The economic value of informal mental health caring in Australia

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Ethics

The study received ethics approval from The University of Queensland Behavioural & Social Sciences Ethical Review Committee (approval number 2015001907).

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Glossary, acronyms and definitions

ABS	Australian Bureau of Statistics
ADL	Activities of daily living, e.g., feeding, dressing and bathing.
AIHW	Australian Institute of Health and Welfare
Care recipient	A person who receives informal care on a regular and ongoing basis.
CAW	Carers and Work program
CMO	Community Managed Organisations, see also NGO
Consumer	A person who is obtaining treatment or support for a mental illness. The term suggests that there is a reciprocal contract between those who provide a service and those who use a service.
Co-resident	A carer who provides care and assistance to a person who lives in the same household.
CPI	Consumer Price Index
FMHSS	Family Mental Health Support Services program
FTE	Full time equivalent
Informal carer	Any person, such as a family member, friend or neighbour, who is providing regular, ongoing assistance to another person, due to a disability, long-term health condition or old age, without receiving a salary, wage or fee for the care given. Carers may be co-resident with the person they care for or provide support while not residing with the care recipient.
Mental health carer	A person who provides regular and sustained informal care to a care recipient whose main health condition is a mental illness, where the care recipient is aged 16 years or over.
Mental illness	A health problem that significantly affects how a person thinks, behaves and interacts with other people. The term covers a wide range of disorders such as depression, anxiety, schizophrenia, bipolar disorder and personality and eating disorders. For this report, the following conditions were considered out of scope where they are the care recipient's main condition: autism spectrum disorder (ASD), intellectual disability, substance use disorder or neurological disorder (including dementia, stroke and epilepsy).
MHCSP	Mental Health Carer Support Program
MHR:CS	Mental Health Respite: Carer Support program
NDIS	The National Disability Insurance Scheme is a national scheme to provide targeted support and better coordination of, and access to, services for people with disabilities, regardless of their disability type or where they live. The NDIS was launched on 1 July 2013 and will be progressively rolled out over the next five years in each state and territory.
NGO	Non-government organisation

NMHSPF	The National Mental Health Service Planning Framework is a national mental health planning tool which provides benchmarks for the range of services required to deliver adequate mental health care at a systems level.
NRCP	National Respite for Carers Program
NSMHWB	The National Survey of Mental Health and Wellbeing is conducted by the Australian Bureau of Statistics. The survey collects information from Australians aged 16–85 years about mental illness, health services used, physical conditions, social networks and caring. The most recent national survey was conducted in 2007.
PHaMs	The Personal Helpers and Mentors program is a Commonwealth-funded initiative that aims to assist people aged 16 years and over whose ability to manage their daily activities and to live independently in the community is affected by a severe mental illness.
Primary carer	A person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities.
RANZCP	Royal Australian and New Zealand College of Psychiatrists
RSCYP	Respite Support for Carers of Young People with Severe or Profound Disability program
SCHADS	The Social, Community, Home Care and Disability Services award provides standardised national wage rates for employees in the social and community sector. Pay rates change from 1 July each year.
SDAC	The Survey of Disability, Ageing and Carers is conducted by the Australian Bureau of Statistics. The survey collects information on people who may need care and who provide care in Australia. The latest survey periods were 2003, 2009 and 2012.
Secondary carer	A person who shares or assists with informal care duties to a person with one or more disabilities, but who is not the primary carer as defined above.
SHIP	The Survey of High Impact Psychosis 2010 was conducted by the SHIP Study Group and funded by the Australian Government Department of Health and Ageing. The survey collected a wide range of information from adults with psychosis who were in contact with Australian mental health services.

Foreword

It has long been recognised that informal carers constitute a significant ‘hidden’ workforce in Australia. Without carers and the support they provide, our health system would be on its knees. Faced as Australia is with an ageing population and burgeoning chronic disease, data on the contribution that carers make and the consequent savings to governments and other ‘payers’ need to be articulated, and more support needs to be given to this important group in the community. Carers are part of the health care workforce and should be recognised as such.

Carers in the mental health arena are particularly important. They face significant challenges, and these have been articulated extensively by Sandra Diminic and her colleagues from the Queensland Centre for Mental Health Research at the University of Queensland in this report.

