THE PERSPECTIVES OF CARERS ON HOUSING NEEDS AND MENTAL ILLNESS

A LODDON MALLEE MENTAL HEALTH CARERS NETWORK HOUSING PROJECT

JACQUI THEOBALD
RACHAEL SANDERS
JENNIFER LEHMANN

Social Work & Social Policy, La Trobe Rural Health School, Bendigo, La Trobe University
THE PERSPECTIVES OF CARERS ON HOUSING NEEDS AND MENTAL ILLNESS

A LODDON MALLEE MENTAL HEALTH CARERS NETWORK HOUSING PROJECT

JACQUI THEOBALD
RACHAEL SANDERS
JENNIFER LEHMANN

Social Work & Social Policy, La Trobe Rural Health School, Bendigo, La Trobe University
What are the housing options for people with mental illnesses in rural Loddon Mallee in Victoria, and how does the availability of these opportunities affect families?

The Loddon Mallee Mental Health Carer Network (LMMHCN) established itself to advocate for and support the development of effective mental health services and supports in this rural area. The Network engages with carers across the region, and they consistently speak of their deep concern regarding the unavailability of housing in the area and the impact this had on their families. In collaboration with Bendigo Health Carers Support Services (BHCSS) and Mallee Family Care, the LMMHCN decided that housing would be the first issue they would formally tackle. A small pilot study was undertaken which demonstrated the multiple housing issues for this target group.

Armed with preliminary information, LMMHCN worked in collaboration with BHCSS to conduct this study. La Trobe University was the obvious partner to approach to undertake this work, as they had a track record in the geographical area and had previously done work on ageing carers.

This study is the first of its kind in capturing carer perceptions of housing needs for people with mental illnesses in a rural area and was planned to meet high quality research standards. The study, led by Dr. Jacqui Theobald, Lecturer in Social Work and Social Policy, College of Science, Health and Engineering, was subject to and approved by the institutional Ethics Committees of both the University and Bendigo Health. It was actively supported by Sue Petruni and Kerry Meiers BHCSS, and the LMMHCN took an active role as the consultant body for this study in all stages of its development.

A comprehensive review of the literature was undertaken that confirmed what local carers were saying: there is a paucity of appropriate housing, and 40% of people in receipt of care in Australian studies lived with carers. In response to a questionnaire associated with this study, one parent said: *He needs to feel safe in his own environment. His battles to recover are limited without his own place to call home. Living with parents is not living his own life.*

Another carer, representing the views of many, indicated: *In rural areas we definitely do suffer from a lack of public housing. There is just not enough...(my son) had investigated going to Bendigo and the Housing Commission people told him...there would be a 10 year wait for him because he was a single man.*

This research also confirms what we know in practice - that support is a critical element to make housing successful. Reflecting on the availability of support services in rural areas another carer reflected: *Maybe you can get a house in one of these little townships. The trouble is, there’s no services. There’s not even transport. So you might get a house …but you’re marooned there. You haven’t even got anything. No service, no buses, no trains …So you really can’t afford to live there otherwise you’re just going to get sick.*

This collaborative research clearly documents rural carer experiences of inadequate housing and support opportunities. As the CEO of Wellways Australia operating across rural areas in Victoria, NSW and Tasmania, I can only echo these findings are not unique to Loddon Mallee; they are also experienced by organisations and families across Australia. I recommend this report to you and commend the foresight of the Loddon Mallee Mental Health Carer Network in commissioning this research.
ACKNOWLEDGEMENTS

There are always many people and groups who make an essential contribution to projects such as the one presented in this document. Foremost are the carers who contributed to the establishment of the project, and who participated in the survey and interviews. This always takes time and can be emotionally draining, so we thank them for the commitment made to achieving the results reported here. In addition, there are a number of past representatives of the Loddon Mallee Mental Health Carers Network (LMMHCN) and the LMMHCN Committee of Management who we would like to acknowledge: Mike Bruty, Liz Howard, Louise Payne, Lyn Marie Richards, Andrea Smith, Anne Graham, Pam Lingenberg, Kerry Meiers, Jason Minter and John Forrest.

The Bendigo Health Carer Support Services and Mallee Family Care have also made a substantial contribution to the project, together with Sue Petrini, Di Dean, Deb Murphy and Cath Murphy.

The initial La Trobe University staff working on the project included Prue Bagley and Karen Anderson. Subsequently, Byron Perrin and Steve Begg have supported the project with advice and guidance whilst Jacqui Theobald, Rachael Sanders and Jennifer Lehmann oversaw its completion.

Thanks are also extended to those who funded the project, with monies provided by Bendigo Health Carer Support Services and a La Trobe University Research Grant from the College of Science, Health and Engineering.
# CONTENTS

- Foreword ......................................................... 3
- Acknowledgements .......................................... 4
- Contents ......................................................... 5
- List of Tables and Figures ..................................... 6
- List of Acronyms ............................................... 7
- Executive Summary ........................................... 8
- Background to the Research ................................ 9
- Introduction ..................................................... 9
- Mental Illness and Caring and the Loddon Mallee Region ........................................ 10
- Housing and Mental Illness ................................... 11
- Literature Review .............................................. 12
- Policy and Service System Context ......................... 12
- Ongoing Challenges of Accessing and Maintaining Housing ........................................ 15
- Consequences of Lack of Housing and Support .......... 16
- What is Needed? ............................................... 17
- Research Methodology ........................................ 19
- Quantitative Research Results and Discussion ........... 20
- Demographics of Carers and Recipients of Care .......... 20
- Housing and Other Living Experiences ..................... 21
- Challenges of Housing ........................................ 23
- What is Needed? ............................................... 28
- Qualitative Research Results and Discussion ............. 30
- Demographic Characteristics of Interview Participants and Those for Whom They Cared .... 30
- Challenges of Accessing and Maintaining Housing ........ 30
- Consequences of Lack of Housing and Support .......... 35
- Housing and Support Needs ................................. 41
- Summary and Recommendations ......................... 44
- Reference List .................................................. 46
LIST OF TABLES AND FIGURES

Table 1. Age of carers
Table 2. Age of recipients
Table 3. Recipients’ accommodation
Table 4. Housing meeting needs and type of accommodation
Table 5. Awaiting alternative housing
Table 6. Financial means to live independently and accommodation type
Table 7. Age of carers
Table 8. Living situation of recipients of care
Table 9. Age of recipients of care
Table 10. Gender of recipients of care

Figure 1. Carers’ primary source of income
Figure 2. Location of carers
Figure 3. Importance of housing for wellbeing
Figure 4. Issues contributing to housing suitability and sustainability
Figure 5. Cost as a barrier to private rental
Figure 6. Cost as a barrier to public housing
Figure 7. Adequate financial means to live independently
Figure 8. Availability in Loddon Mallee compared with other regions
Figure 9. Discrimination as a barrier to private rental
Figure 10. Discrimination as a barrier to public housing
Figure 11. Difficulty with finding suitable accommodation
Figure 12. Ease of access to information
Figure 13. Ease of navigating housing processes
Figure 14. Narrowness of eligibility criteria for community housing
Figure 15. Requirement for protection/safety in housing
Figure 16. Agency provided assistance
Figure 17. Knowledge of suitable housing
## LIST OF ACRONYMS

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
</tr>
<tr>
<td>BHCSS</td>
<td>Bendigo Health Carer Support Services</td>
</tr>
<tr>
<td>DHHS</td>
<td>Department of Health and Human Services</td>
</tr>
<tr>
<td>DSP</td>
<td>Disability Support Pension</td>
</tr>
<tr>
<td>FCDC</td>
<td>Family and Community Development Committee</td>
</tr>
<tr>
<td>HASI</td>
<td>Housing and Accommodation Support Initiative</td>
</tr>
<tr>
<td>HREOC</td>
<td>Human Rights and Equal Opportunity Commission</td>
</tr>
<tr>
<td>LGA</td>
<td>Local Government Area</td>
</tr>
<tr>
<td>LMMHCN</td>
<td>Loddon Mallee Mental Health Carers Network</td>
</tr>
<tr>
<td>LMR</td>
<td>Loddon Mallee Region</td>
</tr>
<tr>
<td>MHA</td>
<td>Mental Health Australia</td>
</tr>
<tr>
<td>MHCA</td>
<td>Mental Health Council of Australia</td>
</tr>
<tr>
<td>NDIS</td>
<td>National Disability Insurance Scheme</td>
</tr>
<tr>
<td>NMHC</td>
<td>National Mental Health Commission</td>
</tr>
<tr>
<td>OPA</td>
<td>Office of the Public Advocate</td>
</tr>
<tr>
<td>SRS</td>
<td>Supported Residential Services</td>
</tr>
</tbody>
</table>
This study used a mixed methods approach to investigate the housing and support needs of people with mental health issues in the Loddon Mallee region. It was initiated by Bendigo Health Carer Support Services in consultation with Loddon Mallee Mental Health Carers Network and used a survey and interviews for data collection. Taken together, these tools provide a clear picture of some of the challenges faced by carers and those for whom they care in both the short and longer term.

There is ample evidence that carers recognise the accommodation and support needs of people with mental illness to be entwined in complex ways that encompass the nature of housing and financial capacity, access and location to supports, and planning for future needs. While much of the evidence found in this study echoes that of previous research investigations, the rural and regional context adds complexity to this picture because of the distances and costs involved in accessing services, and the limited availability of private and public housing options. The particular concerns of participants in this study related to accessing affordable, safe and appropriate housing in a timely manner. Housing was both a short-term and long-term concern for carers who wanted the security of a holistic planning process that gave clarity and security of tenure to people with mental illness.

Recommendations emerging from this investigation are that:

1. A holistic approach to the care and planning for people with a mental illness be adopted by service providers in a manner that supports carers and includes attention to long-term planning. Help with navigating the service system, reducing the silo effect of servicing, together with practical assistance to seek and attain housing for those for whom they care, were important changes sought by carers.

2. Detailed population planning is needed to address the current and projected affordable housing needs of people with mental illness and their families, with attention given to the specific context of rural and regional people.

3. The National Disability Insurance Scheme (NDIS) processes need to include attention to housing, taking account of regional and rural factors in the care of people with mental illness and issues related to their carers’ involvement in meeting needs.

4. Housing be set aside for people with a mental illness, taking account of the range of accommodation that might be affordable, safe, and have appropriate proximity to carers and services. This needs to include the expansion of models of integrated housing and support, such as the HASI and Doorways models, to regional and rural areas of Victoria including the Loddon Mallee Region.

5. An exploration be undertaken of options to develop or expand a programme model based on the not-for-profit HomeGround Services (Real Estate) in Melbourne, to aid in addressing discrimination in the private rental market.
BACKGROUND TO THE RESEARCH

INTRODUCTION

The research for this report was initiated by the Bendigo Health Carer Support Services (BHCSS) in consultation with the Loddon Mallee Mental Health Carers Network (LMMHCN). Originally auspiced by BHCSS in partnership with the Mallee Family Care Mental Health Carer Program, the LMMHCN is now an independent, incorporated body that represents mental health carers from around the Loddon Mallee Region (LMR). It was the LMMHCN that initially identified housing for people with mental illness as a primary concern of carers in this part of country Victoria.

It is widely recognised that mental health carers play a central role in maintaining the wellbeing of people with mental illnesses, and their involvement is often crucial to good recovery and management (Browne & Hemsley, 2010; Leggatt, 2011; Mental Health Australia [MHA], 2016). What this research aims to contribute by focusing on mental health carers is an understanding and representation of their views on the housing and support of those for whom they care. The research presented here pertains to non-professional adult carers with caring responsibilities for another adult (not their partner) experiencing mental illness, who, in the majority of cases, was the carer’s adult child. Literature searches suggest this research is unusual in its focus on the perspectives of non-urban carers drawn from across the LMR. The LMR has a current population of just over 308,000 people and is made up of 10 local government areas (LGAs) including the Shire of Macedon Ranges, Shire of Mount Alexander, Shire of Central Goldfields, City of Greater Bendigo, Shire of Campaspe, Shire of Loddon, Shire of Buloke, Shire of Gannawarra, Rural City of Swan Hill and Rural City of Mildura.

As a whole, the research project investigates the perspectives of carers to answer three core research questions:

- What are the biggest challenges with regard to accessing and maintaining housing for people experiencing mental illness?
- What are the consequences of the challenges described?
- What kind of housing and support is needed for people experiencing mental illness?

Before describing the processes used to investigate these questions, an understanding of the dimensions of mental health in Australia, particularly in regional and rural Australia, is necessary. The following sections address this, and provide an overview of what is already known about mental health, carers and housing issues.

---

1 A mental illness is defined as a clinically diagnosable disorder that significantly interferes with an individual’s cognitive, emotional or social abilities (Department of Health, 2009). In this report ‘mental illness’ is used to describe a wide variety of mental health and behavioural disorders, which can vary in both severity and duration. The most prevalent mental illnesses are depression, anxiety and substance use disorders. Less prevalent mental illnesses, which are also known as psychotic illnesses, include schizophrenia, schizoaffective disorder, bipolar disorder and delusional disorder.
MENTAL ILLNESS AND CARING AND THE LODDON MALLEE REGION

In Australia, statistical information about mental illness is patchy and there is no single data set providing episodes of mental health service use. The Australian Bureau of Statistics (ABS) Survey of Mental Health and Wellbeing found that 45% or 7.3 million Australians aged 16-85 years had a mental disorder at some point in their life, and that 20% of Australians experienced a mental disorder within the 12 months prior to their survey (ABS, 2008). It has been calculated that this corresponds to approximately 860,200 Victorians experiencing a mental illness in any given year (Family and Community Development Committee [FCDC], 2009). Notably, the Department of Health and Human Service (DHHS) figures for 2016 suggest that the LMR has a higher number of registered mental health clients (16.5 per 1,000) compared to the state average (11.3 per 1000) (DHHS, 2016).

The ABS estimates that 2.7 million Australians identified themselves as informal carers in 2015, and in Victoria there were an estimated 736,600 carers, which is 12.6% of the Victorian population (ABS, 2016). Of the 2.7 million carers nation-wide, 856,000 were primary carers who provide the majority of care. Almost all primary carers care for a family member (ABS, 2016). Women made up the majority of carers, representing 68% of primary carers and 55.5% of carers overall (ABS, 2016). The highest number of carers are aged 55 to 64 years, and approximately 79.3% of primary carers live with one or more of the recipients they provide care to (ABS, 2016).

With regard to mental health carers specifically, there is no official data that captures their numbers in Australia because most figures rely on people accessing formal services. However, Centrelink data from 2011 indicates that 77,000 Australians aged 16-64 years with a mental illness had carers in receipt of a carer specific government payment (quoted in MHA, 2016). Furthermore, the People Living with a Psychotic Illness Survey found that of the 63,533 people accessing public mental health services in 2011, 65.4% had daily face-to-face contact with family and nearly one-fifth were living in a family residence (Morgan et al., 2011). Taken together, this data suggests that the number of people caring for someone with a mental illness is considerable.

