

**The housing careers of
persons with a disability
and family members
with care
responsibilities for
persons with a disability**

**National Research Venture 2: 21st century
housing careers and Australia's housing
future**

**Project C: Qualitative data collection
report of focus groups**

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for the

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ACRONYMS

ABI	Acquired brain injury
AHURI	Australian Housing and Urban Research Institute
CRU	Community Residential Units
DHS	Department of Human Services
DSP	Disability Support Pension
GARSS	Gippsland Accommodation and Rehabilitation Support Service
MOH	Ministry of Housing
NRV	National Research Venture
TAC	Transport Accident Commission

EXECUTIVE SUMMARY

This report summarises the results of seven focus groups that were conducted in Melbourne and Gippsland during April, May and September 2007 to gain insights into how people with a disability and carers of people with a disability view their past and present housing careers. This report addresses the themes that emerged from the focus group sessions.

The overarching themes that emerged from the focus group sessions included:

- Modifications to housing by people with a disability were expensive and placed pressure on limited financial resources;
- Moving house to find a better house design suited to their specific needs was not a viable option due to the high 'sunk costs' in the current accommodation;
- Carers of people with a disability and people with a disability lament the tyranny of distance regarding access to services. Country locales were universally agreed to have fewer services;
- Long-term housing poses uncertainty for people with a disability and their carers as the needs change for the person with a disability with age and also the level of care provided by spouses and family member's change with age;
- Entry into the private rental market posed challenges in securing appropriate accommodation and then in trying to gain permission to carry out modifications;
- People with a disability felt they were discriminated against when trying to enter the private rental market;
- Access to transport is a major factor in determining where people with a disability would like to live;
- Ongoing medical costs and housing modifications deplete financial reserves causing uncertainty;
- Surging housing prices have trapped people in their current housing. The costs of moving plus higher house prices in more suitable places, prohibits moving to more appropriate accommodation;
- Housing stock, both private and government owned, is universally seen as having declined in numbers, quality and availability over the last two decades;
- Rural locations have limited housing options in comparison with Melbourne;
- Changes in the needs of carers as they age are not being properly addressed or properly understood;
- The State Government is perceived as talking big, but delivering little and the affected people feel that disabled people are being let down and that there is continual stalling by government at every step of the way;
- There was a need for legislation in the Building Act that would ensure all new buildings had accessibility included in their design.

The number of participants in the focus groups varied and the individual participant profiles represented a wide range of personal circumstances and were sufficiently varied to give a clear insight into the needs and satisfaction levels of the participants and their housing careers. Participant ages ranged from 18 to 75 plus years and participants in the focus groups occupied a broad range of housing circumstances. Their dwellings consisted of houses, cottages, flats, bed sits, townhouses and CRU

units and while most were owner/occupied, or public housing, there was representation from the private rental market.

The discussion in the focus groups centred on seven topics including:

1. General characteristics
2. Current housing
3. Previous moves, plans to move again
4. Housing markets
5. Care and services
6. Disability sector and housing
7. Open discussion

The key issues by particular focus groups are:

Gippsland Region (Morwell) – People with a mobility disability

- Absence of suitable government housing stock located in the region;
- Respondents had traded off affordable housing in Gippsland that enabled them to enter home ownership against higher levels of support and service provision in Melbourne. The focus group participants were comfortable that this was the correct decision;
- Older participants did not know how they would cope with their housing and other needs if their partner – who is the primary care giver – was to die;
- Modifications to the family home are a financial burden, with much of this shouldered by the person with a disability and their immediate family.

Gippsland Region (Morwell) – People with a cognitive/psychiatric disability

- The presence of noisy and inconsiderate neighbours diminishes the housing experience for both people with a disability and carers;
- Discrimination by landlords made securing properties in the rental market difficult;
- The source of disability can have a significant impact on the housing career of persons who acquire a disability later in life. Persons who acquired a brain injury through a motor accident or other compensatable accident had more housing options available to them than those who acquired an injury through illness or at birth;
- The poor location of government housing stock adversely affected the happiness and well being of people with a disability living in this accommodation.

Gippsland Region (Morwell) – Carers of people with a disability

- Lack of understanding and compassion displayed by governments;
- Government has failed to build new housing stock to accommodate the needs of people with a disability and their carers;
- Cost and the presence of too many unknowns, deters family members with care responsibilities from moving to better housing.
- Gippsland Region (Sale) – People with a disability
- Housing stock, both private and government owned, is universally seen as declining in numbers, quality and availability over the previous two decades.

- Limits on the hours of paid work allowed when receiving a pension and the resultant low income restricted access to loans for a home;
- Access to services, principally transport to Melbourne was a major concern;
- Some participants considered living in Melbourne would provide them with a better lifestyle but it was prohibitive financially;
- Having a disability was not necessarily seen as a 'priority need' within the public housing sector.

Gippsland Region (Sale) – Carers of people with a disability

- Living in the East Gippsland posed problems in gaining access to services;
- The negative impact of a disability on finances was stressful and created much anxiety and uncertainty;
- Caring for a person with a disability was a full-time job and respite care was minimal.

Melbourne (Inner and Outer) – People with a disability and the carers of persons with a disability

- The Office of Housing was seen to provide good quality housing and was praised for its willingness to modify its dwellings. However, there was concern that only limited modifications – such as the provision of grab rails and ramps – were undertaken while more comprehensive modifications – such as kitchen benches at wheelchair height – were ruled out;
- The high cost of housing in inner Melbourne was seen to limit the potential for movement through the housing stock;
- There was on-going reliance on family members to provide support/assistance with housing;
- The housing stock was seen to be inappropriate for many persons in a wheelchair, especially as they age and lose both strength and mobility;
- Persons in a wheelchair have a strong aversion to multi storey residences.

Melbourne (Inner and Outer) – Persons with a Hearing Impediment

- Persons with a hearing impediment were concentrated in private rental housing and all lived independently, although there was substantial use of support services;
- There was a low rate of participation in the labour market, with relatively few opportunities to find work outside the Auslan community;
- Some respondents had experienced discrimination in the housing market, with one person bullied by adolescents within the caravan park within which he lives;
- Participants believed that there was a need for better information for deaf people on housing options and how to gain entry to a range of tenures;
- Public rental housing was seen to be a desirable tenure for persons with a hearing disability but access to the stock was seen to be difficult.

1 INTRODUCTION

This report presents the outcomes of six focus groups undertaken in April and May 2007 that examined the housing careers of persons with a disability and family members of persons with a disability with care responsibilities. The research was undertaken as part of National Research Venture 2: 21st Century Housing Careers and Australia's Housing Future.

National Research Venture 2 (NRV 2) has a focus on the nature and direction of housing careers into the 21st Century and the implications of these changing patterns of housing consumption for housing policy in Australia.

The NRV seeks to answer the overarching question:

How are housing careers changing in Australia and what are the implications of change for government-provided housing assistance and housing policy?

Through this NRV researchers will advance the evidence base around 21st Century housing careers in Australia and shed light on how shifts in household structure, the labour market, fertility patterns, attitudes to home ownership and government assistance, will influence the demand for government interventions in housing markets over the next 10, 20 and 30 years.

NRV 2 was developed through an extensive process that included the development of a comprehensive Research Plan. That Research Plan was completed in two phases, with the Plan approved by the AHURI Board in late June 2004 and endorsed by the Housing Ministers Advisory Council in September 2004. A version of the NRV Plan is available on the website of the Southern Research Centre <http://www.ssn.flinders.edu.au/ahuri/src/>

NRV 2 comprises two parallel research paths – one for the mainstream population and secondly an explicit focus on the housing careers of persons with a disability and family members of persons with a disability with significant care responsibilities. The research plan for NRV 2 includes:

Project A: A review of contemporary literature on housing careers in Australia and other nations

As part of this project the research team reviewed published and 'grey' literature on the housing careers of persons with a disability.

Project B: An analysis of existing data sets – such as ABS data sets - and the insights they offer for the understanding of 21st Century housing careers.

The chosen data sets were reviewed with reference to the housing careers of persons with a disability.

Project C: Qualitative analysis of 21st Century housing careers.

The AHURI-funded component of Project C has used a mix of Delphi analysis, focus groups and in-depth interviews to map out a deeper understanding of contemporary housing careers. This aspect of the research has paid particular attention to the 25-34 and the 55-64 year age groups. Within the disability component of Project C, the research uses both Delphi analysis and qualitative analysis to identify key issues in the housing careers of persons with a disability and carers of people with a disability.

Project D: The Housing 21 Survey

The Housing 21 Survey is a large scale quantitative survey of 21st Century housing careers in Australia. It is representative at the State/Territory level and was

undertaken by Computer Aided Telephone Interview (CATI). The parallel work for the disability component of NRV 2 involves a number of face-to-face and postal interviews with persons with a disability and carers.

Project E: Validation of Housing 21

The final project within the NRV is a piece of qualitative work that will be used to assess the validity of the conclusions drawn from Project D. It will contain both a disability and non-disability component.

This report constitutes the larger part of Project C as there is a separate report of the outcomes of the Delphi analysis (Zakharov and Minnery 2007)¹ and as noted previously, the purpose of this component of the research is to add depth to our insights into the housing careers of persons with a disability and those of family members of persons with a disability who have care responsibilities.

¹ Zakharov R. and Minnery J. 2007 21st Century Housing Careers Project Disability Delphi Study Report, AHURI NRV 2 SRC AHURI <http://www.ssn.flinders.edu.au/ahuri.src/>

2 METHODOLOGY

A total of seven focus groups were conducted in April, May and September 2007 in Gippsland and Melbourne. Attention was paid to both rural and metropolitan locations in order to mirror as closely as possible the data collection being undertaken in Project D. A variety of techniques were used to recruit participants into the focus groups – including the distribution of flyers and postings on email distribution lists – but the most successful strategy was working in collaboration with local agencies who encouraged their members to take part in the research and often organised the venue and catering. Their knowledge and networks provided the linkages necessary to successfully and confidently recruit participants. An incentive was also used in order to attract volunteers to participate in the research. Respondents were reimbursed \$20 for their costs associated with attending the meeting. The structure of the sessions and topics discussed can be found in Appendix 1.

Where possible, persons with a disability attended one focus group while family members with care responsibilities attend a simultaneous meeting at a separate venue. This arrangement applied throughout Gippsland but in Melbourne the numbers involved were too small to justify the separation into two groups.