This is the first report to attempt to put a ‘value’ on informal caring for those with mental illness – a fact that in itself suggests that doing so has not been a priority for governments over the years. There were an estimated 2.8 million informal carers in Australia in 2015, of whom around 240,000 were mental health carers. These people provided an estimated 208 million hours of informal care per year to people with mental illness, the equivalent of 173,000 full time equivalent FTE formal support workers. Even adjusting for some cost offsets of over $1 billion, the total annual replacement cost for all informal mental health carers in 2015 would have been $13.2 billion.

When it is taken into consideration that this report only addresses those informal carers involved in mental health, who constitute less than 10% of all informal carers, these figures should give governments of all persuasions some cause for concern. For too long, governments have ignored carers; they have failed to provide adequate and appropriate training for them, failed to adequately support them financially and, in many situations, failed to provide them with a safe working environment in which to deliver their important caring.

Some years ago, we interviewed groups of carers in an Australia-wide project on carers. Almost all of the participants told of the difficulties that they had in being considered part of the caring team. Very rarely were carers included in discussions between those they cared for and health professionals, be they a general practitioner, specialist or community nurse. Carers being ignored, not only by governments but also by health professionals, seems to be a major part of the problem.

This is a landmark report that identifies and quantifies the economic significance of this issue for the Australian community. The question of how to support carers to carry out their important role is complex and multi-layered, but it is clear that they need many different types of support. What is required is an integrated response that combines the recognition of their worth with income support, workforce and service delivery. The economic data in this report are very powerful and can assist those policy makers, government agencies and politicians who will have carriage of these decisions.

The solutions will be challenging, both for governments and the community, particularly as we move to a more fiscally constrained economy, though, as the report points out, some major reforms are likely to impact on the caring role and access to consumer and carer support services over the next few years. These include the National Disability Insurance Scheme (NDIS), the new Carer Gateway and development of an integrated carer support service and the Department of Social Services’ review of Carer Payment and Allowance.

The impact of this report will be influenced to some extent by how we as Australians – governments and community – approach the fundamental issue of how we want to look after and support our most vulnerable, which, of course, includes those with mental health issues and the wonderful carers who make a difference to their fractured lives.

All Australians can be engaged in this debate, and this report can serve as a basis for good and rational health policy around the mental health workforce and caring into the future.

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Executive summary

Background and aims

Informal carers play a significant role in providing ongoing support and assistance to people with mental illness. In the absence of carers, people with mental illness would receive significantly less support or their support requirements would need to be met through formal services, at additional cost to government. However, there has been no attempt to assess the value of the care delivered by Australian mental health carers each year, in terms of the estimated cost to 'replace' this care. Information about the types and amount of support provided by mental health carers, and the replacement cost of that care, is needed to quantify the input of mental health carers into the mental health system, quantify the full range of support needs of their care recipients and describe the support needs of carers to ensure they can continue to perform their caring roles.

The aims of this project were to:

1. provide a profile of mental health carers and the types of care provided
2. estimate the replacement cost of informal mental health care
3. estimate bed-based service replacement costs
4. review current government spending on mental health carers and unmet support needs.

For the purposes of this project, a mental health carer was defined as a person who provides regular and sustained informal care to a care recipient whose main health condition is a mental illness (excluding primary substance use disorder, autism spectrum, intellectual disability and neurological disorders), where the care recipient is aged 16 years or over.

Methods

We drew on published estimates as well as analyses of a number of mental health surveys. These surveys included the Survey of Disability, Ageing and Carers (SDAC) 2012, the National Survey of Mental Health and Wellbeing (NSMHWB) 2007, a purpose-designed online survey of carers (the University of Queensland (UQ) Carer Survey 2016), the Survey of High Impact Psychosis (SHIP) 2010 and key informant interviews with clinicians. Briefly, the methods involved in addressing aims 1 to 4 inclusive were:

1. Profile of mental health carers

This part sought to provide a detailed profile of mental health carers in Australia, describing the total number of carers, carers' sociodemographic characteristics, characteristics of their care recipients, characteristics of the caring role, the hours of care provided by carers and the types of caring tasks performed. Data for the carer profile were drawn from a systematic search of the published academic and grey literature, and from analysis of descriptive data from the SDAC 2012, NSMHWB 2007 and UQ Carer Survey 2016.