Support provided by carers can include providing support in the family home, as well as support to and advocacy for a family member in supported accommodation or living independently in the community. It has been estimated that carers provided 1.9 billion hours of care in 2015, and that if this care were replaced with services purchased from formal care providers, it would cost $60.3 billion (Deloitte Access Economics, 2015).

More than half (55%) of primary carers care for at least 20 hours per week (ABS, 2016). This may be as high as 104 hours per week for those caring for people with a mental illness (Mental Health Council of Australia [MHCA], 2000). Carers are over-represented in the lowest quintiles of household income, which results from lower workforce participation and the greater likelihood that they will be in receipt of a government income support payment. Primary carers are more likely to be in receipt of a government pension or allowance (42.7%) (ABS, 2016). The unpaid work of primary carers, in particular, underpins and sustains the mental health service system in the current context of community care.

Approximately 13% of all carers live outside major cities in areas like the LMR (ABS, 2016). The current population profile of the LMR is older than the Victorian population average. In 2012, 27.4% of people in the LMR were aged between 45-64 years compared with 24.8% overall (Department of Health, 2013). Notably, all LGAs in the LMR, other than the Shire of Macedon Ranges, are relatively disadvantaged (Department of Health, 2013). For example, the LMR has a higher than average number of people on low incomes (43.4% compared to 39.9%) and women are particularly disadvantaged as 50% receive less than $400 per week compared with 36.3% of men (Department of Health, 2013). There are also considerably higher numbers of people in receipt of the Disability Support Pension (DSP) (86.1 per 1,000) compared to Victoria as a whole (54.9 per 1000).

Caring is clearly a gendered issue. The available data indicates that there is likely to be a large number of older women on low incomes at risk of, or experiencing, income poverty, who are caring for people with a mental illness in the LMR. Women in primary caring roles are forfeiting significant time that could otherwise be spent on paid work or leisure activities. This decision is often not a choice as many primary carers report they take on the role because of a sense of family responsibility, feeling they could provide better care, and emotional obligation (ABS, 2016).
The perspectives of carers on housing needs and mental illness

Housing and Mental Illness

People experiencing mental illness face significant challenges accessing and maintaining appropriate and secure housing for a range of interconnecting reasons including: a lack of available and affordable housing, poverty, the nature of mental illness, discrimination, difficulties with managing finances, insecurity of tenure, lack of safety and security (MHCA, 2009a; O’Brien et al., 2002; Robinson, 2003). These issues are canvassed in more detail below in a discussion of relevant literature.

Information about the proportion of people experiencing mental illness requiring accommodation is fragmented. As noted by Cameron and Flanagan (2004) it is “difficult to measure precisely the level of unmet need for accommodation types for people with serious mental illness” (p. 39). This difficulty stems from challenges in “identifying the size of the population, lack of consistent data collection in existing services and the highly transient lifestyle of many people with serious mental illness” (Cameron & Flanagan, 2004, p. 39).

The People Living with a Psychotic Illness Survey 2010 (Morgan et al., 2011) provides some indication of the housing situation for people experiencing mental illness. It found that one in eight (12.8%) people had periods of being homeless in the previous year. The most common accommodation type reported in the Survey (Morgan et al., 2011) by participants was public or private rental housing (48.6%), with 26.8% in publically rented houses or units and 21.8% in privately rented houses or units. One-fifth (19.1%) were living in a family residence that was not their own and a further 13.1% were in their own home or unit. The latter contrasts significantly with the 69% of Australians that own or are buying their own home (ABS, 2012). The survey also reported that one in ten (11.0%) were in supported accommodation and almost one quarter (22.7%) of participants were on a public housing waiting list, which indicates that their current housing situation was unsuitable or unsustainable (Morgan et al., 2011). People experiencing mental illness are over-represented in boarding houses, caravan parks and prisons (Carers Victoria, 2014).

In the LMR a large number of residents with a history of mental illness also live in pension-level Supported Residential Services (SRS) and “This reflects the lack of other affordable accommodation options” (Office of the Public Advocate [OPA], 2014, p. 28). In addition, “When these residents are depressed, distressed or unwell this often affects other residents” (OPA, 2014, p. 28). These services cannot provide sufficient care and support for this population (Carers Victoria, 2014). Furthermore, DHHS (2016) reports that the level of rental stress in the Loddon Mallee is higher than the Victorian measure—26.2% (LMR) compared to 25.1% (state wide).

Other forms of supported accommodation in the LMR for people experiencing mental illness, such as those provided through Housing Associations and Transitional Housing Programs, appear extremely limited in number, particularly outside of regional centres, and are known to have lengthy waiting lists (Couch, 2014). In Bendigo, specifically, “there is a shortage of emergency and transitional housing and few low-cost supported accommodation options other than SRS” (OPA, 2014, p. 54). As a consequence, many mentally unwell patients are staying in Community Care Units much longer than is required, making badly needed beds unavailable (OPA, 2012). At present Mildura lacks any short-term clinical accommodation-based services for people transitioning from inpatient care to the community. However, funding for a new Prevention and Recovery Centre has been allocated and will open in June 2017 (OPA, 2016). The social policy context that has given rise to the lack of affordable accommodation options in the LMR and Australia more broadly is discussed below.

Support provided by carers can include providing support in the family home, as well as support to and advocacy for a family member in supported accommodation or living independently in the community.
The following literature review has been developed through the analysis of a range of documents, largely Australian in origin, many of which have resulted from investigations by key organisations. The perspectives of the authors of these reports are generally those of sociologists and social policy analysts, with studies designed to provide an overview using the available data. There are few studies into the issues faced by carers of people with mental illness that address housing and support needs, in particular for carers located in regional and rural contexts. Drawing on the literature, this chapter commences with an analysis of the social policy context and associated findings on the outcomes of social policy on housing and support in the mental health sector. This is followed by a review of studies relating to three key themes: challenges of accessing and maintaining housing, consequences of lack of housing, and forms of housing that are needed.

POLICY AND SERVICE SYSTEM CONTEXT

Public policy, housing, mental illness and carers

Two key areas of social policy are relevant to the housing needs of people with a mental illness and their carers—that of achieving mental wellbeing and that of gaining affordable and suitable housing. These two issues are, of course, inextricably linked. Public policy at state and Commonwealth government levels has consistently provided a framework for the attainment of improved mental health for Australian citizens that recognises the significance of access to housing. However, public policy regarding affordable and suitable housing remains inconsistent and subject to the political orientation of individual governments. Worryingly, Australia currently has no coherent framework to tackle the lack of affordable housing.

Affordable housing—A challenge

The housing system in Australia has increasingly failed to meet the needs of a growing proportion of low income Australians. A lack of affordable housing options has long been identified as a critical issue for people with serious mental health conditions and a substantial body of literature reports that many people experiencing mental illness live in precarious housing circumstances, experience trajectories of insecure housing, or are homeless (Costello et al., 2013; HREOC, 1995; Johnson et al., 2007; MHCA, 2009a; Robinson, 2003).

Social work academic and former public advocate David Green (2003) has pointed to the significance of deinstitutionalisation to the problem of inadequate affordable housing and support for people experiencing mental illness in Australia. He has argued that deinstitutionalisation was not “accompanied by an adequate conceptualisation of the essential requirements of housing, healing, care and protection of vulnerable people in the community” (Green, 2003, p. 6). Green further contends that governments have continually failed to recognise the necessary functions institutions formerly fulfilled and to fully cost and transfer these to community programmes. Instead, as outlined above, the burden of care has been transferred to families and individuals (Green, 2003, p. 6). Green also notes that deinstitutionalisation resulted in a significant increase in demand for low cost housing and services at the same time as there was a dramatic decline in the availability of affordable housing. The impact of these changes for people with mental illness has been “devastating” and cannot be divorced from a neo-liberal agenda concerned with cutting public expenditure across all public services including health and human services (Green, 2003, p. 7).
This decline in the availability of affordable housing in Australia has been a direct result of government initiatives over the last 30 years. Government policies designed to promote private home ownership and investment in housing, such as negative gearing and capital gains tax concessions, have forced up house prices which has led to a decline in home ownership among households since the 1980s (Toohey, 2014). This has impacted on the private rental market where the number of affordable and available properties in Australia is shrinking. The annual Anglicare Australia Rental Affordability Snapshot (2016) found that in regional and coastal areas of Victoria, affordability for those in receipt of income support payments “remained uniformly very low” (p. 82). It also documented that of 4,148 properties listed, there were only seven that were affordable and appropriate for a person in receipt of a Newstart Allowance, and 49 available for those in receipt of a DSP (Anglicare, 2016, p. 83). The shortage of rental properties that are affordable and available to households in the lowest 40% of incomes is estimated to be 298,000 (Toohey, 2014). This has occurred alongside a sustained reduction in investment in public and social housing. Real funding for public housing decreased by 25% between 1991 and 2001, and by a further 10% between 2003 and 2013 (Toohey, 2014).

Growing demand within the community combined with declining government investment has meant there were 164,000 on the public housing waiting list in 2012 with a wait time of up to 15 years in some areas (Toohey, 2014). Australia requires an investment of $67.4 billion to build enough accommodation for those currently on social housing waiting lists, or $90 billion to meet housing needs of low-income households (Toohey, 2014). This lack of investment in public housing has been paralleled by a lack of investment in suitable housing options for people experiencing mental illness including supported accommodation models.

**Achieving mental wellbeing**

Social policy, in relation to the issue of mental health, is underpinned by the ideas of individual rights, recovery, social inclusion, and early intervention (Commonwealth of Australia, 2015a; National Mental Health Commission (NMHC), 2014; Victorian Government, 2015). Reflecting these ideas, care for those with mental health issues is now provided primarily in community-based settings as opposed to inpatient services and institutionalised settings that characterised Australia’s mental health system in the past. In many cases, the responsibility for caring for people with mental illness is taken up by their family. In this context, the involvement of those experiencing mental illness, as well as their families and key support people, is recognised as critical in planning towards appropriate care and support to promote wellbeing and recovery. The need for these groups to have greater involvement in policy development has also been acknowledged (Commonwealth of Australia, 2015a; NMHC, 2014; Victorian Government, 2015).

Social policy also reflects the widely accepted view that good mental health is directly shaped by a range of social determinants, which includes access to community support services alongside adequate and affordable housing (Commonwealth of Australia, 2009, 2015a; Victorian Government, 2015). At the level of service provision, state governments are responsible for the provision, regulation and monitoring of services in relation to mental health. This includes clinical services that are managed by public hospitals and mental health community services, which are often co-located in non-government community service organisations. Yet Australia is without a nationally agreed approach to mental health service delivery in regional, rural and remote areas and for closing the gap between city and non-city dwellers. This is also the case at the state level where in Victoria there is no systemic approach to ensure mental health services’ responses are matched according to need and this results in “uneven service capacity and access … particularly for … rural areas” (DHHS, 2015, p. 21). People living in regional, rural and remote areas of Australia make up 30% of the population, but do not receive anywhere near 30% of funding and services for mental health programmes. In its recent commissioned review of mental health services, the NMHC found high levels of unmet mental health need in rural and regional communities requiring immediate attention (NMHC, 2014).

In its response to the NMHC report, the Commonwealth provides no clear plan or commitment of resources for how this inequity will be tackled, but does indicate that “over time an increased pool of program funding” will be made available for rural areas and particular population groups including those with severe and complex illness (Commonwealth of Australia, 2015a, p. 11).

With regard to housing, social policy rhetoric reflects a long-standing call made by a range of government and non-government actors about the need to ensure all Australian citizens, including those with mental health issues, have access to affordable, secure and suitable housing in Australia because the housing market has failed to meet their needs (Chamberlain et al., 2014; Commonwealth of Australia, 2008; Mental Health Council of Australia, 2009a, 2009b; National Housing Supply Council, 2014).
Alongside investment in affordable housing, the need to improve the integration of mental health support services and housing agency programs, to provide properly tailored assistance to people with mental illness, has been recognised in government policy and reports (Commonwealth Government, 2009, 2015). So too has the need for a greater range of accommodation options offering varying levels of support, because consumers and carers report experiencing difficulties in accessing the right care at the right time (Commonwealth Government, 2009).

A commitment to reduce homelessness and improve access to affordable housing characterised social policy for several years under the former Rudd-led Labor Commonwealth Government (Commonwealth of Australia, 2008; Council of Australian Governments, 2008; 2015a). The relationship between homelessness and mental illness was examined in a recent longitudinal study based in Melbourne, where Johnson and Chamberlain (2011) found homelessness to be both a cause and consequence of mental illness. The lifetime prevalence of mental illness was found to be 31%, with 15% experiencing mental illness before homelessness and 16% reporting mental illness after homelessness (Johnson & Chamberlain, 2011). This was also given recognition in the Rudd-led Government’s 2008 White Paper on homelessness, which identified the need for a strategy of “No Exits into Homelessness” for a range of groups including those being discharged from psychiatric care without stable housing (Commonwealth of Australia, 2008).

Despite these policy initiatives, successive governments have failed to invest in adequate resources to tackle Australia’s lack of affordable housing and, as such, it has been found that they have merely worked to slow the rate of growth of homelessness rather than reduce it (Bullen, 2014; Toohey, 2014). In fact, the policy context in relation to affordable housing has shifted markedly since the election of the Coalition government in 2013, which substantially reduced investment designed to tackle homelessness and the dearth of affordable housing in Australia. This is at odds with the long-established consensus that the housing needs of Australians experiencing mental health issues are far from being met (MHCA, 2009a; NMHC, 2014), and the recent argument forwarded by the NMHC (2014) that resources need to be re-directed to meet the housing needs of people with mental health problems. In fact, the challenges of accessing and maintaining housing continue, with NMHC commissioned research also documenting that people with mental health issues in regional and rural locations face significant levels of housing stress and were at risk of homelessness (Craze & Reddy, 2014). In its response to the NMHC report, the Commonwealth provides no rejoinder to these recommendations (Commonwealth of Australia, 2015).