Each focus group was led by a senior member of the research team with another team member taking notes of the meeting. In one instance we relied upon the assistance of a local agency member for taking notes. For reasons of confidentiality, the focus group meetings were not recorded.

Table 1: Focus group make-up

<i>Group No.</i>	<i>Type</i>	<i>Number of Participants</i>	<i>Make-up of Participants within Groups</i>	<i>How Participants were Recruited</i>	<i>Location of the Focus Group</i>
1	People with a disability	12	5 female 7 male	Rural Access	Morwell-Rural Victoria
2	People with a disability	10	4 female 6 male	Rural Access	Morwell-Rural Victoria
3	Carers of people with a disability	11	6 female 5 male	Rural Access	Morwell-Rural Victoria
4	People with a disability	7	3 female 4 male	Rural Access	Sale- Rural Victoria
5	Carers of people with a disability	4	2 female 2 male	Rural Access	Sale- Rural Victoria
6	People with a disability and carers of persons with a disability	7	4 female 3 male	ParaQuad/Disabled Motorists Association	Inner Melbourne
7	People with a hearing disability	7	2 female 5 males	VicDeaf	Inner Melbourne
	Total	51	26 female 32 male		

3 MORWELL GIPPSLAND RURAL VICTORIA – PEOPLE WITH A DISABILITY

3.1 General characteristics

The Morwell focus group of people with a disability had 12 participants, five females and seven males, with ages ranging from 30 years to over 70. Disabilities amongst the group included vision impairment, spinal injury, double amputee, RSI-back problems, scoliosis, asbestosis and acquired brain injury (ABI).

The group consisted of people with families, partners and single people. Some participants had had their disability for many years while others had acquired their disability more recently. The majority lived with immediate family such as wives, husbands, children, brothers and sisters, while some lived on their own and one participant specifically mentioned living with their pets.

Housing was seen as an important issue by the group. It was recognised as being costly to secure appropriate accommodation and financially taxing to undertake modifications to suit their individual needs.

3.2 Current housing

The amount of time participants had lived in their current house ranged from eight months to 22 years. In between were periods extending from 12 months to three to four years, seven years, eight years, nine years, 14 years and 18 years. Dwelling types ranged from two storey homes, two bedroom units, single storey homes, and townhouses. Of these, the majority owned their own housing with three participants being in the rental market and one person boarding in the family residence. Of the renters, two persons were in the private rental market and one was in the Community Residential Units system. The renters all indicated that finding appropriate accommodation was difficult and diminished greatly the options for where they lived. The owner/occupiers within the group expressed how fortunate they were in being able to live in their own homes as they did not have the stress of being in an uncertain environment. One of the owner/occupiers stressed how “Being paid out made buying a home and modifying it possible to do. I don’t know where I would be without the payout”.

Modifications to houses were a major issue with the renters for two reasons;

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

Owner/occupiers also voiced their concern at the expense of modifications. One person had door handles lowered, light switches lowered and remote controlled doors installed and this cost them close to \$50,000. These costs were substantial and with some owner/occupiers still paying off mortgages in the vicinity of \$660 per month, many modifications were not done and this adversely affected these people. Most prominent among the desired modifications was the provision of access for wheelchairs and this usually involved ramps and doorway widening. Other modifications common within the group were door handles repositioned, easier

access to light switches, bathroom modifications, grab handles installed and removal of carpet.

Two storey homes pose unique challenges especially when the sleeping (bedrooms) accommodation is entirely upstairs. One participant had to use a room, modified, downstairs for a bedroom as they were unable to climb stairs. This also affected the family as the children were separated from the parent and this separation caused anxiety for both the parent and children. The participant stressed that two storey homes were not conducive to people with a disability and that they would move if they could, but the location was seen to be good and to buy something similar would be financially impossible. The participant inquired about a lift for the home but the cost, in excess of \$45,000, was prohibitive for them, especially in the absence of financial assistance.

One focus group participant had acquired their disability in the last five years and this had resulted in losing their job. They had been in their own home which had a mortgage but the job loss meant they had to sell the property and move into a rental place. This was a substantial blow as now they lived in an area determined by the availability of rental properties. It was not where they would like to live and the uncertainty of the rental market affected them in a negative way. The participant had to accept rental accommodation in areas where there was easy access to services. The rentals that met this criteria did not offer accommodation to suit their needs.

An innovative participant had overcome the lack of access for wheelchairs by installing temporary/portable ramps that could be moved when the lease expired. Whilst it was not a low cost solution, it made movement through the rental property market less demanding and meant that accessing properties in the future would be less challenging.

3.3 Previous moves, plans to move again

Marriage, ageing parents, purchase of own home and family issues were the main reasons for the participants moving out of their parent's home. Most of the participants left their parent's home before the age of 30 with two participants moving out at age 18 and one participant at age 50. The majority indicated that it was their choice to move out. Many had moved several times since leaving their parents home, with two participants moving 15 times or more. Half of the group had moved two to three times whilst the remainder had moved between six to eight times.

The majority of the participants had moved from the Morwell area with Melbourne as the main destination. Several participants had moved around neighbouring areas such as Warragul and Bairnsdale. One participant had moved to Tasmania and back to Morwell. When asked about if they would like to move again, four participants said that if given the opportunity they would. The areas/regions they identified as most desired included Queensland, Perth, Sale, Warragul, anywhere and a mobile home. Queensland and Perth were desirable for their climate, Sale and Warragul were desirable as the participant thought the air in these areas was cleaner and the participant who expressed a desire to live in a mobile home stated "I could see Australia, go where I want and design the mobile home to suit my disability needs".

The majority of participants, however, had positive comments about where they currently live. The location was the prime source of satisfaction with comments such as "quiet area", "homely, close to golf club", "good view", "close to shops" and "live next to lake with ducks". One participant expressed some dislike for their location stating the "house is close to facilities, but location is not good".

3.4 Housing markets

There were three participants who were in the rental market and of these, two were private tenants and one participant rented one of the Department of Human Services' Community Residential Units. There was also a participant who was a boarder with a family. When asked about the advantages and disadvantages of renting, one participant stated that "don't pay for maintenance" as the biggest advantage of renting while two participants said the biggest disadvantage was that "maintenance does not get done". The absence of maintenance of rental accommodation was experienced by the two participants who were in the private rental market.

The renters all agreed that reliance on the rental market limited their choices with respect to where they can live. They were also concerned that rental prices were increasing with rents between \$100 per week to \$150 per week. Rent also increased closer to the town's centre and services, placing extra strain financially. One participant said "it is a trade-off to live near services or pay lower rent. There was no real win-win situation".

The home owners in the focus group all agreed that having their own home had given them more certainty and allowed them to make modifications with the knowledge that they would be able to remain in the home. Some participants said that owning their home was made possible by receiving payouts as a result of the way they had acquired their disability. An older focus group participant who had lost their legs at age 70 claimed "it was very difficult to lose legs at 70. I had to modify my house myself and this was extremely hard financially as I was only receiving the pension". Some participants who had received payouts also explained how they lived on very tight budgets as the constant need for modifications to their homes put a major strain on their financial resources.

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

3.5 Care and services

Participants in the focus group received a varied quantity of paid and unpaid care. The overarching issue was the volume of family-provided care with the belief amongst focus group participants that governments expected this care to be provided. Focus group participants felt that family members providing care were taken for granted by governments. Most, if not all of this care was unpaid and this severely affected the family: emotionally and financially. There was, however, some paid care received by focus group participants funded by government agencies (DHS and TAC) and the local shire. Some participants said a small amount of extra help can make a significant difference as tasks such as hanging out the washing and keeping gardens clean are not easy for them and as they age these chores become increasingly more difficult. They also made the point that as their family members age the care they provide becomes more of a burden on them as they were not able to lift, push and generally "keep up the pace" as they previously could.

Most participants agreed that the level of care received was less than that available in Melbourne but that housing in Melbourne was far too expensive and they therefore

had to remain in the country. This in turn meant that access to a higher level of care was a trade off to living in a home that they owned outright. The group expressed the view that this effectively restricted their choices of places/regions in which to live and the lower level of services available to them outside Melbourne did not outweigh the security of owning their own home.

One participant was unsure of what help was available and said information they had received implied they would not be eligible for any. The group in general disagreed and there was discussion around this issue as to who to contact and what assistance may be available. There seemed to be a lack of clarity as to where to find information as well as what entitlements the participants were eligible to receive. In many cases the time taken to find information about entitlements to receive support was considerable. A one stop shop for information was suggested as a way of helping the disabled meet their various needs, including housing.

3.6 Disability sector and housing

The overarching theme when questioned about the impact of disability on long-term housing goals and life aspirations was the financial impact. This was summed up by a participant who said:

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

Some participants also commented that when they acquired their disability there was not enough immediate support. The impact on the lives of individuals was substantial when they first acquired their disability and whilst many have “refocused aspirations for life”, additional immediate support following the acquisition of a disability would have been beneficial.

Several of the participants also expressed a desire to find some form of work as “being on a pension limits options financially and therefore restricts housing options. Being disabled means you cannot get a job and this means you cannot improve your housing options”. The lack of employment limits their capacity to buy housing at a time when house prices have been rising sharply. The participants agreed that entering home ownership was an immense challenge and one that the non-owner occupiers in the group thought they would never attain. In general the group was resigned to the fact that they would not be able to move to improve the location of their accommodation in terms of amenity and access to services, simply because of soaring house prices.

The older members of the focus group expressed concern at where they will live if they lose their partners/primary caregivers. This was a concern in general as many in the group were very reliant on spouses/partners for care. One older person in the focus group summed up their resignation at not knowing what will happen in the event of losing their spouse/partner by saying “I will get a spot outside the cemetery and wait”. It seemed as though the group in general saw a degree of uncertainty in the event that they lost their spouse/primary caregiver.

When asked about the design of houses that would best suit their needs the key point made by the participants was that disability housing requires customised solutions. Open plan living, easy access in, out and within the house, flexibility to add modifications cost effectively and a location convenient to transport and services, were the four most important elements identified by the group. The older participants emphasised to the younger participants “as you get older you have to continually

change the environment you live in". The younger members agreed that flexible design should be a key driver in designing suitable housing solutions for disabled people. The group also expressed a desire to see minimum standards in building design.

A hostel was considered a good option by the older participants in the group but the cost of moving into this style of accommodation was a significant concern. One participant was worried that living in a hostel would mean they would not be able to take their pets and this would be unacceptable.

