregate accommodation, in some cases sharing a room with others). The closure of a large boarding house prompted two participants to think about independent living options. For example, Matt (50–60, Barwon,

psycho-social disability) had lived in a boarding house for close to twenty years and was highly dissatisfied with this living arrangement:

> I was in a bedroom with two other blokes … I didn't enjoy that at all. I didn't have any privacy and it was very expensive. (Matt)

Importantly, sharing with others was not described as a negative aspect of housing in itself, as much as a lack of choice about who they share with and where. Several people reported that their previous housing did not meet their basic needs. This included dwellings that were too small, not set up for disability access or unsuitable for a guide dog. For several participants, risk of or actual breakdown of informal caring arrangements and strained or abusive family relationships were key reasons for seeking alternative housing. In many cases, support workers played a key role in initiating the transition by encouraging and supporting people with disability to move out of unsuitable housing or living arrangements.

4.2   Transition stages

Participants had different experiences planning and preparing to move home. In some cases the move happened unexpectedly—described by one participant as a 'happy coincidence'—with relatively little preparation. In part, this resulted from participants' expectation of a lengthy process of finding and securing suitable housing. For example, one mother of a young person with intellectual disability who moved into a private rental after just four months of searching for a rental unit, commented on their surprise:

> We didn't think we would get the unit. We went through the process, but thought—'well 15 years on the housing wait list'—we can manage that' … [laughs]. We actually didn't believe that she would strike it this lucky. (Mother)

In most cases however, the planning and preparation for the move took a significant amount of time and effort, lobbying, viewing properties and housing options, trialling alternative housing, seeking support as well as skills building prior to the move.

The length of the transition period—from the initial thoughts about moving to the settlement in a new home—was determined by a range of factors, including: the participant's motivations to move and the urgency to find alternative housing and support; clarity about their preferred housing and support and the availability of person-centred plans; access to financial resources; assistance from participants' social networks; the availability of appropriate housing in the desired area; and access to support to live independently. For most of participants with intellectual disability, the planning and transition period took around three to five years. For a few, it was a quicker process and they spent only several months planning and seeking appropriate housing. For participants with physical disability, the planning and transition period (between several months to three years) was generally shorter compared to those with intellectual disability.

The stages of the transition process varied between participants. For some, moving meant only finding appropriate housing as they already had clear goals and the skills and support in place to live independently. For others, however, the process started with identifying the type of home they would like to live in and organising support and building skills, sourcing funding and housing, and in some cases identifying flatmates. In broad terms, the following common transition stages were identified in different variations:

→ Planning: vision, goal setting, road maps and risk management strategies.

→ Identify, seek, and establish required funding and formal and informal support.

→ Develop independent living skills and confidence.

→ Find appropriate housing.

→ Transition arrangements (pre- and post-move).

→ Move and settle in.

Some of these steps in transition planning (e.g. accessing housing) are discussed elsewhere (Chapter 5). In the following sections we elaborate on: planning and goal setting; developing living skills and confidence; transition arrangements and the actual move; access to formal and informal support.

4.2.1 Planning and goal setting

For some participants, planning and goal setting started with defining a vision of realistic and desired home and living arrangements, for example whether to live alone or with others; in which location, in which type of housing and with what forms of support or modifications. Others already had a relatively clear vision of where and how they wanted to live, so they focused on planning and realising these goals. In addition to goal setting, planning involved more detailed 'road maps' to achieve goals as well as risk management strategies, including fall-back plans to address unexpected difficulties. Participants and their families identified resources that assisted them in the planning process, including:

→ person centred planning

→ grass-roots networks

→ support funding applications.

Person-centred planning

Participants who experienced person-centred planning described it as a helpful approach, enabling them to think outside of disability service boxes, and consider a wider range of options for their preferred housing and lifestyle. Some participants began the person-centred planning process before they applied for housing or support funding. Andy (30–40, Perth, intellectual disability), for example, gathered all his friends and family with a planner to think together about his future when a Community Living Fund package becomes available.

Grass-roots networks

Several participants and their families sought assistance in planning from their informal support network. Mostly these networks were founded or organised by dedicated family members of people with disability (see Box 1). In our study, parents of participants with intellectual disability were most likely to be involved in such networks. Some participants with disability were also involved in self-advocacy organisations and activities that influenced their thinking about housing and living options. Through engagement in such networks participants received valuable emotional support, and practical information, such as access to resources and support. In some cases participants were able to find suitable flatmates or private rental properties through these networks (see Section 4.4).

Box 1: Adults Needing Supported Accommodation (ANSA)

The ANSA network offers a case study of best practice in grassroots networking of families who have a member with disability. The network was established in 2010 as a grassroots initiative by family members of people with disability who were frustrated with the lack of known pathways for their relatives to fulfil their aspirations to live more independently. The network aims to develop opportunities for their family members to 'live in homes of their choosing, born out of their personal desire for a full and rich life' (Lambert 2015).

The network is premised on the view that informal support networks are 'creative, competent and capable of building sustainable and innovative systems of support for those who they love…[and] are best positioned to be able to support the person with the disability prior to and throughout their independent living experience' (Lambert 2015).

The ANSA network is self-governed, with facilitation from the Samaritans Foundation. It runs 10 structured meetings a year providing members an opportunity to share knowledge and support each other by celebrating achievements, fostering respect for each family's choices and nurturing connections and friendships between its members and their relatives. The network reaches out to engage with experts and stakeholders who can provide useful information and influence on decision making. Since last year the ANSA network has been funded by Carers NSW at approximately $1500 per annum to meet operational costs.

Despite its modest funding, ANSA has been successful in achieving its goals, and most relatives with disability supported by members of the ANSA network have already moved or are in transition to independent living in the community in a wide range of housing and living arrangements. The network assisted these moves with families offering encouragement and support for each other, connecting flatmates and linking members with housing opportunities.

Support funding application

Some participants applied for funding programs specifically designed to promote independent living for people with disability, such as ILSI and SLF in NSW. The process of completing funding applications, and receiving feedback on applications that had not been successful, was described as a valuable planning exercise. It particularly helped people to use goal mapping and planning tools to identify and spell out every single aspect of their future goal, and break down the steps in finding the required formal and informal support as well as suitable housing. For example, one participant's family applied for the SLF three times without success. Each time the reviewers raised questions about support arrangements that the family had not clearly spelled out or even considered in their application (e.g. need to be turned over regularly at night). The reviewers' feedback was helpful for the family to continue to modify their plans and identify required support needs or equipment for that person to be able to live independently.

4.2.2 Developing living skills and confidence

Like most people, for many participants, building independent living skills had been a lifelong process of learning and growing throughout their adolescent years and into young adulthood. In the months or years prior to the move, several participants sought additional and more targeted support to enhance their confidence and learn particular skills. Common skills people with intellectual disability or with limited mobility and motoric skills focused on included: meal preparation and planning, shopping, budgeting and financial management, using transport, internet and other resources, performing simple house tasks/cleaning, accessing community resources and public places (independently and/or with support), and maintaining daily routines (hygiene, personal care, etc.). Some participants attended community courses, including in one case a TAFE course for people with intellectual disability, to become more independent. Others received one-on-one support to develop their confidence and living skills. In the case of people living with their families, parents were often key partners in confidence

building, for example by gradually handing over household responsibilities. One family converted an old railway carriage in their backyard into a room and ensuite for their son. They employed a social trainer to help him develop a routine and learn daily living skills such as preparing his clothes for the following day. Other families taught their sons and daughters to cook, perform small household tasks, and use public transport.

Developing living skills, and by doing so, building confidence about one's capacity to live independently, was an important step for many people to feel ready and prepared to move (in particular those who lived with their family or in supported accommodation). However, other participants—such as Mazy—have successfully adjusted to independent living after the move, with little prior preparations but sufficient formal and informal support to assist in the initial transition period after the move.

4.2.3 Transition arrangements

Some participants tested transitional living arrangements before settling into longer-term housing and living arrangements. These transition arrangements varied depending on the persons' support needs, housing preferences and housing options available. For example, three people with intellectual disability rented together as a transitional stage to trial their compatibility before buying a shared house. In one instance, a single mother moved out of her home for a week so that her daughter and another young woman could see if they liked living together.

Some participants with intellectual disability experienced a 'graded' transition, in some cases over periods of several months, by gradually increasing the amount of time they spent in their new homes without their parents, and gradually reducing the amount of time they spend in their parents' home (e.g. fewer weekends with parents) or the group home they left.

The transition period was considered successful by participants when they felt they had sufficient formal and informal support (before and after the move) to adjust to the separation from a safe or familiar environment; and to settle into a new routine, home and neighbourhood.

4.2.4 Moving in

Once the transition arrangements were complete, most participants were excited to move after a relatively long period of anticipation. All participants received substantial support with the move and the setting up of their new homes. The main support required for a successful move included: help with finding and paying for furniture and white-goods; assistance in moving; setting up direct debit and other payments; and adjusting participants' daily routines to a new home and environment.

Several participants received a government grant to assist them with the purchase of new and used furniture and white goods to set up their new home. Many people also received financial assistance from their families and support providers to pay the bond/deposit or advance rent payments. Such assistance was often crucial in enabling the move:

> I sometimes wanted to move from [the boarding house] but I didn't have where to start. But here [my new unit] my support workers gave me a government grant and everything you see here was paid for by the government. They gave me I think $2500 to buy furniture and white goods and all that. I didn't have any furniture or anything like that. (Matt, 50–60, Hunter, psycho-social disability)

4.3 Formal support

4.3.1 Accessing support funding

Participants accessed a variety of support funding programs including NDIS packages (in trial sites); ILSI, DHASI, SLF (NSW); ISPs (Victoria); YPRAC, CLF (WA). The support funded by these programs was a crucial factor enabling their transition into more independent living

arrangements. The size of support funding packages varied across a wide spectrum, ranging between two to 40 hours of support a week. Support funding was used for a variety of purposes including: daily living tasks; social activities; day program; training and skills development; case management; transport; and medical expenses. Support was also often used for housing-related purposes, including assistance in the housing transition (e.g. planning; and applications for social housing); home modifications; and rent for live-in carers.

4.3.2 Choice and control

Not only the amount, but also the structure of support funding—whether it was individualised, and the extent to which it was flexible and portable—had important implications for participants' choice and control. Some participants (Susan, Sarah, Eden, Stephanie), were able to transfer their funding from one support provider to another. These participants felt empowered by their ability to exercise control over the management of their support:

> I am running the show. (Susan)

> They listen to me. (Sarah)

For example, Eden's (30–40, Sydney, intellectual disability) previous support arrangements worked well until the brokerage service commissioned an alternative service provider which was unreliable. Consequently, Eden experienced significant stress and anxiety. She then successfully applied to transfer her DHASI support funding to her original service provider and original support workers with whom she had been very satisfied. Similarly, Stephanie transferred her individualised funds to a new support agency in order to be supported by a particular support worker whom she knew for many years.

Two participants (Mitchell, Michael) also valued the potential of self-managing their individual funding packages, to reduce administration costs and gain greater control. At the same time, participants noted the level of skill and effort required (from participants or their families) for self-management of funds.

Individualised packages provided flexibility that also increased participants' housing options. Stephanie (30–40, Melbourne, physical disability) for example, was able to stay with her preferred support worker even as she moved to a new home. When individualised funding was flexible rather than restricted to particular types of support, participants used these to support housing transitions, including preparation, applications, and even pay a live-in carers' rent. Some participants in WA were able to secure an individualised funding package equivalent in size to their share of funding in a group home, enabling their transition to more independent living. However, there were also examples in our study of block-funded services that were flexible in their use of such funds and responsive to individual choices.

4.3.3 NDIS participants

Fourteen participants in the trial sites had NDIS funding. Most of these participants had generally good experiences with the NDIS planning process and their outcomes, but a few were disappointed. For some participants in the NDIS launch sites, the scheme was life changing, providing them for the first time with the support they needed to move to independent living (Nathan, Fiona).

> We did something different … moving out of a group home model to a much more individual home for Nathan. This wouldn't have been possible without the NDIS. (Nathan's mother)

Positive experience was associated with high levels of assistance and advocacy from the participants' support agency, medical/health professionals and an NDIS planner. It appears that families who had previous experience in goal setting and planning were in a better position when dealing with NDIS planners:

> I think if you have a clear vision of what you want, and you go to the NDIA with that vision, then they will be only too happy to support that. But I think a lot of parents are sort of fiddling in the dark. (Mark's mother)

Participants who negotiated their NDIS plan with little if any external input were more likely to be dissatisfied with the process and its outcomes. Concerns were raised about exclusion of families from planning sessions. Some felt the NDIS planner did not understand their needs and requirements. Three participants' NDIS support funding was smaller than what they had with previous funding schemes. Despite this, all three have been able to move to their preferred housing and described overall positive outcomes from the move. One of these participants, however, expressed concern about being able to sustain independent living with existing levels of support should her health deteriorate.

Concerns were raised by service providers with respect to the engagement of NDIS planners with people with psycho-social disability. One concern was for people missing their planning meetings if they are not supported to attend. Another concern was that when the planning session took place on a 'good day', a lower and inadequate amount of funding will be allocated to support that person.

Participants who did not yet have NDIS funding were almost evenly divided in their views about the implications of the scheme. Some were hopeful that the NDIS would enable them to achieve their housing and other goals, and would give them more control, for example allowing them to switch from one support provider to another. Others were anxious that their existing support entitlements would be reduced or eliminated once the NDIS replaced existing funding. Some participants were not aware of the NDIS reforms.

4.3.4 Housing and support nexus

Participants' support arrangements were tightly linked with their housing and living arrangements in a variety of ways. Many participants were able to use their support funding as a means to move to preferred housing and living arrangements. In many instances, the availability of new support funding options enabled participants to move from their family home or a group home to independent living. Furthermore, many participants used their support package as a means to assist with their negotiations with housing providers (e.g. applying for social housing; negotiating modifications). In contrast, one participant was not able to sustain existing housing arrangements because the support provided to them was insufficient. In one case, a disability service provider in a remote area signed an agreement with a community housing provider in which they guaranteed to cover any potential rent arrears for their tenants.

Likewise, some participants' housing and living arrangements enhanced their access to formal and informal support. This included for example home sharing arrangements allowing participants to pool together support (or share support with someone who had none). Some participants were able to offer housing in exchange for support, for example providing rent-free accommodation to a live-in carer, or in some cases using individualised support funding to pay a carers' rent. The location of housing impacted on participants' access to support. Some participants were assisted by community housing providers to deal with a support provider. This confirms expectations in the community housing sector that under the NDIS housing providers will increasingly play a role as advocates for tenants in their relationships with support providers to ensure their ability to sustain tenancy obligations (CHFA 2014, p.4). However, this demonstrates the need for independent advocacy to ensure people with disability do not rely on housing providers for this purpose.

One difficulty for some participants was matching their housing and support funding. Two participants in the Pilbara region, for example, could not access support funding until housing was confirmed due to the eligibility criteria of funding schemes. Other participants faced difficulty moving into a new home before formal support was arranged. Some overcame this barrier by using their informal support network as a temporary substitute for formal support. A

more integrated housing and support package provided through the DHASI program appeared to have assisted one participant in accessing both housing and support (delivered by separate providers) at the same time. In contrast, another participant felt locked into a particular support provider because it provided both her housing and support.

A disability service provider commented that when housing is managed by a support provider, the resident's choice and control is compromised because they do not have their own tenancy agreement, and the agency that is supposed to help them with budgeting is also their landlord. To address this, some disability service providers have transferred their housing assets to management by community housing organisations. One disability service provider also noted the difficulty of providing support for people who are homeless:

> The girls are homeless. We find them each day to provide support and help one of them … We are doing all the things we can, leaning towards her goals while she continues with her itinerant lifestyle staying with friends.