More promising has been a recent investment by the Andrews-led Victorian Labor government into social housing (Media release, Premier of Victoria, 2016). In addition, the National Disability Insurance Agency had recognised the need to fund housing for some recipients in the National Disability Insurance Scheme (NDIS) and plans to leverage private and social investors to build new housing. However, it is unclear what proportion, if any, of this will be earmarked for people living in regional, rural and remote areas (Bo’sher, 2016).
Ongoing Challenges of Accessing and Maintaining Housing

Low incomes and housing stress
People experiencing mental illness often have low incomes because they are reliant on income support payments which, in turn, affects their capacity to access and maintain housing (Brown & Hemsley, 2010; Cameron & Flanagan, 2004; Lambert et al., 1999). The People Living with a Psychotic Illness survey (2011) found that government income payments are the main source of income for 85% of people. This means they have limited choices in relation to housing and often find themselves experiencing housing stress in the private market (Craze & Ready, 2014). It has also been shown that people with mental illness are particularly vulnerable to being trapped in a cycle of social disadvantage (Cameron & Flanagan, 2004; Lambert et al., 1999). Highlighting the relationship between income poverty and access to housing, Jones et al. (2014) have reported that people in receipt of disability pensions now face difficulty obtaining affordable accommodation in rural areas, which had historically been more affordable.

Nature of mental illness
The nature of mental illness can make it difficult to maintain housing because people may experience symptoms that interfere with their ability to manage finances, pay rent on time, live with neighbours, maintain their property and feel safe (Reynolds et al., 2001). People can also be socially isolated with less access to support, and have the additional challenges of physical health issues—all of which present hurdles for accessing and maintaining housing (O’Brien et al., 2002). It is also the case that mental health often becomes neglected or worsens as other pressing issues relating to housing take priority (MHCA, 2009a).

Discrimination and stigma
It is evident that the lack of understanding about the nature and effects of mental illness in the wider community “can lead to discrimination, stigma and fear [and these] responses can adversely affect and often compound difficulties of living in the community with a mental illness” (O’Brien et al., 2002, p. 6). For example, people may experience discrimination from landlords, which results in their exclusion from the private rental market (Browne & Hemsley, 2010; Cameron & Flanagan, 2004).

Mental health support
There is a significant unmet need in relation to mental health services and this gap in service provision has been recognised in social policy as discussed above. The ABS (2008) National Survey of Mental Health and Wellbeing found that almost two thirds of people surveyed who experienced a mental health problem in the previous 12 months did not receive treatment or support for their illness. This is consistent with concerns raised by carers, who report a lack of available support, particularly when the person they care for becomes unwell (MHCA, 2009a). The problem of inadequate mental health support inhibits people’s capacity to access stable housing. As the MCHA (2009a) puts it:

The failure to increase community-based treatment and support services has contributed to and exacerbated difficulties for people with a mental illness in accessing the stable and appropriate housing that is an essential prerequisite for effective treatment and support. (p. 23)

Without adequate and appropriate support across the range of areas of daily living, people with serious mental illness can become stressed, triggering an acute episode of illness (Cameron & Flanagan, 2004). This impacts on the ability of people experiencing mental illness to maintain their housing, in part because it becomes difficult to meet housing payments (MHCA, 2009a). A lack of support for those with a mental illness can also make it hard to maintain a tenancy due to difficulties with life skills such as housekeeping and personal hygiene (Cameron & Flanagan, 2004). This has particular implications for people in rural areas as discussed further below.

Carers also report feeling inadequately supported and engaged by mental health services. The Wesley Report found that one quarter of carer respondents did not agree there were appropriate services for relatives of those suffering from a mental illness, and 34% actively disagreed services were easy to access (Wesley Mission, 2012). Unfortunately, the inadequate support provided to carers impedes their ability to support and accommodate those for whom they are caring because it significantly disrupts their lives (Flanagan & Cameron, 2004; Leggatt, 2010; MCHA, 2003; MHCA, 2009b). However, as Cameron and Flanagan (2004) put it: “in spite of operating with little professional support, [carers] are called upon to provide substantial housing, financial and advocacy support” (p. 36). Notably, carers have reported they would be happy to provide care in the home or elsewhere if the person they cared for could access appropriate support and carers could access respite services (MCHA, 2009b).
As outlined above, rural and remote areas are particularly under-serviced with regard to mental health support services (Craze & Reddy, 2014). There is also less variety with regard to types of services, and they are often located a significant distance away (MHCA, 2009a). One study that examined the experiences of people with mental illness and housing problems in a rural area of south-eastern Australia found that long travel distances to mental health services were an issue that disadvantaged people in rural areas, particularly because they have less access to private transport (Jones et al., 2014). This had consequences for accessing housing because it has been shown that having access to a support worker is critical to finding and maintaining housing. When this support was not available, family networks were crucial to finding housing options (Jones et al., 2014). The authors argue there is a need for mental health agencies to provide more practical support to assist people to access housing in rural areas.

### Consequences of Lack of Housing and Support

#### Substandard housing and violent victimisation

In Australia, an appalling consequence of the lack of affordable housing for people experiencing mental illness is that many are often forced into substandard housing. Cameron and Flanagan (2004) examined the lived experiences of poverty and mental illness for people forced into inferior housing in Tasmania. They documented a range of negative consequences for their participants including feeling isolated, insecure, unsafe and socially discriminated against. They further argued that these stressors exacerbated their participants’ mental health to the point where hospitalisation resulted (Cameron & Flanagan, 2004). Being forced into undesirable housing situations also makes people “particularly vulnerable to exploitation by unscrupulous landlords”, which in turn leads to them “being forced to move on a regular basis and to live in inappropriate or substandard accommodation” (Cameron & Flanagan, 2004, p. 46). Research has also shown that people experiencing mental illness are at risk of exposure to violent victimisation in substandard and unsupported housing, including public housing and boarding houses (Cameron & Flanagan, 2004; Johnson et al., 2007; MCHA, 2009a; Robinson, 2003).

#### Housing insecurity

The MHCA has reported that a lack of affordable and suitable housing can mean people with a mental illness may be forced to live with carers even if they would prefer to live independently, thereby enjoying less opportunity for independence (MHCA, 2009a). This arrangement can generate housing insecurity as living with parents or other family members is not a legal tenure, and does not necessarily provide long-term security for the person in need of care (MHCA, 2009a). However, the provision of accommodation and support by carers is a significant protective factor for people experiencing mental illness, and a key reason people experiencing mental illness do not become homeless (Flanagan & Cameron, 2004; MHCA, 2009a).

Carers report experiencing stress and anxiety when they have been forced to house adult children with no other housing options, particularly when those for whom they care are violent or threatening (Cameron & Flanagan, 2004). Accommodating loved ones can also lead to disruptions in their own housing security (Cameron & Flanagan, 2004). These findings, in part, explain why carers with family or friends in supported accommodation or residential care report higher levels of wellbeing than those who have family or friends living with them (MHCA, 2009b). Many carers report feeling anxious about what will happen in the future to their loved ones, particularly when older parents die (Cameron & Flanagan, 2004; FCDC, 2009; MHCA, 2009a, 2009b).

More recent research has shown that all types of carers report significant impacts as a result of their caring commitment. For example, in a survey conducted by Wesley Mission, up to 85% of carer respondents reported caring had a negative impact on their mental and physical health (Wesley Mission, 2014). Notably, the survey revealed that when a relative was living at home with a carer the negative impact was greater, and that female carers were more likely to be negatively affected than males (Wesley Mission, 2014). It is clear that the failure of governments to adequately fund affordable and accessible housing has placed an unsustainable burden on carers. It is also evident that women are bearing the brunt of this impact, and experience a decline in their health as a consequence.

Several studies have documented the financial costs facing carers as they attempt to secure housing for those in their care. Carers can be forced to subsidise rent, purchase rental properties, and provide money for bonds or funds for repairs/modifications (Cameron & Flanagan, 2004; Carers Victoria, 2014; MHCA, 2009b). Even when accommodation costs are supported or subsidised, the cost and availability of suitable furniture and whitegoods creates additional burdens for carers, the latter being especially acute in rural and remote areas where second hand items are more difficult to acquire (MHCA, 2009b). Carers also report the need to subsidise food costs because of the high rental costs of their loved ones (Cameron & Flanagan, 2004).
As a consequence of these financial demands, carers report experiencing financial hardship. The Wesley Mission survey found that 57% of respondents indicated their financial situation or work/study situation had been negatively affected (Wesley Mission, 2012). More specifically, the demands of caring meant that more than half of the respondents needed to work less, and 35% had to take a job with lower salary and less responsibility (Wesley Mission, 2012). Financial constraints had resulted in approximately half of those surveyed reporting that they had been forced to rely on government assistance, and one third had to sell possessions to make ends meet (Wesley Mission, 2012). Consistent with these findings, carers are over-represented in the lowest two income quintiles of household income (Carers Victoria, 2014).

WHAT IS NEEDED?

There is a pressing “need for increased housing options which include a range of short, medium and long-term tenancies with corresponding capacity to maximise independence, choice, security of tenure and adequate provision of support” (Cameron & Flanagan, 2004, p. 40). It has been shown that good quality housing can be a protective factor against mental illness (Lambert et al., 1999), while stable housing has consistently been shown to be critical to the effective management of mental illness and enhanced social functioning (Australian Housing and Urban Research Institute, 2002; Cameron & Flanagan, 2004; Robinson, 2003). In light of this, the Senate Committee (Commonwealth of Australia, 2015b) recently recommended the development of a national affordable housing plan that reflects a commitment to the increased provision of public housing. As Cameron and Flanagan (2004) contend:

Safe, secure, affordable and adequately supported accommodation is essential for people living with serious mental illness to manage their illness, maintain good health and maximise their capacity to participate in the community. (pp. 47-48)

The need for housing to be provided with adequate support has been established by researchers who have found that, even when housed, people with chronic or untreated mental health issues are often at constant risk of losing housing (Cameron & Flanagan, 2004; O’Brien et al., 2002; Robinson, 2003). Based on research examining the relationship between persistent homelessness and mental disorders, Robinson (2003) explored the factors which impacted on “people’s capacity to find and hold onto, stable housing” (Robinson, 2003, p. 12). Robinson’s findings were significant in that she argued stable accommodation alone would not ‘fix’ the issue of persistent homelessness in the context of mental disorders. What is needed, she argued, is a point of stability that is more than simply “long term accommodation … there were in fact many factors which needed to come together to construct that stability, including good medication, validation and support, affordability, location and acceptance” (Robinson, 2003, p. 28). Housing was, however, identified as “critical in the development of stability and health” (Robinson, 2003, p. 34).

O’Brien and colleagues (2002) conducted a study with those who experienced a psychiatric disability, examining their views on what was needed to access and maintain their housing. They identified a range of formal and informal supports required to keep people housed, including support to access housing, as well as practical support with daily living activities (provided by formal and informal support networks). Social networks, and having someone to talk to or listen were also identified as important. In particular, the authors argued that support also needs to be provided by people with an “understanding of mental illness and the way it impacts [because this] is central to supporting people with a psychiatric disability [to] stay housed” (O’Brien et al., 2002, p. 60).

Furthermore, the MHCA (2009b) reported a range of factors which carers considered crucial to the accommodation needs of their loved ones. Carers reported that consumer accommodation should be “quiet and safe/secure; therapeutic; affordable; long-term or permanent; age-appropriate; in good condition; well-located; culturally appropriate; and involve a choice of independent, or group house/clusters” (p. 51). Carers have also stressed the importance of having various accommodation options to meet consumer needs and support requirements, as well as provide consumers with choice in their accommodation. Options raised by carers included step-up/step-down facilities for support before or after admission to a psychiatric unit; transitional accommodation to provide consumers with the skills for independent living; and supported independent living models such as the NSW Housing and Accommodation Support Initiative (HASI) (MHCA, 2009b).
HASI provides people experiencing mental illness with access to stable housing, ongoing clinical mental health services and accommodation support, with the aim of achieving recovery from mental illness. It began in 2002 as a partnership between Housing NSW, NSW Health, NGO Accommodation Support Providers (ASPs) and community housing providers. HASI has continued to evolve to meet the diverse support and housing needs of consumers. Support is ongoing and can vary over time according to need. And the programme is available for those who need housing and for those who own or rent privately. Funding for HASI included the costs of housing but this has not been an ongoing commitment, which has been noted as a challenge given the “extremely tight housing market” (p. 15). An independent evaluation found HASI contributed to improving the mental health and quality of life for participants, and assisted most consumers to maintain stable housing (Bruce et al., 2012).

Another integrated housing and care program is the Melbourne-based Doorway, which supports people experiencing mental illness and at risk of homelessness to access private rental accommodation. The Victorian government funded Doorway for 50 people between 2014 and 2018, and delivers the service through a partnership between the Alfred Hospital, Latrobe Regional Hospital, Peninsula Health and St Vincent’s Hospital, with support from the Real Estate Institute of Victoria (Wellways, 2016). The program focusses on supporting client confidence and choice. With regards to the latter, participants are supported to “choose, access and sustain their own private rental accommodation” (Nous Group, 2014, p. 1). They are provided with support in relation to rental payments, independent living and tenancy management. They are also “empowered to self-direct their support needs by designing and managing their own integrated support teams” and are assisted to “develop and/or extend their informal social supports” (p. 2). An evaluation of the programme found “the majority of participants achieved stable and secure private rental accommodation for the first time in their lives” (Nous Group, 2014, p. 5). It also noted that participants experienced improvements in their mental health and social inclusion. Notably, carers reported that the stability provided by the programme improved their relationships with those they cared for, and made them “feel less isolated” (p. 6).

Melbourne-based HomeGround Services (2016) is a not-for-profit real estate agency, which facilitates access to the private rental market for people at risk of homelessness, including those with mental illness. The programme is auspiced by Launch Housing, one of Melbourne’s largest social housing and homelessness support providers. While this particular programme does not provide support for those housed, it does tackle the challenges of stigma, discrimination and affordability faced by those on low incomes seeking access to private rental. It also seeks to tackle the challenges of housing insecurity by working with landlords to offer longer-term leases (Nissam, 2016). The expertise that Launch Housing has in working with people in need of social housing also positions them as experts in “matching people to [the] propert[y] … that is going to be the right option for them” (Nissam, 2016).

In summary, while there is limited research focusing on mental health specifically in rural contexts, it is clear that the issues faced by carers of family members with a mental illness—as well as those experiencing mental illness themselves—have been steadily documented in a range of reports. Affordable and suitable housing continues to be lacking and support services accompanying the provision of housing are scarce. Mental illness and its impacts on the personal wellbeing of people and their carers is enduringly complex, but the chances of stabilising people in the long term relies on their being able to access accommodation and support in a consistent and planned manner. The models described above provide some examples of programmes that work to achieve this end.
RESEARCH METHODOLOGY

The nature of the research questions to be answered provides the foundation for the approach chosen to carry out investigative studies. In this study, the three core research questions were developed to explore the perspectives of carers, as follows:

- What are the biggest challenges with regard to accessing and maintaining housing for people experiencing mental illness?
- What are the consequences of the challenges described?
- What kind of housing and support is needed for people experiencing mental illness?