4 MORWELL GIPPSLAND RURAL VICTORIA – PEOPLE WITH A COGNITIVE/PSYCHIATRIC DISABILITY

4.1 General characteristics

The focus group with persons with cognitive/psychiatric disabilities was comprised of roughly equal numbers of participants from both disability groups. With these groups participants had a range of particular disabilities. Ten people participated in the focus group and it included six males and four females. They all lived in or near Morwell and were all in receipt of the Disability Support Pension (DSP). No participants were currently in paid employment. Ages ranged from 16 to participants in their sixties, though the majority of the participants were middle aged. All participants were of Anglo-Celtic origin except one Indigenous Australian who was a member of the Stolen Generation. The group was low-income as the DSP was the only known source of income and group members had few assets. One participant owned his own house as he had worked full-time for decades before his accident.

The majority of participants had acquired their disability later in life, with some acquiring brain injuries through motor vehicle accidents, work accidents or through accidents in public places. One respondent had acquired a brain injury through illness. Many of the persons with a psychiatric disability reported the onset of their disability at adulthood, though in at least one instance, the disability may have been present earlier but not labelled as such. Since acquiring their disability, participants with a psychiatric disability had moved through housing frequently. Persons with an acquired brain injury or a cognitive disability exhibited stable housing careers, especially if their housing needs were met as a consequence of a compensation package. Persons with a psychiatric disability reported moving for a number of reasons, including moving away from problems/conflicts in that neighbourhood, the need to find cheaper housing, and in order to find better quality housing. In the case of participants with intellectual disabilities, this involved movement to a Community Residential Unit (CRU) or other supported accommodation.

Many of the participants with a psychiatric disability complained about their neighbours but stressed that some were good while one or two could make life “like hell”. Others said that where they lived was like “the Bronx”– a public housing estate with a mix of generally low income residents and people with disabilities. Many people of course fitted into both categories. As one participant said, “The flats are so close and other people have nervous breakdowns”. Most of the participants who had a psychiatric disability were currently living in Office of Housing accommodation or were living in private rental housing which was located close to public housing and problem neighbours. Most of these people live or have lived in public housing for long periods of time.

4.2 Current housing

The focus group involved discussion with a diverse group and disability affected every aspect of their life. Disability negatively affected income, employment prospects, overall financial situation, their relationships with other people, their interactions with the judicial system and the public sector for example. Many participants articulated through their descriptions of their housing pathways the view that they lack the housing choices that people without disabilities have. So limited are their housing opportunities, housing moves only occur when other actors – such as the government, family, or friends – make it possible, through financial assistance or direct provision.

One issue that was important for some participants was problems with landlords or real estate agents in the case of private tenants and the Office of Housing in the case of people renting public housing. As one participant said, "it doesn't matter what disability you have, the landlords and the real estate agents treat you terribly". This was a common view for other participants, particularly those with a psychiatric disability. This problem was less evident amongst those with an intellectual disability because many lived in supported/shared accommodation and did not deal directly with real estate agents or landlords. It is also reflected the reality that some persons with a psychiatric disability struggle to maintain good relationships with others.

Some contact with organisations and authorities is characterised by hostility. This hostility involves dealings with the police, Office of Housing, and real estate agents. In several cases negative attitudes towards the police were deeply entrenched. As one man said, "I have always hated police since I was a kid. I was caged into a police van when I was young. They were very tough on me". These problems with others affect their housing situation and housing prospects.

Participants had left housing due to real or perceived discrimination on the part of real estate agents and landlords. In practical terms, they felt this led to poor maintenance of the properties they occupied. One participant said, "I told the agent that I've got a blocked drain and she just said, Oh the landlord doesn't want to fix it!".

Problems with other people were not limited to housing authorities. Poor relations with other people were a major issue and influenced the decision of some participants to move from their dwelling. Their neighbourhoods were described as excessively challenging and included a mix of residents with problematic backgrounds and characteristics. Some participants gave the impression of a ghetto-like atmosphere where crime and anti-social activities took place continually. That "They have mixed in people with every problem and disability in there. There is lots of drug and sexual abuse". The participants who lived in this type of environment generally want to leave but lacked the capacity and the opportunities to move on. Key barriers to mobility included the lack of funds and the concentration of Office of Housing accommodation in a limited number of estates. Participants felt that there was little choice but low quality private rental housing or Office of Housing accommodation located in problem areas.

The rural nature of Morwell and other small towns in Gippsland was seen to reduce job opportunities for working people or unemployed people who are looking for work. But as all of the participants were not working, and only a handful had the capacity to look for work in the future, the impact of distance from employment was muted. However, participants pointed out that it was social isolation they feared. "Since I got sick I've lived with other people. I haven't lived by my own before. This could change. So I'm afraid I might become homeless."

Participants valued the role of disability sector organisations particularly those providing services including rehabilitation (typically involving activities with other people with disabilities) and people doing advocacy work, "I know a lady who works her ass off supporting us, helping us as people with difficulties. She travels around all over Gippsland, the government should be helping her".

Several participants had praise for the work of the Gippsland Accommodation and Rehabilitation Support Service (GARSS). As one participant said, "I go to GARSS in Morwell. They are really good. There is a great lady who runs it, really nice. She is so helpful."

Some participants were very engaged with the housing issues facing them and had vocal views about who was to blame and what changes should be made.

4.3 Previous moves, plans to move again

One participant moved all the way to Esperance in Western Australia because someone told her that the housing outlook was better for people trying to find desirable government provided rental housing. Many people had only been in their current house for a year, with others settled for much longer periods and a small number owning their own home, "I'm a bit different to the others I've been in my house for 15 years". But this was the minority, for many moving house was a recent and recurrent phenomenon and was looked forward to as a means of providing a better quality of life. As one participant said, "I would just like a house with just a bit of peace and quiet with some bloody room! A friend who came out of jail said it's smaller than a jail cell."

Simply put, the ability to choose to move is extremely limited for many participants, let alone move to appropriate and suitable housing. In most cases this is because the disability requires a reliance on carers (paid and unpaid) that come to their home. The person is essentially dependent on these people for support and this support is often available or in group homes for four or five people with disabilities. One participant who with intellectual disabilities, and serious mobility impairment became very frustrated about his housing:

"I moved out of home last year and then having a hard time dealing with it. I'm trying to leave. We want more housing, more safety. If my staffer isn't going to look after me, I have to walk out. We need to have a protest!"

This situation confronted some people with intellectual disabilities within the focus group. Participants with psychiatric disabilities had a greater apparent capacity to live independently, though as the discussion above has shown, not all of these housing outcomes could be considered successful.

4.4 Housing markets

All but two participants rented from either the public or the private sector using income from the Disability Support Pension and/or Commonwealth Rent Assistance (CRA). As the disability support pension is about a quarter of average full-time male earnings the rental options available to this group were extremely limited. The cost of renting privately in Morwell was considered to be very affordable for someone working regular hours but participants reported that they had little money left over for other needs such as travel. Participants wanted "Cheaper rent and bonds. The problem with rental houses is the price." Another participant added, "I pay \$160 a week for a 3 bedroom house. They don't tell me my rights!".

Home ownership if not attained already is unlikely to be reached unless through inheritance as few had substantial assets or income. The participants in the focus group were typical of the majority of persons with a disability in that they do not work and this constitutes a profound limitation on their income and their prospects for home purchase. As one participant said:

I wouldn't be like this if my mind and body wasn't stuffed. Otherwise I would be out to work. If not for my disability, I would love to work and get the same wage as men because we still don't.

4.5 Open discussion

Some participants in the focus group did not have strong networks with family or friends. In the case of older participants this was because their parents were sick, have passed away, or because the disabled persons and their families have reduced contact or some had completely lost contact with their families. Service providers were important to them, especially those that are seen to be advocating for their rights with regards to housing. In the case of participants with intellectual disabilities, housing and services were interlinked. Suitable housing was only possible with support by paid staff or with a family member, who may now be too old to provide full-time care. For participants with a psychiatric disability, services in-house are not as central to them, instead organisations which provide support at their facilities – such as courses and activities – are well regarded. The risk of social isolation affects both intellectually disabled participants and those with a psychiatric disability, which in time can lead to more acute housing problems such as homelessness.

Participants want more choices as to where they can live and what type of accommodation they can occupy. They also want to pay less in rent and believed that what they pay now is excessive. For those with an intellectual disability, safety is crucial as is the quality of staff who affect so much of their lives and determine whether their current housing will be adequate for them.

Some participants demanded forcefully that the government should give them their own houses, “Why doesn’t the government help us buy our own homes. Then we wouldn’t have these problems”. This raises a serious question over what housing needs are and how they are distinct from the needs of the general population. The ‘housing needs’ of someone with a psychiatric disability may not too different from those of someone without a disability who is unemployed or on a low income.

There was a distinction in the focus group between those with psychiatric disabilities and other participants. Of the latter group, those who have mobility impairment require specific alterations to their housing that would make it possible for them to function effectively in a dwelling. The absence of ramps or graded slopes for access into doorways means that the vast majority of housing in Australia is unsuitable, especially if funding for renovations is not provided or the owner of the property doesn’t want renovations taking place.

About half of those with an intellectual disability did not have obvious mobility impairment, such as the use of a wheelchair or walker. But, their needs also involve access to services such as house maintenance, meal preparation, house cleaning, and assistance with exercising to name a few. These are needs which have to be provided for in a house if they are to live there. For participants with psychiatric disabilities, the link between housing and service provision is less intertwined. Providing better housing options to them it seems is primarily a case of money, hence the demand for assistance into home ownership. The housing options available to participants are limited by their low incomes, hence the dependence on Office of Housing properties and low cost rental properties. Those with intellectual disabilities and those also with mobility impairment face a further reduced set of housing options. This is because of the small number of dwellings which are structurally suitable for wheelchair access and the small stock of housing that can receive staff visits to support the resident.

5 MORWELL GIPPSLAND RURAL VICTORIA – CARERS OF PEOPLE WITH A DISABILITY

5.1 General characteristics

Eleven people attended this focus group and the group was comprised of almost equal numbers of males and females. This group included the extended family (adult daughter and husband) of one of the primary carers as they assist with the caring responsibilities. The people attending the group were caring for relatives (husbands, wives, adult children, brothers, parent) with a range of disabilities including Down Syndrome, Meningitis, Acquired Brain Injury, Cerebral Palsy, Multiple Sclerosis, Diabetes, amputation of limbs, asbestos related conditions and paralysis arising from strokes. Many of the carers in the group were people aged over 55 and therefore currently retired.