Some service providers expressed concerns that the NDIS rollout could interrupt existing working relationships and partnerships between state disability and housing agencies (often as branches of a single human/social services department). Similarly, a recent report by the Community Housing Federation of Australia (CHFA 2014, pp.4–5) commented that partnerships between disability services and housing providers could be challenged by NDIS participants' ability to change their support provider at any time, requiring housing providers to establish new partnerships and relationships with a greater range of support providers. While recognising that this is a concern for some housing providers, people with disability's choice about their support providers, and the capacity to change providers at will, is the very premise of the NDIS.

4.4   Informal support

Family and informal networks played a major role in supporting people with disability to achieve their housing goals. A minority of the people interviewed had no family support because they had been abused by a parent, had destructive family relations, or had grown up in state care without family contact. If they did not have other informal support, these participants were at a relative disadvantage because of their greater reliance on formal support services. However, most participants had extensive family support. These families were closely involved in all aspects of planning and achieving positive housing outcomes for their relative with disability. Families, and sometimes friends, usually worked closely with the formal support systems to achieve these outcomes.

4.4.1   Seeking housing/ planning support

Parents (mainly mothers) played a pivotal role in seeking out housing options and instigating formal planning processes for their son or daughter to live independently (see Section 4.2.1). Parents often sought out other likeminded parents through formal and informal networks. These networks were useful to parents because they expanded their vision of what was possible, provided information, and sometimes led to finding appropriate accommodation and suitable flatmates. Parents sought social housing through formal applications and private rentals through newspapers and estate agents. When parents worked together to create shared housing for their sons and daughters they said it was important that the parents shared a similar vision of the future. The relationship between the families needed to be positive, as well as that of the young people. When shared housing was being considered, parents sometimes organised social occasions for prospective flatmates to get to know each other.

Families typically worked closely with professionals to plan and implement the move. In some instances the extended family, school teachers and others involved in the young person's life attended planning meetings and made detailed plans to ensure the transition was successful.

4.4.2 Financial assistance

Families often provided financial and other practical support to assist the person with disability transition to independent living. Financial contributions included capital contribution to purchase of a dwelling, assistance with rent and other living expenses such as utility or medical bills and purchase of expensive equipment (elaborated in Sections 5.3.2 and 6.1.5).

4.4.3 Coordination and backup of paid support

Sometimes parents provided support in the young person's home and/or coordinated their paid support. In one instance three families organised shared housing, which became available before they had confirmed support. They organised rosters and provided all the initial support until other arrangements were in place. Parents often had their sons and daughters return to the family home for weekly or monthly visits and overnight stays.

Parents also stepped in when planned arrangements failed. For example when a live-in carer moved out, the parents of one participant moved in with him for seven months until another suitable live-in carer could be found. In other cases, when housing arrangements proved to be unviable—due to episodic mental illness or problems with neighbours—sometimes people with disability returned to live temporarily with their parents.

Siblings, too, had an important role in supporting their brothers and sisters. In one instance two brothers lived together, one providing support to the other who had cerebral palsy. While there were reports of siblings providing practical support such as help with moving and setting up new accommodation, more frequently siblings provided social support at family gatherings and personal visits.

4.4.4 Indigenous families

For Aboriginal participants, in particular, the involvement of families was shaped by cultural expectations of supporting family members. Families, including parents, siblings and extended family, were often the primary providers of support for Aboriginal participants, and these informal supporters were important in complementing formal support. At the same time, family commitments also made it difficult for some participants to move to their desired housing. Participants were expected to consult with the extended family about their housing plans, and in some cases were expected to share their home with other relatives in exchange for informal support.

4.4.5 Other significant supporters

Some participants benefited from informal support provided by people who were not relatives. This included flatmates, neighbours and friends. In some cases, such informal support was more structured, for example through 'circles of support' for some participants with intellectual disability, involving family members and friends who committed to meeting regularly and assisting with planning and oversight. Another participant had a host family that provided informal support. He alternated his weekends between his home (with assistance from a neighbour), his parents, and the host family. Neighbours and the neighbourhood were important in creating viable living arrangements, including for example as emergency contacts.

4.5 Chapter conclusions

Participants' motivations to move home varied, but a common thread was the aspiration to live independently in housing that meets their preferences in its design and location.

Participants' housing transitions involved four separate but simultaneous processes: the process of preparing for independent living with clear goals; a plan and development of a set of living skills; the process of planning and securing sufficient formal and informal support for independent living in a new home; and, the process of searching for, securing and moving into

a suitable dwelling (discussed in Chapter 5). The length of the transition, varied from several months to several years.

Participants accessed a variety of support programs, and these were crucial in enabling their housing transition in various ways—from assistance to search for housing through to ongoing support after the move. When support funding was individualised or more flexible (even if block funded), participants' housing options increased, allowing them to choose their preferred support provider in their preferred housing. Furthermore, these participants were able to adapt the support they received at different stages of their housing transition.

Families and informal support networks played a crucial role in encouraging and enabling the move for many participants. Families in particular, mostly mothers, assisted in a variety of ways before and after the move. The emotional, practical and financial support from families was a critical success factor. However, a small number of participants had no informal support, thus were at a comparative disadvantage and were more reliant on formal support for each of the processes to enable the transition.

5 SECURING HOUSING

This chapter examines participants' experiences of seeking housing to meet their needs. It focuses on the barriers they faced and some of the success factors and strategies for those who have managed to secure and transition into suitable housing. We discuss in turn the issues related to access into social housing, private rental and home ownership (summarised briefly in Table 23).

Table 23: Access to housing, barriers and enablers by tenure

Tenure	Barriers	Enablers
Social housing	People living with their parents or in group-homes not eligible for priority housing Shortfall in accessible or adaptable social housing stock	Nomination by support agencies Special programs (access outside general waitlist) Priority housing for those at risk of homelessness Transitional housing Purpose-built housing
Private rental	Affordability Lack of rental history and references Shortfall in accessible or adaptable private rental stock Shortfall in culturally appropriate housing for Aboriginal people with disability	Established relationships with landlords Understanding landlords Low-value housing markets Sharing to reduce costs of housing
Home ownership	Affordability Difficulty accessing finance	Financial support from family Sharing Shared equity Trust ownership Home modifications

Source: authors

5.1 Accessing social housing

A total of 23 participants were living in social housing (public or community housing) at the time of their interview. While most (12) lived on their own, six were living with families (with parents, partners or children) and five were sharing with another person who was not a member of their family. Most participants were in the capital cities (8 in Sydney, 6 in Melbourne and 5 in Perth), and a small number in the regional case study areas (one in the Hunter, one in Barwon and two in the Pilbara). Physical (10) and intellectual disability (10) were most common among social renters, and four had a psycho-social disability.

5.1.1 Barriers to accessing social housing

Non-priority wait list

While many people with disability are eligible for social housing due to their low income, the primary barrier preventing some participants from actually accessing social housing was their ineligibility for priority housing. Social housing registers across Australia are segmented, and while applicants in the 'Priority' segments are likely to receive an offer of housing within several weeks or months, applicants in the non-priority segments could wait for many years, or even indefinitely. Priority housing is reserved for people experiencing or at immediate risk of homelessness, or living in unsuitable housing, and considered unable to secure housing in the private sector. Participants living with their parents were not considered eligible for priority

housing. Similarly, participants living in group homes—regardless of their dissatisfaction with these arrangements—were not eligible for priority housing. Several participants (John, Michael, Fiona, Annie and Chloe) experienced this barrier in accessing social housing. For example, John (30–40, Perth, intellectual disability) has been registered on the waiting list for over 6 years at the time of the interview, and since he could not afford private rental was forced to remain living with his parents, despite being ready in other respects to live independently (see also Box 4).

The difficulty of accessing priority housing also applied to people who have already left their parents' home. One service provider commented that families of people with psycho-social disability will often intervene before their relative becomes homeless, allowing them to return home temporarily. This presents a dilemma for families, because while providing immediate response to crisis, this could potentially disqualify their relative from more stable housing through priority housing.

Design requirements

For some people with physical disability and mobility restrictions, the requirement for accessible housing was a barrier to accessing social housing. Although such needs could in some circumstances qualify people with disability for priority housing (as discussed below), in many cases, suitable social housing placements were simply not available, and modifications to existing dwellings were not possible or were difficult to negotiate with housing providers.

For some Aboriginal participants, housing opportunities were limited by the lack of accessible housing as well as the lack of culturally appropriate, well-located housing for Aboriginal people more generally (Walls et al. 2012). Jim, (30–40, Pilbara, physical disability, Aboriginal) for example, lived with his mother in a social housing unit that was not accessible and therefore unsuitable for his needs. Since no other suitable stock was available, they had applied to get a purpose built house for Jim to live in, but at the time of the interview was not approved. A disability service provider from the Pilbara commented:

> People that want to move out of family homes are basically homeless. Or living in inappropriate housing.

In addition to mobility restrictions, participants commented on other design requirements that related to their disability, but were not always recognised by housing providers as special needs that must be met. This significantly limited the availability of social housing stock that was suitable for these participants. Examples of such design requirements included: Separate bathrooms to enhance privacy in sharing arrangements; Fencing to prevent a man with autism from 'wandering off'; courtyard for a guide dog for a blind participant; and a ground-floor apartment for a woman with epilepsy.

> High-rise apartments not suitable for a woman with epilepsy. (Susan)

Some participants fought hard battles—including multiple appeals and complaints—to force housing providers to recognise such design specifications as legitimate housing needs.

Live-in carer

For participants requiring 24-hour support, having a live-in carer in social housing can be problematic if the carer's income is included in the assessment of the household rent. One participant, for example, did not advise his housing provider of his live-in carer, in order to allow the carer to stay in the house rent-free in lieu of a carer's wage.

Another participant, Ash (36, Pilbara, physical and intellectual disability, Aboriginal), declined an offer for a social housing vacancy because his brother—who was also his carer—could not move in with him and would have remained without a house if Ash had accepted it.

Bureaucratic hurdles

Applying for social housing was difficult for some participants due to the requirement to demonstrate they had sufficient support in place once they moved in (see also Section 4.3.4 on coordination of housing and support). Other bureaucratic hurdles involved, for example, the status of guardians on participants' social housing applications (see Box 4).

One participant felt that crucial information about her disability and housing needs was not effectively shared between disability services or medical practitioners and housing providers, resulting in the decline of her priority housing application:

> Unless your doctor is completely aware of the way the forms are filled out, you don't necessarily get priority [Priority Housing]. Your doctor might miss ticking one box, which doesn't mean much to them, but the people from Housing who are not medically trained, that means a lot to them. (Keira, 43, Sydney, physical disability)

While many participants experienced very positive interactions with housing officers, several participants described a paternalistic response from the housing officers dealing with their applications.

Misgivings about social housing

Several participants (e.g. Lucas, Meg) delayed their social housing application, citing concerns about stigma and safety in social housing estates. Meg (50–60, Melbourne, physical disability), for example, did not even consider social housing as an option until facing homelessness. Since access is largely determined by 'time served' on the non-priority waitlist, such delays stretched further an already very lengthy wait time.

> We should have applied 5 years ago for social housing, but we didn't want him to have that stigma of going to public housing. (Lucas's mother)

Ineligibility for social housing

One participant was ineligible for social housing, due to having assets above the eligibility threshold. This could potentially be a barrier impacting on people with acquired disability and a history of prior paid employment, leaving them in the position of being income-poor (unable to work), but with personal savings and assets that leave them above the social housing eligibility threshold.

Chloe (60–64, Sydney, physical disability), acquired a physical disability and was forced to quit her job after many years in paid work. She applied for public housing but was advised that she is ineligible because her assets were too high. She continued renting privately for 10 years, consuming her savings to cover rent and living expenses until she became eligible for social housing and then reapplied.

Barriers to sharing in social housing

Moving in to share with an existing social housing tenant was mentioned by some participants as a potential pathway into social housing. None of the participants, however, experienced such a path, and a number of barriers were identified. Their existing social housing units were too small to conveniently include a new flatmate. Opportunities to transfer to a new unit appropriate for sharing were limited. Furthermore, the rent-setting system—whereby the rent is based on the income of all household members—provided little or no financial incentive for existing tenants to share with a new flatmate.

5.1.2 Success factors

Support with applications

Participants who successfully entered social housing almost all received significant assistance from a case worker, a disability support worker or a disability, housing or other advocacy

agency to prepare the paperwork for their housing application. Some participants commented that without such help, they would not have been able to access social housing. Barbara, for example, (40–50, Barwon, autism), described the stress she experienced when having to deal with housing officers and the application process, and the support of her case worker who assisted her with this.

Paul (20–30, Pilbara, intellectual disability, Aboriginal), received assistance from a Local Area Coordinator who facilitated the development of his Community Living Plan. This plan was instrumental in encouraging and assisting Paul to apply for social housing, including a non-recurrent $16 000 fund to assist in his transition to social housing.

Another participant, Meg, (50–60, Melbourne, physical disability) was at imminent risk of becoming homeless when she coincidentally passed by the offices of an advocacy service for older people, and decided to go in to seek advice and information. Despite being younger than their minimum eligibility age, the advocacy service provided Meg with information, referrals and financial assistance to assist with the application for, and transition into, social housing.

Transitional housing and nomination by support agencies

Eight participants—with a range of psycho-social, physical and intellectual disabilities—moved into transitional housing as a temporary arrangement before moving into long-term social housing. Rather than access through a housing provider's waiting list, these participants were nominated to transitional housing placements by various types of support agencies: a disability support service (Sarah); a homeless shelter (Sidney; Melvin) or Homeground (Susan); a women's refuge (Keira, Chloe); an independent living program for young people (Jarred); and a mental health service (Yvette). Tri-party agreements were signed between the participant, the nominating support agency and the housing provider, specifying that participants would continue to be supported by the nominating support agencies whilst in transitional housing (see Box 2 on nomination rights).

Participants stayed in transitional housing between 18 months to three years. At the time of the interview, three participants—Chloe, Sarah and Jarred—had already moved from transitional housing to long-term social housing. The others (Sidney, Melvin, Keira, Susan and Yvette) were still living in transitional housing. Despite being temporary tenancies, four of these participants were assured by their support and housing providers that they could remain in transitional housing until they are offered a long-term tenancy. Only Yvette was not given such assurance—possibly because her nominating support service had closed down—and at the time of the interview her transitional tenancy was close to expiring, with no alternative housing in sight.

Box 2: Nomination rights

'Nomination rights' arrangements involve properties owned or managed by community housing providers that are reserved for the clients of a particular support provider. Nomination rights typically arise when support providers who originally managed these dwellings transfer them to the management of community housing providers, or when capital grants or operating leases for housing are tied with requirements for 'nomination rights'.

Nomination rights enable the support provider to nominate one or more of their clients as preferred applicants for a new housing vacancy, typically with implicit or formal commitment to support that person throughout the duration of their tenancy (often in the form of MOUs describing the roles and responsibilities of support and landlord agencies, but not contractually binding).

The advantages in nomination rights for housing providers include: reduced risk and increased certainty that the selected tenant will be supported through their tenancy; better matching of properties to tenants—drawing on the support provider's familiarity with the person they support—leading to more appropriate and sustainable tenancies (CHFA 2014, p. 7; Connellan 2015, p. 57).

A critical concern with respect to nomination rights is the potential impact on people with disability's choice and control. There is a risk that such agreements will limit opportunities for participants to change their support provider in order to remain in their home. It is important to ensure that while such agreements enable support providers to make a nomination, the person who was nominated has their own lease agreement and is not required to remain with the nominating support provider in order to stay in their home. As noted by CHFA (2014), in some cases housing providers will need to enter into a new formal or informal agreement with the new support provider chosen by the person.