Thus, the strategies used to carry out this research project included both a quantitative method and a qualitative method—often referred to as a mixed methods research approach. This was based on the assumption that the commissioning of the study was due to existing concerns about mental illness and housing and support, and the need to develop understandings about the real-life experiences of carers, as well as grasp the extent of the difficulties being faced. Ethical issues were addressed and project approved by the Ethics Committee of Bendigo Health and also by La Trobe University.

A structured survey approach was used and a survey tool developed in collaboration with LMMHCN to capture the views of carers. This was followed by the distribution of 200 surveys to a purposive sample of registered mental health carers using the BHCSS and Mallee Family Care databases. A total of 77 carers returned a survey—an initial response rate of 39%. Data from all questionnaires were coded and entered into the Statistical Package for the Social Sciences (SPSS) for analysis. Data analysis consisted of descriptive statistics as a way of summarising participants’ views on issues of housing.

It became apparent during the analysis of survey data that there were two distinct groups with different experiences of housing. The responses provided by carers who were the partners of the person for whom they cared were markedly different when compared with all other relationship categories (sibling, offspring, parent, other relative, friend/community member). Almost all of the partnered respondents said that the recipient lived with them, while in the mixed group almost half the recipients lived with the carer and just over half lived elsewhere. Other differences were found between the partnered versus mixed groups. For instance, only one of the partnered respondents, compared with 21 respondents in the mixed group, said their current accommodation did not suit their needs; the 10 survey respondents who were awaiting accommodation were all from the mixed group; and none of the partnered respondents indicated they had experienced discrimination in relation to housing, compared to 16 in the mixed group who believed they had. In addition, where there were unanswered questions almost all of the missing data came from the partnered group.

As a consequence, it was apparent that responses given by the partnered group were going to mitigate the importance of the stories being told by the mixed group, so the final analysis is based on the data provided by the 52 respondents who were not in a partnered relationship with the person they cared for. While the experiences and opinions of the 52 carers presented here are not necessarily representative of the broader population of Australian carers, the results are, nevertheless, largely congruent with other qualitative findings and existing literature.

In addition, 10 people were chosen to participate in in-depth, semi-structured interviews. Eight interview participants were members of the LMMHCN and lived in a range of LGAs. Two additional interviewees were recruited through BHCSS to ensure greater coverage of the LGAs in the LMR, although the Shires of Macedon Ranges and Lodden were not represented.

The combination of data from the surveys and interviews form the sources of evidence about the challenges and needs currently being faced by carers in the LMR. It is this body of data, and its statistical and thematic analysis, that provides the foundation on which this report has been built. In addition, a narrative approach was adopted by asking carers to tell their story. A number of direct questions were also asked to gain demographic information such as the carer’s age, the age of the person being cared for, and their current accommodation. To maintain their privacy and to ensure anonymity, pseudonyms are used. All data and preliminary findings were checked carefully and subject to extensive discussions between the three authors of this report.

As in all research projects there are some limitations that need to be acknowledged. This study focussed on the perspectives of carers, and it is important to recognise that the recipients of care may have had different points of view. In addition, the research did not focus on the enabling aspects of the caring relationship but, rather, as outlined above, was designed to investigate challenges and needs in relation to housing and support. The low return rate of only 77 surveys may also mean that some carers did not have concerns about housing and support issues, although, equally, it could reflect the reluctance to share personal information. The researchers acknowledge that while some people have good intentions to respond to surveys, it is not seen as a priority and may even be associated with particular personality traits. It is important, therefore, to maintain a level of caution when interpreting the results.

Both the quantitative and qualitative data provide a useful picture of the housing experiences and needs of this group, but with a limited response rate it is difficult to generalise the results to the broader population. Finally, one respondent, originally living in the LMR, was found to have moved outside the region. Whether temporary or permanent, the move is not thought to have affected the person’s response in a manner likely to skew the results.
DEMOGRAPHICS OF CARERS AND RECIPIENTS OF CARE

The sample consisted of 52 participants, all of whom were over 45 years of age (Table 1). Ninety percent of the respondents were female and 83% were the primary carer. The primary source of income for most respondents was a government pension (Figure 1).

Twenty carers resided in the regional cities of either Bendigo or Mildura, while the remaining 32 resided in rural towns spread throughout the LMR (Figure 2).

The people being cared for by this group crossed the full gamut of age categories (Table 2) and, while the majority were the daughter or son of the carer (87%), there was a small range of other relationships including 3 siblings, 2 parents, 1 other relative and 1 friend/community member.

**Table 1. Age of carers (N=52)**

<table>
<thead>
<tr>
<th>AGE CATEGORY</th>
<th>FREQUENCY</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>6</td>
<td>11.5</td>
</tr>
<tr>
<td>25-34</td>
<td>13</td>
<td>25.0</td>
</tr>
<tr>
<td>35-44</td>
<td>19</td>
<td>36.5</td>
</tr>
<tr>
<td>45-54</td>
<td>11</td>
<td>21.2</td>
</tr>
<tr>
<td>55-64</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td>65+</td>
<td>2</td>
<td>3.8</td>
</tr>
</tbody>
</table>

**Table 2. Age of recipients of care (N=52)**

<table>
<thead>
<tr>
<th>AGE CATEGORY</th>
<th>FREQUENCY</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>6</td>
<td>11.5</td>
</tr>
<tr>
<td>25-34</td>
<td>13</td>
<td>25.0</td>
</tr>
<tr>
<td>35-44</td>
<td>19</td>
<td>36.5</td>
</tr>
<tr>
<td>45-54</td>
<td>11</td>
<td>21.2</td>
</tr>
<tr>
<td>55-64</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td>65 or older</td>
<td>2</td>
<td>3.8</td>
</tr>
</tbody>
</table>
HOUSING AND OTHER LIVING EXPERIENCES

Type of accommodation – Forty percent of the people in receipt of care lived with their carer, and the remainder lived in either private rental, public/community accommodation, in a home they owned, or in supported accommodation (Table 3). These figures differ considerably from the results of the People Living with a Psychotic Illness survey (Morgan et al., 2011). Only 7.7% of people in the present study lived in public housing, compared with 26.8% who participated in the survey of 2010. While a similar proportion of people were living in privately rented accommodation, there was a substantial difference between the numbers of people who lived in a family residence. Forty percent of people being cared for in this study were living with carers in their family home compared with 19% in the 2011 study. A possible explanation of the difference between these percentages may be that the carers in the present study were more motivated to participate because they are directly and negatively affected by this living arrangement (Cameron & Flanagan, 2004; Wesley Mission, 2014).

The particulars of arrangements leading to home ownership or rent of accommodation were not sought, but four of the respondents said that they purchased the home for the person for whom they cared. This appeared to be unproblematic for one respondent who said, “Fortunately, as carer, we have been able to purchase a flat for the person we care for which therefore provides housing security going into the future.” In comparison, another carer found this to be a difficult financial undertaking:

I made a huge sacrifice to buy a humble unit because I could see that my son needed us close by … My husband’s pension was terribly affected because it [the unit] was deemed as an income. I had no choice but to find employment. My son needed to live elsewhere because it affected the rest of the family in a small house. What we did at the time was the only way to give each other some space—mentally and physically.

This raises questions about the extent to which carers would prefer to purchase a home if they had the financial means to do so, and, for those who cannot, the extent to which their own satisfaction with their living arrangements is being compromised.

Importance of housing on wellbeing – The overwhelming majority of participants rated housing as one of the more important challenges faced by the person for whom they cared (Figure 3). This result clearly indicates that issues of housing are critical to the wellbeing of people with a mental illness, and it is not only an important topic to investigate, but essential that people with a mental illness are provided with the support required to ensure their housing needs are being met.

<table>
<thead>
<tr>
<th>TYPE OF ACCOMMODATION</th>
<th>FREQUENCY</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lives in family home with carer</td>
<td>21</td>
<td>40.4</td>
</tr>
<tr>
<td>Private rental</td>
<td>13</td>
<td>25.0</td>
</tr>
<tr>
<td>Public/social housing</td>
<td>4</td>
<td>7.7</td>
</tr>
<tr>
<td>Supported accommodation</td>
<td>4</td>
<td>7.7</td>
</tr>
<tr>
<td>Home owner</td>
<td>9</td>
<td>17.3</td>
</tr>
<tr>
<td>Currently homeless</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 3. Recipients’ accommodation (N=51)

![](image1.png)

Figure 3. Importance of housing for wellbeing (N=51)
Housing meeting their needs – Sixty percent of respondents said that the housing needs of the person they cared for were being met. With the exception of home owners, who appear to be more satisfied with their living arrangements, no form of housing appeared to be meeting their needs more than any other (Table 4). This result is surprising and contradicts some of the responses to questions discussed later. It might be that the majority of people are content with their living arrangements, or it may be that the respondents interpreted the question differently to the way it was intended. For example, while recipients who live with their carer may prefer alternate accommodation, their immediate needs are identified as being met in that they have safe and secure accommodation with their carer. A differently phrased question or follow-up question about their preferences may have yielded a different response about, for example, long-term housing preferences.

Waiting for accommodation – Forty percent of people reported that those they cared for were not living in accommodation that met their needs. Of this group, just over 50% were living with their carer. This supports the findings of the MHCA that people with a mental illness may be forced to live with carers rather than by preference, thereby lessening an opportunity for independence (MHCA, 2009a). Of those 40% who reported housing needs not being met, only half (20%) said they were waiting for suitable accommodation. This is similar to the percentage of people from the People Living with a Psychotic Illness survey (2011) who were on the public housing waiting list (22.7%). Overall, then, 20% of those cared for were reported to be living in accommodation that did not meet their needs and they had no plan for alternative housing.

There was no significant pattern to emerge between the type of accommodation people were living in and whether they were waiting for alternative housing. The only pattern that was noted, unsurprisingly, was that none of the home owners were waiting for alternative accommodation (Table 5).

<table>
<thead>
<tr>
<th>TYPE OF ACCOMMODATION</th>
<th>HOUSING NEEDS BEING MET</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>With carer</td>
<td>10</td>
</tr>
<tr>
<td>Private rented</td>
<td>8</td>
</tr>
<tr>
<td>Public</td>
<td>3</td>
</tr>
<tr>
<td>Supported</td>
<td>3</td>
</tr>
<tr>
<td>Home owner</td>
<td>7</td>
</tr>
</tbody>
</table>

Table 4. Housing meeting needs and type of accommodation (N=51)

<table>
<thead>
<tr>
<th>TYPE OF ACCOMMODATION</th>
<th>WAITING FOR ACCOMMODATION</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>With carer</td>
<td>4</td>
</tr>
<tr>
<td>Private rented</td>
<td>3</td>
</tr>
<tr>
<td>Public</td>
<td>1</td>
</tr>
<tr>
<td>Supported</td>
<td>1</td>
</tr>
<tr>
<td>Home owner</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 5. Awaiting alternative housing (N=49)
The length of time that people had been waiting for accommodation ranged from six months to “years”, suggesting they find it a lengthy or even impossible task. One respondent said that “What is required for her is not available”, which may echo the thoughts of those 20% of people who said the accommodation was not meeting their needs, but did not appear to be waiting for alternative housing either. Perhaps, like this carer, they believe it is not available or too difficult to find, a prospect that will be examined in more detail below.

CHALLENGES OF HOUSING

Carers were asked a series of questions about a number of issues thought to impact on the housing needs of the people for whom they cared. A number of important issues were raised, but the two most significant were housing affordability/financial restrictions, and proximity to carers, families and support services.

Issues that contribute to housing suitability – Respondents were asked to rate the importance of a number of issues that are thought to contribute to housing suitability and sustainability. Housing affordability was by far the most important issue for most people, as illustrated in Figure 4. Accommodation space and proximity to employment were not considered as important, while the other issues, mostly relating to proximity to significant others, fall somewhere in between.

The final question on the survey asked carers what they considered to be the biggest challenge facing the person they cared for with regard to housing. The response to this question ranged from brief one-word answers through to page-long narratives about their current circumstances, all of which revealed some unique and some shared experiences. Like the previous question, the most common answer elicited was affordability, with 15 carers identifying this as a challenge. Access to support, safety, suitability, and the need to be independent, were mentioned as other challenges by 5-6 people, and 1-3 people mentioned access to services, availability, rental history, stability, daily support, reluctance to live alone, transport, loneliness, the ability to maintain house, and the need to be in temporary accommodation while on suicide watch. Some of the comments made by carers in response to this question were as follows:

The portable unit on our property is only a temporary solution. It has been very successful up to a point. But we would like something more stable and permanent in the near future before we as parents/carers get much older.

He needs to feel safe in his own environment; his battles to recover are limited without his own place to call home. Living with parents is not living his own life.

To know she can find permanent housing before I die.

To find a safe place with support available by support workers, mental health workers. To enable him to become an independent person again.
Housing affordability and other financial issues – Housing affordability was further examined by asking participants if they thought cost was a significant barrier to private and public/community rental accommodation. As indicated in Figures 5 and 6, cost is more of a concern with regard to private rental, with 83% of the respondents saying they either ‘agree’ or ‘strongly agree’ with this statement, but it is also considered a barrier within the public housing sector with 54% ‘agreeing’ or ‘strongly agreeing’ with this statement. These results support earlier research that suggests people who experience mental illness often have low incomes, which impacts on housing affordability, particularly in the private market (Cameron & Flanagan, 2004; Jones et al., 2014; Lambert et al., 1999). Moreover, the high number of participants responding ‘neither agree nor disagree’ to the public housing statement suggests that a considerable number of respondents are not familiar with the costs associated with public housing. As will be discussed later, there are significant numbers of people who have had no involvement with public housing services, which may explain why they were unsure about issues of cost.

There was a relatively even distribution between carers who thought the person they cared for had adequate financial means to live independently (38.5%) and those who did not (40.4%), with the remaining respondents either unsure or not answering the question (Figure 7). While 40.4% may not be a majority, it is a significant proportion of individuals and highlights what may be a concerning problem for many. As indicated in Table 6, the carers who lived with the recipient were significantly more likely to report that they did not have the financial means to live independently, which may be one reason for their cohabitation.

When asked if the person they cared for was able to manage their own living expenses, half of the respondents answered ‘no’. Forty percent of carers indicated they were managing the person’s affairs themselves, while the remainder were being assisted by a trust fund (2%), a service provider (4%) or Centrelink (4%). Some of the respondents who said that they helped manage living expenses were keen to qualify that response by saying that they ‘helped’ rather than managed the finances as a way of preventing mismanagement or avoiding a situation in which the person they cared for was unable to pay for daily living expenses.