For many, caring responsibilities involved a full-time commitment. For the home owners in the group the onset of disability for a partner later in life means a reassessment of a once suitable home and what changes are, and will be, needed to further accommodate the person's disability or whether moving would be a more appropriate option. For the participants who were currently renting, their housing choices (type of housing and location) were dictated by the needs of the person with the disability rather than the needs and wants of other household members. For two carers in the group, the future housing and care of an adult child with a disability was of concern.

5.2 Current housing

Many participants in the group had been settled in their homes for a reasonably long time, 23 years, 25 years, 33 years, 35 years, although some had been resident for less than ten years and two participants had only been in their current home for a few months. Around half the participants were owner occupiers, while the rest were renting from the Department of Human Services. One lady sold her house and helped her daughter (with an acquired brain injury) with the assistance of the First Home Owners Grant to buy a previous Office of Housing home that they now share. While the participants who were home owners were relatively happy with their homes – even though they may be unsuitable for a person with a disability and increase the burden or difficulty of caring for a person with a disability – public housing was seen to be too small, with narrow unsuitable doorways and passageways. While rails may be necessary, they also reduce the space available to manoeuvre a wheelchair. Living in public rental housing, however, meant that if there is a minor problem with the house then someone is available to fix it and this was seen as very helpful as “we don't have the money to fix thing”. Major structural modifications to the publicly-owned home, however, were much more difficult to obtain or simply not available.

5.3 Previous moves and plans to move again

Most of the focus group participants left their parents' homes many years ago upon marriage, entering the workforce, or for other reasons, such as travel. Since that time most have moved three or four times although one lady had moved approximately 12 times to try to find the perfect place for her handicapped son. About 12-14 years ago as a divorcee with four sons she moved to Queensland in search of appropriate accommodation that she felt was not available in Victoria. The situation in Queensland was no better than that in Victoria and so she returned. However, she found it difficult to find private landlords that would accept her disabled son and the

changes that may be needed to accommodate him. He is now in other accommodation and she is renting from the Department of Human Services.

While many participants were happy with their housing, a number felt they may need to move as their homes become less functional and suitable because of the condition of the person they are caring for. One lady spoke of how she and her husband had moved from a home with 11 steps to make life easier for her husband suffering from asbestos related conditions, but the four steps at the current home are becoming too much and they may need to move again. Although they could build a ramp, the current regulations of 1 in 9 slope ratio (the previous regulation was 1 in 14 and this was seen to be much more appropriate) means the ramp would be very long and difficult for the ageing wife to push a wheelchair the distance required. Another man commented that 20 years ago he built his home with what was considered then to be a good feature, a sunken lounge, but as his wife now has Multiple Sclerosis this feature is a hindrance and totally unsuitable. Another woman who lives with her daughter who has an acquired brain injury feels that in ten years when she is around 70 she will move. This gives her ten years to find someone who can take over her role and live with her daughter in a caring capacity. This time frame also gives her daughter time to get used to her mother not being there for her on an ongoing basis. While this woman is obviously trying to plan for her daughter's future as she ages, she had no idea how to go about finding this ideal person to care for her daughter (who owns her own home) and was concerned about how to safeguard against any type of abuse into the future.

Another parent of a Down Syndrome adult child had made no plans for the daughter's future. Although the daughter is fairly self sufficient she still needs daily care and cannot live on her own. Her mother believes cluster housing would be ideal but they had no future plans as such housing was not available and they don't know what to do. Currently they are procrastinating in the hope that something will 'turn up'.

For a number of participants moving, or the idea of moving, was very stressful. For those people who were home owners there was concern that the cost of a two bedroom unit was the same as the value of their home, which would mean that they would probably lose money. In addition, there were other considerations such as the need and cost of modifications, the need to live in the urban centre as three to five kilometres outside the city centre there was no transport. This group was also reluctant to move away from their current neighbourhood where they know their neighbours and this offers them a measure of support. This assistance may be absent if they were to move. The result of all this is that you "stay where you are rather than movin".

5.4 Housing markets

All the participants in the group who were renting from Department of Human Services – public housing were thankful for this housing but felt that it wasn't necessarily suitable. Funding for remodelling is available but "you can wait a long time" and "everything is a compromise" as you can't afford to do what is necessary and the needs of the person with the disability come first. For example one participant explained how she liked a bath but had to move from a house with a bath to a home with a bathroom more accommodating of her partner's disability. In addition, they had to relocate from Morwell to Traralgon to get a DHS home and to be closer to services and this meant moving away from family and familiar schools.

The possibility of home ownership for people with a disability and carers of people with a disability seemed limited unless the disability arose later in life after entrance into the housing ownership market had already occurred. The barriers to home

ownership were seen to be the price of housing, the need for modifications and a lack of income or diminished income.

Retrofitting of houses was seen as a difficult and expensive exercise and features (such as no steps, door frames to 920mm) that allow all housing to be suitable to people with a disability should be incorporated in the building regulations.

In Morwell there are two demonstration 'disability friendly' houses that have sold for around \$130,000 to \$135,000. This housing was constructed as part of the Work for the Dole Program, a program supported by the three tiers of government, to train unemployed people. Each house can take up to two years to construct as teaching people is a slow process and each new house has to be sold to provide funds for the next project home.

Overall, it was felt that finding housing that is suitable for a person with a disability that you are caring for is difficult. You cannot always live where you wish to, in the size and style of housing that you would like. It is necessary to live in town to be close to services and transport. It was felt some carers and people with a disability move to areas where housing is cheaper but these areas are often more insecure and the neighbourhood not as pleasant as other, more expensive, areas.

5.5 Care and services

For many in the group caring was a full-time occupation, on call 24 hours a day, and in terms of the influence it has on other aspects of their life (employment, social activities etc) the general consensus was that there was no time for anything else – "there is no other life".

The mother of the daughter with an acquired brain injury felt she (and her daughter) were very fortunate to receive around 30 hours a week of care (five hours help a day six days a week). This care included housework, shopping and taking her daughter out into the community. This assistance releases the carer to go away at times and to do voluntary work for disability organisations such as Headway Victoria (advocacy and information service for people with acquired brain injuries). This care is provided by the Home First Program of the Department of Human Services, Victoria.

The general consensus of the group was that help and assistance (support packages) is difficult to obtain and it is easier to get if you have a physical disability, "if you can't see a disability then you haven't got one." If the disability is other than physical, people assume the person with the disability can do things they are not capable of and they try to get the person into the workforce. Even though there is a policy of individualised service, some felt the structured selection criteria for assistance still excluded people or made it very difficult. Some participants seemed unaware of the programs that could benefit them.

5.6 Disability sector and housing

The participants believed that governments have not adequately addressed the concerns of carers as they felt they were further down the list – "they don't look after people with disabilities so it is difficult for carers". Many carers felt they needed to justify that they were worthy of receiving payment and assistance. In fact, it was suggested that people making decisions need to come and spend at least a day, if not a week with people to fully understand what commitment is needed to care for a person with a disability. Some participants found government departments lack understanding, while others had had good experiences.

Finding appropriate housing for people with a disability and carers of people with disabilities appeared to some to have changed little over the last decade. The fact

that the government was not building houses anymore was seen as a major issue as housing needs to be matched with individualised needs and this is so much harder in the private rental market. In addition, people need a range of services and support to be able to live in the community, not only in terms of transport and services specific to the disability, but also in terms of managing finances and home maintenance.

This group believed that in order to improve the housing options available to them there is a need for greater funding, reduction of financial waste by bureaucracy, greater understanding of individual needs and better housing design and regulations.

6 SALE EAST GIPPSLAND AND WELLINGTON RURAL VICTORIA – PEOPLE WITH A DISABILITY

6.1 General characteristics

Seven people participated in this focus group comprising three females and four males with ages ranging from their early 20s to late 50s. One lived in rural East Gippsland, one in Bairnsdale, one in Rosedale – a small town in Wellington Shire and others in Sale. The people in the focus group had disabilities such as Muscular Dystrophy, quadriplegia, brain tumour, stroke and acquired brain injury. Some participants were born with a disability and some participants had acquired them as recently as five years ago. The participants received some level of government support via the disability support pension and some were also in employment on a part-time or casual basis.

The focus group participants' work commitments ranged from 12 to 20 hours per week and the work that they were engaged in included; group training, reception work, home support worker, consultancy and after school care. The group said there was little incentive to participate in work for more hours as their disability pensions were reduced if they exceeded 30 hours per fortnight. This they thought restricted their ability to access loans for homes as their incomes were restricted and banks would not consider them for loans. They all agreed there should be a better way to allow them to earn more without the threat of losing their pension.

The restriction on hours was a major concern for people aged 18 to 21 as the pension was only \$250 per fortnight and this made it very difficult to find housing as the rent would consume most, if not all, of the pension. According to the focus group participants there were no housing options available in East Gippsland or Sale to people in this price range.

The level of involvement of all participants in the focus group was enthusiastic and all agreed that housing issues were a major concern regarding their standard of living now and into the future. The level of support offered to them via government was considered unsatisfactory and they all felt that acquiring a disability through work or road accident was financially better than being born with one, as financial support for people who had acquired a disability in a way that was subject to compensation was greater than that available to persons born with a disability. Overall the general attitude of the group was “this is our lot and we get on with our lives as best we can”.

6.2 Current housing

Of the seven participants in the focus group only one was in the private rental market and this person was happy with the landlord and has been allowed to undertake modifications with the landlord's approval. The owner occupiers in the group had lived in their home for up to 30 years and the types of housing they currently occupied included three bedroom homes, and units. One other participant lived in a granny flat located in the rear of her parent's property. This granny flat was provided by the government and she pays a small amount of rent. She chose this option to enable her parents to continue providing some care.

One participant lived in rural East Gippsland and was 20 kilometres from a major township. They stated that this was isolating given that she was unable to drive herself and depended on her carer. She commented that going out to the supermarket was sometimes the only social activity she had for the week.

Generally the participants were happy with their current housing both structurally and also with respect to its location. Some small issues of access caused problems, such as the absence of footpaths, the presence of hills and unmade roads but in general the group participants liked their current housing as neighbours were both good to them and helpful and living in Sale provided access to jobs.

All the participants had undertaken modifications to provide a better environment suited to their needs. One participant had built a custom home (demolished their old home) to suit their disability. Most of the modifications were paid for by the individuals and they stressed that this was quite an expensive task. The most common modification was the provision of handrails and ramps to allow wheelchair access. Some doorways also required modification and outside areas were modified to enable wheelchairs to be used safely. A concern for the older participants was that the house would need to keep undergoing modifications as their disability became more pronounced with ageing and their carers, husbands and wives were unable to provide the level of care they could previously. The extra cost of these modifications will impose a financial burden that participants felt they would be unable to meet. Their disabilities had already placed a financial burden on them with one participant claiming "we are surviving on my partner's inheritance. I don't know what will happen when that runs out".