Special programs

Several participants were offered priority access to social housing due to their participation in special programs, such as the DHASI program in NSW and the Exits Project in Victoria. Such programs involved close collaboration between government and non-government disability, housing and advocacy agencies. Social housing providers offered priority access to participants in these programs, even if they would not necessarily otherwise have qualified for priority housing.

For example, people with disability living in group homes are generally ineligible for priority housing, as from the social housing providers' perspective this did not count as unsuitable housing (see Box 4). However, this general rule did not apply to participants in the Exits Project in Victoria (Jeremy, Tom), who were offered priority access to social housing—as well as financial assistance for the transition—to allow them to move out of group homes. The Exits Project was designed to encourage and support participants with low support needs to move out of group homes, so as to create new vacancies for higher need applicants. However, concerns were raised by some professionals about the inequity of the Exits Project because participants were prioritised over people in similar circumstances who have been on the waiting list for social housing for many years.

Similarly, people with disability living with their parents—even as adults—are considered by housing providers to be housed appropriately and therefore ineligible for priority housing. This general rule, however, did not apply to participants in DHASI in NSW through which one participant was able to access a suitable social housing tenancy relatively quickly.

With the closure of a large boarding house in the Hunter region, housing providers were involved in a coordinated effort to rehouse residents with disability. While some of these residents could have potentially qualified for priority housing regardless, thanks to the coordinated planning effort they were offered more housing options to choose from, and it was generally 'quite easy to find the right place for people out of [the boarding house]' (Professional interviewee), as in Matt's (50–60, Hunter, Psycho-social disability) case.

Priority housing

Five participants—all with a physical disability—entered social housing through the priority housing segment, due to being homeless or at immediate risk of homelessness at the time of their application.

In most cases, these were participants who were forced to leave their existing housing in crisis, due to circumstances such parents' divorce (Mary), termination of private rental tenancy (Meg), leaving an abusive partner (Sam) or parent (Mitchel), or leaving a private rental unit assessed as a fire hazard by the support provider (Stephanie). These participants were housed within less than a year.

As evident in Mitchel's case, having a physical disability can increase the likelihood of being approved for priority housing, since accessible units were not available in the private rental market. However, it appears that accessibility requirements need to be coupled with additional crisis factors to qualify for priority housing.

Purchase of private rental unit by community housing provider

A unique pathway into social housing was experienced by Carly (40–50, Perth, Intellectual and physical disability). After long months of planning and transition, Carly finally moved from a group home to a private rental unit that was suitable and affordable for her. When the landlord then put the unit for sale, Carly's tenancy was at risk. With some encouragement from her case manager, a local community housing organisation purchased the unit from the landlord, allowing Carly to remain there as a tenant, with a more secure tenancy and rent that will remain affordable.

Purpose built housing

In some cases, social housing providers constructed purpose-built dwellings for participants with specific design requirements. Mary (40–50, Melbourne, physical disability), for example, was consulted about her and her partner's locational and accessibility needs, and a purpose-built unit was constructed for them by the SHA.

One participant was about to move into a purpose-built house funded under the Federal Supported Accommodation Innovation Fund (SAIF) scheme, and managed by a community housing organisation. She was offered the tenancy while the house was still being constructed, thus allowing her and her family to have input into its design, resulting in some significant modifications to the original plan, such as lower shelves, wider doors, and handle bars in bathrooms (although not all of their requests were met).

Purpose built housing was also constructed for two Aboriginal men—an uncle and nephew—living in a remote area with no accessible housing. Funding for purpose built housing for people with disability is provided through the CDHP program in WA (Box 3).

Box 3: Community Disability Housing Program (CDHP), WA

The purpose of the CDHP program is to provide affordable rental housing for people with disability. The program is funded through the WA Disability Services Commission (DSC), which transfers funding to the Department of Housing to either source existing or construct new properties. Applicants for the program need to be eligible for the community housing program and demonstrate they have sufficient support funding to sustain independent living in the community.

The CDHP provides affordable rental housing for people with disability identified as eligible, either through purchase of existing homes or the construction of new purpose-built homes through a collaborative process involving consultation with the prospective resident and their support provider. Tenancies are managed by community housing providers.

In total, there are over 800 CDHP properties, and a burgeoning waitlist. As of January 2015 there were approximately 130 approved applicants on the CDHP program, including 27 in urgent need for housing. (Information provided by the DSC)

'The long game': wait list access

Several participants kept their social housing applications active and up-to-date, although they were not on the priority waiting list. This included two participants who were already appropriately housed (Fiona, Lucas) in private rental, but wanted to maintain the prospect of one day—even if many years ahead—being offered a more secure and affordable social housing tenancy. The social housing application was seen as a fall-back plan, if for whatever reason they were no longer able to sustain their existing private rental tenancies (in which case, the time they have already waited on the list may be an advantage over other priority housing applicants).

> It's going to take a long time [on the wait list], but if something happens to me at least he's on the list, eventually he will have his own place. (Lucas's mother)

Box 4: Michael's story

Michael is 18 years old and has both physical and intellectual disability. He is non-verbal, has a vision impairment and cerebral palsy. He needs support with all activities of daily living. He lives in Perth in a group home in with four other people and 24/7 staff support in shifts.

Michael is dissatisfied with life in a group home. His room is the furthest away from the living areas which means he cannot be heard when calling out in distress. Residents are often 'parked' by support staff in front of the TV and there are very limited opportunities for interaction between them. Michael likes to spend time outside the house but often there is no support staff available to assist him. He wants to see his family more, but his brother and sister do not feel comfortable or welcome in the group home. Michael would also like a dog but was told he could not because other residents may not like it. Referring to Michael's support staff, his mother commented: 'Maybe they don't know how, and I don't think they really see him as a person'.

Because of these many issues, for the last five years Michael and his family have been thinking of ways for him to move out to independent living. While Michael would continue to receive sufficient support funding once he moves out, the biggest barrier has been trying to find affordable accessible housing close to his family. To date, they had not found a suitable private rental tenancy. Access to social housing has also proved difficult for a range of reasons. Most importantly, because Michael was already housed in a group home—despite being dissatisfied with this placement—they were advised that he does not qualify for priority housing. They were also required to provide documentation to prove that Michael will have sufficient support funding in place, in order to be eligible for social housing. At one point, they were advised by a housing officer that 'We don't do housing for someone like Michael'. Other bureaucratic hurdles included contradictory information they received about Michael's mother's need to apply for guardianship in order to assist with his social housing application.

At the time of the interview Michael was still living in the group home, with the family continuing to explore other housing options. Several months following the interview an appropriate private rental unit was found for Michael and he moved in. Although housing was organised and support funding available, the family had difficulties setting up and managing a roster of support, making the transition difficult for both Michael and his family ('we are burnt out now … so don't glam it up too much').

5.2   Accessing private rental

Across the sample, 12 participants have transitioned to private rental at the time of the interview, including four in the Hunter, five in the Barwon region, two in Perth and one in Sydney. Most (8/12) had an intellectual or cognitive disability, three had a psycho-social disability, and one had a physical disability. Six of these participants lived in sharing arrangements, the rest on their own.

5.2.1   Barriers to accessing private rental

Affordability

Affordability was the primary barrier to accessing private rental, particularly in the capital cities—only three of the 30 participants in the capital cities lived in private rental at the time of the interview. Affordability was also a barrier in remote towns in the Pilbara case study area where during the mining boom rents peaked at $2000 per week. Participants described their difficulty finding suitable properties—of a suitable size, condition and location close to services and their formal and informal support networks—within their affordability.

Affordability in private rental is discussed in Section 6.1.2.

Rental history and references

A second barrier to accessing private rental was the lack of references when applying for a private rental tenancy, in the absence of a private rental history for participants who moved

from their family home or from specialist supported housing. In Australia, having no previous history of private rental is a common challenge for many young people living with their families (Wiesel et al. 2012). For people with disability this disadvantage is compounded by some landlords and real-estate agents' concerns about renting to a person with disability. Consequently, several participants' applications were rejected (see, e.g. Box 5). The disadvantage of a lack of rental history and references appeared to be more significant for participants in capital cities, because the competition for properties was greater.

Inaccessible housing stock

In the absence of regulatory access requirements, housing in the private rental sector is largely inaccessible for people with mobility restrictions. There are also significant barriers to modification of existing private rental stock. As noted by Franz et al. (2014, p.18) under the *Disability Discrimination Act 1992* tenants have the right to modify a rental property within reason but are obliged to remove the modifications at the end of their tenancy. Many tenants are unwilling to make this financial commitment without security of tenure and landlords are often reluctant to allow modifications even when they are not obliged to pay for them. For people with physical disability in our study, the difficulty finding accessible private rental units, or modifying inaccessible units, was apparent in the fact that only one participant with physical mobility restrictions (Ash) lived in private rental, and the unit he rented was not suitable for his needs. The inaccessibility of the dwelling limited Ash's independence in day-to-day activities such as showering or even entering or leaving the house. There were no accessible private rental units in this town. Like Ash, other participants with physical disability and mobility restrictions were forced to seek alternative housing outside the private rental sector.

5.2.2 Success factors and strategies to access private rental

Formal and informal support

Most participants who were successful in accessing private rental did so with much assistance from their family, support workers and case workers, who helped them attend inspections and put together rental applications.

Some participants noted that searching and applying for private rental properties was one of the main things they were doing with their support workers. One participant, Yvette (20–30, Sydney, psycho-social disability), noted her frustration and concern that her conversations with her case worker were almost exclusively about seeking private rental due to the pressure to find housing before her current lease with a community housing provider expired. While recognising that keeping a roof above her head was a first priority, there is a risk that diverting all support to assist in home hunting may detract from other important areas where support is required to maintain her mental health stability.

The availability of support, and the presence of a support worker or a family member in inspections and meetings with real estate agents, was also important as a means to ease concerns about renting to a person with disability. Family members and support staff negotiated with landlords and agents by convincing and reassuring them that they would be able to step in and assist anytime an issue with the tenancy arose.

Established relationship with landlord or real estate agent

Importantly, half of the participants who successfully secured a private rental tenancy had some informal relationship with the real-estate agent or landlord prior to applying for a tenancy. In most cases, a parent or a support worker of the participant knew the landlord or agent well. This created a relationship of trust and an advantage for these participants when competing with other applicants.

> It just so happened that one of the parents knew the [real estate] agent. … We were really lucky to be in the right place at the right time. It was about the second place we

were looking at … We thought it was going to take forever, but it just happened. This blew us away. (Mark's mother)

In another case, two participants in Newcastle (Nellie and Pamela) were able to secure a private rental tenancy owned by a friend of one of their mothers. The landlord guaranteed their tenancy several months in advance, while the previous tenants were still living there (See also Box 5). One participant rented a property that was owned by his parents for many years, sharing it with another person and splitting the rent equally between them.

Some disability service providers have proactively worked to develop close working relationship with real estate agents. In one instance, a relationship formed between a staff member in a disability services agency and a real estate agent led to the housing of several people with disability supported by this agency (service provider interview, Victoria).

Sympathetic landlords

While some participants described discriminating practices by landlords and real-estate agents (discussed above), others benefited from landlords who preferred renting to a person with a disability for personal or ideological reasons. One landlord had a history of renting to people with disability prior to offering a tenancy to one of the participants. Another participant's mother noted the landlords' support of the idea of independent living for a person with intellectual disability:

They liked our idea of what we wanted to do and supported it … The owners of the house happened to be teachers apparently, and quite happy to let us have the house in view of what we were trying to do. (Mark's mother)

Box 5: Mazy's story

In early 2014, at her early 20s, Mazy moved from her mother Sarah's home to her own home, a private rental unit in a suburb of Newcastle, seeking a more independent life. Mazy and Sarah were so focused on looking for housing that they did not start planning Mazy's support arrangements for the time when she did find a suitable house. With the assistance of Mazy's case-worker, they applied for housing assistance through the NSW 'Housing Pathways' register. Mazy was put on the waiting list for social housing and offered a 'tenancy guarantee' to assist in securing a private rental tenancy, but was not offered priority housing.

Mazy and Sarah spent four months looking for private rental accommodation, but were unsuccessful despite the tenancy guarantee. The competition over advertised properties was intense, in one case competing with 17 other applicants.

> She didn't really get a look because she had no rental record, and because of who she is really … In spite the fact she had money in the bank, and all the documentation she had and despite the [tenancy guarantee] it wasn't going to happen. For about four months we went to every single one of them [property inspections] … The real estate agents were pleasant but weren't really very helpful. (Sarah)

Mazy's fortunes changed when Sarah became involved in a local carers' support network. About a month after joining the network, another member of the network offered to take Mazy as a tenant in his own investment property. The property was suitable for Mazy because it was relatively close to Sarah's home, on Mazy's bus route to her day program and in a 'safe' spot at the end of a cul-de-sac where there were fewer unknown passers-by.

The availability of a rental property caught Mazy and Sarah by complete surprise. With no support arrangements in place, for the first weeks Sarah provided all the support Mazy needed, including sleeping over, helping with cooking, cleaning and other household chores. At the same time they asked for an 'emergency review' meeting with an NDIS planner, and were allocated 12 hours of support a week for the first six months of the transition period, and then five hours a week. The 12 hours of support was sufficient and Mazy is now mostly happy with the move. She enjoys having her own space, but she also likes living relatively close to her mother ('If I have episodes I can call Mum and I can still visit my cat, my little baby'). She likes the privacy of living on her own ('It's fun. I like it, having my own place and getting up to mischief'), but often feels too lonely on her own and in the future may consider the option of moving in with a flatmate.

Private rental assistance

Some participants had made use of private rental assistance packages aimed to ease access into private rental, such as 'Tenancy Guarantees' which provide up to $1500 on top of the rental bond to a landlord or agent, to cover costs if the rent is not paid or the property is damaged when the tenant leaves. Such assistance, however, was not always effective (see Box 5). Overall, there appeared to have been relatively little awareness among participants about the types of funds available to assist in access to private rental.

Private rental in regional areas

Several participants in some (but not all) regional areas were able to access private rental more easily due to weaker housing demand, and less competition over vacant tenancies compared to the capital cities. These participants described a relatively short period of house hunting compared to those in metropolitan areas, and in some cases applying for properties without any competing applications, as in the case of Jarred and Peter in the Barwon region:

> There was no one else here for the viewing. (Jarred, 20–30, Barwon, intellectual disability)

> It wasn't difficult to move at all. (Peter, 20–30, Barwon, physical disability)

However, many other participants across all regional areas (including the Barwon area) faced lengthy periods of searching and applying for private rental in highly competitive local markets (see Box 5).

Sharing in private rental

Some participants managed to overcome the affordability barrier to private rental through home sharing, typically with one or two other people. See Box 6 on sharing arrangements and Section 6.1.2 on affordability for further discussion on the benefits of sharing in private rental (as well as other tenures).

Box 6: Home sharing

Several participants lived in home sharing arrangements, with one or two other people. This included people in private rental, social housing and home ownership. Their flatmates were either other people with disability or a person providing them support (in exchange for money and/or payment). Some shared their home with the owners of the property in which they rented a room.

The key advantages of shared arrangements were:

→ Housing costs were reduced, increasing affordability and housing options.

→ Support costs were minimised by pooling together flatmates' individual support packages.

→ Informal supports were shared.

→ Social contacts increased and loneliness decreased.

Participants faced challenges setting up and sustaining sharing arrangements. Most notably, this included difficulties finding suitable flatmates and the risks for housing and support arrangements for all members of the household should one flatmate choose to move on.