<table>
<thead>
<tr>
<th>TYPE OF ACCOMMODATION</th>
<th>FINANCIAL MEANS TO LIVE INDEPENDENTLY</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>With carer</td>
<td>2</td>
</tr>
<tr>
<td>Private rented</td>
<td>8</td>
</tr>
<tr>
<td>Public</td>
<td>2</td>
</tr>
<tr>
<td>Supported</td>
<td>3</td>
</tr>
<tr>
<td>Home owner</td>
<td>5</td>
</tr>
</tbody>
</table>

Table 6. Financial means to live independently and accommodation type (N=49)
History of housing instability – Thirty-one percent of respondents said the person they cared for had experienced some form of housing instability. This was mostly due to financial difficulties that impacted on housing affordability, and mental health and/or substance use impacting on their ability to live independently and adequately care for themselves. In accordance with findings by other studies (Cameron & Flanagan, 2004; MHCA, 2009a), some carers said the recipient had limited self-care abilities, and others reported that the person they cared for felt lonely and isolated or stressed living alone without adequate support:

He cannot live on his own. He cannot do basic household chores, and he is bored and overspends his money that is supposed to be for rental and utilities.

We tried various types of housing independence over the last 40 years. Too isolating. Trouble with other unstable tenants. Budgeting problems. Loneliness.

Location of housing – Participants were asked a range of questions about suitable housing in their region, which revealed a broad lack of knowledge about the availability of suitable housing and the services able to help source these. Forty-five percent of respondents ‘agreed’ or ‘strongly agreed’ that more suitable housing is available in metropolitan areas compared with rural areas. However, with 39% providing a neutral response, the evidence suggests that many carers did not know, which is further evidenced by the 69% of respondents stating they did not know how the availability of housing in the Loddon Mallee compares with other regions in Victoria (Figure 8), or the 50% who did not know whether it had changed over time.
Carers were asked if the person they cared for would be able to accept accommodation outside of their area. Fifteen percent said that they would, a further 15% did not answer the question, but a significant majority said that they would not (69%). Of the 40 responses to the question about what they considered to be a major barrier to moving outside of the area, the majority (27) said that proximity to family/carer support was essential. This is exemplified by the participant who said, “[being] away from his support would be so detrimental to his health” due to his need for security being a significant issue. Another said, “He needs to be close to people he knows and that care about him. We have tried this and it didn’t work. He cannot drive and needs to be close to family for continued love and care.” In order of frequency, respondents mentioned access to services (9), transport issues (3), access to employment/education (2), financial implications (2) and isolation/disorientation (2). These challenges are particularly pertinent in rural and regional areas where there are fewer transport and health services in less populated areas.

Notably, the negative impacts of moving from an area were not limited to the care recipient but also recognised as potentially affecting carers themselves. One carer said that if the woman she cared for moved out of the area, she “would not be able to support her due to my age, as I am 70.” The issue of proximity to ensure that carers are able to provide support has been raised by a number of other studies too (Cameron & Flanagan, 2004; FCDC, 2009; MHCA, 2009a, 2009b).

**Discrimination/Stigma** – Thirty-one percent of respondents thought that the person they cared for had experienced some form of discrimination or stigma in relation to housing, but this figure was substantially higher for those not living with their carer (25%) compared with those living with their carer (6.3%). Many more ‘agreed’ or ‘strongly agreed’ that discrimination was a significant barrier to accessing private (71%) and public housing (56%), suggesting that the perception of discrimination exceeds direct experience (see Figures 9 and 10). While fewer people perceive discrimination to occur in relation to public housing, with 56% ‘agreeing’ and 25% ‘neither agreeing nor disagreeing’ with this statement, there is evidently a widely-held view that access to public housing, although established for the more vulnerable members of society, is subject to discriminatory processes. While the majority of respondents ‘agreed’ with the statements that discrimination was a barrier, interestingly most of the 45-54 age group selected ‘strongly agree’ (67%), compared with the two older groups who tended to select ‘agree’ or ‘neither agree nor disagree’.

**Figure 9. Discrimination as a barrier to private rental (N=49)**

**Figure 10. Discrimination as a barrier to public housing (N=48)**

**Figure 11. Difficulty with finding suitable accommodation (N=50)**
The Perspectives of Carers on Housing Needs and Mental Illness

Housing services and availability – Most participants agreed that it is difficult to find suitable housing (81%) (Figure 11), but only 37% of those who were not waiting for accommodation, compared with 80% who were waiting for accommodation, said they ‘strongly agreed’ with this statement. Similarly, 24% of those whose housing needs were being met ‘strongly agreed’ with this statement, compared with 76% of those who housing needs were not being met.

This may offer some explanation for why people were not seeking alternative accommodation, even though they indicated that their housing needs were not being met. If they strongly believed that it is difficult to find appropriate accommodation, they may have been reluctant to seek it out. Alternatively, this group may have previously looked for alternative accommodation without success, leading them to the opinion that it is difficult to find.

Only a minority of participants felt that information about the availability of suitable housing was easy to find (Figure 12). The carers of people who were living in public housing or supported accommodation were more likely to think this information was easy to obtain, most likely because they had dealt with services to gain access to the accommodation in the first instance.

Even fewer respondents felt that the process of obtaining suitable housing was easy to navigate (Figure 13). Taken with the answers provided in the next section, this suggests there is a need for greater professional or expert support for those seeking suitable accommodation.
WHAT IS NEEDED?

As already mentioned, carers’ responses showed that 40% of care recipients were not having their current housing needs met. Twenty-two carers among this group made suggestions about what was required to better meet their needs. The most common needs included being closer to family, carers and services; living independently; having access to supported accommodation; living with or closer to people of similar age; and securing accommodation that was cheaper, but of good quality.

Forty-four percent of respondents said the person they cared for had other specific needs that were difficult to meet. Among the 23 responses, there were some one-off examples that related to particular circumstances, such as the issue of having a house that was too big to manage. But in the main responses related to financial difficulties and the need for more supported accommodation or intensive services. Several respondents said that the person they cared for required regular assistance with activities of daily living (such as showering, shopping, budgeting, etc.), and several said the person they cared for was unable to manage or maintain an adequate level of cleanliness, which would not be tolerated by some housing providers.

Eligibility for public housing – When asked if public and community housing should give priority to people living with a mental illness, there was a fairly equal split between those participants who believed it should (48%) and those who ‘neither agreed nor disagreed’ with this statement (42%). Respondents who indicated that their recipient of care had adequate financial means were more likely to ‘agree’ (39%) or ‘neither agree nor disagree’ (61%), whereas the carers of those who did not have adequate financial means were more likely to be evenly spread between ‘strongly agree’, ‘agree’ and ‘neither agree or disagree’ (30%, 25% and 40% respectively). This suggests that when finances are perceived to be constrained, greater importance is placed on priority access to housing for people with a mental illness. However, when respondents were asked if the eligibility criteria for public and community housing was too narrow, the most prevalent response was ‘neither agree nor disagree’, indicating that knowledge of criteria might also be limited (Figure 14).

Safety and Protection – Most respondents agreed that the person they cared for required protection and safety in housing (Figure 15). The respondents who reported that the current housing was not supporting their needs were more likely to ‘strongly agree’ with this sentiment. In comparison, those who answered that their housing needs were being met were more likely to choose the moderate option of ‘agree’.

Assistance from organisations – Most respondents said the person they cared for had not received professional assistance to find accommodation (Figure 16). Likewise, the majority were not aware of good housing examples for people with a mental illness (Figure 17). While those who had engaged with a support organisation were more aware of services, it was not clear whether these were the services they had been involved with, or if they were aware of others as well. The housing services that were used generally provided a satisfactory service, with 80% of those who had received support finding the service ‘helpful’ or ‘very helpful’ (n=15).
When asked how the services could have been improved, participants made comments about specific programmes and the system in general. One respondent called for “more options/choices and not just private expensive rentals,” while another said “more housing for singles” was needed. “The accommodation she requires does not appear to be available in the country area,” was another response given, along with a wish “To have an office to help assist us to find accommodation.”

Examples of good housing – Seventy-seven percent of carers were unable to describe examples of good housing, indicating limited experience with effective options or solutions. Those examples that were provided by respondents most commonly described supported or shared accommodation models, suggesting that ‘good’ housing involves more than just a roof over one’s head and entails adequate support as well.

A couple of participants raised an important issue not examined by the present survey: the needs and wellbeing of carers themselves. For example, in one family the person being cared for was reported to be content living with the carer, but the rest of the family were “greatly affected by the mental health issues from which there is never any respite.” Another carer summed up the emotional strain of the role by declaring all that was wanted was “to know she can find PERMANENT housing before I die,” indicative of the drain on carers’ energies caused by perpetual uncertainty.

The frustration and emotional burden experienced by carers, particularly those who live with the recipient of care, are also reflected by the frequency with which they selected ‘strongly agree’ or ‘strongly disagree’ in response to the statements in the survey. By contrast, the carers who did not live with the recipient of care were more likely to select the moderate responses of ‘agree’ or ‘disagree’. This might be indicative of the deeper emotional attachment that comes with close and constant proximity to the recipient of care. Equally, it may be indicative of the extent to which carers themselves are negatively affected by the disruptive impacts of mental illness and housing dilemmas. This issue was, in fact, raised within the qualitative interviews and is also indicated in the extant literature.

Earlier studies have certainly reported on carers’ experiences of stress and anxiety, and the experience of living with an adult child requiring care (Cameron & Flanagan, 2004; Wesley Mission, 2014). Stress is often greater for those carers who live with the person they care for compared with those who live in supported accommodation or residential care (MHCA, 2009b). Moreover, many older parent carers report feeling very anxious about what will happen to their adult child when they die (Cameron & Flanagan, 2004; FCDC, 2009; MHCA, 2009a, 2009b) when care arrangements have depended on living together. The needs of carers (and other members of the household) were not examined explicitly in this survey, but statements by a number of respondents suggest that carers’ health and wellbeing is an important area to explore, and should be factored into assessments of housing suitability.

As noted at the outset, there are a variety of issues that impact on housing security and stability for people with a mental illness. However, financial challenges, including housing affordability, and the need for adequate and close support, are the two key findings in this survey data. For many people, it seems, living with a greater sense of independence is an important goal, but one that may be hard to realise within the current housing system.

These findings highlight only some of the housing-related difficulties experienced by people with a mental illness and their carers, and raise some interesting questions about accessing and engaging with service systems. There appears to be a lack of assistance—either sought or offered—to meet people’s housing needs now or as their circumstances change. In accordance with earlier studies, the findings show there is demand for a variety of accommodation options, and these must be flexible to meet the changing needs of people and their carers as health and support needs change over time (MHCA, 2009b).
A ROOF OVER YOUR HEAD UNDERPINS YOUR LIFE. IF YOU HAVEN’T GOT THAT, YOU’RE IN BIG STRIFE. (LEONARD)

DEMOGRAPHIC CHARACTERISTICS OF INTERVIEW PARTICIPANTS AND CARE RECIPIENTS

Interviews were conducted with two men and eight women. Participants represented a range of LGAs in the LMR excepting the Shires of Macedon Ranges and Loddon. All 10 interviewees were primary carers for their adult children. All described their children’s mental illness as severe and persistent.

The following discussion is organised to reflect three overarching themes that emerged from the interviews and that correspond to the key research questions. These themes are: the challenges of accessing and maintaining housing, the consequences of lack of housing and support, and housing needs for those experiencing mental illness. Each theme has several sub-themes that are described sequentially below. However, it will be evident from the quotes of participants that the different themes are often interconnected, as shown, for example, in the observation shared below by Lucinda, a carer from a small town in the Shire of Buloke:

I see [providing care] as a wheel that’s broken up into sections and if you can combat each little section, eventually you’ve got a whole wheel, but at the moment it’s got cracks in all the areas and we’ve just got to try and fill those cracks … [and] … if you can’t do the housing bit … you’ve got this gaping hole.

Lucinda’s comments offer a useful starting point for conceptualising the centrality of housing to the array of complex issues the interviewees outlined. Lucinda’s choice of the word “combat” is also telling of the sense of struggle—the fight—experienced by carers as they go about trying to ‘fill the cracks’ in our social welfare system in order to resolve the housing issues and related difficulties of those for whom they care.

CHALLENGES OF ACCESSING AND MAINTAINING HOUSING

Availability of affordable housing

As we know, the lack of affordable housing in Australia is currently considered to be at crisis point (Anglicare, 2016; Costello et al., 2013; Toohey, 2014). We also know that people experiencing mental illness face additional challenges accessing suitable housing (MHCA, 2009a), especially in regional and rural areas (Craze & Reddy, 2014; Jones et al., 2014). All interview participants confirmed this by identifying the dearth of available and affordable housing across the LMR as a key concern. All forms of housing including public/social, private and crisis accommodation were identified as being extremely limited in availability.
For some participants, public housing, in particular, was seen as an unrealistic option for the person they cared for because of lengthy waiting lists for single people. This was indicated by Emmy, who felt unwilling to pursue public housing for her 29-year-old son in Bendigo because of the anticipated wait time for him to be housed. “He would probably never get housed,” she said, “the one bedroom units are very rare within public housing … so I haven’t encouraged him to go down that path … [but] we need to be living separately now.”

Several participants raised the importance of having a choice of housing options for people experiencing mental illness, a theme that will be discussed later. Specifically in relation to accessing public housing, participants expressed concern that the choice of locations was inadequate. Location was deemed critical due to the intensive nature of the carer support role, and the carer’s need to be nearby. As we have seen, the importance attached to location was also reflected in the survey data, with most respondents reporting that the person they cared for would not be able to readily accept accommodation in another location because of the family support they required.

Private rental accommodation was seen by the majority of participants as a restricted option too, and that which was available was often substandard and/or out of reach financially. This is consistent with a study by Anglicare Australia which found that rental affordability in regional areas for those in receipt of income support payments “remained uniformly very low” (Anglicare, 2016, p. 82).

As Leonard, who cares for his 36-year-old daughter in a regional centre in the Shire of Campaspe, said in his interview for the present report: “In small towns there’s not much to rent. Or if it is, it’s a real mess.” Some participants explained that those they cared for were able to sustain private rental for a period of time, but indicated the role of the carer was critical in maintaining the arrangement, and often entailed additional financial and emotional demands. Private rental was more sustainable for people living in a partnership with dual incomes, making rent more affordable. However, carers noted that when relationships broke down, housing often became unaffordable as a result.