6.3 Previous moves, plans to move again

Most participants had moved out of their parent's home due to marriage, migration, to attend university and to chase work. Some participants had moved 20 times or more since moving out of their parent's home and most thought it had been a good move to leave the family home. The participants that had moved out of their parent's home had done this over 30 years ago. Two participants had tried living away from their parents in the last 18 months yet found this too difficult and both moved back home. Nevertheless the experience has allowed one of these participants to ascertain if it is possible to live away from the family home. He believes it is possible, but emphasised that the style of housing accommodation and services to suit his requirements and this environment would be best found in Melbourne.

When asked what they like or disliked about their current housing and where they lived they all generally liked the structural form of their housing but disliked the location relative to suitable transportation. Access to services, principally transportation, was a major concern and the low level of train services to Melbourne made getting to medical specialists a very substantial logistical exercise. A participant summed this up by saying:

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

All the participants were unanimous in agreeing that the scheduling of rail services to larger centres from Sale and Bairnsdale was poor and that this should be improved as there were no bus services.

The poor transport service in Sale was the main reason that the participants would like to move. The participants all agreed that Sale offered a satisfactory environment for them to live in terms of services such as hospital, social structure, and flat topography for moving around and reasonable prospects for work but Sale did not offer a lot for the younger participants in the group. One participant said he would like to move to Melbourne as "younger have better options and access to broader range of

activities. Spare parts (for wheelchair) are also more accessible and I don't have to wait 2-3 weeks as I do now". In addition he stated "Activities that appeal to the old are not necessarily appealing to the young" and he also claimed, somewhat despondently that "dating is a pain in Sale". Another participant also stated they would like to move to Melbourne as they would be "closer to children and medical services and this would take pressure off the partner as they did not drive and catching the train to Melbourne was a very tiresome exercise".

Other factors that adversely affected their satisfaction with their current housing included the condition of roads and footpaths, steepness of location of house for access and that Sale did not have the spectrum of services that existed in Bairnsdale. Of the group, only two or three participants expressed any real desire to move away from Sale and the most favoured destination was Melbourne or Bairnsdale.

6.4 Housing markets

One participant was in the private rental market and expressed satisfaction with the accommodation and was also pleased with the landlord for allowing modifications. The renter would like to move into her own home but financially is unable to do so at this stage. Renting, however, did minimise the costs of maintenance and this was considered an advantage. A major concern was that as the housing market continued to strengthen, the chances of entering the market were diminished. The owner occupiers of the group all were thankful that they had their own places as they believed "it would be impossible to enter the housing market due to rising prices" and "securing a loan on part-time or casual work was difficult".

The group also thought that the housing stock owned by the government was generally in areas that were undesirable. This was in relation to access to services and the type of neighbourhoods in which government owned properties are located. There was a general consensus that people would feel insecure in most of the government owned housing. Another issue related to the private rental market. Some participants thought private landlords discriminate against persons with a mental/psychiatric disability and that this in turn affected the health and disability of these people. They said they had heard of cases where people had supplied false information to private landlords in an attempt to secure more desirable housing.

A recent story that emerged was the plight of a young person with a disability who was wheelchair bound. The person had to leave the family home and was unable to find suitable accommodation so at the time of the focus group was residing with a focus group participant in accommodation unsuitable to their disability. The focus group participant said that the person had contacted agencies to find suitable accommodation but there was none available suitable for a wheelchair. The participant implied that the affected person appeared to be treated less favourably "as the person is single therefore they don't get the same priority as a person, woman, with a child when it comes to government housing".

6.5 Care and services

The level of care received from government agencies varied considerably between the participants. One person received two or so hours per fortnight of paid care with assistance provided in cleaning the house, others had three to four hours per week, seven hours per week, ten hours per week and one had more than ten hours. All the participants strongly emphasised that family and friends contributed large amounts of time to their care and in nearly all cases this was unpaid. Any paid care to family members was minimal and the focus group participants felt this needed addressing in some way. One participant expressed their dissatisfaction at the poor level of funding

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

Access to services was a major source of discontent and a negative aspect to living in Sale and Bairnsdale. The group said access to doctors with relevant expertise was not available and there was no access to occupational therapy due to massive waiting lists for publicly funded services, while to pay for it privately was unaffordable. Dental services also have long waiting lists and accessing the private system was believed to offer a better service but was too expensive.

The participants reported problems in finding information about the range of services available to them. The lack of readily available information meant that sometimes they did not realise what services are available and that they may have been missing out on various services. Quite often the information about services was found by chance through conversations with different people but in many cases the participants said that the people who provided care quite often knew of places or where access to services may be available. They all said that this varied from person to person and also there was quite a disparity between agencies.

As mentioned previously, transport was an area of concern. Bus services were virtually non-existent in Sale and train services to neighbouring centres, principally Bairnsdale, were minimal, with two services per day. The scheduling of these services was agreed by all participants to be poor. Car services that could be accessed by people with a disability were thought to be non-existent. If you could not drive yourself or had a family member who could provide transport, then getting around Sale and Bairnsdale was difficult.

6.6 Disability sector and housing/open discussion

In all, the focus group participants displayed optimism and were generally positive in their outlook, including their thoughts about housing. They did, however, have a wish list of what could be achieved or done to improve their lives and lifestyles and minimise the impact of their disabilities on themselves, their family, friends and carers. They all agreed housing should be subject to a minimum standard that accommodates a broad spectrum of disability needs. This means houses should have access for wheelchairs, doors wide enough for easy access, hallways able to accommodate hand rails and wheelchairs, open plan construction to allow easy manoeuvring and the ability to add modifications when needed.

Government provided housing in Sale and all over East Gippsland appeared to be non-existent. There were a few participants who expressed a desire for a community housing group that would cater for all disabilities. Some of the older participants claimed that the housing stock, in general and government owned, suitable for their disabilities had diminished compared with 10-15 years ago. With reference to what could be made available in terms of increasing housing options, the participants said the government was “good at saying a lot but delivered little”. They all believed it was up to themselves, family and partners to provide suitable housing, as government provision or support was not seen as an option.

They all expressed their appreciation of family and carers in making housing suitable to meet their needs and they were all concerned that if they were to lose family members, partners and carers they would be forced to move. This may leave them in housing that is unsuitable and undesirable in terms of location. They all thought the government was unappreciative of the massive commitment that family gave to help in caring for them and felt that the expectation of government on family members to

care for people with a disability impacted negatively at times on the family members and carers lives.

When asked what could be done in general to help or improve housing the group came up with a wish list which included:

- Sale and Bairnsdale need a community housing group for people with a disability (must cover all areas of disability);
- Nursing homes are not suitable for people with a disability under the age of 65. More options should be made available to younger people with a disability;
- Interest free loans to help with renovating/modifying homes as needs arise;
- Assistance in designing house to suit disability now and in the future;
- Access ramps at road crossings and footpaths to be friendly to wheelchairs;
- Better tree selection when planting next to paths. Poor tree selection sometimes means roots cause damage to paths and this makes wheelchair use dangerous;
- Increased transport options;
- Changes to carers allowance and disability pension.

7 SALE (GIPPSLAND) – CARERS OF PERSONS WITH MOBILITY AND OR COGNITIVE DISABILITY

7.1 General characteristics

The Sale focus group with carers involved discussing housing issues with carers of people with either mobility and/or cognitive disabilities. Four people attended the focus group. The group was evenly split between genders (two female and two male) and included two middle aged women and two older men. They were not related to each other and cared for partners or children who were at home. They were reliant on the carer's allowance (three people) or the carer's pension (one person). The carer pension payment is means tested and is the more generous payment, providing a similar income to the aged pension.

No focus groups participants currently worked due to their status as full-time carers and the burden on time that comes with that role. The financial impact of not working and caring was a major theme among the participants. As one woman said:

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

Nevertheless it should be noted that carers who are worse off financially than those present at the focus groups would not have been able attend the meeting due to travel costs, time constraints etc. One of the four participants was living in government provided housing in one of four units on a block of land. The other three participants owned their homes outright. The concern for them was the burden on resources, which would otherwise contribute to retirement savings, and the pressure to keep working into old age.

The frequency and number of housing moves of participants varied. Participants made moves no different from the general population until their family member acquired a disability or had a child who was born with a disability. After they became carers, further movement through the housing market was focussed on gaining suitable housing for the person with the disability. Indeed, participants were sad about leaving houses on hilltops with good views which were familiar to them and were worried about the need to move in the future in order to enhance accessibility.

Participants in the focus group recognised that living in a rural area inevitably meant that accessibility to services was poor when compared with Melbourne, On the other hand, rural life was recognised as ascetically pleasing and peaceful. The interest in moving to Melbourne to gain greater access to services was reduced somewhat by the concern that as one person put it, “I’ve been told that it is better in the country than in Melbourne where you are just a number”.

7.2 Current housing

Three participants lived in a privately owned house and had paid off their mortgages. One person lived in public housing in a one of four units occupying a block of land. Generally participants were fond of living in a medium sized country town. The large property sizes provide space between neighbours and provide a calming affect. Most respondents expressed an attachment to their homes particularly if they had lived in it for a long time or it was purposely built to suit disability. As one woman said, “It’s home, my kids were born there, grew up there, and finished their school there. It’s everything”. The size of the houses and properties were also valued. Leaving the area

was considered to bring some benefits by participants and often division existed between partners as to where to live. As one male participant said:

“My wife would like to move to the seaside which would require us to leave and build again possibly to a flat. I couldn’t live in a flat. My brother has a great flat in Melbourne but I would feel like I’m in cage. I couldn’t do it.”