Factors were identified that assisted people to have successful shared arrangements. These were:

→ Participation in community networks creating opportunities for people with disability (and their families) to identify potential flatmates.

→ An extended period of planning before moving as flatmates, sometimes up to two years, giving prospective flatmates (and families) time to get to know each other and form a relationship before deciding whether and where to live together.

→ Planning that considered the optimum number of flatmates (typically two or three).

→ A trial period of home sharing in private rental prior to shared home purchase.

→ Families with a common vision who got on well together when they were supporting shared arrangements.

→ Agreed, and in some cases formalised, exit and entry strategies to manage risks of changes in household composition.

→ Housing size and design that maximised privacy in living areas in addition to shared spaces for socialising.

5.3   Accessing home ownership

Five participants were living as owner-occupiers at the time of the interview, including two (Mark and Fletcher) who shared a house owned by a trust set-up by their families, two (Simon and Nathan) who lived in homes purchased through a shared-equity scheme with a community housing provider, and one (Fanny) who lived alone in her own home. Two other women (Nellie and Pamela) were in the last stages of purchasing their shared home at the time of the interview.

5.3.1 Barriers and challenges in accessing home ownership

Like most Australians, many of the participants in our study expressed an aspiration to become home owners. Some have more actively examined their options to purchase their own homes. Most participants, however, faced major barriers to fulfilling these aspirations, as elaborated in the following subsections.

Affordability

The primary barrier to accessing home ownership for most participants was the high cost of purchasing suitable properties in appropriate locations. Most simply could not afford either the initial capital investment, or the ongoing costs of home ownership including loan servicing, maintenance, strata, insurance, water, energy and council levies (see Section 6.1.2 for further elaboration on housing affordability).

Physically inaccessible housing stock

The absence of physically accessible housing stock was another major barrier for people with mobility restrictions. Simon (40–50, Barwon, physical disability), for example, struggled to find a house with doors wide enough for a wheelchair within his preferred location and budget. In some cases, modifications to existing dwellings would have been too expensive

> When I was looking there wasn't much housing around to choose from. (Simon)

Simon searched for a suitable property for over two years to find 'the right house in the right area'.

Access to finance

Capacity and willingness to commit to the long-term legal and financial responsibilities associated with home ownership was a barrier for some participants with intellectual disability. For example, Lucas (30–40, Hunter, intellectual disability), had enough funds to pay the home loan deposit, but decided against it, noting his concerns regarding such a significant long-term responsibility. In another case, Nellie (30–40, Hunter, intellectual disability) and Pamella (30–40, Hunter, intellectual disability) were keen to purchase the unit they were renting together. Because of their intellectual disability they were required by their financier to go through a 'capacity assessment' procedure in order to qualify for a home loan. The capacity assessment was designed to examine borrower's understanding of their legal and financial responsibilities as mortgaged home owners. However, since people without an intellectual disability are not required to undergo such an assessment, it can be understood as discriminating against people with intellectual disability by placing additional barriers to their access to housing finance. Eventually Nellie and Pamela successfully overcame this hurdle, passing the assessment after spending several months of intensive preparation with the assistance of their parents and support workers.

The lack of financial records is another barrier in access to home loans:

> I was on the Department of Housing website and thought that as they have all these shared equity loans, maybe we could get [two homeless women with disability] to buy their house. You have to show a history of savings. They can't do that. They're not going to have a deposit. (Disability service provider, WA)

Sharing complexities

Because of the high transaction costs and risks associated with home purchase or sale, the risk of sharing ownership of a home with another person can be high. Should one or more flatmates choose to leave the household, they face the risks and costs of having to sell their share. Remaining flatmates also face the risks associated with replacing a resident who had contributed to home loan repayments, as well as other household expenses. To mitigate against these risks, four people who were planning to share as home owners (Mark and

Fletcher, Nellie and Pamella), have chosen to first 'test' their partnership as private renters rather than owners. Furthermore, in Mark and Fletcher's case, rules concerning the 'exit' of a resident out of the household were formalised in a contractual agreement as part of the 'trust' model they have established (see Section 5.3.2).

Lack of information

One of the challenges was the difficulty in finding information about home ownership options and models, and about the experiences of other people with disabilities who have successfully made such transitions:

> People have done it in the past, I don't think it was that different, but we just couldn't access that information … We haven't had a model … We hadn't been able to find any. We know they are there, but they're quite hard to find. We went and asked the NDIA if they know anybody else and they went kind of 'no ….' (Mark's mother)

Despite these barriers, some people were able to draw on other experiences and skills of their parents and informal support and social networks. Fletcher's father for example, used his skills and experience as an accountant to assist with setting up the trust for his son's home.

5.3.2 Becoming home owners: strategies and success factors

A small number of participants have successfully entered home ownership. They were motivated by financial considerations (investing in their own asset rather than paying rent), desire for more secure long-term occupancy, and the pride of owning one's own home. The following subsections describe the key factors underpinning their success in pursuing their aspirations to become home owners.

Drawing on savings and assets

Two participants were able to fully finance a deposit for home purchase by drawing on their own savings and assets, including inheritance money (Pamella), and insurance compensation following a car accident (Jason).

Financial support from family

Most other participants who have purchased, or were about to purchase, their own home did so with significant financial assistance from families who paid most, if not all, of the initial capital investment (either purchasing the house outright, or paying off a deposit).

Most of these parents, who had reached retirement age at the time of the purchase, drew significant funds from their superannuation funds to finance in full, or in part, their son or daughter's home. Some parents also released equity from their own homes.

While parents expressed some concerns about the impact of such assistance on their own retirement, they also noted their deep sense of satisfaction in being able to assist their son or daughter with disability attain a more secure housing future:

> Q: Does that affect your retirement?
>
> A: Slightly (laughs). But that's a choice we made. And we think it was a good choice. It's an investment. It's a good sense of satisfaction to know we've done all we can to put it in place … Mark will be a lot more confident and independent living here. (Mark's mother)
>
> We're lucky, because we're middle class people who had good jobs and earned good money, so we were able to afford it. But there would be a lot of people who couldn't do that. So our sons are quite lucky to have parents in the financial position who can afford to do this for them. (Fletcher's mother)

In one case, Fanny's (20–30, Melbourne, intellectual disability) family used the long years of planning and training for the transition as an opportunity to save money for a deposit.

Sharing

Sharing with other flatmates with disability was a key strategy used by four participants (Nellie and Pamela, Mark and Fletcher) as a means to reduce the costs of entering owner-occupation, as well as other benefits such as sharing formal and informal support, and enjoying the company of other people at home. Sharing is discussed further in Box 5.

Shared equity

Two participants (Nathan and Simon), both in the Barwon area, overcame the affordability barrier—as well as other barriers—to home ownership by entering (separately) into a shared equity scheme managed by Housing Choices Australia (HCA) and Gateways Support Services (Box 6). Nathan was introduced to the scheme by his case worker, and Simon by his OT. Both men had individualised support funding in place, and sufficient finance (from their family) to purchase a share of the equity in the property. The scheme provided Nathan and Simon a number of significant advantages: a share in the ownership of their homes, which may also accrue capital gain; an affordable rent on the housing provider's share of the property, capped at 25 per cent of their income, plus Commonwealth Rent Assistance. The two were able to choose the specific property they wanted to purchase. With financial assistance from their parents, neither of these participants were required to take a home loan to cover their share. HCA also negotiated all financial and administrative details on their behalf.

> I didn't have to do anything, only sign the contract with Housing Choices Australia for the shared equity. (Simon)

Box 7: Housing Choices Australia (HCA) and Gateways Support Services' shared equity program

> → Targeted at recipients of individualised funding.
>
> → Purchase of existing properties selected by end occupiers.
>
> → Occupiers contribution up to approximately $130 000.
>
> → Average cost of unit $320 000.
>
> → Shared equity between HCA and occupiers.
>
> → Rental 25 per cent of income plus Commonwealth Rent Assistance.
>
> → Maintenance costs covered by HCA.
>
> (Housing Choices Australia 2015)

Trust ownership

Two participants, Mark and Fletcher, along with a third flatmate, shared a house purchased and owned outright by a trust set up for them by their families. The families consulted with lawyers who helped them with the details of the trust structure. One parent described several advantages of the trust model:

> Rights of occupancy are secured for the residents. The trust model has reduced the risk of residents being exploited, e.g. if another person moved in or somehow manipulated residents into transferring their ownership: 'No one can take it away from them. And even when we [the parents] go, they still have occupancy rights. (Mark's mother)

The trust provides a clear legal structure for the partnership between families and flatmates, including exit strategies. If one family wants to move out and sell their share in the trust, the other two families have a first right to buy that share at market value. If the families are unable or uninterested in buying the share, it is then sold on the market. There is also an 'entry strategy' for selection of new residents, including a three months trial period for the person moving in to test compatibility. Every decision made by the trust has to be unanimous. Despite

being able to potentially afford a more expensive house, the trust purchased a relatively low-cost one, so that if the need arises it is easier to sell one family's share at the market value. Similarly, buying the house outright was important so that no debt would complicate future exit or entry of residents. The trust model helped overcome the potential hurdle of a capacity assessment for a home loan to a person with intellectual disability.

The three flatmates pay rent to the trust, which funds the maintenance of the house as well as an individual savings account for each resident, to be used for medical and living expenses. One important advantage of the trust is that the residents are eligible for rent assistance which provides an important supplement to their income.

Home modifications

While the inaccessibility of housing stock and high costs of modifications were mentioned by some participants as a barrier to accessing home ownership (e.g. Simon), others received NDIS funds to assist with such modifications (e.g. Nathan), after a long and complicated approval process. Other barriers to home modifications relate to lengthy processes of getting approvals from a landlord, body corporate or local council. Furthermore, many older strata title dwellings do not comply with current access to premises legislation (Easthope & van den Nouwelant 2013).

Timing and endurance

Some participants managed to overcome critical barriers—affordability, lack of suitable housing stock—through endurance and patience, relentlessly searching for opportunities over lengthy periods of time. Simon, as discussed above, searched for a suitable accessible property for over two years until an opportunity eventually came up. Similarly, Fanny's family searched for a property within their budget and desired area for over two years until finding the right opportunity. This highlights the importance of having stable formal and informal support to undertake such a long journey in search of appropriate housing.

Being able to act swiftly on opportunities when they did arise—in some cases while taking risks—was another success factor. Fletcher and Mark's families found an appropriate property much faster than they anticipated, even before they had set up a trust and support arrangements to facilitate the transition. However, they did not want to miss up on the opportunity and acted swiftly, providing support for their sons on their own for the interim period.

> We thought, it's a good opportunity and the longer you wait the higher the prices get. (Fletcher's mother)

State Housing Authority assistance

SHAs have historically delivered a range of programs to assist low-income households become home owners. While the range of such programs has declined substantially in recent years, some programs are still available in some SHAs. In WA, for example, low-income households can be eligible for a Keystart loan, where the minimum deposit requirements are significantly lower than those offered by private financiers.

No participants received any assistance from State Housing Authorities in accessing home ownership, yet two participants in WA (Annie and Mitch) mentioned Keystart loans as one of the options they were actively exploring. Mitch commented that SHAs might further assist people with disability into home ownership by charging discounted rents from social housing tenants in paid employed, thus allowing them to save enough for a Keystart deposit.

5.4   Chapter conclusions

People with disability who successfully secure formal and informal support to live independently still face barriers to accessing suitable housing that meet their needs. The

barriers vary and are experienced differently across different housing tenures in the private and public sectors. The barriers include: unaffordable costs of housing in the private sector; ineligibility for priority housing for people living with parents or in group homes; a shortfall in housing that is appropriately designed for people with disability in the social and private sectors; bureaucratic hurdles in the social housing sector; disadvantages and discrimination in competition over private rental tenancies due to low income and the lack of rental history and references; challenges in accessing home loans for people with intellectual disability; and lack of information about options and models available for families seeking to assist a relative become an owner occupier.

A primary success factor that enabled people to overcome these barriers and access housing—in both the private and public sectors—was the availability of formal and informal personal and financial support throughout the period of planning and house hunting.

While some participants were able to access priority housing, due to being at risk of homelessness, for others access to social housing was facilitated through nomination by a support agency into transitional housing, or by participating in special programs such as DHASI (NSW) or the Exits Project (Victoria).

A key strategy to address the affordability barrier—in both private rental and home ownership—was home sharing. Sharing significantly reduced the costs of housing, in addition to other significant advantages such as the pooling of formal and informal support, and the expansion of social networks. From a policy perspective, sharing arrangements can achieve a more efficient use of support services as well as housing stock. However, our findings point to complexities such as compatibility between co-residents, the risks for all members of the households when one person chooses to move, and the barriers to sharing arrangements in the social housing system.

Purpose built housing was identified as a viable path into social housing and owner-occupation for some people with specific design requirements. The findings also highlight the importance of closely conferring with prospective residents about the design of their designated properties, given the diversity of individual needs that are often not met through standard accessible design.

Home modifications were identified as another key strategy to improve access to housing for people with mobility restrictions as well as other design requirements. Modifications for social housing tenants and home owners—in some cases funded by the NDIS—proved instrumental in enabling transition to independent living. Our findings suggest modifications of private rental housing stock can be difficult to achieve, but the exclusion of people with physical disability from this housing tenure highlights the need for resolute policy action on this matter.

In recent years, home ownership has become difficult to access for many Australians on low incomes, both with and without disability. A small number of participants in our study nevertheless overcame the affordability and other barriers to enter home ownership. Most people reduced the costs of housing by sharing with other people with disability or by entering a shared-equity arrangement with a housing provider. Significant financial assistance from families was a crucial factor enabling some people to purchase a share in their home.

6 HOUSING TRANSITION OUTCOMES

> I was a wreck and now things are heaps better … I love it [the unit] … Things have gone from bad to good (Jane)

> It's the best move I've ever made (Jarred)

> Extremely happy living on my own (Lucas)

> I couldn't be more happy … happier than I have ever been. (Sarah)

In this chapter we examine the various shelter outcomes and non-shelter (Bridge et al. 2003) outcomes resulting from housing transitions experienced by participants. We focus on those outcomes that can be more directly attributed to the housing transition—and to specific attributes of the housing people moved into—as opposed to other factors such as changes to levels and forms of support required and received.

6.1 Housing affordability

All participants in our study were low-income. Most relied on the Disability Support Pension (DSP) as their primary source of income, and housing was their most significant living expense. In this section we discuss the impact of housing costs and some of the strategies used to manage financial stress.

6.1.1 Affordability for participants paying income-related rent

Participants living in social housing (or shared equity) paid rent that was set as a proportion of their income, typically 25 per cent (but in some cases up to 30%). After paying rent, these participants' remaining disposable income was more than twice as high as that for some participants in private rental.

> I can finally afford to eat without worrying about whether I will have enough money for it. (Barbara, 40–50, Barwon, intellectual disability)

Most people living in social housing reported that the affordable rents allowed them to live within their means, at a relatively modest standard of living (e.g. without a car, internet or cable television). Some budgeted their ongoing expenses such that they were able to save some money for annual or bi-annual holidays (in Australia) or occasional purchase of more costly and non-basic goods such as an a smartphone.

Paying income-related rent meant people in social housing (or shared equity) had a weaker financial incentive to share with others, as this would not have made a significant difference to their rent (although some savings could be made in overall living expenses, for example by sharing food and bills). Furthermore, sharing in social housing put some participants at financial risk in case their flatmate did not pay their share (as occurred to one participant, Sarah).