Supported and emergency housing for people experiencing mental illness in rural and regional areas was seen as practically non-existent by most interviewees. Gillian, who cares for her 46-year-old son at their family home in the Shire of Central Goldfields, also thought that people with other forms of disabilities received better access to housing: 

_They don’t identify people with mental illness needing that emergency housing at all. It just doesn’t come into the equation … If you’re autistic, or you have a physical disability, you seem to be able to manage to get housing. If you’ve got a mental illness it’s not even on the table._

Gillian’s experience is borne out by the evidence—it has been documented that the provision of supported accommodation for people with intellectual disabilities far outweighs the provision of mental health supported accommodation (FCDC, 2009). The Office of the Public Advocate has also highlighted the lack of emergency and supported accommodation for people experiencing mental illness across the LMR (OPA, 2014). Another interviewee who highlighted the lack of supported accommodation for people experiencing mental illness was Karen, who cares for her 33-year-old daughter. Karen lives in a rural town in the Shire of Gannawarra, and commented on the lack of housing for women in particular and the need for greater government investment:

_[H]ousing here for people with a mental disability, it is very, very short. Like there’s nothing. What I can see is we’ve got one independent living house … and that’s for men, but we need one for women … they’re probably more vulnerable than men. The government needs to channel their money towards that sometimes I think._
In Lucinda’s case, her son, for whom she is primary carer, currently resides in a caravan on her property because there is no emergency accommodation available in the small farming town where they live. Her son was forced to move three times during the previous two years because of a lack of suitable housing in the area. She describes the combination of challenges with regard to the lack of housing in all forms:

In rural areas we definitely do suffer from a lack of public housing. There just is not enough ... [my son] had investigated going to Bendigo and the Housing Commission people told him ... there would be a 10-year wait for him because he was a single man ... Private rental, apart from finding the money for the bonds and the month’s rent, they’re very exorbitant. Whilst [being in Bendigo] would have put him closer to services, it was going to put a huge strain on his finances, which are very limited when you’re not working, in fact it put it out of reach.

Lucinda also expressed concern that her family was being ‘punished’ for choosing to live far from a regional centre, and felt that basic services to maintain people’s welfare should be available regardless of where they lived:

There should be no reason that you should be penalised simply because of the choice you have made ... You should be able to educate your children, you should be able to have all medical services that are necessary and ... have all public transport ... and any other necessities to maintaining an orderly life, like housing.

Low income

The limited availability of affordable housing in Australia compounds the difficulties of obtaining housing for people on low incomes, particularly those on government support payments. This issue was identified by all carers interviewed for this project, most of whom were caring for someone in receipt of either Newstart Allowance or the DSP.

Kirsty’s 29-year-old son had lived with her in Bendigo for the past two years since losing his own home after his mental health deteriorated and he became unable to work. Reflecting on the challenge of finding private rental accommodation on a low income, Kirsty remarked, “He is on the dole at the moment ... So private rental on Newstart is impossible. There’s nothing you can really do there ... His father is not in a position to help and I couldn’t possibly afford another rental on top of my own expenses.”

Gillian observed a similar situation for her son who was in receipt of a DSP: “How do they afford the rent? They can’t, and that’s why we’ve got so many homeless people suffering mental illness — there’s nowhere to go, nowhere they can afford to go.”

Being on a low income generated other financial challenges for those in locations far from regional centres. The costs associated with private travel to access clinical mental health services, and the inadequacy of public transport in in regional centres, were raised by several participants.

As Lucinda explained:

My son, when he goes down to Bendigo, he has the psychiatrist which is $200, we fill the car up, so $60/$70 there, then you’ve got to have a lunch and a drink because it’s two hours down to Bendigo and back again ... so that’s $300 ... it’s $600 or something a fortnight that they get.

Lucinda’s experience reveals how a single trip to access essential mental health care can consume close to 50% of an individual’s income on a government support payment. The impossibility of affording rent in these circumstances is self-evident. Other studies have also identified long travel distances to reach mental health services as an issue that disadvantages people in rural areas (Browne & Hemsely, 2010; Jones et al., 2014).
Stigma

Stigma was perceived by all the carers to have impacted, subtly or overtly, on the person they were caring for, including on their access to housing. Leonard described how stigma served to limit access to private rental accommodation in the following way:

*You can imagine if someone has got three applicants for the flat, and they say: this person here has a crook back and hasn’t worked for a while but it is going all right and hopes to get back to work; this person here has been off with cancer for a while. They haven’t been able to work but they’re nearly right. This person has got schizophrenia. What chance has a person with schizophrenia got of being selected? … I think people [believe] will they be unreliable and not pay their rent … Some of those things are true. Because of their health they might be unreliable in paying their rent. They might have behaviours which the general community finds difficult … [but] … A lot of it is to do with stigma and lack of understanding.*

This view is consistent with a study undertaken by Brown and Hemsley (2010), which found that mental health carers saw stigma as a “major issue” from “estate agents” (p. 25). Consequently, overcoming stigma associated with mental illness was also highlighted by some participants as an important factor for improving access to affordable housing.

Laura lives in Swan Hill and has cared for her 40-year-old son since he was a teenager. Her view is that, even when suitable housing can be found for people experiencing mental illness, stigma from neighbours generates a barrier: “People don’t want them next door to them. It’s sad, they’re like the lepers of years ago”.

Lucinda also observed the prevalence of stigma in the small town where she lived and how it operated as a barrier for people trying to access public services like a community car:

*T hey’re trying to get a public car with a volunteer driver … Unfortunately, my past experience and knowledge of that is that it’s predominantly for the aged … If you get somebody with a mental health issue, because of the stigma, people say ‘they’re only druggies’… I wouldn’t say it’s stronger out here in the country, but it’s more fervently upheld because of the old ways. As we don’t have enough of the younger population to break down some of those barriers.*

As Lucinda indicates, stigma can persist more stubbornly in rural areas, despite the view often perpetuated in pioneer mythology and the media that rural communities are closer knit and better at looking out for their members.

Sometimes stigma was able to be alleviated when carers approached real estate agents directly and advocated on behalf of those for whom they cared. Emmy’s comments, which describe taking this action, reveal the demanding and time-intensive nature of the process:

*I got to a point where … I just didn’t think we could continue living together. Things were getting a bit tough. So I would search out the private rentals, I’d fill out the whole application, go and pick him up, leave work, so I had a very supportive manager at the time … I knew we were up against it basically. So I would be just upfront with people and I’d say, ‘Oh, you would notice from Tim’s application that he doesn’t have rental history and that he’s on the disability support pension’. There is a letter from me, that I will guarantee that the rent will be paid and that the property will be maintained, and assuring you that he has strong family support.*

Notably, in the experience of the two carers below, obtaining private rental accommodation was ultimately dependent upon the personal attributes and knowledgeability of individual real estate agents. For example, Emmy learned that her real estate agent had a personal experience of mental illness and would be more inclined to approve a lease. Similarly, Leonard obtained private rental accommodation for his daughter because the agent was also involved in the disability field. These examples highlight how precarious the market provision of housing can be when it comes to meeting the needs of people experiencing mental illness.

Nature of mental illness

Most interviewees described their children’s lives as being characterised by a history of housing instability, intimately connected to the nature of their mental illness and their capacity to maintain well-being. This was consistent with other studies that have identified the significant links between mental illness and accessing and maintaining housing (MHCA, 2009a; O’Brien et al., 2002; Reynolds et al., 2001).

Emmy’s 29-year-old son recently returned to living in their family home after renting privately. While renting, he became unwell and his capacity to maintain his housing was undermined by impaired decision-making and organisational skills associated with his illness. As Emmy explains:

*[T]he new Mental Health Act came in … psych services took him off the community treatment order and he immediately stopped taking his medication … So his relationship broke up … he stopped paying the rent … One of the impacts of my son’s mental illness appears to be poor decision-making and challenges with planning, including in regards to budget management … This is the tricky thing with mental illness … it’s the affordability of the place, but it’s also to me, the fact that he’s just irrational.*
Emmy’s comments point to the tension underpinning the current legislative environment, which endeavours to promote people’s human rights and autonomy by prioritising voluntary treatment for people experiencing mental illness, even though the refusal to take medication may undermine autonomy and wellbeing.

Amy lives in a rural town in the Shire of Mount Alexander and cares for her 39-year-old son, who recently resumed living with her after being evicted from a substandard private rental property because the owner intended to renovate. Amy described how her son struggled to maintain independent living due to the nature of his mental illness, and her involvement was critical to his survival:

He’s not able to care for himself. He’s too chaotic in his mind. Even though he wasn’t living with me, I was still very much involved—laundry, everything else, otherwise he would just wear dirty clothes. He gets very stressed and can’t cope and won’t eat … well he’ll just eat Mars Bars … if it wasn’t for me giving him meals … I don’t think my son would be alive without me. I’m not patting myself on the back. I’m just stating that for a lot of people with mental illness, they wouldn’t be around if it wasn’t for their families being there.

Several carers interviewed, including both Emmy and Amy, alluded to the specific challenges of caring for someone with a mental illness who is unwilling or unable to engage with support services and manage their condition. As Emmy reflected, this added another layer of complexity to the task of solving the housing dilemma:

My son isn’t interested in engaging with support. It’s not about independent living skills. It’s not as simple as, ok, okay, so if there was a place that was available that was affordable, and he had somebody working with him regularly around independent living skills, it would all be fine. He wouldn’t accept that … he would find that quite humiliating.

Lack of support services

In common with other studies (Craze & Reddy, 2014; Jones et al., 2014; MHCA, 2009a) several interviewees identified a lack of mental health and other services in rural areas. In small rural towns outside regional centres, in particular, the lack of services, including public transport, meant that sustaining housing was difficult even if housing was available. As Leonard comments:

Maybe you can get a house in one of these little townships … The trouble is, there’s no services. There’s not even transport. So you might get a house … but you’re marooned there. You haven’t even got anything. No service, no buses, no trains … So you really can’t afford to live there, otherwise you’re just going to get sick.

The need for mental health support to keep people housed has been well documented (Cameron & Flanagan, 2004; O’Brien et al., 2002; Robinson, 2003). Lucinda’s personal account reflects this, revealing how, upon release from hospital, her son was unable to access psychiatric support services in the small town where they lived in the Shire of Buloke.

My son said, ‘Mum I’m going home and I’ve got no support’. And there was no support. I investigated. District nurses are not trained up here to visit mental health. Bendigo triage will come up and visit them as far as Charlton … There’s no one that’ll come out … They’ve started to come to Wych[proof] now, but that’s it. … If you have physical illness, you come home after you’ve attended rehabilitation to the district nurse, home help, whatever else you need basically. So that could be your physio … all of these are put into place before you leave. You leave hospital in Bendigo with a mental illness with nothing … they send you home. Now in my son’s case we kept a home for him, but what about the people that don’t have a home?

Lucinda’s experience clearly highlights the persistent bias in the focus of health care, which prioritises those experiencing physical ill-health over those with mental illness—and outside regional centres in the LMR the inequity appears to be worse.
The lack of support to help carers navigate the housing needs and changeable competency levels of the person they cared for was identified by several interviewees. Emmy explained:

As a carer you are constantly guessing about the right level of responsibility to expect or ask for from the person. If you load too much responsibility on the person too quickly they can experience a relapse that can take months or longer to recover from. If you don’t give them enough responsibility they don’t have the opportunity to grow and develop self-confidence in their skills. In regards to keeping a roof over my son’s head I am really just making it up as I go along. There is no guide or advisor to assist you with the decisions you need to make daily in your role as a support person.

Kirsty and Amy also commented that, in their experience, mainstream health care services like GPs are not always helpful in terms of providing support and information outside the prescription of medication. Describing the lack of advice offered by her GP, Kirsty observed: “At no point did he say, ‘You could hook into this and you can do that.’ There was no information at all. So from a consumer point of view it’s really challenging … I wouldn’t even know how to get [him] on a [public housing] waiting list. I wouldn’t have a clue … The doctors don’t tell you.”

Finding support to navigate service systems like Centrelink was also highlighted by Kirsty as a huge challenge for her and her son while he was unwell. Kirsty felt that, if she had not been available to support him through an arduous process of applying for a Newstart Allowance, he would have had no income and become homeless:

[C]an these services not see? Do they not understand mental illness? … I had to try to help him get onto Centrelink online, and we went to Centrelink, and then we had to go home. The thing at home didn’t work so we went back to Centrelink. Then by the time we got back to Centrelink, they said ‘Oh, that’s expired, now you’ve got to do it again’. So it was like three times and I had to sit with him at home and do it and … at the end of the form, he was wrecked … I just don’t think that these services understand how mentally taxing it is for someone with a mental health issue, because he’s exhausted. He would be on the street now because he just wouldn’t know what to say and he’s not silly. He’s an intelligent person.

CONSEQUENCES OF LACK OF HOUSING AND SUPPORT

Housing instability and insecurity

A key consequence of the challenges described above in relation to housing and support was that most people receiving care were reported to have histories of unstable and insecure housing since the onset of their mental illness. The impacts of this on sufferers and their carers have been considerable. For example, Lucinda emphasised that her son, Brian, had moved three times in the past twelve months, which generated constant uncertainty and financial pressure. The financial pressure, in particular, was compounded by living in a small town, which meant paying higher travel costs. These circumstances produced enormous stress that only exacerbated Brian’s mental illness and hampered his recovery.

“The housing is a huge issue and I think it compounds their problems,” said Lucinda:

When you’ve got a mental illness and the stresses involved in this, this escalates everything right out of proportion and made life very difficult for everybody … So obviously their recovery is so much slower because of this extra stress and worry. With that is the financial stresses and worry which [is greater] because of the distance. So your recovery expectation is going to be half, I would suggest, of what you could expect … in a city where things are … closer and more readily available than what they are here.

Notably, only two interviewees were able to report a stable housing history for the people they were caring for because the family home had remained the primary residence since the onset of mental illness at a young age. However, even this arrangement was considered insecure because long-term housing arrangements remained unresolved. Indeed, the concern that carers expressed in relation to the future housing needs of their children will be discussed further under ‘Burden of Care’.
Substandard and inappropriate housing
Substandard or marginal housing, especially in the private market, was an issue which most participants had experienced as a result of caring for a person with mental illness. The lack of affordable and supported accommodation, and the stigma associated with mental illness, had seen a number of individuals forced into poor quality and/or unsafe housing. As Amy commented, “vulnerable people like my son—who are desperate, no one else will take them—they will go there.”

Research findings indicate that stressors associated with substandard housing and homelessness exacerbate mental illness (Cameron & Flanagan, 2004; Johnson et al., 2008; Robinson, 2003). This is exemplified by Laura’s account of Tom, her 42-year-old son. Laura explained that Tom had a long history of residing in substandard housing and homelessness, which included sleeping rough. These conditions contributed to Tom becoming frequently psychotic and receiving admission to psychiatric inpatient units several times a year in Mildura and Bendigo. He was, as Laura recounts, often discharged from hospital to inappropriate housing or homelessness without support:

“It’s cruel how he has had to live … once I went up there and he was living out a dirt track, going towards the river, in an old caravan with three other people in the same condition as what he is … so not able to get into town or anything like that. He got, I think it was a $50 food voucher and it was 45 degrees’ heat … I’d been up there for about eight days trying to organise this, and that’s what they gave him in the end … Another time I went there screaming for somewhere for him to go and they gave me a tent and a sleeping bag.