Participants had put substantial effort into modifying their existing home (two cases) or moving to another dwelling including houses and units built to suit the person with the disability. All participants were carers of people who were wheelchair bound, so the need for special changes was significant compared to households without a mobility-impaired person living in the dwelling. Changes ranged from handrails put in, to having steps removed and graded paths built linking outside areas to doorways. Most respondents would have spent thousands in disability-related modifications or additional disability-related costs to a newly constructed home. As one former builder, the carer of his wife, said:

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

Most carers rely upon cars to get around Sale as there is little public transport. They use trains to get into Melbourne when that is required. The participants in the focus group lived in a variety of locations ranging from next to the town centre to 30 kilometres out of town, with one person taking up to 20 minutes in the car to get into Sale. The participants stressed the importance of transport:

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

All the participants in the focus group could drive and the person they cared for is reliant on them for their mobility and access to services, socialisation and shopping needs. Losing the ability to drive the person with the disability around and assist with mobility outside the vehicle e.g. pushing the wheelchair was expected to become a challenge as the carer ages. This was an acknowledged concern of carers who recognised the strain that ageing is having on this element of their care provision. As one participant said, “I can’t go to Melbourne for the day anymore because it just takes too much out of me, if I’m pushing the wheelchair all day and waiting for trains.”

Participants in the focus group reported that their care responsibilities limited their involvement with sporting, social and other groups as caring is a “twenty four seven” responsibility. The participants noted that providing care is both mentally and physically tiring and, to a certain extent, socially isolating.

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

7.3 Mobility decisions and future housing

The impact of caring for a person with a disability reduces substantially the options available for further movement through the housing market due to the specific requirements of the disabled person’s needs. Indeed the constraint is considerable and the carer’s available choices are reduced substantially. The participants noted

that one obvious constraint is limited finances to purchase a home that is more expensive than their current dwelling.

The focus group participants noted that available assets are quickly diminished in paying for medical costs, particularly in meeting the cost of specialist physicians. The travel and accommodation costs for overnight stays in Melbourne have eroded the resources that would otherwise be directed at movements through the housing market. In addition, the carers were aware that houses most affordable to them in metropolitan Melbourne are located on the periphery of the metropolitan area. The most recent developments typically involve townhouses, or three bedroom houses on small blocks of land which are likely to be distant from necessary services. The carers were also concerned that contact with relatives might not be as frequent as hoped, if the person with the disability and the carer are forced by price to live in a part of Melbourne that is distant from their children.

Other factors were seen to increase the attractiveness for carers in Sale of 'staying put' rather than trying to move. Sale and its region were considered to have better services and closer contact with relatives than may be possible in Melbourne. This was seen to include strong familiarity with the available services provided, personal contact and relationships with the relevant groups (e.g. with social workers, disability access workers at Councils), and the investment already made in home modification and renovation to accommodate the person's disability. As one participant commented,

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

All participants bemoaned the lack of housing which is appropriate to the needs of a person with a disability within the region. In some instances, the absence of appropriate housing was seen to limit the housing options and careers of the carers. The housing opportunities available to carers are directly related to the housing options and choices of the person with the disability, especially when the carer is the parent of the person with a disability. Many carers recognised that they would benefit if the person they cared for had more housing options available to them, including a capacity to live with a greater degree of independence. The ability of a younger person with a disability to move out of the family home would open up housing opportunities for their parents. As one carer articulated:

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

People of a similar age who are not carers of someone with a disability have greater choices. Preparing for life after being a carer (if that happens at all) is put on hold due to the drain on finances and time. As one female carer put it: "We have to replace the car, the daughter wants to leave home, these costs are huge. My husband is four years from 60 and wants to stop working someday!".

7.4 Housing markets

Housing affordability was seen to be an issue of considerable importance for those focus group members weighing up whether to move to Melbourne or another location such as the Gippsland coast. The group overall recognised that affordability was a

challenge, but acknowledged that it was but one limiting the housing choices of this group.

One participant, noted that 20 years ago housing prices were comparable between suburbs of Melbourne and in Sale and other towns in Gippsland. Now the option of moving to Melbourne and living in a comparable property is unlikely due to the disparity in house prices. She said that people are trapped in a sense and that she “made the mistake of selling a house in the early 1990s in eastern Melbourne because the housing price actually dropped, but in the following couple years it probably doubled in price. But that’s life isn’t it?”.

7.5 Disability sector and housing/open discussion

Carers in the focus group brought attention to a number of other issues. First, they felt some degree of frustration that as someone ‘not in the system’ (ie as carers rather than the person with a disability) they received very little support simply because they earned too much or had too many assets. When they were looking for support, it was difficult to find out where to obtain help. They considered the system of provision involving agencies, councils, or departments was a “mine field to get through”.

They had concern over the future regarding their retirement and if their child had a disability, what their future would involve. One participant expressed considerable concern about retirement because they would retire as a self-funded retiree and had incurred many years of high expenditure on health care and other costs related to disability, as well as reduced income from working less or not working at all. All participants in the focus group had received lower life time earnings because of restrictions on the amount of work they could undertake because of their care responsibilities.

There was also some concern by participants over whether other relatives would support and assist the person with the disability if that person moves away or the parents/carers pass away or became unable to care for them due to old age. As one carer said, “would relatives care for her when she moved out by herself like to Melbourne, if so that is a major effect on their lives”.

Participants described the shock to their lives associated with the onset of disability within their households and empathised with others in their situation, especially those financially less well off. The group overall accepted that many housing moves had been forced upon them due to the need for suitable and affordable housing, rather than making a choice between genuine alternatives that may have better suited their needs as an individual. This reflects both reduced earnings as well as the disruption on a family’s life an acquired disability causes, that is, both the carer(s) and the person with a disability need to reorient their lives in order to deal with the consequence of disability.

8 MELBOURNE – PEOPLE WITH A DISABILITY AND CARERS OF PERSONS WITH A DISABILITY

8.1 General characteristics

The Melbourne focus group was conducted in inner Melbourne and was comprised of four persons with a mobility impairment and three carers. The carers present at the focus group provided support for their partners. The small size of the group meant that a single focus group was undertaken, rather than separating out those with a disability from the carers. Most of the persons recruited to the focus group had been affected by polio, with many using callipers and walking frames earlier in their life but dependent upon wheelchairs later in life. Many reported a significant loss of mobility as they aged, due to a loss of strength and flexibility. While most of the persons affected by polio were relatively mature, there was one younger victim who had immigrated to Australia from Sri Lanka.

8.2 Current housing

There were two couples present at the focus group and both lived in public housing. The older household was comprised of a couple in their mid 70s and they had lived most of their lives in public rental accommodation – when public rental was “housing for working men and their families”. The husband cared for his wife and had previously worked as a toolmaker in an engineering firm before being made redundant in the early 1990s. His wife had worked for most of her adult life in a sock manufacturing plant, before her disability limited her mobility to too great a degree and she was forced to give up work. The younger couple lived in purpose-built public housing at Broadmeadows, and both received disability support pensions, although the wife alone was in a wheelchair. One participant in the research lived alone and was currently in temporary accommodation while she thought through her housing options into the future. A male participant owned his own townhouse and lived nearby.

8.3 Previous moves, plans to move again

Most of the participants in the focus group had relatively stable housing careers. The older couple who lived in public rental housing had been in their home since the 1950s and had no plans to move. The younger couple living in public rental housing were satisfied with their accommodation and had no intentions to move. The woman in this relationship had had very stable housing all through her life – including living in the family home in Sri Lanka, living with a sister following immigration to Australia and then movement into the marital home. Her partner had had a more varied housing career including periods in the private rental market, and two stints in public rental housing. His more varied housing career is typical of persons with a psychiatric disability. One of the participants living alone had purchased his townhouse when he was employed by Telstra. His job made it possible to get a home loan but later redundancy after 24 years with the company both provided capital which he invested in his property and also made it difficult to meet mortgage repayments. Financial assistance from family helped sustain home purchase and independence. The other person living alone had previously spent periods living in the private rental market, as well as in her parent’s home. This person had also considered home purchase in the 1980s when she was working full-time or close to full-time. She approached a bank for a loan but her request was declined because of her disability and the related concern that she would be able to maintain an income and service the loan. She noted that

“...now they will lend you anything, but you would need to have an enormous income to service the mortgage.”

For this person, living in the parental home presented some significant challenges because of her busy lifestyle – including a considerable quantity of volunteer work and activity in running associations. She was currently living in housing that is made available on a temporary basis to persons in a wheelchair by one of the community groups she works with, but is considering her future. This involves weighing up the pros and cons of moving back in with her mother, as her father died and her mother may need some assistance in staying within the family home. These examples reinforce the point that persons with a disability are often providers of care, as well as the recipients of care, within current policy frameworks. The focus group participant who was born in Sri Lanka was also active in volunteer work, while two others ran a disability community group.

8.4 Housing markets

The housing market in Melbourne had largely failed – or was not relevant to – the participants in this focus group. Only one member of the group was an owner occupier and no-one rented privately. At least one participant and one carer had rented privately in the past, but the private rental market was seen to be difficult because of the inaccessibility of the housing stock, high rents and the inability to find and sustain work. Respondents reported that while work is available for them, it is often short term in duration, part-time and not especially rewarding financially. There are often significant challenges in the journey to work as the place of employment needs to be accessible by public transport – preferably by train. In addition, the workspace needs to be wheelchair accessible and – hopefully – on the ground floor. One participant told how he was stranded for two hours on the sixth floor of a building during a fire alarm because by the time the fire-fighters reached him they needed to rest, and they then faced the prospect of carrying an adult male and a motorised scooter downstairs. Others noted that as they aged, they lost strength and health and it became more difficult to sustain employment. Declining health, therefore, was a significant barrier to paid employment.

There was considerable discussion in the focus group about the unsuitability and inaccessibility of the housing stock. For instance, participants noted that many toilets simply are not accessible to them, and that if they can get in, they cannot get out again. Similarly, many reported ad hoc arrangements for having a shower that lasted for years. Many noted that they avoid meeting in friends homes – preferring to meet in cafés or restaurants – simply because of problems in going to the toilet.

Participants also discussed the need to modify their housing. The Office of Housing was praised for keeping maintenance up to date and for making minor amendments to the housing stock – such as the addition of grab rails and ramps – but concern was expressed at its failure to make more substantial modifications. For example, the couple who had a house built for them at Broadmeadows asked for kitchen benches at wheelchair height. This request was refused on the basis that it may reduce the future capacity to let the dwelling to other tenants.

8.5 Care and services

The participants in this focus group had modest requirements for care and services. For roughly half the group, their partner provided most of their care. There was considerable discussion around the need for adequate transport services. The participant from Sri Lanka made extensive use of bus services, and noted that ‘kneel down’ buses with the capacity to accommodate her ran less frequently than most bus

services, but she was happy with the service nevertheless. She made use of public transport to get to hospital appointments, shop and engage in a range of volunteer activities. Others felt that trains were a better form of public transport for people in a wheelchair and access to railways influenced housing decisions.