6.1.2 Affordability in private rental

Rents paid by participants in the private rental sector varied significantly across and within regions (Table 15). The Barwon was the most affordable, on average $169 p/w. The Hunter, on average $262 p/w. In the Hunter, although typically renting housing at the lower end of the private rental market, private renters nevertheless paid approximately 58 per cent of their income, including the DSP ($388) and Commonwealth Rent Assistance (CRA) ($63). Thus, these participants paid close to double the rent that would be considered affordable (30% of their income). In the capital cities, no participant was able to afford renting privately without sharing, except for Jackie (20–30, Sydney, psycho-social disability) who paid a relatively affordable rent of $180 per week, for a very small studio (bedsitter) apartment.

Sharing reduced rents to more affordable levels, even in one of the capital cities, Perth. For Pamela and Nellie, in the Hunter region, the rent per person went down to $180. Rents were therefore only just over a third of their income, falling within the 30:40 affordability benchmark[3], allowing Pamela and Nellie to not only live within their means, but also save money for their planned home loan deposit.

Table 24: Costs of private rental

Participant	Region	Rent ($ per week)	Comments
Nancy	Barwon	160	
Fiona	Barwon	190	
Jarred	Barwon	185	
Sylvia	Barwon	210	
Peter	Barwon	100	
Lucas	Hunter	235	
Mazy	Hunter	290	
Jackie	Sydney	180	Studio (bedsitter) apartment
Pamela and Nellie	Hunter	180 each	Sharing. Total $360
Andy	Perth	150	Sharing. Total $300
Thor	Perth	213	Sharing. Lives in garage. Rent includes electricity.

Most participants were able to manage their living expenses despite their low incomes and high rents, by budgeting tightly, requiring careful and modest expenditure on the most basic expenses such as food and electricity. Energy costs among people with disability may be 10 or more times higher due to the use of heating and cooling for medical reasons and the need for medical equipment (Hodge 2012; Australian Productivity Commission 2011). When occasionally spending more money than they had budgeted, some people said they 'ran into trouble'.

Two people in private rental, Lucas (30–40, Hunter, intellectual disability) and Mazy (23, Hunter, intellectual disability), could not cover their living expenses using only their income, and were drawing on a regular basis from their savings (that were accumulated while living with their parents). Mazy, for example, lived on an income of about $450 p/w, including DSP and CRA. Her rent, $290 p/w, was nearly two-thirds of her income. With electricity and other bills averaging $50 p/w, she only had a little over $100 p/w remaining for food, transport and other living expenses.

> She's working within her budget but it's basic. Nothing to spare. Truly, she's on a *budget* … this much for food. This much for buses. She's been doing that since she moved in. (Mazy's mother)

In some cases, housing stress has impacted on participants' capacity to pay for other non-housing expenses related to their disability, such as treatments or medication, transport and household expenses which were not covered by their individualised funding packages.

Keira, for example, commented that at times she runs out of certain medicines and then goes for some days or weeks without them because she cannot afford more. Another participant,

---

[3] The 30:40 is a commonly used housing affordability benchmark meaning those spending more than 30 per cent of their income on housing, while earning in the bottom 40 per cent of the income range, are in affordability stress.

Simon, was able to solve this problem by getting some of his medical expenses covered in his NDIS package.

Transport costs, in particular, highlight the potential long-term savings in non-housing expenses achieved through well located housing. Sarah (31, Melbourne, intellectual and physical disability), for example, once paid over $100 for a taxi because it was raining and unsafe for her to use her wheelchair in the wet.

6.1.3 Financial management

Despite the housing affordability stress experienced by many participants—particularly those living in private rental—the risk of arrears was generally low. Many people used financial management services (voluntarily or in some cases as a tenancy condition) such as automatic deductions of their rent—and in some cases also bills—from their Centrelink income through the Centrepay program. Such arrangements reduced the risk of arrears, and made budgeting easier and less stressful:

> Rent and other expenses are taken out before it gets to me, so I don't have to worry about them! (Barbara, 40–50, Barwon, intellectual disability)

Some—particularly those with intellectual disability—also received assistance from a parent or a support worker in managing their budgets. Several participants with intellectual or psycho-social disability had their finances tightly controlled and monitored by a public trustee or financial guardian. In most cases, rent and bills were paid by the public trustee or financial guardian, and part of the remaining income was given to participants as a weekly or fortnightly allowance for other expenses such as food. They were able to apply for additional payments from their funds for expenses such as purchase of clothing or home appliances and furniture. Most participants were generally satisfied with the management of their finances by a public trustee because they 'did not have to worry about this' (Fiona), despite occasions when their request for funds has been declined by the public trustee. However, one participant, Neil (20–30, Perth, degenerative disability) was very dissatisfied with the lack of control over his finances, being managed by the public trustee. In contrast, Matt (50–60, Hunter, psycho-social disability), who did not receive assistance in financial management, expressed some concern about his difficulty in managing finances on his own, particularly the challenge of saving enough money for electricity and water quarterly bills.

6.1.4 Earned income

Eleven of the participants earned income from paid employment. In all cases, these were very modest earnings from casual or part-time employment, and in some cases under the 'Supported Wage System' which allows employers to pay reduced wages to people whose work productivity is significantly reduced as a result of disability. The positive impact of earned wages on housing affordability was therefore modest, not only because earned income was relatively small in the first place, but also because it resulted in reduced pension rates, and increased rent for those living in social housing.

One participant, who had an investment property (acquired through the insurance paid due to his injury and disability), did not lease it out because such income would have had an adverse impact on both his pension and rent in a specialist group home. Rather than leasing the property, he often invited friends to live there rent-free in exchange for their friendship, time and support with daily tasks.

6.1.5 Financial assistance

Many participants received occasional financial assistance from family members, sometimes friends, or charity organisations such as St Vincent Paul and the Salvation Army. While most participants managed most of their day-to-day costs, some family members, particularly parents, contributed to larger expenses such as buying disability specific appliances,

household items, or paying costly medical expenses such as specialist appointments and medicine.

As discussed in Section 5.3.2 some parents also provided substantial financial assistance to buy a house, in some cases having a significant impact on the parent's own finances. Fanny's mother, for example, commented 'I don't go on holidays or spend on any extras'. Other parents withdrew funds from their superannuation funds, thus reducing the savings available for their own retirement years.

6.2 Housing security

6.2.1 Secure occupancies: social housing and home ownership

People living in housing with relatively secure tenancies—those in social housing or home owners (including shared equity)—overwhelmingly expressed a preference to remain in their home permanently, and had a strong sense that their housing was secure.

> I want to stay in my own house, I like it here. (Simon, social housing)

> I will continue living here. (Barbara, Social housing)

> If I ever had to move I wouldn't know what to do. I'd be happy to stay here the rest of my life. (Matt, social housing)

> I'd like to stay here all the time (Fanny, home owner)

Some parents also expressed their sense of relief at knowing their son or daughter's home will be secure in the long term:

> Because we bought part of this property, this is going to be Nathan's home for many years. And as parents we feel relieved that he's stable, happy and cared for in a way that he needs it and that's good for him. (Nathan's mother)

The sense of secure occupancy related not only the terms of the lease, but also more broadly to the suitability of dwellings to participants' current and future needs:

> Seeing him so happy and his behaviours calm down is a good sign. Here he can come home from a stressful day … and just be himself, in his own little 'safe haven'.(Nathan's mother)

Only three of the 22 participants living in social housing expressed their desire to move out of their tenancy, but they also acknowledged the lack of any realistic alternatives. Stephanie (37, Barwon, physical disability) was dissatisfied with the level of noise in her home, and was actively seeking alternative housing, including private rental options. Two people considered their social housing tenancy only a transitory arrangement, one man was aspiring to save up for a deposit to buy his own home (Jarred). The other person was worried about the security of his tenancy, which he had put at risk by not reporting a live-in carer. And Barbara (40, Barwon, intellectual disability) although content with staying in her current housing permanently, considered the option of seeking an internal transfer to a less noisy, social housing unit.

6.2.2 Insecure occupancies: private rental

In stark contrast to social housing tenants and home owners, those in private rental had little security about the long-term sustainability of their tenancies. Mazy, for example, moved to private rental with a six-month lease, and little certainty about the future of her tenancy:

> Maybe it's temporary, but I don't know yet (Mazy)

Furthermore, most private renters did not express a desire to remain permanently in their current tenancies. Most hoped to eventually (in the medium or long term) move out of their current private rental dwelling—to a bigger unit (Nancy); to a better located home (Peter, Thor);

others hoped to move into social housing (Fiona); into their own home (Jarred, Pamela and Nellie); or wanted to share with a flatmate (Lucas).

The general desire among private renters to move suggests their satisfaction with their housing and outcomes were generally poorer compared to those of social renters, possibly because of the higher costs of housing. It is also possible that private renters, precisely because their tenancies were less secure, more actively considered alternative housing options.

6.2.3 Non-housing tenancy risk factors

The long-term sustainability of tenancies depended on non-housing factors such as people's access to formal and informal support to be able to sustain independent living, and the future stability of existing sharing arrangements. These factors affected participants living in all types and tenures of housing.

Some participants, (Sarah, Mary, Will) were concerned about deterioration in their disability or health and the availability of funding for increased levels of support they would require to live independently. Some parents expressed concern about the availability of informal support once they are no longer there:

> There's a level of support that is there, but that's distant support. (Mazy's mother)

> I've always looked after her on my own with little outside support. (Fanny's mother)

Participants outside the NDIS launch sites had little understanding of the potential impact of the scheme on their support and housing options. Some expressed concern about the review of their existing support entitlements when the NDIS is rolled out in their area. Another participant, Thor, (28, Perth, cognitive disability) hoped that the portability of NDIS funding would allow him to move interstate to be closer to his best friend.

The possibility of dissolution of a sharing arrangement was another risk factor for the long-term sustainability of housing. People were concerned about the challenge of identifying a new suitable flatmate to be able to stay in their existing housing. To avoid this risk, Mark and Fletcher's parents set-up detailed formalised 'exit' plans to deal with such circumstances (see Section 5.3.2). While acknowledging the potential risk for existing housing, they also noted that the knowledge and experience they have gained will assist in setting up a similar arrangement in the future, if necessary:

> If by chance it did fall down, I think we would still set up another one—do the same again. We'll be a bit wiser next time. But we hope that won't happen. (Fletcher's mother)

6.2.4 Inheritance of family assets

Parents were concerned about the impact of their own ageing on the future of their son or daughter with disability. The loss of a primary informal carer was the most crucial concern. At the same time, most of the parents interviewed had wills in place to ensure their son or daughter with disability inherited a share in their remaining assets, including in some cases right of residency in their home.

One dilemma for participants was whether or not to leave a son or daughter with disability a larger share than their siblings. One mother commented:

> No favouritism because he has a disability. They are all my kids. (Lucas's mother)

Yet some parents were concerned that they will eventually fully consume their own savings and assets, for example if they had to sell their home to move to a nursing home, thus having little remaining to pass on to their children.

6.3 Other housing outcomes

In this section we discuss other housing outcomes, including the suitability of location of their home, its design and space; relationships with neighbours; and less common outcomes related to ability to keep pets or participate in housing management.

6.3.1 Location

The location of participants' new homes was a critical factor influencing their overall satisfaction and housing outcomes. Many people (Pamela, Nellie, Meg, Barbara, Fiona, Nathan, Jarred, Peter, Matt, Susan, Mark, Lucas, Fanny, Jeremy, Melvin) noted good access to local services in close distance (shopping centres, cafes, pubs, libraries, church. parks, TAFE, community services and health services) and good access to public transport as key positive outcome of their housing transition.

> It was almost impossible to get anything delivered to my old property or to even get taxis to pick me up because no one could ever find it. This one [address] is very easy to find, so it is easy to get things delivered and to get taxis. (Barbara)

Where people moved into housing far from necessary medical services, the costs of transport (taxis) and support to assist with travel were very high (Mary). Noise—particularly traffic related—was a key factor reducing some peoples' satisfaction with their homes (Barbara, Jarred). Living in a safer neighbourhood (after the move) had a positive impact on people's sense of safety, wellbeing, health, and ability to participate in their communities. Jarred, Barbara, Susan, and Sam perceived their new neighbourhoods to be safer than those they had left:

> I feel safer and hence walk more. This is good for my health. (Barbara)

> I can go everywhere now without being scared. (Sam)

Mazy, for example, felt living at the end of a cul-de-sac was a safer environment for her, because there are fewer strangers passing by. Others, however, felt the area they had moved to—and in some instances even the specific building—was unsafe due to drug related violence and crime (Sidney).

Moving closer to nature was a positive outcome for others. Some participants liked particular features of the environment they lived, such as being close to the sea or a lake (Mazy, Matt). Staying in a familiar local area was important in enabling people to maintain relative independence, for example using public transport (Sylvia), as well as contact with established social networks and family.

> I was raised in this area and I know the area very well. It's very familiar to me. (Sidney)

Most participants chose housing that was relatively close to their families, either walking distance or on a direct and short bus route, allowing frequent visits (Simon, Jarred, Mazy, Fanny). One woman (Sarah) preferred living in an outer suburb of Melbourne that was distant from the city and the advocacy service in which she volunteered, but closer to her daughter.

Three people stressed that they were dissatisfied with the location of their new home (Mitch, Keira, Daniella) because it was far from their relatives. This appears to be an issue for social housing tenants who have relatively little choice about the location of their home apart from a very large geographic catchment they can nominate in their application. Mitch, for example, was disappointed to be offered a public housing unit far from his friends and familiar environment, but felt compelled to accept it because of the long wait for another offer. Another participant, Keira, although grateful to be offered a unit in a very central location close to shops, emphasised the difficulties arising from the distance from her parents and informal support network who were all in another part of Sydney.

> It's been very very difficult, being sick, not having that support network. (Keira)

Three young men (Lucas, Mark, Peter) chose to live further away from their parents who lived in smaller town, as they preferred more central and accessible locations. For Lucas, being more distant from his mother was also an important expression of independence, which was the key driver for his move in the first place:

> If I would live closer to mum she'll be coming to my place every single day (laughs). (Lucas)

Some people also emphasised the importance of being close to medical services and specialists that they have used for long time, such as a mental health counsellor (Yvette), a GP (Keira) or disability specialists (Sidney, Jason). Keira noted the difficulties arising from long travel time to visit her long-time GP, who is familiar with her complex medical history and needs, and whom she visited up to three times a week.

6.3.2 Neighbours

Some participants described positive relationships with their neighbours (see Section 6.4.4 on social inclusion outcomes). For others, difficulties with a particular neighbour were some of the more negative aspects of their housing. This affected participants with different types of disability, in different housing tenures. Some people sought assistance from family members, their social housing provider, support workers and in the last instance the police to manage difficult neighbours.

> There are some neighbours I'd get rid of if I could. (Simon)

Tom, for example, experienced ongoing harassment by school kids regularly passing by his front fence. Another woman felt threatened by neighbours' anti-social behaviour, and eventually moved out of her home (back to her parents) for six months until the situation was resolved when the neighbour moved. She continued to pay rent for the unit during these six months, so as not to lose her home.

6.3.3 Accessibility and housing design

Some participants required specific adjustments for mobility, such as steps and barriers to movement; size and design of bathrooms; handrails, hand held showers or space to sit in the shower; gradient of surfaces for wheelchair users; height of furniture; need for special equipment installed at home.

Such adjustments were most likely to be made for people who moved to social housing. Nine participants living in social housing had accessible housing (Barbara, Sarah, Lisa, Mary, Meg, Susan, Mitchell, Jim, Sam). The standard of accessibility varied from purpose built housing designed specifically to meet people's personal needs (Lisa, Mary); accessible housing for people with physical disability, though not individually tailored (Meg, Susan, Mitchell, Jim); and, housing modified to suit a person's specific needs (Barbara, Sarah, Sam).