In the last two years, however, Laura explained that Tom’s housing had stabilised after he had exited from hospital into private bed-sit accommodation. Laura identified the importance of mental health outreach support as well as assistance with daily living for Tom’s ability to maintain his housing. This assistance had also helped to reduce his substance use and improve his mental health. However, an ongoing challenge for keeping his mental health stable was the poor condition of his substandard private rental property. As Laura explains: “It’s not a very nice environment the way he lives … there’s cockroaches everywhere …. When I go up there we’ve got to go and hire the shampoo thing.”

Substandard private rental accommodation was identified as a problem by other carers too. Amy described how her son had resumed living with her after being evicted from a poorly maintained private rental property, where a level of filth characterised the conditions her son was forced to live in:

“[It]’s so degraded that you could clean as much as you like, it’s not going to be any good … there was a dripping tap … and it was hot water too, which meant that his bill was huge. The door wouldn’t lock properly. The curtains were all half hanging off. I mean it was terrible.

Amy’s specific examples of disrepair and shoddy fittings are indicative of how substandard housing can exacerbate mental illness. For example, a door that won’t lock properly certainly doesn’t promote a feeling of safety, and the financial implications of something as simple as a leaking hot tap are clearly significant for people on low incomes.

Substandard housing, as Emmy reflected, is depressing to live in and has the potential to further undermine the ability to recover from mental illness:

“It is quite interesting when you look at … entry-level rental bits. Some of them are pretty depressing places. If you’re already suffering from a mental illness, you could almost have to be super resilient to live in some of those really cheap rentals. If you’ve got a diagnosis of severe and persistent mental illness, you’re generally not renowned for being super resilient … stuff that’s available to low income people, or vulnerable people, the toughest, most resilient people would probably not manage. But people who are offered these options haven’t necessarily had life opportunities that have left them with resilience.

The lack of supported accommodation options in the small town where Irma lived in the Shire of Gannawarra resulted in a psychiatrist recommending her then 37-year-old daughter, Sonya, be placed in a nursing home following her first admission to a psychiatric inpatient unit in Bendigo five years ago. As Irma recounts: “Our original diagnosis from the psychiatrist at ABC was to take her home and put her in the nursing home. I said, ‘I beg your pardon?’ … We just think, how far she’s come from there.”

As Irma’s remarks suggest, living in a nursing home was a far from ideal way to facilitate Sonya’s recovery. Bob from Mildura—who had cared for his now 42-year-old son, Dan, for over twenty years—likewise spoke of his son’s difficult experience living in a privately managed aged care facility. Bob emphasised how residents “made fun” of Dan, who left the accommodation within a few months of staying there. There were also the financial challenges: “They were charging $300 a week for food and to stay there, $340 or $350. That didn’t leave him much of his pension.” These accounts highlight the multiple disadvantages imposed on people experiencing mental illness when they are forced to live in inappropriate housing. In this instance, Dan was not treated respectfully, and was left experiencing income poverty—factors which no doubt exacerbated his mental illness.

THE PERSPECTIVES OF CARERS ON HOUSING NEEDS AND MENTAL ILLNESS
Shame
Some of the carers recognised that a more subtle issue affecting relationships for people with mental illness was the sense of shame that arose from inadequate housing arrangements. For example, Kirsty was aware that her son was "extremely embarrassed" by the fact that, as a 29-year-old, he was "living with [his] mother". In Lucinda’s case, her son had told her that he felt like a “burden” and struggled with the fact that he was “a young man” with “kids of [his] own” who had "had to come home". Many of those in receipt of care were clearly sensitive to the impacts of their condition on others and their ‘failure’ to conform to cultural ideals of social and economic independence. This should be taken into account as another stressor in some instances, with the potential to exacerbate existing mental health issues such as depression or anxiety.

Leaving or staying in rural areas
When Karen’s daughter became unwell, she made the decision to leave the small town where she grew up because of the lack of accommodation and formal support services. Karen explained how her daughter decided to go to Melbourne because: “That’s the only way we could get some support … I’m talking about accommodation, I’m talking about mental health specific services.” For others who made the decision to stay with family in their home towns, a significant challenge, referred to already, was the lack of mental health support services, particularly upon exiting hospital or other forms of clinical care. As Gillian exclaimed, the consequence could be a vicious cycle of improvement and relapse: “They build them up to get them on their medication, regulate them, and then toss them out when they say they’re better, and then they go out on the street and fall down!”

Relationships with children
Two participants talked about the challenges that the lack of suitable accommodation had on the relationships between parents experiencing mental illness and their children, particularly in terms of building relationships with younger children. Amy’s son had court-appointed supervised access to his children, but, because he had no housing, they were forced to conduct visits in public spaces. Amy explained how this was especially difficult in winter and hampered the quality of time spent together:

We see [the children] on the streets. We see them once a week. I come along to give him some support and he wants me to come along. We’re just walking the streets for two hours and … it’s winter now … We’ve got nowhere to go, so we go to the library and then we go to the park. We have to have their nappies changed and they have to be fed a good lunch in that two hours, which is really hard when you’re out on the streets. I bring along a bag with all their lunch and … I cook them a nice meal and feed them … but we were just on a boardwalk the other day changing their nappies out in the open. We’ve got nowhere to take them, whereas if he had some accommodation we could take them there.

Amy’s comments also reveal the critical role that carers play in the provision of material resources, as well as supporting positive, ongoing relationships with children and other family members. This is further illustrated by Lucinda who revealed how essential her carer role was for enabling her son to have a relationship with his children while he resides in a caravan on their property:

[M]y son can’t cope with his children on a full time basis. So they come to us and he interacts and shares time with them and he comes in and has a meal. But I do the bathing and putting them to bed and they get up in the morning and they say, ‘Oh Dad’s still sleeping’, so they watch TV and have breakfast and then about mid-morning or late morning he might come out.
The burden of care
While many factors can make caring for a person with mental illness stressful, there was no doubt in participants’ minds that managing housing instability was one of the most significant stressors they confronted. For some, this involved needing to house their children at short notice, and then support them to get well and live independently again, many times over. This was emotionally exhausting for Amy, who describes below how having her son return to live with her generated enormous stress and worry, particularly because of the unpredictable nature of his behaviour, which at times made her feel unsafe:

I have a health problem and an anxiety problem which has come from 20 years, longer, 30 years of looking after this person, and I don’t know how much longer … [I can do it] … when he left I thought I can’t ever, ever have him back, but I don’t have a choice. I can’t send him out to the streets. There are times … when he treats me very badly too … I can’t say I feel frightened because I know he won’t hurt me physically, but I don’t know that he’s not going to damage things … be neglectful and burn down the house or something, let my dogs out on the road to be killed. I worry. I stress about all of that all the time. [My] chronic illness comes on with stress and I’ve just had a big bout of it and it’s terrible. I mean it’s potentially life threatening what I have and I think, ‘Is this going to kill me?’

Research by Cameron and Flanagan (2004) has found that Amy’s experience is not unique. Many carers experienced stress and anxiety when forced to house adult children in the absence of other housing options, particularly when their child could be violent or threatening. Moreover, as Amy reveals, this stressful situation exacerbated her own precarious health condition.

Emmy describes how emotionally demanding and time-consuming it was for her to help her son move out of her home into private rental housing, when living together was no longer possible:

The emotional energy on my part to get that happening was massive, because I had to coax him and cajole him, go and collect him, “Come on … it’ll be great” … I’d have to cop the whole abuse afterwards … but we just kept on at it because I thought, we’ve just got to make this happen … But I look back now [and think] … “Oh my God, I can’t believe that didn’t nearly kill me doing that” … it was quite stressful or intense to make that happen. [It’s not like you’re doing it with someone [and you can] say, “Oh yes, the inspection is at 2pm, I’ll pop by and pick you up at 1:50pm.” I’d have to ring him at 1pm [and say] “now you realise that the inspection is at 2pm.”

Beside these emotional demands placed on carers, the burdens could also be physical. Bob recalled how he had assisted his son to move locally and interstate many times over twenty years by driving trucks and loading possessions:

I had to organise truck, trailers and shift him in and out of different places … I don’t know where I found the strength to leave home and go to Adelaide, Alice and Melbourne with trailers and load up everything because he wouldn’t load anything. I just couldn’t do it anymore, I don’t think.
Most participants also emphasised, to varying extents, the financial implications of supporting their children to obtain or maintain housing. This finding has a substantial existing evidence base (Cameron & Flanagan, 2004; Carers Victoria, 2014; MHCA, 2009b). Perhaps the most extreme example in our study was offered by Emmy, who purchased a property for her son to ensure his housing needs were met because she had no other options:

So I’ve ended up buying a property, which he won’t live in, so I’m living in the property, and he’s living in my house … and I’ve just … moved into the new property that I’ve bought … Which means I have taken out a significant mortgage to do that … but at the time I just felt it was the right thing to do. I felt I didn’t have any other options. I felt it would be really difficult for him to get private rental again … [T]he reality at the moment [is] it’s probably working okay for him … But I’m under significant financial stress and I haven’t got the solution to that … That’s the challenge I guess of the impact of the mental illness … as a carer you go, ‘Oh well, actually this isn’t something I’m prepared to continue to live with. I will have to do something about it.’

Like all the carers interviewed, Emmy was not prepared “to cut [her son] off”, and has been forced into serious, ongoing financial stress as a consequence. Leonard had also resorted to purchasing a property for his daughter after other housing options failed. Other participants thought about buying a house for their child, but were either unable to afford it, or felt it could not meet all their housing needs. For example, Lucinda had investigated buying a unit for her son, but while it potentially resolved the issue of proximity to mental health support services, it generated others: “If we buy it in Swan Hill then he’s near to services, but then he’s still on his own … So the conundrum is in our case the isolation and the travelling.”

Financial stress also arose from other associated costs of housing children. As Amy revealed below, the nature of her son’s mental illness generated enormous costs to her in relation to amenities like water and electricity. This was particularly challenging for her because she was already on a low income: “He just leaves heaters on all night. He leaves taps dripping. He costs a fortune to keep and I’m only on a pension, so I have insisted that he gives me board.” In another instance, Emmy, whose son was living in private rental, was forced to pay the rent for a long period of time when he became unwell and could no longer manage it.

Participant’s stories reveal how carers are being forced into financial hardship as they absorb the costs of housing loved ones experiencing mental illness, in the absence of a housing market able to cater to their needs.
Worry for the future
Uncertainty about future housing options was one of the greatest concerns of all for parent carers of adult children, and the significance of this issue has been well-substantiated by other research (Cameron & Flanagan, 2004; FCDC, 2009; MHCA, 2009a, 2009b). Indeed, future housing prospects were a concern for all participants in this study, but for those who were older carers, it was understandably identified as an issue of greater urgency.

Irma, for example, explained how important it was to find a permanent housing solution for her daughter, Sonya, because the ability of herself and her husband to provide round-the-clock care was slowly diminishing: “We’re aging parents. I’ll be 69 this month, my husband’s just gone 77 and it’s really important that we get something in place … we do everything.” Similarly, Gillian was increasingly concerned about her and her husband’s age, and the question of who would care for their son when they were no longer able to do so. Their son was in no position to maintain the family’s rural property on a low income. As Gillian put it: “I’m in my seventies, and my husband’s in his seventies, it’s becoming more of a worry now … what’s going to happen when we’re no longer there to care for him. He won’t be able to afford to run the place, he’s on a disability support pension.” This worry was also experienced by Amy (aged 65), who felt concerned she was “not going to be around forever,” and was “really worried how her son was going to live without [her].” Like many participants, Amy felt that “What he really needs is supported accommodation.”

Leonard was also concerned about the future care of his daughter but, unlike most participants, her physical housing needs were resolved because they had purchased a unit for her close to their own home in the rural town where they lived. As such, Leonard’s concerns related to her ongoing support needs, and how they would be maintained when they were no longer able to provide them:

The big issue always with mental health, and as a carer, is what’s going to happen when you’re not there … So we’re trying to put as much in place as we can. So we got the house, well that’s a good building block. But she still needs supports. So there’s quite a lot of caring to do, and monitoring and everything else. So we don’t know where that’s going to come from.

As indicated by this discussion, a key consequence of the lack of formal support services in rural and regional areas is that carers are forced to provide an intensive level of support themselves to meet the everyday needs of the person for whom they care. This support role is inextricably linked to their ability to maintain housing. Lucinda’s comments below illustrate how her support was critical to maintaining the housing and wellbeing of her son and his family:

We went away for a while there … but when we got back things had deteriorated so dramatically it was just astounding … The lack of us being able to cushion them that little bit, whether financial or supporting them and keeping them up, sometimes I’d just go and do a grocery shop and drop it at their door and that would help. It was amazing how they’d got themselves into an awful pickle. I hadn’t realised how much cushioning we were doing either because I’d go in with some of the niceties of life. I’d call in and I’d say, ‘Well, I’ve been to the bakery’ … So they had … the little treats that I knew they couldn’t afford [or] I’d start a meal … Get them making soup or something. I probably hadn’t been aware of how much … that had assisted them.

Lucinda’s comments also reveal how her ability to undertake leisure activities like holidays were hampered by the demands of her caring role. This was raised, too, by Irma who felt that their caring responsibilities, combined with the lack of respite care in the small town where they lived, limited what they could do with their life:

It’s just that we’re getting older and the caring … it’s limited our life. Like we should be off and travelling and doing things, and to do this we’d have to take [our daughter] … [W]e can get weekend 24-hour respite care going into a place, but you can’t get it for two weeks if we wanted to go off on a holiday.

Taken together, these accounts demonstrate the enormous personal costs that carers experience in the current context of community care, where responsibility for the housing and support needs of people experiencing mental illness are largely absorbed by individuals and families. Leonard’s observation summarises the overarching challenge:

People with a mental illness are struggling to get through the day, and their carers are struggling … because it’s so difficult and so consuming … so they’re all dragged down … they are battling to exist.
HOUSING AND SUPPORT NEEDS

Permanent housing
While it has been documented that there is a need for a range of short, medium and longer term housing options for people experiencing mental illness (Cameron & Flanagan, 2004; MHCA, 2009a), carers interviewed for this study clearly emphasised the need for long-term and permanent housing options. The provision of long-term housing was perceived to be critical because it provides a secure base on which all other elements required for recovery and stability can be built. As Gillian commented, what was needed for her son was “Something permanent, something that he can say, ‘This is where I’m going to live and die.’ Not a 12-month lease, or ‘We’ll see how you go,’ … housing is the biggest form of recovery I think, if they’ve got a permanent home.”