2. Estimated replacement cost of informal care

A total replacement cost was estimated for informal mental health care in Australia. This approach to valuing informal care assumes that in the absence of a carer, the care recipient would need to receive equivalent levels of support from formal mental health or other support services, paid for by the relevant level of government. Estimates were for the year 2015 and costed from a government funder perspective. Input data were sourced from analysis of the SDAC 2012, UQ Carer Survey 2016 and NSMHWB 2007, supplemented with publicly available population and cost data.

The economic model included four steps:

1. Estimate the total number of mental health carers in Australia

The proportion of Australians who are informal carers and the proportion of these who are mental health carers, by 20-year age group, were obtained from the SDAC 2012 and applied to the June 2015 Australian Bureau of Statistics-estimated resident population of Australia for these age groups. These estimates were split by those who are confirmed primary mental health carers and 'other' mental health carers (including secondary carers, carers aged below 15 years, primary carers not living with their care recipient and primary carers to a secondary care recipient with mental illness where the main recipient has a different condition).

2. Estimate the total hours of care provided by mental health carers annually

Weighted average weekly hours of care provided by primary mental health carers was calculated by applying the proportion of carers reporting their hours of care in each of four time categories (<20 hours, 20–29 hours, 30–39 hours, 40+ hours per week) from the SDAC 2012 to mean hours of care for each of these time categories derived from the UQ Carer Survey 2016. For other carers, the mean average weekly hours of care for mental health carers identified in the NSMHWB 2007 was applied; this sample is more representative of secondary mental health carers. Average weekly hours of care were apportioned across types of care task (supervising and monitoring; emotional support and encouragement; responding to behaviour, including crises; other emotional support; household tasks; health care coordination; literacy and communication; transport; other practical tasks; and activities of daily living), based on data from the UQ Carer Survey 2016. The total annual hours of care was calculated as the average weekly hours of care per carer, multiplied by 52 weeks in a year, multiplied by the number of mental health carers in Australia (from step 1); this was separated by type of care task and for primary versus other carers.

3. Estimate the cost per hour to replace this care with formal services

Formal support workers were selected from available service types to replace informal mental health carers, by type of care task, based on the similarities of their respective job roles. A Personal Helpers and Mentors (PHaMs) worker was identified as the most suitable replacement service, with this role covering nearly all types of mental health caring tasks. For the exceptions not normally included in the PhaMs worker job role, a disability support worker was selected to replace assistance with activities of daily living and a crisis accommodation worker to replace managing behaviour and responding to crises.

Costs for these workers were calculated from a government perspective for the year 2015. Base hourly wages were obtained from the Social, Community, Home Care and Disability Services (SCHADS) award, based on levels reported in a review of job advertisements for these roles (PhaMs worker at Social and Community Services Employee (SCSE) Level 4 pay points 1–4; disability support worker at SCSE Level 2 pay point 1 to Level 3 pay point 4; crisis accommodation worker at crisis accommodation employee Level 1 pay points 1–4). The total annual cost of a full time equivalent (FTE) support worker was calculated by converting the base hourly wage to annual salary (assuming 38 hours per week and 52.14 weeks worked per year) and adjusting for the inclusion of salary on-cost (23%) and organisational overhead (20%) rates sourced from the National Mental Health Service Planning Framework (NMHSPF). Annual hours of actual consumer service delivery time per FTE (equated with informal caring hours) were calculated as per the NMHSPF, adjusting for seven weeks of leave and 70% of working time involving direct consumer support (as opposed to travel, training, meetings and so on); each FTE worker was assumed to deliver 1,201 hours of consumer support per year. An hourly replacement cost for each worker was calculated as the annual cost per FTE, divided by the annual consumer support hours per FTE.

The total replacement cost for mental health carers was calculated by type of care task for primary versus other carers and then summed. For each type of task, the hourly replacement cost for the equivalent formal sector worker was multiplied by the total annual hours of care provided by mental health carers for that task.