One member of the focus group owned a van that he could not drive but that he had so that friends and/or relatives could drive him to appointments. He owned this van because he felt that he could not rely upon taxis. His opinions were mirrored by all members of the group who reported very long waiting times for taxis and an impression on their part that taxi drivers did not like dealing with customers in wheelchairs.

8.6 Disability sector and housing

Focus group participants believed that the Ministry of Housing (MOH) have a building program to meet the needs of persons on the waiting list, but that the program was slow to provide housing relative to demand. The younger couple noted that they were on the waiting list for four years, and during that time they were very active in seeking accommodation – they made representations to their local member, kept in constant correspondence with MOH staff and finally addressed the Minister personally. Group participants believed that persons with a disability do not get priority with respect to the MOH waiting list. In addition, they did not believe that the MOH provided housing in all parts of the metropolitan area and that public housing for disabled people “was really only available in outer suburbs that were flatter”. The participants noted that they did not like going to places with lifts and were concerned that future housing options for people in wheelchairs may involve an increasing reliance on high density dwellings where a dependence on lifts was inevitable.

The participants noted that most persons with a mobility impairment will, over time, find that they need a DHS-provided care package but they will also need family help and assistance from private providers, for which they will need to pay.

8.7 Open discussion

A lot of the discussion within the focus group concentrated on issues of physical design. These participants in the study were very much aware of the range of impediments to limitations on mobility for people in wheelchairs and noted that some housing cannot be occupied simply because it does not have car parking with sufficient space for a person in a wheelchair. This requirement further restricted the range of housing options available to this group.

The group overall felt that there was a pressing need for the MOH to build more housing units for the population overall and for the disabled population especially. The participants were also aware of the impact of recent house price movements. The homeowner in the group noted that when he bought his unit he did not think about his needs “but now doesn’t want to leave”, largely because any move would require relocation to an outer suburb where the only affordable housing is located.

The participants commented on how housing for persons with a disability had changed over time. Once persons with a disability were expected to stay in the family home but now there is greater awareness of wheelchair access and less acceptance by the mobility impaired that they will stay in the family home.

9 PERSONS WITH A SENSORY DISABILITY - MELBOURNE

9.1 General characteristics

The VicDeaf focus group of people with a disability had six participants all being males with ages ranging from late teens to late forties (estimate). Disabilities of the group included vision impaired and intellectual. The group was comprised of mainly single people and the participants had had their disability since birth. The majority of the group lived on their own and one participant lived with their partner.

Housing is seen as an important issue with the group clearly frustrated at the unsuitable housing available and difficulties in understanding complex rental agreements and purchase contracts. They claimed this is a major barrier in improving their housing situation both in potentially purchasing a property or when looking to move through the rental market, especially the private rental market. There was acknowledgment by the participants of the role their individual case workers had in helping them maintain and securing appropriate accommodation.

This focus group proved to be significantly different to previous focus groups undertaken by the research team as the communication between facilitators, Auslan interpreters and case workers for the individual participants meant questions had to be posed that were short and concise, and that ongoing questioning as participants responded could not be achieved. This process of relaying information was indicative of how the participants in the focus group would need to conduct affairs with housing authorities and rental agencies and showed the research team that the overarching problem faced by people with a hearing impairment are the barriers put in front of them to communicate effectively with people concerned with housing. The case workers are an integral link between the hearing impaired and the agencies that these people would deal with to gain housing and to seek information on housing choices. The communication barrier is a major disincentive for the hearing impaired to seek better housing.

9.2 Current housing

The time period the participants have lived in their current housing accommodation ranged from four to six years and in one case 30 years. The main type of housing the participants live in currently are units with one participant living in a granny flat and another living in a cabin within a caravan park. The locations where the participants currently live include Mitcham, Montmorency, Wantirna, Chadstone, and St Albans.

Of the group two were in the private rental market and one lived in an independent granny flat and was not paying rent and the others were in government supported housing such as the housing commission. One participant stated that they were paying \$200 per week whilst living on their own. There was only one participant who lived in accommodation with unrelated people and this was in government supported housing.

Modifications to housing for group participants were quite minor with half saying they have had no modifications done and that their accommodation had not had any modifications done that were helpful to their disability. This inferred that they were unable to find, in the private rental market, any accommodation that had modifications relevant to their disability needs. The participant who lives in a granny flat indicated that there had been modifications done to accommodate wheelchair access and another participant also indicated there had been, minor modifications carried out.

These modifications include a rail in the toilet, the bathroom, the passage and a flashing light to indicate there was someone at the front door or trying to call on the telephone. The modifications for the participant to have better wheelchair access included lowering of kitchen cupboards and bench height.

The participants when questioned about what they like or dislike about their current housing gave a variety of responses. Some of the things that they liked included 'being close to shops and transport', 'good area, place and environment', "close to friends", 'close to work', near parents' and 'close to doctor'. Being close to transport and shops was the most common response from the participants in what they liked about the area and this reflects the fact that only one participant was identified as being able to drive.

Some of the reasons given for not liking where they currently live were related to the house itself and usually involved getting maintenance done. Small issues such as heater, hot water, and unsafe kitchen floor were identified as small issues but hard to resolve as there were communication problems dealing with real estate agents and landlords. This meant that the participants continued to 'put up' with the problems as they were unable to deal with real estate agents and landlords without the assistance of a case worker. Other issues which they expressed dislike about with their current housing included small lounge, small kitchen and house is not clean.

The location of the housing was also an issue as one participant expressed real concern at the neighbourhood claiming the suburb 'Noble Park is not safe, has lots of drugs, murders' and felt 'it was a higher risk area to live'. Also being located to a major highway was seen as bad due to large volume of traffic and noise. Other concerns were pedestrian access where the pathways and roads were not sealed (unmade) and one participant in a shared situation expressed their dislike towards another member of the household and that they tended to fight.

9.3 Previous moves, plans to move again

When asked when participants moved away from the family home and why, there were surprisingly no participants still living with their parents. All had moved out of the family home and this had happened at ages 16, 18, 20 and 25. One participant had been out of the family home since 1991 and one left four years ago. Reasons for leaving the family home ranged from "my mother wanted me out", "family moved to country and thought I would be better off in Melbourne", 'arguments with parents' and 'looking for independence'. One participant sought to leave the family environment to gain more independence but said his family was 'quite protective' so he lives in an independent granny flat on his siblings property. This participant thought it would have been better to live totally independent but his family (parents) wanted him to be around family.

A common characteristic of the group apart from one was the number of moves they had made since leaving the family home. One participant has moved an extraordinary 34 times and blamed high rents and difficulties with rental agents as the cause. The other participants had moved approximately four times and causes for the number of moves ranged from 'landlord wanted to sell property', 'lived with hearing boys and there was fighting so had to move', 'case worker only available 1-2 days per week in Geelong', and also 'to be closer to elderly parents'.

The participants were asked if moving from the family home had been a good experience. Responses were good and bad. One participant expressed how bad their experiences had been since moving out of home and also expressed that he was very lonely. Two participants stated that moving out had allowed them to be more

independent and one of these participants said that they had learned a lot. The other participant said that they had to be more responsible in the family environment but living on their own allowed more flexibility. The participant originally from the country said 'at times it was difficult as he only saw his parents at Easter and Christmas' but also stated he had had some 'good experiences'. Another participant stated that it had been difficult and lonely as he was the only deaf kid living in the caravan park. He said that because of his difficulties in communicating he was 'teased by hearing kids as they didn't understand me'. Another participant declared that his parents 'wanted him to move on' and that this had allowed him to learn and be independent. All the participants indicated to some degree that they were happy to live alone but if they did not have partners would like to find a partner to share their lives with.

Whilst the group expressed a degree of happiness with their current housing they all responded yes to the question "would you like to move again? Why and where". The reasons stated as why they would like to move ranged from 'to be closer to support and work', 'closer to shops', and 'closer to Melbourne CBD as there are more suitable jobs'. The participants all had a fairly strong view as to where they would like to live, and the areas they desired to live in reflect their reasons they would like to move. For example one participant wanted to live in Melbourne CBD as he felt job opportunities would be better for him. Another participant wanted to move to Glenferrie to be closer to shops as he liked to shop with his partner. One participant expressed a desire to move to Nunawading as this is where he worked and had a good level of support. St Kilda was the location another participant wanted to move to as he thought it was a nice area and would mean he would be closer to VicDeaf than he currently is. Another participant expressed a desire to return to Geelong as he liked the area even though services and support were not as good as where he currently resides. A younger participant thought the Gold Coast would be a great place to move to as it was an exciting and fun environment. The participants all agreed that it would be costly to move and that they would be unable to afford and even find suitable accommodation in their desired locations. They indicated that this was a problem whenever they move. A couple participants expressed a desire to move into multi level apartment living if they were to move and they thought that there may be a possibility that this would be more readily available in the areas they would like to live but they were not really sure if that is the case.

9.4 Housing markets

Of the group two were in the private rental market and one lived in an independent granny flat and was not paying rent and the others were in government supported housing such as the housing commission. One participant stated that they were paying \$200 per week whilst living on their own. There was only one participant who lived in accommodation with unrelated people and this was in government supported housing.

The participants were asked "how difficult is it for you to buy your own home?". The general response from the group was that it was quite difficult. The reasons given that it would be quite difficult ranged from the financial situation required to secure and service a loan and the major hurdle of understanding a contract to purchase a home. They all agreed that they had no knowledge of the housing markets and did not know what a house cost. They all also stated that they had no idea on what the process involved in buying a house. They all agreed that they would need a representative, either family member or case worker, to help them as the contracts were too complex (legal wording) for them to understand. The main reason however that they thought made it difficult to buy a house is the cost. As many of them have no jobs, and rely on the pension they all believed that it would be impossible to buy their own property and

therefore they did not consider it as an option. However they all expressed a desire to own their own home and that this would be a good thing.

9.5 Care and services

The group was asked 'how important is access to services in choosing where to live?'. Responses to this question were varied with two participants not concerned about living near services and one of these actually enjoying the travel to services outside of his area that he lives. One participant likes to live near his work and sport but was not overly concerned about living near any particular services. Two other participants expressed more of a desire to live near services and in particular VicDeaf. One of these participants would like to see VicDeaf move more of its services to more areas in the Melbourne region rather than the CBD as they are currently.