From Leonard’s perspective, a secure base in the form of housing was necessary because even when things were all “lined up”, the chaotic nature of mental illness means support needs are likely to change frequently:

So you can have everything lined up and everything working and then the health can tip it all out of balance. This is the big problem with mental health … It’s like building blocks. You pull one block out, the whole thing starts to tumble over. That’s why … by having her own place … that’s one solid building block she’s got. It’s really at the bottom of the building block structure. If you haven’t got a roof over your head, well, your life is in the gutter.

As Leonard indicates, his daughter’s housing welfare was secure. However, for all the others interviewed, this situation was much more precarious. Indeed, Lucinda recounted how obtaining permanent housing in the current context was seen by her son as requiring “a miracle”, but he continued to hope for “a good place where I don’t have to move anymore, where I can have a long-term stay.”

Affordable Priority Housing
Inextricably linked to the issue of permanent housing is that of affordability. Permanency is undermined if affordability is not guaranteed. As discussed previously, accessing affordable housing was seen as near impossible by all carers interviewed, and most held the view that more was needed in both regional centres and small towns across the LMR. Research confirms the lack of affordable housing in regional and rural areas, especially for people experiencing mental illness (MHCA, 2009a; NMHC, 2014). The need for governments to invest strategically in more affordable housing for people on low incomes generally has also been argued (Commonwealth of Australia, 2015b). As Emmy commented: “Having more affordable housing is an issue for this cohort, as well as many other people on low incomes. I mean it’s a major issue throughout the country basically.”

Interestingly, Leonard recognised the growing role of philanthropy in the provision of social housing, yet saw this as insufficient for tackling the problem. Instead, Leonard maintained that further government investment, alongside the prioritisation of housing for people experiencing mental illness, was needed:

[T]here does need to be housing where mentally ill people have got a priority to get. That’s really what it amounts to … because the open market won’t cater for it. You need a lot of money to build all the housing that’s needed. It’s too big a job just for fundraisers … to build all the houses that are needed. It’s something the government really should have a responsibility for.
Forms of safe housing

Housing that provides genuine security and privacy, without requiring house sharing, was strongly desired by participants. Congregate care options or group homes were considered unsafe by most interviewees given the challenges that can attend living with others experiencing mental illness. Browne and Hemsley (2010) also found that carers identified safety and space as critical to housing. Secure private space, where vulnerability to abuse from others is minimised, was seen as critical by those interviewees, in particular, who reported instances when the person they cared for had experienced assault or abuse. Leonard commented:

[Persons with a disability are vulnerable to attacks … of all types. This means housing must be suitable to make the client as safe as possible. Unfortunately, clients are also vulnerable to abuse from care workers and other clients they may live with. Even in the psychiatric hospitals [some] have not kept the females safe from the males—an extraordinary situation to exist.

Most interviewees preferred the option of stand-alone housing that was integrated in the community with support attached as needed. For young people in particular, as Kirsty explains, having your own space is critical to wellbeing and being able to develop a sense of identity:

I feel that it would be great for him to have his own place again … He’s 29 … He doesn’t want to be living with his mother. Well, he says, look, he’s really grateful and all that sort of stuff, but I just feel that he can’t really be himself to the full extent. Do you know what I mean? He’s used to living in his home.

Interviewees caring for those with children of their own also indicated that housing needed to provide space to facilitate visits from family members in order to maintain healthy relationships.

Some interviewees thought that some form of cluster model with self-contained units and on-site support was needed. This was deemed necessary by Irma, whose daughter’s sense of personal security depended on someone being immediately available: “For security she needs someone around. Like she’s lying in bed now and she’s quite happy to do that because she knows I’m out here, but she’d be on the phone if I wasn’t.”

Karen also thought that cluster model housing with onsite support staff was needed to provide the requisite sense of security that other models had not proved able to offer. Governments, she said, “wanted people to get out into the community … In one way it was good but in other ways it hasn’t worked because people want to feel secure … and if they haven’t got that security … they don’t cope.”

The importance of feeling safe, as well as connected to the community, in order to main housing is illustrated in the following comment from Emmy. She had made the decision that her son would stay living in her home while she moved out because that was where he felt comfortable and safe:

One of the reasons I feel comfortable about him staying in my place is that … he’s lived there most of his life. He’s very comfortable there. The neighbours know him, he knows the neighbours. It’s in walking distance to town and everywhere else … So even though the house isn’t probably as secure as his flat [was] … it’s probably better for him anyway to stay there, because he feels comfortable and safe there.

Emmy’s observation highlights the importance of choice and involvement in decisions about housing for people experiencing mental illness. When he purchased the property for his daughter, Leonard was able to involve her in the decision-making process. This meant that the housing was working well because she liked its design and location, which was near to her carer and in a community with which she was familiar.

Other suggestions were also made in relation to ensuring safety needs. Emmy, for example, highlighted useful design features that could inform the development of housing for people experiencing mental illness: “If I was going to purpose build there would be safety bits in there. Stoves that automatically turn off if they’re not touched within 20 minutes … units that are easy to clean, with a few safety features in there [like] good security lighting.”
Location
Most participants identified the need for housing to be well located and close to public transport, shops and other practical support services. Being close to public transport was particularly important for some participants, who were unable to drive as a result of their illness. Ensuring that housing was not segregated, but rather integrated into the community was also considered critical. “[T]hey need to build more housing, but not in blocks and shove them in that corner and … forget about them,” explained Gillian. “I’d like to see two little units together or something—oh you could dream, dream on.”

For Gillian, like Lucinda’s son, accessing quality, permanent housing in the current context remains in the realm of “dreams” and miracles.

Support to obtain and maintain accommodation
In conjunction with the need for permanent, affordable and secure accommodation, all interviewees emphasised a requirement for ongoing support to maintain housing for those they cared for. In effect, a permanent level of interdependence was recognised as necessary. Like most participants, Amy commented that ongoing support was needed for her son because in her view he would “never be able to manage on his own.”

Interviewees saw that ongoing support was required in a range of forms, including mental health outreach support, case management, practical living skills, clinical mental health services, family support, and assistance with accessing housing. Jones et al. (2014) found that access to a support worker is critical to finding and maintaining housing in rural areas, and that there is a need for mental health agencies to provide more practical support to assist people to access “housing information, education and support” in rural contexts (p. 231).

The amount of support needed varied, but all carers thought it should be flexible, responsive to need and not time limited. Some carers, like Irma, said those they cared for had intensive, 24-hour support needs:

“As for caring for our daughter now. Well, we do everything. Like if I put the gas on to cook a meal … she’d forget to turn it off. Or remind her to have a shower … virtually has to be reminded to do everything … she would never take a tablet if somebody wasn’t there to supervise her to make sure she does.”

Leonard’s daughter also had high support needs and he estimated that the cost of providing formal care to replace what he provided was considerable:

“I did some figures of … what it would cost. She’s 26. Given that she might live another 40 years just say, you would want $10 million invested for her so she could live off like an annuity. So the money lasts for the 40 years and to pay for the supports that we provide. So it’s quite a big issue.

By contrast, Kirsty suggested her son’s support needs were less intense than the experiences described above, but that he required some form of ongoing case management involving “someone to look in on him and make sure that he’s okay and that type of thing.”

Kirsty emphasised the importance of support services being able to respond when the person experiencing mental illness is ready to engage: “This is the thing with services that I feel they really need to understand: with mental illness [people] do not operate on the same time frame as everybody else …[Yet] there’s these very finite time frames [provided by services] for these people to engage.” Similarly, Gillian believed that outreach support should be “on hand when needed.”

Carers also articulated that those they cared for needed support and advocacy when dealing with other service systems like the courts and Centrelink—and that carers were not always available or able to take on the role. Kirsty remarked that if her son had greater access to formal support services in this way, she could focus more attention on other areas like their relationship, and facilitate the “loving nurturing relationship … that he needs for his wellbeing.”

Most carers identified the need for assistance with daily living skills as well as practical assistance to develop skills in relation to meal preparation, cleaning and washing.

Finally, the benefits of an increase in the provision of clinical mental health services were identified by Karen. In the small regional town where she was living, there was only one psychiatrist who visited every four weeks, which meant that there were always many people waiting for appointments. Financial implications arising from the lack of mental health support in small towns were a related issue for those obliged to travel privately to regional centres for support. Lucinda argued that a response was needed to tackle this significant issue disadvantaging people like her son: “The maths are just not adding up. It’s just not working. They’ve either got to improve the benefits or fund public transport … Even subsidised transport would be a little way to fixing the problem.” Kirsty had been notably unlucky in recently seeing her local bus service in Bendigo reduced rather than improved:

[I]n rural areas the funding seems like it just gets cut and cut and cut … like we had a bus service in Bendigo that’s had to cut their services … Wouldn’t it have been great if the government had of just given them a help up and said, “Keep your services. You’re doing a great job. You are a really necessary part of this community. We’ll meet the shortfall.”
SUMMARY AND RECOMMENDATIONS

This study took a modest, mixed methods approach to investigating the housing and support needs of people with mental health issues in the LMR. It used a survey and interviews for data collection and, taken together, these have provided a snapshot of some of the challenges faced by carers and those for whom they care in both the short and long term.

There is ample evidence that carers find the accommodation and support needs of people with mental illness to be entwined in complex ways with financial capacities, the nature of housing, access to and the location of supports, and planning for future needs. Much of the evidence of this study echoes that of previous research investigations, some of which were on a much larger scale and covered metropolitan areas. The rural and regional context adds complexity to the current picture due to the distances and costs involved in accessing services and the limited availability of private and public housing options. Some of the key findings are described below.

Summary of challenges
It was evident in both the quantitative and qualitative data that housing in regional and rural areas is limited in availability to people with a mental illness, and that cost was a major barrier to access. In particular, accommodation in small towns can be difficult to locate as well as access due to poor affordability, particularly in the private rental market. The choice of housing is thus limited. The lack of choice is exacerbated by the low incomes of people with mental illness, and often their carers too. As found by the Senate Committee (Commonwealth of Australia, 2015b), there is a need for a national affordable housing plan that reflects a real commitment to increasing the provision of public housing, even if this doesn’t address, specifically, housing needs in rural and regional areas. While the State of Victoria is embracing the need for more housing at the time of writing this report, efforts to date appear to have a metropolitan focus — thus a shift of attention is needed to country areas like the LMR if this issue is to be overcome for carers and those for whom they care.

The lack of, and difficulties in accessing, affordable housing are a concern, but so too are the nature of the accommodation and access to support services. Firstly, there needs to be an increase in housing options for low income people with mental health support needs. Secondly, housing options need to be located in proximity to the support being provided by carers, family/friends and/or by service providers.

With limited supports for people with mental illness, the pressure is falling on carers to prop up current accommodation needs and to fill the gaps that are frequently occurring and ongoing. Stability can only be maintained if support is able to continue without interruption. While it is hoped that the NDIS arrangements may, to some extent, address support needs for people with mental illness, it is the complexity and the entwined nature of the issues that need to be taken into account. In addition, the NDIS arrangements must address the specific housing challenges presented by rural and regional contexts.

It is of concern that public housing is not being pursued or seen as an option for many people in this study. This suggests that people give up, or enter alternative arrangements in order to maintain suitable accommodation — some of which place stress on families, and most of which involve private housing due to the absence of public housing options. There is no doubt that mental illness is exacerbated by the stresses of housing and other needs going unmet, but during periods of acute mental ill-health that can involve hospitalisation, maintaining housing and supports may become a stress factor in itself. This suggests that every effort should be made to maintain accommodation and supports, even through the periods of ill-health to ensure that the stability of day-to-day living can be resumed at the earliest possible time. Loss of housing and support in the short term needs to be prevented but, equally, long-term planning and monitoring needs to be an essential part of managing individual case situations.

It was clear from the findings of this study that most carers had concerns about the nature of the support needs of the person for whom they were caring. The support was clearly financial and practical in terms of ensuring bills were paid, home tasks completed and appointments kept, but there was also a keen awareness of the high level of emotional support being provided. This had, in some cases, already resulted in considerable stress for carers, and carer stress has been noted in other research. Carer stress is, unfortunately, commonplace and includes the stress of worrying about keeping the person being cared for as stable and well as possible — and the knowledge that, if needs are not met, the wellbeing of everyone will be undermined. It is not acceptable for carers to be left with the responsibility of responding to housing and support needs alone.

Planning for future needs also contributes to the stress of carers, particularly those who are older and concerned about adult children with a mental illness. They are often worried not only about where their son or daughter will live in the event of incapacity or death, but who will provide the ongoing support to keep their adult child stable and well.
It was of additional concern that there is a perception of discrimination that is preventing attempts to access public housing, as well as actual discrimination in relation to accessing private rental accommodation. These issues have already led to the development of the not-for-profit Homeground Real Estate programme in Melbourne, which has had considerable success in generating safe and appropriate housing for vulnerable people including those with mental illness. In addition, there is a need for a holistic approach to meeting the needs of people with mental illness that is not reliant on carers’ advocacy. The perception of discrimination may be addressed through additional awareness raising by service providers, but it is equally essential that a holistic process of intervention and support, including attention to affordable, suitable and safe accommodation, is provided by funded services.

**Recommendations**

The following recommendations are distilled from the issues raised by the findings of this investigation:

1. It is recommended that a holistic approach to care and planning for people with a mental illness is adopted by service providers in a manner that supports carers and includes attention to long-term planning. This should include help to navigate the service system, reducing the silo effect of servicing, and providing carers with practical assistance in seeking and attaining housing for those for whom they care.

2. Detailed population planning for current and projected affordable housing needs of people with mental illness and their families is recommended, in keeping with the Carers Victoria (2014) recommendation to the Senate Inquiry into Affordable Housing. Attention to the specific context of rural and regional people needs to be a fundamental element of this planning.

3. As the NDIS begins to address the needs of people with mental illness, the issues related to their carers’ needs should be included, together with provisions for housing that take account of regional and rural areas and issues.

4. It is recommended that housing be set aside for people with a mental illness, taking account of the range of accommodation that might be affordable, safe, and have appropriate proximity to carers and services. This needs to include the expansion of models of integrated housing and support, such as the HASI and Doorway models, to regional and rural areas of Victoria like the LMR.

5. Options to develop or expand a programme model based on the not-for-profit HomeGround Services (Real Estate) in Melbourne should be explored for the LMR. This may be beneficial in addressing discrimination and affordability in the context of the rural and regional private rental market.
REFERENCE LIST


THE PERSPECTIVES OF CARERS ON HOUSING NEEDS AND MENTAL ILLNESS

A LODDON MALLEE MENTAL HEALTH CARERS NETWORK HOUSING PROJECT