Even in social housing, however, modifications were in some cases difficult to negotiate:

> When I finally got offered the place after four years on the wait list [in 2012–13] there were ongoing negotiations that needed to take place in relation to getting certain modifications done to the property, some of which are unfortunately still going on today. The case managers were instrumental and remain so in assisting with that process. (Barbara)

One participant's strategy to negotiate modifications was to challenge the housing provider's Occupational Therapist (OT) assessment with an assessment of a privately funded OT. Others paid for certain modifications on their own. Susan and Sam, for example, with assistance from relatives, modified their yards to make them more accessible. Previous research has found that many people with disability choose to undertake or manage their own modifications to maintain a sense of control and independence and avoid an 'institutional' look in their homes. However

a lack of information around products and skill, as well as challenges in communicating modification requirements to tradespeople can undermine positive outcomes (Bleasdale et al. 2014).

Some people had relatively 'low-level' needs, such as being able to climb stairs but with some difficulty. Such 'low-need' accessibility adjustments were not always met and requests for modifications were declined. This resulted in various challenges for participants in their daily lives, such as reduced independence—such as need for assistance to get in and out of an inaccessible bathtub (Sidney). Another participant, Keira, lived on a first floor unit without a lift, despite impairments in her neck and joints and her chronic fatigue:

> It's such a struggle to get up the stairs. My neck and my joint really ache. And when my energies can be quite low it can be tricky. (Keira)

Three participants were consulted about their design requirements before their home was built. Lisa, for example, was invited to comment on the original plans for the house, and negotiate changes such as to the design of kitchen, bathrooms, doors and height of shelves which will enable her to live independently.

Accessible or modified social housing units provided an opportunity for people to live independently:

> Lisa is so fortunate … because there are no houses around, especially not for people with a physical disability. All the places we ever saw either had steps, or small doors or just didn't suit her needs. This is such a great opportunity for her, to become fully independent and live alone. (Lisa's mother)

> When I moved here, it was so much better, we made some basic adjustments but everything else was perfect, down to my level. So now I can get everything myself … I can go everywhere myself. I can also go to the backyard now. (Sam)

Despite being purpose built in consultation with participants, the design of some dwellings did not fully meet all their needs. In some cases, requests for certain changes to the design were declined. In other cases, participants themselves were not able to anticipate their long-term needs. This had some negative impact on participants' housing and well-being outcomes, for example avoiding use of the kitchen because its design was not appropriate (Mary).

An accessible home was also an accessible venue for other social opportunities for some participants. In an environment that is by and large inaccessible, an accessible home was one of very few places where people could participate in social gatherings. Mary and Tony, for example, held their own wedding at their home, and often have friends over to their place for social gatherings because the homes of their friends and public places are often inaccessible.

For most people living in social housing we had limited data on the costs of modifications, and on the question of whether modifications for social housing were paid for by housing providers or disability departments/NDIS. In one case, the responsibility for the costs of modifications was the focus of on-going negotiations between ADHC, the housing provider and the NDIS.

For participants living in their own homes or shared-equity, many of the barriers to home modifications were more easily overcome. Jason and Nathan modified their own homes to meet their accessibility requirements. Jason used his own money, including insurance compensation following an accident, to purchase and modify a house to meet his needs (However, following his divorce, he was no longer able to continue living in the house without appropriate support). Nathan moved into a shared-equity house, that was modified (using NDIS funds obtained through an application process that he described as tedious) to meet his accessibility needs.

Participants with mobility restrictions or other physical disabilities, struggled to find accessible housing stock in the private rental sector, and were largely absent from this housing tenure.

For example, Ash (30–40, Pilbara, physical and intellectual disability) lived in a private rental unit without a ramp or an accessible bathroom, and had not been able to modify the unit.

6.3.4 Space

Many participants noted that their disability meant that they spend a lot of time at home, and therefore valued having more spacious homes. Bigger spaces at home allowed people to pursue private leisure activities, such as woodwork and art (Simon, Lisa) or physical exercise (Nellie). Several people emphasised the importance of having sufficient space for hosting visitors and also for their general wellbeing and physical and mental health (see Section 6.4.3). Some valued having a back yard, as a space for a pet or a guide-dog, a safe-play area for a child (Keira) and a place for quality leisure time.

Several people expressed dissatisfaction with the size of their home (Nancy, Meg). Some transitioned from relatively large houses with their family to small apartments on their own. Nancy, planned to leave her private rental bedsitter unit, which she felt was 'too small', with the bed and living area in the same room (her bed tucked behind the couch).

6.3.5 Dwelling maintenance

Most participants were generally satisfied with the maintenance of their housing, although some people in public and community housing (Barbara, Sarah, Sam, Jeremy) noted difficulties in getting repairs fixed promptly, and sometimes requiring lengthy negotiations with state housing departments.

6.3.6 Pets

Several participants kept pets (Jane, Barbara, Stephanie, Meg, Simon), and valued having homes that enable keeping pets, including landlord permission or strata bylaws allowing pets, or having a yard for a dog. One participant, Mazy, was restricted by her rental agreement from keeping her cat. Mazy cited this as the most negative aspect of her moving out of her mum's house.

6.3.7 Participation in housing management

One participant—Sam—felt empowered by being able to participate in a tenants' committee at the community housing complex he moved to. He felt proud to be taking part in strategy and financial decisions related to the management of his home and immediate community.

6.4 Non-housing outcomes

Participants' housing transitions had direct impact on a variety of 'non-housing' outcomes. Most were proud to have achieved independence, and commented on the improvement in privacy, wellbeing, physical and mental health and social inclusion.

6.4.1 Independence

A sense of independence was a central factor contributing to participants' positive experience of the housing transition (particularly for those who have moved out of their parents' home). Pamela, for example, described living independently in terms of living an 'ordinary life'. Even when the home was rented from a private or social landlord, most participants still considered it their own home, and a sign of their independence.

Some participants' experienced independence by completing, in some cases for the first time in their lives, various house chores such as cleaning, laundry, grocery shopping and cooking on their own (in some cases with support from staff or family) (Nathan, Peter, Fanny, Carly). They felt they were learning and developing new living skills (Nathan).

It's good to live independently and do it yourself (Jarred)

I can look after myself … and I learned how to cook my meal properly … Sweeping, washing my hair nicely, and brushing my teeth, putting out the garbage—I learned heaps of things … I don't want to live with my mum any more. (Fanny)

For some people who moved to independent living for the first time, extra support was required during the preparation and transition period in the months before and after the transition. Over time, for a small number of participants the amount of support required declined or was expected to decline significantly. Mark and Fletcher, for example, expected to shift from having a support worker staying in their home overnight (4pm to 8.30am), to having support workers to assist them only in the mornings and evenings. Such a shift depended not only on the development of their confidence and independent living skills, but also the development of relationships with neighbours who could potentially serve as emergency contacts. Similarly, Mazy was allocated 12 hours of support a week for the first six months of her transition, then dropping to only five hours a week. Another participant, Lucas, used only two hours of the 35 weekly hours of support that had been allocated to him before the transition.

For one participant (Sam), moving away from an abusive partner was an important form of independence. Relief from some of the restrictions enforced in their previous housing (e.g. in a group home or a boarding house) was also central to participants' sense of independence, as expressed by Matt:

The other day I had one of the neighbours over, this older lady, because I have some Galliano [drink] in the house. And we were sipping Galliano [laughs]. In [previous boarding house] you couldn't bring alcohol on the premises. (Matt)

For people with physical disability, independence was also associated with the design of their new homes, which suited their needs and offered them greater autonomy.

Participants in home sharing arrangements were required to be more considerate of their flatmates, and in some cases lost some of their privacy and autonomy (e.g. having to advise flatmates of when they will be back home at night because of shared meals). However, they saw sharing as a personal choice rather than a restriction on their independence.

Some participants were described by relatives as revelling in their newfound independence. Tom, for example, for a while after moving to his new home refused to let visitors in, saying it was his right to choose who came in.

Particularly for some people with intellectual disability, independent living fundamentally changed relationships with their parents:

She [Fanny] loves her space and is very protective of it, I can't change or do anything without asking her first. (Fanny's mother)

It's improved our relationship, because she's not confronted all the time, I'm not telling her what to do all the time. That's the bonus. She was over me saying 'don't do this'. And whilst I still do that, I can do that at a distance and she ignores me—which most of the time she does. (Mazy's mother)

We've always been carers first, and parents second in a way. And now we are parents, and we're kind of looked at this way. And it's a really nice thing which I never thought that would happen. (Mark's mother)

Most parents felt not only pride at their son or daughter's growing independence, but also a deep sense of relief looking at the future:

Eden amazed us … what we're seeing is a constant development of her social skills, her literary and verbal skills, her ability to focus on what needs to be done … She continues to grow, even now after four years. She loves being here. She has matured, she has a great life which she loves … Living independently, she actually learned who she is. She likes her own privacy, she comes home goes and sits in the garden with a

cup of coffee. We've seen this young woman who's 35, who knows what she wants to do … she sets her own goals … She's got verbally much more assertive. And she continues to learn. It's brilliant. If I died tomorrow, I know she'll cope. She'll be devastated, but not as devastated as she would have been five years ago when we'd just started this. She would have just fallen apart then. (Eden's mother)

While the transition to independent living was generally successful and highly fulfilling for most participants, the experience was difficult for one—Fletcher—who more than a year after a relatively stable and successful transition experienced a mental illness episode that led to his hospitalisation and some difficulties when returning from hospital to live with his flatmates.

6.4.2 Privacy

Closely related to independence, many of the participants placed high value on the increased privacy following their housing transition:

> I just like the space here and my privacy … in my [previous] unit you could hear the neighbours and their kids all the time. I could hear what was going on all the time. (Simon)

> I've been here nearly three weeks now … and I'm really enjoying the independence because I've got really sick of living with groups of people … there's no privacy or anything like that. Like this, this is a much better way to live. (Matt)

Privacy was also associated with independence, being able to do as one pleases at home, and living the life they wanted (e.g. have a partner, intimate relationships):

> It's fun. I like it, having my own place and getting up to mischief. (Mazy)

> And the privacy is good, [laughs] you can walk around naked if you want, no one can see you! (Matt)

Having relative privacy from parents was also part of people's sense of independence (Peter, Lucas). Lack of privacy was a source of dissatisfaction for Stephanie, whose social housing unit was located next to a main entrance to the building where people congregate throughout the day and the night. Stephanie was actively looking for alternate private accommodation at the time of the interview.

6.4.3 Physical and mental health outcomes

Some participants felt that the improved housing conditions, such as more space and privacy at home, a more attractive and safe neighbourhood, had a positive impact on their overall wellbeing, mental and physical health, with reduced depression, improved sleeping patterns and people becoming more physically active, as evident in the quotes below:

> In my old unit I was getting pretty depressed, it was a one bedroom place very small and depressing. I wasn't really getting out that much. Now that I've moved, my mood is much better and I feel like getting out of the house and doing things. My health has got better. I started going to the gym a couple of times a week. (Simon)

> As I have difficulty accessing the community and spend much time at home, having a bigger place in which I can move around has helped my mood immensely. The property also meets needs in other ways, so I cope better and sleep better. (Barbara)

> Health changed—mainly my mood—I was very depressed where I lived there was nothing out there. The house was located in the nowhere … I was very unsettled where I lived because there were many people with drugs and alcohol around there. (Jarred)

> I found living here awesome … my sleeping pattern and my health is much better. (Mitch)

One participant, Nellie, used a spare bedroom in her flat as a gym for regular exercise. She also described the relaxing effect of the views from her room's window as 'soothing, relaxing—you feel on top of the world'.

Housing transitions had positive and negative impacts on some people's alcohol and substance consumption patterns. One participant, Carly (40–50, Perth, physical and intellectual disability), associated her housing transition from a group home to a social housing unit with a shift to a more healthy and positive lifestyle after previously being a smoker and heavy drinker. Similarly, Will's (40–50, Pilbara, cognitive disability) housing transition had a stabilising effect due to reduced access to alcohol and other substances compared to his previous home. In contrast, Paul, (20–30, Pilbara, intellectual disability), blamed his increased alcohol and substance use on his move to an area with a high concentration of social housing and common anti-social behaviours to which he was exposed.

6.4.4 Social inclusion & participation

Many people commented that their social lives had improved since the housing move. They regularly saw existing friends, made new friends, and in some cases also new intimate relationships (Peter, Matt).

> I'm sort of branching out more, meeting other people and seeing my family more, I'm more accessible for my family here, and what else? (Matt)

Several participants were very pleased to be able to have visitors in their home thanks to its space, privacy (Meg, Fanny), and physical accessibility (Simon, Mary). Fanny, for example, installed disco lights in her living room to be able to host regular disco parties with her close friends.

Several people were able to maintain meaningful friendships they had in previous housing, such as the group home (Carly, Tom) or boarding house (Matt) they had lived in. Some participants made friends with neighbours in their new social housing complexes (Steph, Sam, Tom, Meg) around shared interests such as activities, sports and pets, and similar experiences of disability. Others described generally pleasant encounters with neighbours and local community members (e.g. businesses' and cafe staff) and highly valued these interactions. Such casual encounters were important and made people feel welcome in their community, irrespective if they developed into more meaningful relationships (Jarred, Sylvia, Eden, Lucas, Fanny).

> It's good everyone is really nice, I walk down the street and say hello and good morning, stuff like that and everyone I've met has been really nice. Like, I go to the second-hand shops down the main street and I know people's names, in one store I'm friendly with the ladies who run it. (Matt)

Mark and Fletcher's parents commented on their proactive approach to initiating and developing relations between their sons and their neighbours, not only for improved social inclusion outcomes, but also as a means to have neighbours available as emergency contacts. They noted that such relations were developed in their previous home, in another suburb, and losing these relationships was a negative aspect of the housing transition.

People who moved into sharing arrangements described flatmates as close friends (Mark and Fletcher, Nellie and Pamela). In Andy's case, the flatmate is assisting Andy to build a broader social network, by introducing Andy to his own friends. For Mary and Peter the housing transition was also her opportunity to move in with their partner.

Several of our participants experienced some social isolation and feelings of loneliness. In most cases, these circumstances predated the housing transition, and were not directly related to their housing. Mazy, a young women in her early twenties with intellectual disability, moved from her mother's home to live alone for the first time. The move accentuated her sense of

loneliness and isolation, which existed prior to her transition. Since the move, and having left her sheltered employment for different reasons, she spends much of her time alone at home watching TV:

> I feel lonely. But I choose to watch TV and be optimistic so I don't think about that. (Mazy)

6.4.5 Paid and unpaid work

Most participants had no income from work. Eleven were in low waged, mostly supported employment. One man was self-employed and also volunteered. Several people said they were proud to contribute to their communities by volunteering, for example, Fanny helped out one day a week at Woollies (a supermarket), and several other people were active as disability advocates, trainers or peer-mentors (Peter, Lucas). For most of these participants, the housing transition did not make a difference to their employment or volunteering status. However, some people felt the stable housing provided them a base from which to seek work. Jarred (20–30, Barwon, intellectual disability) took on a new manual job soon after moving into his current home; and Peter (20–30, Barwon, physical disability) started his own business after moving.

Some participants' housing situations had a negative impact on their employment outcomes. Yvette (20–30, Sydney, psycho-social disability) commented that despite having completed a TAFE diploma recently, she will not actively seek work until she sorted out her next housing, because of the impending expiry of her current housing contract. Similarly, Meg (50–60, Melbourne, physical disability) was unable to work while experiencing a housing crisis, since her time and emotions were consumed with finding housing. Having now secured stable housing, she felt more ready to seek a new job and re-enter the labour market. Another participant—Paul (20–30, Pilbara, intellectual disability)—lost his existing job following his housing transition, and blamed the exposure to anti-social behaviour in a social housing estate as a key reason.