9.6 Disability sector and housing

The participants in general felt that their disability impacted quite significantly on their current housing and their future housing goals and aspirations. They all believed that their financial situation was the most limiting factor in moving through housing markets. Comments that reflected these attitudes included 'live in caravan park so will find it hard to move as I don't have much money and therefore I don't have many options', and 'any move I wish to make would depend on my finances so unlikely to move'. Some participants felt that access to Government housing should be more readily available as this was less costly than the private rental markets.

A case worker at the focus group said that the deaf people were in a catch 22 situation as they cannot afford anymore rent so have to accept housing from government when it became available and that the housing was usually unsuitable and in poor locations. The case worker said that this situation quite often led to deaf people becoming more desperate to move and they then entered in contractual arrangements that they did not fully understand the ramifications. She stressed that the communication and financial situation of the deaf people made it extremely difficult for deaf people to participate in the housing markets.

The group was asked "what needs to be done to help deaf people enter the housing markets?". The main response was to make access to information simpler so that the deaf people could better understand what the relevant situation entailed. Some suggestions to help make it easier included more documents in plain English, better funding for signing services and workshops on buying and renting houses. One of the more significant points they raised was the use of cues and prompts, especially pictures as they felt this would be a simple way of explaining points and would allow them to grasp more quickly the issues. More extensive use of interpreters was also seen as important but this had its limitations as many deaf people have their own 'dialects' which requires personal case workers to interpret. This is why they stressed that pictures were a more universal (generic) way of giving them better understanding of the situation.

Other suggestions included government should provide more suitable housing, there should be better access to government housing stock for people on pensions, increase first home owners grant to \$60-70k for people on pensions, support agencies have more defined roles to support people with a disability in the housing needs, more funding for Vic deaf and more research on deaf people and their housing needs.

10 CONCLUSION

This Project C report has presented the outcomes of six focus groups undertaken in Melbourne and Gippsland in April and May 2004. Some of the focus groups were with persons with a disability alone, some were with family members with care responsibilities, and one was undertaken with a mixture of participants. The research demonstrates the complexity of circumstances confronting those affected by disability – and this includes both the person with the disability and the family/household within which they live. While there is government provided care for many people with a significant disability, the reality is that the overwhelming majority of care is provided by unpaid family members. The carers payment and the carers allowance bears no relationship to the level of effort and commitment provided by family members who take on care responsibilities.

Disability unequivocally shapes the housing careers of persons with a disability and the family members who provide them with care. While there is considerable variation across groups and individuals, it is possible to identify a number of key themes:

- Disability reduces household income because of the limited employment opportunities available to many persons with a significant disability and in many case they have an impaired capacity to sustain paid employment. In addition, the care responsibilities of family members may reduce the amount of time they are able to work, and hence their earnings. Reduced earnings over the lifetime significantly restrict the housing opportunities available to these people. This results in 'flatter' housing careers when compared with the general population;
- Many households direct a considerable percentage of earnings into health and related products that are needed because of the disability. This in turn reduces household disposable income that could otherwise be directed into housing consumption;
- House price rises over the last seven years are seen to limit the housing opportunities available to persons with a disability. Those who are home owners acknowledge that they cannot afford to move to potentially more appropriate housing, while those outside home purchase cannot see the circumstances under which they would enter the tenure;
- Persons living in rural areas such as Sale and parts of east Gippsland report significant challenges with access to public transport. This makes the cost and effort of attending health and related appointments in Melbourne much greater;
- How a person comes to have a disability appears to have a significant impact on their housing career. Some people acquire a disability in ways that bring with them compensation – road traffic accidents or civil actions – and this group is able to access higher levels of support and capital payments for their housing that simply aren't available to persons who were born with a disability or acquire a disability through ill health;
- Many carers are concerned about how their family member will be looked after once they are unable to provide care because of age, death or ill health. Few were able to articulate concrete solutions to this challenge. Some of the persons with a disability also articulated views about this potential risk;
- Public housing was important for many people with a disability. It was the source of housing for many of the participants in this study and in the main was presented in a positive light. However there were clearly problems with the accommodation of persons with a psychiatric disability in public housing, with some suggestion

that the policies of the MOH contributed to the concentration of persons with complex needs in a limited area;

- The majority of the housing stock appears ill-suited to persons with a disability, especially those in wheelchairs. Participants in the study noted that they are often reluctant to move home because of the cost – but also because of the difficulty in finding a home that is either accessible or could be made accessible at low costs. While government financial assistance is available to make minor alterations, that assistance is quickly eroded;
- The cost of modifying the home was a major concern, especially for people in wheelchairs who may face substantial costs. In turn, the expense of modifications discourages people from moving through the housing market as they may need to adjust their housing each time they move which can be a cost they simply lack the resources to meet;
- The presence of professional carers in the home is welcome by many family members with care responsibilities because it offers respite, but it also adds another dimension to the relationship between the individual and their home. Their home becomes a place of work for others, and this changes the way in which that space may be used;
- There was a belief that landlords were prejudiced against those with a disability, especially those with a psychiatric disability. Others felt that landlords made matters difficult for persons in wheelchairs by not allowing them to modify the dwelling to meet their needs;
- Some participants in the study believed that governments had failed to meet their needs despite rhetoric to the contrary;
- Finally, it is worth noting that many people with a disability and their family members with care responsibilities are in circumstances – housing related and in other dimensions of life – that are confronting. The woman in Gippsland who felt that they should be wheeled to the cemetery and left there if their family member who provided them with care was to die, and the man with an acquired brain injury who wanted to initiate a protest because of the conditions in his group home, are indicative of the challenges confronting some persons with a disability and their families.

This report has contributed to the overarching goal of NRV 2 to establish how housing careers are changing in Australia and what the implications of change for government-provided housing assistance and housing policy are, by shedding light on how the housing careers of persons with a disability and family members with care responsibilities are changing. The report has shown that over the last 20 to 30 years there have been significant drivers of change, including increased demands by persons with a disability to be housed appropriately and independently; shifts in house prices that have limited the capacity of some groups with a disability to relocate or move to more appropriate housing; the emergence of new forms of care – including group homes; and price pressures in association with shifts in dwelling form and public housing provision that appear to be concentrating persons with a disability in outer suburbs .

APPENDIX – INTERVIEW SCHEDULE

Appendix 1: Housing 21 survey for people with a disability

Focus Group Question Schedule (with prompts)

General characteristics of group

- Gender
- Age
- Type of disability – (mobility, sensory, mental illness; life long or more recently acquired)

Current housing

- How long have you lived in your current house?
- Describe the housing you live in currently?
 - Type of Dwelling (Detached, etc.)
 - Tenure,
 - Who do you live with
 - How long lived in dwelling
- Have changes/modifications been made to your housing to accommodate your disability?
 - What were the changes?
 - How easy was it to do this, financially and practically?

If not living at home with parents:

Previous moves, plans to move again

- When did you first move out of your parent's home?
- Why did you move out of home?
 - Was it your decision to move or someone else's decision?
- Was moving a good experience or was it difficult to move?
- How many times have you moved since leaving your parents home or your original place of residence?
 - Why have you moved?
 - Where have you moved to?
 - Who have you lived with?
- What do you like about your current housing and where you live?
- What don't you like about your current housing and where you live?
- Would you like to move again?
 - Why do you want to move?
 - Where do you want to move?

If still living at home with parents:

- Are you happy with this arrangement; if not why not?

- Would you like to move?
 - Where would you like to move (location and type of dwelling)?
 - Do you want to live with other people or on own?
- What is preventing you from moving?

Housing markets

If renting:

- Who do you rent from?
- What are the advantages and disadvantages of renting?

Home Ownership:

- How difficult is it for people with a disability to enter into home ownership
 - finding the right type of home (adaptability);
 - affordability;
 - need to undertake renovations
 - difficulty in acquiring loan
 - Lack of employment/income

Care and services

- How many hours of care do you receive each week?
- Who provides this care?
- How important is access to care and services in enabling you live where you want or in restricting where you would like to live?

Disability sector and housing

- Overall what influence do you think your disability has had on your long term housing goals and life aspirations and goals in general?
- Overall what are the most important factors which impact on the housing choices and plans of people with disabilities (including effect on living standards)?
- Do you feel the housing choices available to people with a disability have changed over the last 10-15 years and what have the changes been?
- What do you feel needs to be done to improve the housing options available to people with a disability (s)
- What are your thoughts/concerns about your future?

Appendix 2: Housing 21 survey for carers of people with a disability

Focus group question schedule (with prompts)

General characteristics of group

- Gender
- Age
- Type of disabilities cared for – (mobility, sensory, mental illness; life long or more recently acquired)

Current housing

- How long have you lived in your current house?
- Describe the housing you live in currently?
 - Type of Dwelling (Detached, etc.)
 - Tenure,
 - Who do you live with
 - How long lived in dwelling

Previous moves, plans to move again

- When did you first move out of your parent's home?
- Why did you move out of home?
 - Was it your decision to move or someone else's decision?
- Was moving a good experience or was it difficult to move?
- How many times have you moved since leaving your parents home or your original place of residence?
 - Why have you moved?
 - Where have you moved to?
 - Who have you lived with?
- What do you like about your current housing and where you live?
- What don't you like about your current housing and where you live?
- Would you like to move again?
 - Why do you want to move?
 - Where do you want to move?

Housing markets

If renting:

- Who do you rent from?
- What are the advantages and disadvantages of renting?

Home Ownership:

- How difficult is it for people caring for persons with a disability to enter into home ownership
 - finding the right type of home (adaptability);
 - affordability;
 - need to undertake renovations
 - difficulty in acquiring loan
 - Lack of employment/income
- Have you made changes to your home to accommodate a person with a disability?
 - What were the changes
 - How easy was it to do this, financially and practically?

Care and services

- How many hours of care do you provide each week?
- What influence does caring have on other aspects of your life?
 - Employment
 - Social activities
- Is adequate help, assistance or support available if you need it?
- How important is access to services in enabling you live where you want or in restricting where you would like to live?

Disability sector and housing

- Overall what influence do you think caring for someone with a disability has had on your long term housing goals and life aspirations and goals in general?
- Overall what are the most important factors which impact on the housing choices and plans of people who care for someone with a disability or disabilities (including effect on living standards)?
- What is the most difficult thing about being a carer?
- Is being a carer more difficult or easier now than say 10 years ago?
- Do you think governments have adequately addressed the concerns of carers?
- What could governments do that would make life easier for carers?
- Do you feel the housing choices available to people with a disability have changed over the last 10-15 years and what have the changes been?
- What do you feel needs to be done to improve the housing options available to people with a disability (s)
- What are your thoughts/concerns about your future and the future of the people you care for?

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