6.5 Chapter conclusions

The chapter highlights overall very positive outcomes for most participants as a direct result of their housing transition. Following their move, most people experienced a growing sense of independence and greater wellbeing. For some, the need for support in daily living was reported to have reduced over time, suggesting a potential for savings on the costs of support over parts of their lifetime. Many people also experienced improved mental and physical health and improved social lives. Secure stable housing was perceived by some participants as an opportunity to extend their effort to search for paid and unpaid work, however there was little evidence of improved employment outcomes for all but a few people in the short term.

Most participants were satisfied with the location of their new home, in close proximity to services, to their families and friends, and in safe neighbourhoods. Most people with physical disabilities transitioned into accessible housing that met their needs, albeit only partially in most cases.

A closer look at the finances of participants suggests that housing affordability is not only a major barrier to moving to independent living, but also an ongoing issue after such moves. Most participants spent a high proportion of their very low incomes on housing, leaving very little disposable income for other basic day-to-day expenses, including in some cases medical expenses. Financial stress was particularly acute for participants who moved into private rental, and in some areas they paid close to two-thirds of their income on rent—almost twice as high as the 30:40 affordability benchmark. Living in social housing (or shared-equity) and sharing the rent with flatmates were the primary strategies used to reduce the costs of housing.

Many participants' finances were managed with the assistance (and at times close control and monitoring) of family, support workers and public trustees. Thus, despite the affordability challenge, the risk of rent arrears appears low for participants in our study. However, this was

at the cost of being restricted to very modest lifestyles, and at times giving up much of their control over financial decisions.

Overwhelmingly, people living in social housing or their own homes felt their housing was secure and they wished to stay in their homes permanently. In sharp contrast, most participants in private rental expressed a desire to move on to other housing, suggesting overall poorer housing outcomes and the desire for more secure tenancies.

7 POLICY IMPLICATIONS

Drawing on the research findings, we now address in turn each of the study's three primary research questions, and then discuss the implications for housing policy, disability policy and the design of the NDIS.

7.1 How do innovations in the funding and delivery of disability support services impact on housing demand among people with disability?

With the rollout of the NDIS, housing demand will be impacted by both the availability of a substantially larger pool of funds for disability support services, and the individualisation of funds. The flexibility and portability of individualised funds will increase the capacity of participants to consider new housing options and choices. Most participants in our study were able to use their support funding as a means to move to preferred housing and living arrangements, not restricted to the housing offered by any specific support provider.

The motivations identified indicate the potential impact of the full national roll out of the NDIS on housing demand. In particular, the desire for independence indicates the high demand for housing among the large population of people with disability who are over 25 years old and live with their parents. This population is estimated at close to 100 000 people with disability (Qu et al. 2012), including over 51 000 who have a profound or severe core activity limitation and more likely to receive NDIS support (Chapter 2).

Most participants who lived in shared supported accommodation were dissatisfied with these living arrangements, but they are not necessarily representative of the full population of people with disability in group homes. In our study we identified only a small number of people who successfully moved out of group homes. This reflects the barriers to such moves in the current funding system. However, the literature points to common problems of incompatibility between residents in group homes (Wiesel 2011), indicating that the individualisation of support funding with the NDIS could potentially trigger movement of people within and out of the group home system—currently housing over 16 000 people with mostly intellectual disability (AIHW 2014). Importantly, our findings indicate many people with disability are open to the option of sharing housing with others, but expect to have meaningful choice about who they share with and where, suggesting new forms of shared housing could emerge.

A majority of NDIS participants (close to 80%) are expected to have low or very-low income, and would be eligible for social housing, highlighting the need for new supply of social and other affordable housing.

7.2 When and how do people with disability participating in innovative support programs secure their preferred housing?

People with disability who have successfully secured formal and informal support to live independently, still face barriers to accessing suitable housing that meets their needs. Such barriers, operating in different variations across housing tenures, include:

→ Unaffordable costs of housing in the private sector, particularly in major cities and regional centres.

→ Discrimination or disadvantage in competition over private rental tenancies due to low income and the lack of rental history and references.

→ Shortfall in supply of housing that is appropriately designed for people with mobility restrictions (or other design requirements related to their disability) in the social and private sectors, and difficulties getting home modifications funded and approved.

→ Shortfall in supply of housing that is culturally appropriate for Indigenous people with disability.

→ Low priority in social housing allocations for people living with parents or in group homes.

→ Challenges for people with intellectual disability in obtaining home loans.

→ Lack of mechanisms or brokerage systems to share information about housing options.

→ Difficulty obtaining housing without confirmed support funding, or vice versa.

These barriers have impacted on participants in our study, and are likely to be accentuated with the progressive rollout of the NDIS which will further increase demand on scarce affordable housing. Participants in our study who managed to secure suitable housing despite such barriers represent a minority of people with disability, but the learnings from their experiences are valuable in highlighting some of the key success factors in access to housing, summarised in the following subsections.

Formal and informal support in searching and applying for housing

Participants who successfully secured preferred housing received substantial assistance from a relative, a case worker, a disability support worker or a disability, housing or other advocacy agency to search, apply and negotiate access to housing.

Sharing

Home sharing enabled people with disability to reduce the costs of housing, while also pooling their support packages and achieving other social benefits. Our findings highlight many people's willingness to share when they had a meaningful choice about who they share with. Community networks were important in enabling participants to identify potential flatmates. Agreed, and in some cases formalised, exit and entry strategies, assisted in managing risks associated with changes in household composition. Housing size and design that maximised privacy in living areas—in addition to shared spaces for socialising- was an important factor influencing the success of a home sharing arrangement.

Financial contribution from families

Financial assistance from families of people with disability was a key success factor enabling many people with disability to access housing, including both private rental and home ownership. Much of the assistance was provided by retired parents who withdrew funds from their superannuation savings, or equity from their own homes, to assist their son or daughter.

There is a policy expectation that families will provide a major source of finance to deliver housing solutions for people with disability, and NDIS participants more specifically (Bonyhady 2014). Indeed, financial assistance from families could potentially be scaled-up through sophisticated financial mechanisms, such as reverse mortgages to unlock equity in the homes of family members. Shared equity schemes were identified as another mechanism to leverage finance from families and people with disability who can afford to make only a small capital contribution to home purchase. Shared equity schemes enable people with disability to access home ownership, with enhanced choice of housing, long-term security and affordability and opportunities for accumulation of capital. Such schemes are yet to be scaled-up significantly. As noted by Connellan (2015, p.58), such 'equity-capture mechanisms, likely to be a part of the future, are yet to be developed at scale'. At the same time, it should be acknowledged that many—potentially most—NDIS participants, and people with disability more generally, have no family members who are able or willing to provide such assistance.

Accessible design

Despite the short supply of accessible housing suitable for people with mobility restrictions, some participants managed to secure an accessible home that met their needs to varying degrees. This included moving into an accessible social housing dwelling, or negotiating the

modification of an inaccessible dwelling. A few participants were consulted about their design requirements before their home was built by a social housing provider. While some participants in social housing and home ownership/shared-equity successfully negotiated access to funds to modify their home, this was not an option for participants in private rental.

Negotiating home modification funds was described by participants as challenging, and those who were successful applied strategies such as providing independent occupational therapy assessments or in some cases financing and managing modifications on their own. Having an accessible home was a crucial factor influencing their housing outcomes, including ability to move independently into, within and out of their home, and the ability to have guests over.

Priority and 'special' access to social housing

While several participants were able to access social housing through priority allocations on the basis of their urgent need for housing (i.e. unstable housing and homelessness), others accessed social housing outside the priority or general waitlist, through nominations or other special programs delivered in partnership between disability and housing providers. While achieving positive outcomes for participants, such programs generally distort the equity principles of social housing allocations and cannot be scaled-up substantially. As long as social housing continues to provide priority assistance narrowly targeted at those who are in greatest housing need, there is a need for a separate system that is not-crisis driven and inclusive of people with disability who do not qualify for priority social housing.

Relations with landlords and real-estate agents

Importantly, half of the participants who successfully secured a private rental tenancy had some informal relationship with the real-estate agent or landlord prior to applying for a tenancy. This highlights the importance of capacity building programs that facilitate such informal relationships between people with disability, their support networks and stakeholders in the housing industry (builders, landlords and real-estate agents). This could potentially assist in reducing discrimination against people with disability, as well as reducing barriers to home modifications in rental properties.

7.3 What are the shelter and non-shelter outcomes for people with disability participating in innovative support programs who moved to their preferred home?

The study demonstrated that with appropriate support, moving to their preferred housing can have multiple positive outcomes for people with disability. Most participants were satisfied with the location of their new home, in proximity to services, to their families and in safe neighbourhoods. People with physical disabilities who transitioned into accessible housing that met their needs, experience greater independence and social inclusion. People with a history of unstable housing were able to secure more stable housing.

Following their move, most participants experienced a growing sense of independence. For some, the need for support in daily living reduced substantially over time, suggesting a potential for savings on the costs of support over their lifetime. Many also experienced improved mental and physical health and improved social lives. Secure stable housing was perceived by some people as an opportunity to extend their effort to search for paid employment. Although earned income could result in reduced pension rates, and higher rents for those living in social housing, there was no evidence in our study that this was a disincentive preventing people with disability from seeking employment. Overall, there was little evidence in our study that housing transitions had a significant impact on employment outcomes, however further research is required to examine the complex relationship between disability, housing and employment.

These empirical findings are largely consistent with those in the program evaluations reviewed in Chapter 3. However, most evaluations did not focus on the affordability stress for people with disability, particularly those who moved to private rental. A closer look at the finances of participants suggests that housing affordability is not only a major barrier to moving to independent living, but also an ongoing issue after such moves. Most people spent most of their very low incomes on housing, leaving very little disposable income for other basic day-to-day expenses, including in some cases medical expenses. Financial stress was particularly acute for people who moved into private rental, and in some areas they paid close to two-thirds of their income on rent, almost twice as high as the 30:40 affordability benchmark. These findings are consistent with those published by NDS (2014). Similarly, Taleporos et al. (2013, p.32) highlight the risk of tenancy failures due to affordability stress.

People living in social housing or their own homes felt their housing was relatively secure and wished to stay in their homes permanently. In contrast, most private renters did not see their housing as a permanent solution.

7.4 Implications for housing policy

The barriers to accessing housing experienced by people with disability are underpinned by the absence of more detailed strategies and policies on housing for people with disability (NDS 2014, p.30). Despite the urgency associated with the timeframe for the national rollout of the NDIS, very little information has been made public about policy solutions to address the impact on housing demand. As observed by Connellan (2015, p.58):

> The absence of clarity from the NDIA and the State Housing Authorities around their respective positions, objectives, and processes are preventing housing developers (private, public, and not-for-profit) from formulating and commencing their development plans. Even when there is clarity, the project development processes will need to be at a scale and complexity not confronted before in housing development in Australia, let alone in housing for people with disabilities.

Our study highlights some potential areas of focus in new policies to address the expected boost in demand for affordable housing, as well as the availability of NDIS user cost of capital funds for new housing supply.

Social housing in its current form will continue to provide a solution for people with disability who are experiencing unstable housing or homelessness. However, the crisis-driven allocation of existing social housing stock is a key barrier that could prevent most future NDIS participants, and other people with disability, from accessing their preferred housing until experiencing crisis. Special programs that involve collaboration between housing and disability agencies, including nomination rights, could provide pathways of entry into existing social housing for a small proportion of people with disability (Section 5.1.2) but as discussed above these can be difficult to scale-up.

Ultimately, existing social housing stock falls far short of meeting existing levels of demand, let alone the growth in demand expected with the national rollout of the NDIS. As discussed in Section 2.4, only 13.5 per cent of people with severe or profound disability are public renters. The COAG (2013, p.10) agreement that social housing 'will continue to provide accommodation for people in need of housing assistance in line with existing allocation and prioritisation processes', suggests this proportion is not likely to change significantly. If social housing continues to be allocated through a crisis-driven priority system, then new affordable housing supply needs to be managed through a separate allocation system to improve housing outcomes for NDIS participants and people with disability more generally.

The findings indicate the type of housing that is likely to be in high demand by NDIS participants. Rather than 'specialist' housing, most will prefer 'mainstream' housing that is affordable and in locations with good access to services, shops and public transport as well as

people's families and informal support networks. Our finding that most people wished to remain permanently in housing that is secure and meets their preferences also highlights the need for adaptable design to allow ageing in place. Legislative requirement for non-discriminatory access standards in new housing construction will be the most effective strategy to increase supply of adaptable and accessible housing, with minimal cost for government. In addition, funds for home-modifications will improve accessibility in existing housing stock, and adaptation of properties to meet specific individual requirements. Evidence of challenges in accessing such funds (Section 6.3.3) suggests the roles of the NDIS, private and social housing providers in resourcing this needs to be more clearly defined in policy.

The findings highlight the importance of closely conferring with prospective residents about the design of their designated properties, given the diversity of individual needs that are often not met through universal accessibility standards. The literature shows that adaptations during the design stage are substantially cheaper than later modification of existing dwellings (Victorian Government 2010). Furthermore, more appropriate evidence-based design of housing for people with disability can assist in reducing the costs of paid support (Carnemolla & Bridge 2014) as well as reducing costs of living, for example by reducing energy and water consumption (Wiesel et al. 2012) which can be high for people with disability (Hodge 2012).

Home sharing will improve affordability outcomes for people with disability, enable the pooling of support funding, and improve overall utilisation of existing and new housing stock. Home sharing can also have positive shelter and non-shelter outcomes for people with disability as long as they have meaningful choice about who they share with (Section 5.3.2). Housing development and management strategies are necessary to ensure people with disability are able to choose their flatmates and share comfortably, for example through design that maximises privacy. Shared equity schemes were identified as a model that, if scaled up, can assist in both leverage of finance from families, and positive shelter and non-shelter outcomes for people with disability.

The geographic variation in housing opportunities calls for more nuanced policies tailored to the specific challenges and opportunities in different local housing markets. In areas where private rental is more affordable, strategies are needed to overcome discrimination and disadvantage for people with disability. For example, programs can be designed to support people with disability to enter their first private rental tenancy, to assist in the creation of a track record of renting that could potentially facilitate access to future tenancies. Assistance could also be targeted at private renters with disability whose tenancies are at risk, for example when the property is being sold by the landlord. Acquisition of the property by a social housing provider was identified as one strategy to address this.

In recent years home ownership has become very difficult to access for low-income Australians of all abilities. For people with disability in particular, home ownership rates are lower than the general population. A small number of participants in our study have nevertheless overcome the affordability and other barriers to enter home ownership, in most cases with substantial financial assistance from their families. The costs of housing was reduced either by sharing with other people with disability or by entering a shared-equity arrangement with a housing provider. Expansion of shared equity schemes, as well as other low-income home ownership assistance programs such as Keystart in WA, is likely to increase the number of people with disability able to access home ownership, however this will be mostly limited to people who can contribute their own capital or seek financial assistance from families.

7.5   Implications for disability policy and the NDIS

Successful transition of people with disability into their preferred housing is essential for successful implementation of the NDIS and national disability policy more generally. Housing that is close to participants' families and informal support networks can reduce their reliance on formal support. Furthermore, home sharing arrangements with preferred housemates would

allow participants to pool together their individual funds to reduce the costs of support. Housing in locations with good access to public transport is likely to reduce ongoing costs of transport with substantial long-term savings for both the NDIS and its participants.

While the NDIA is not responsible under current legislation for the funding and delivery of affordable housing, it has a critical role to assist its participants in accessing housing. This includes the NDIS user cost of capital which could potentially be used to catalyse new supply of affordable housing (Bonyhady 2014) as well as other forms of support that would directly influence housing opportunities.

The findings demonstrate that sufficient support for people with disability to search and apply for housing—over and above ongoing day-to-day support—need to be factored into participants' support plan. There is a critical role for independent advocacy, information and tenancy management services in preparing and supporting people with disability in the planning and pre-planning process. Risk management plans are also necessary to address risks, such as deteriorating health, that could impact on the long-term sustainability of housing arrangements. NDIS funding—through ILC rather than personal support plans—is also needed for capacity building and support targeted not only at people with disability themselves, but also their formal and informal support networks. Such capacity building programs could assist in strengthening the social capital of people with disability—for example by expanding their social networks—thus increasing housing opportunities. A more specific focus needs to be placed on building relationships with landlords and real estate agents, financial institutions, builders and social housing providers.

There is an opportunity for the NDIS to design and distribute its user cost of capital funds in a way that ensures that housing that is developed meets the desired outcomes for participants in terms of maximising choice and independence, affordability, suitability for a diversity of needs and preferences, security, access to services and transport, and access to formal and informal support.

Our findings suggest that prospective NDIS participants should be supported to be well-prepared for the transition into the Scheme long before its rollout in their area. People who already have person-centred plans and social support when first engaging with NDIS planners are in a better position to negotiate their individual support plans.

7.6   Directions for further research

The implications of the NDIS for housing policy are immense, yet existing research is scarce. Effective policy development and planning need to rely on a much stronger evidence base. There are many potential directions for research on this topic, but here we highlight five areas which directly build on findings from the current study:

→ Options to increase leverage on NDIS user cost of capital to develop sufficient supply of housing to meet demand.

→ Design of housing that achieves positive shelter and non-shelter outcomes, including long-term financial savings on paid support, utilities, health and transport. Longitudinal studies may be necessary to assess long-term outcomes. Evidence about the impact of design and home modifications needs to be made accessible for people with disability.

→ Policy options to assist ageing parents of people with disability to secure comfortable retirement, to reduce risks for those who choose to invest financially in housing for their son or daughter with disability.

→ Investigation of the range of forms of coordination between disability services and housing providers and their effectiveness in overcoming some of the barriers in access to housing or support.

→ Geographically fine-grained assessment of the NDIS's impact on housing demand.

REFERENCES

ABS (2011) Census of population and Housing. Canberra: Australian Bureau of Statistics. [Online] Available from: http://www.abs.gov.au/websitedbs/censushome.nsf/home/data?opendocument&navpos=200 [Accessed: 2 August 2015].

ABS (2012) *Disability, Ageing and Carers, Australia: Summary of Findings, 2012*. Canberra: Australian Bureau of Statistics. [Online] Available from: http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0 [Accessed: 27 April 2015].

AIHW (2012) *Services provided under the National Disability Agreement 2010–2011*. Canberra: Australian Institute of Health & Welfare.

AIHW (2013a) *Disability support services: services provided under the National Disability Agreement 2012–13*. Canberra: Australian Institute of Health & Welfare.

AIHW (2013b) *Housing assistance in Australia 2013*. Canberra: Australian Institute of Health & Welfare.

AIHW (2014) *Disability support services: Appendix 2012–13*. Canberra: Australian Institute of Health & Welfare.

AIHW (2014b) *Disability support services: Services provided under the National Disability Agreement, 2012–13*. Canberra: Australian Institute of Health & Welfare, Bulletin 122.

Anglicare (2015) *Rental Affordability Snapshot, April 2015*. Canberra: Anglicare Australia.

Australian Government (2011) *2010–2020 National Disability Strategy: An initiative of the Council of Australian Governments*. Canberra: Commonwealth of Australia.

Australian Government (2013) *Medicare levy increase to fund DisabilityCare Australia*. [Online] Available from: https://www.ato.gov.au/general/new-legislation/in-detail/direct-taxes/income-tax-for-individuals/medicare-levy-increase-to-fund-disabilitycare/ [Accessed: 27 April 2015].

Beer, A., & Faulkner, D. (2008) *The housing careers of people with disability and carers of people with disability*. Melbourne: Australian Housing and Urban Research Institute, AHURI Research Paper.

Bleasdale, M., McNamara, N., Zmudzki, F. and Bridge, C. (2014) *Positioning Paper: DIY home modifications: point-of-sale support for people with disability and their carers*. Sydney: University of NSW, Home Modification Information Clearinghouse, July. [Online] Available from: http://www.homemods.info/ [Accessed: 27 April 2015].

Bonyhady, B. (2014) The National Disability Insurance Scheme: A catalyst for large scale, affordable and accessible housing for people with disability, in *Housing, Disability and the NDIS Forum*. [Online] Available at: http://chfa.com.au/sites/default/files/sites/default/files/docs/bonyhady_bruce_-_presentation_-_chfa_ndis_forum_-_27_march_2014.pdf [Accessed: 30 July 2015].

Bridge, C. (2005) *Accessible Housing in Australia: HMMinfo Consultation Paper Response*. [1st ed.] Sydney: University of NSW, Home Modification Information Clearinghouse, Occasional Paper (May). [Online] Available from: http://www.homemods.info/ [Accessed: 27 April 2015].

Bridge, C., Flatau, P., Whelan, S., Wood, G. & Yates, J. (2003) *Housing assistance and non-shelter outcomes*. Melbourne: Australian Housing and Urban Research Institute, AHURI Final Report 40.

Bruce, J., McDermott, S., Ramia, J., Bullen, J., & Fisher, K. (2012) *Evaluation of the Housing and Accommodation Support Initiative* (HASI). Sydney: Social Policy Research Centre.

Carnemolla, P. & Bridge, C. (2011) *Home modifications and their impact on waged care substitution.* [Online] Available at: http://homemods.info/publications-by-hminfo/occasional/home-modifications-and-their-impact-on-waged-care-substitution [Accessed 15 April 2015].

Community Housing Federation Australia (2014) *Providing housing for people with disability.* Sydney: Community Housing Federation Australia (CHFA).

Connellan, J. (2015) Commentary on Housing for People with Intellectual Disabilities and the National Disability Insurance Scheme Reforms (Wiesel 2015), *Research and Practice in Intellectual and Developmental Disabilities*, 2(1), pp.55–59.

Council of Australian Governments (2015) COAG Disability Reform Council Communique, 24 April 2015. Canberra: Council of Australian Governments (COAG). [Online] Available at: http://mitchfifield.dss.gov.au/media-releases/coag-disability-reform-council-communiqu [Accessed 27 April 2015].

Council of Australian Governments (2013) *NDIS—principles to determine the responsibilities of the NDIS and other service systems.* Canberra: Council of Australian Governments (COAG). [Online] Available at: https://www.coag.gov.au/node/497 [Accessed 30 March 2015].

Department of Health and Human Services (2013) *Review of the Disability Gateway Final Report: Tasmanian Government.* Hobart: Tasmanian Department of Health and Human Services (DHHS).

Disability Policy Research Working Group (2011) *National Disability Research and Development Agenda.* Canberra: Department of Social Security (DPRWG). [Online] Available at: https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/national-disability-agreement/national-disability-research-and-development-agenda [Accessed 27 April 2015].

Easthope, H., & van den Nouwelant, R. (2013) *Home Modifications in Strata Properties: Final Report.* Sydney: City Futures Research Centre.

Endeavour Foundation (2008) *Homes for everybody.* Brisbane: Endeavour Foundation.

Fisher, K.R. and Campbell-McLean, C. (2008) *Attendant Care Program Direct Funding Pilot Project Evaluation Final Report.* Sydney: Social Policy Research Centre, SPRC Report 11/08.

Fisher, K.R., Gleeson, R., Edwards, R., Purcal, C., Sitek, T., Dinning, B., Laragy, C., D'aegher, L. & Thompson, D. (2010) *Effectiveness of individual funding approaches for disability support.* Canberra: Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Occasional Paper Number 29.

Fisher, K.R., & Purcal, C. (2010) Effective Personalised Housing Support for People with Disabilities-Case Study Analysis. *Australian Journal of Social Issues*, 45(4), p.527.

Franz, J., Adkins, B., Petriwskyj, A., Bitner, G., Ward, M. and Rolfe, A. (2014) *Person-centred approaches to private housing for people with disability: impediments, difficulties and opportunities*, Final Report. Brisbane: University of Queensland.

Fyffe, C., & Bigby, C. (2008) *Strategic Issues and Directions for KeyRing in Victoria.* Melbourne: Marillac House and Northern Support Services.

Goldblatt, B., Edwards, R., McHugh, M., Katz, I., Abello, D., Eastman, C., Heese, K. (2010) *Evaluation of the Leaving Care Program Final Report.* Sydney: Social Policy Research Centre.

Head, M., & Conroy, J. W. (2005) Outcomes of self-determination in Michigan. In R. Stancliffe & C. Larkin (Eds.), *Costs and outcomes of community services for people with intellectual disabilities* (pp.219–240). Baltimore: Paul H. Brookes.

Health Outcomes International (2011) *Evaluation of the NSW Younger People in Residential Aged Care (YPRAC) Program*. Sydney: Department of Ageing, Disability and Home Care (AHDC).

Hodge, C. (2012) *More power to you: Electricity and people with a physical disability*. Sydney: Public Interest Advocacy Centre Ltd.

Housing Choices Australia (2015) Innovative Supported & Independent Living Options. [Online] Available from www.housingchoices.org.au/data/HCA_presentation_NDIS.pdf [Accessed 30 July 2015].

Imrie, R. (2003) Housing quality and the provision of accessible homes. *Housing Studies*, 18(3), 387-408.

Kozma, A., Mansell, J., & Beadle-Brown, J. (2009) Outcomes in different residential settings for people with intellectual disability: A systematic review. *American Association on Intellectual and Developmental Disabilities*, 114(3), pp.193–222.

Lambert, L. (2015) The potential of vested interests, ANSA (Adults Needing Supported Accommodation) (slides provided by author).

Livable Housing Australia (2012) Livable Housing Design Guidelines. [Online] Available at: http://www.livablehousingaustralia.org.au/library/help/Livable_Housing_Design_Guidelines_Web1.pdf [Accessed 15 April 2015].

LIME Management Group (2005) *Evaluation of Support & Choice Implementation*. Melbourne: Victorian Department of Human Services.

Mansell, J., Beadle-Brown, J., & Bigby, C. (2013) Implementation of active support in Victoria, Australia: An exploratory study. *Journal of Intellectual and Developmental Disabilities*, 38(1), pp.48–58.

National Housing Supply Council (2010) *2nd State of Supply Report*. Canberra: National Housing Supply Council (NHSC).

National Housing Supply Council (2013) *Housing supply and affordability issues 2012–13*, Canberra: National Housing Supply Council (NHSC).

NDS (2014) Home ownership and affordability for people living with disability in Western Australia. Osborne Park: National Disability Service.

NSW Parliament (2011) Fourth Review of the Lifetime Care and Support Authority and the Lifetime Care and Support Advisory Council. Sydney: NSW Parliament, Standing Committee on Law and Justice.

Parliament of Australia, (2013) *National Disability Insurance Scheme*. [Online] Available at: http://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/BudgetReview201213/NDIS [Accessed 15 April 2015].

Poll C. (2006) *A report on in Control's first phase*, 2003–2005. London: Control Publications.

Productivity Commission (2011) *Disability Care and Support, Productivity Commission Inquiry Report*. Canberra: Australian Government.

Purcal, C., Fisher, K., Jones, A., Lutz, D., Meltzer, A., Hill, T., Robinson, S., Kayess, R., & Smedley, C. (2014) *Supported Accommodation Evaluation Framework Report*. Sydney: Social Policy Research Centre, SPRC Report 31/2014.

Qu, L., Edwards, B. & Gray, M. (2012) *ageing parents of people with a disability*. [Online] Available at: http://www.aifs.gov.au/institute/pubs/carers/carers.pdf [Accessed 15 April 2015].

Slowinski, K., McCall, R. & Rogers, N. (2012) *Evaluation of the Younger People in Residential Aged Care Program—The closest thing to home*. Adelaide: Department for Communities and Social Inclusion.

Stone, W. (2015) Sustaining private tenancies: experiences & Opportunities, In: *Motivations and transitions: targeting housing assistance to best support tenant outcomes*. Adelaide: Australian Housing & Urban Research Institute, seminar, 11 June 2015.

Taleporos, G., Craig, D., Brown, M., McNamara, C., & Forbes, S. (2013) *Housing and Support for Younger People with Disabilities Transitioning to Independent Living: Elements for success in the design and implementation of Disabilitycare Australia, National Disability Insurance Scheme*. Melbourne: Youth Disability Advocacy Service (YDAS).

United Nations (2006) *Convention on the rights of persons with disabilities and optional protocol*. New York: United Nations. [Online] Available at: http://www.un.org/disabilities/default.asp?navid=14&pid=150 [Accessed 15 April 2015].

Victorian Government (2010) *Accessible Housing—public consultation on the visitable and adaptable features in housing regulatory impact statement*. Melbourne: Department of Sustainability and Environment. [Online] Available at: http://www.dse.vic.gov.au/DSE/nrenpl.nsf/LinkView/10E80E70836F36FBCA2575DE00 1CFC9EB6D5337005FB3718CA2572CF007A0F0A [Accessed 22 July 2010].

Walsh, P.N., Emerson, E., Lobb, C., Hatton, C., Bradley, V., Schalock, R.L., & Moseley, C. (2010) Supported accommodation for people with intellectual disabilities and quality of life: An overview. Journal of Policy and Practice in Intellectual Disabilities, 7(2), pp.137–142.

Walls, R., Millikan, L. Bridge, C. & Davy, L. (2012) Home modifications in Aboriginal housing. [Online] Available at: http://homemods.info/publications-by-hminfo/occasional/home-modifications-in-aboriginal-housing [Accessed 15 April 2015].

West, R., Warth, S. & Scott, M. (2013) *Final Evaluation Report for Project 2.22: Young People Leaving Care Support Service ‐ North Coast*. Sydney: Westwood Spice.

Wiesel, I. (2011) Allocating homes for people with intellectual disability: needs, mix and choice. *Social Policy & Administration*, 45(3), pp.280–298.

Wiesel, I. (2015) Housing for People with Intellectual Disabilities and the National Disability Insurance Scheme Reforms. *Research and Practice in Intellectual and Developmental Disabilities*, 2(1), pp.45–55.

Wiesel, I., & Bigby, C. (2015). Movement on shifting sands: Deinstitutionalisation and people with intellectual disability in Australia, 1974–2014. *Urban Policy and Research*, 33(2), pp.178–194.

Wiesel, I., Davison, G., Milligan, V., Phibbs, P., Judd, B., & Zanardo, M. (2012) *Developing sustainable affordable housing: a project level analysis*. Melbourne: Australian Housing and Urban Research Institute, AHURI Final Report 183.

Wiesel, I., H. Easthope, E. Liu, B. Judd & E. Hunter (2012) *Pathways into and within social housing*. Melbourne: Australian Housing and Urban Research Institute, AHURI Final Report 186.

Wiesel, I., & Fincher, R. (2009) The choice agenda in disability housing provision. *Housing Studies*, 24(5), pp.611–627.

Yates, J. (2011) 'Explaining Australia's trends in home ownership'. *Housing Finance International,* Winter, pp.6–13

AHURI Research Centres

AHURI Research Centre—Curtin University

AHURI Research Centre—RMIT University

AHURI Research Centre—Swinburne University of Technology

AHURI Research Centre—The University of Adelaide

AHURI Research Centre—The University of New South Wales

AHURI Research Centre—The University of Sydney

AHURI Research Centre—The University of Tasmania

AHURI Research Centre—The University of Western Australia