4. Offset the cost of current government spending on carers

The Commonwealth Government provides income support to eligible informal carers, including mental health carers; these outlays would not be required if all informal caring was replaced with formal support services. Data on spending for Carer Payment, Carer Allowance and Carer Supplement were sourced from the Department of Social Services *Annual Report 2014–15*. Expenditure on mental health carers for these payments was estimated by applying the proportion of payment recipients who are mental health carers to expenditure on all carers. The number of mental health carers receiving Rent Assistance with their Carer Payment was estimated by applying this same proportion to the total number of Carer Payment recipients, then multiplying this by the percentage who were renting from the SDAC 2012. Expenditure on Rent Assistance for mental health carers was calculated as the average fortnightly rate paid to Carer Payment recipients (from the Department of Social Services), multiplied by 26 fortnights per year and the estimated number of mental health care recipients.

The sum of these cost offsets was subtracted from the estimated replacement cost for primary mental health carers to obtain an adjusted estimate of total annual replacement costs for informal mental health carers. An uncertainty analysis was conducted using Ersatz to produce 95% uncertainty intervals around the estimates.

3. Estimated bed-based service replacement cost

The above replacement cost modelling focused on hours of care delivered, but it was also of interest to examine potential cost savings to government of consumers with a carer being discharged early from bed-based mental health services. The key question of interest was: do people with mental illness who have a carer spend less time in hospital than their counterparts without a carer? Limited data were available to inform this analysis; this part drew on the combined findings of a review of the academic literature, analysis of data from the SHIP 2010 and key informant interviews. Analysis of SHIP 2010 data compared people with psychosis who were admitted to hospital for their mental health in the past 12 months, who either reported they had an informal carer or did not and examined differences in the total nights they had spent in hospital, controlling for confounding variables (such as diagnosis and global functioning). Several clinicians familiar with the operations of bed-based mental health services were asked semi-structured questions about their experience of patients accessing these services and whether those with a carer had a different length of stay.

4. Carer support services and unmet needs

Two desktop reviews of published websites, annual reports, budgets, program documentation and other available reports were conducted to identify expenditure by governments on mental health carers at the Commonwealth and state/territory level. This was in addition to the Commonwealth expenditure on income support payments identified under Aim 2. Additional data analyses were conducted to explore Australian mental health carers' use of support services, barriers to service use and unmet support needs. Data were drawn from the SDAC 2012, the UQ Carer Survey 2016 and a literature review of published papers and reports on service use, barriers and unmet needs.

Results

1. Profile of mental health carers

The majority (54%) of Australia's mental health carers are female, with 73% aged 25–64 years and 15% young carers aged below 25 years. More than half (54%) of mental health carers are married, 61% live in a capital city and 54% are employed. Primary carers have lower levels of employment and educational attainment than the general mental health carer group, which may be due to the impact of their significant caring role. The individuals receiving support from mental health carers have a similar demographic profile to the carers themselves, with a slightly younger age distribution. Compared with their carers, fewer mental health care recipients are employed (28%). The most frequently reported mental illnesses are depression and anxiety, and the majority (85%) of care recipients have one or more other health conditions; substance use disorders and physical health conditions are common comorbidities.

Most care recipients (79%) report having only one carer, however one-fifth (22%) of mental health carers are providing informal care to more than one individual. Mental health care recipients aged 15 years or more are most commonly the carer's partner (46%) or child (32%). Roughly half of primary carers have been providing informal care for ten or more years. Most mental health carers (68%) provide emotional support to their care recipient (e.g., encouraging and/or prompting to do things; encouraging and motivating; managing crises; and providing intensive emotional support and companionship). Most also assist their care recipient with practical tasks (64%), especially assisting, informing and liaising with health professionals, but also with many other tasks. Less commonly, some mental health carers also provide assistance with activities of daily living (32%). A greater proportion of primary mental health carers perform these types of caring tasks.

Primary carers report providing on average about 36 hours of care per week, with 38% caring for 40 or more hours per week. On average, two-thirds (67%) of this time is devoted to emotional support, 30% to assisting with practical tasks and only 3% to assistance with activities of daily living. Primary carers also report spending large amounts of time 'on standby' so that they are available to the recipient of care in a crisis; this is estimated to be for an additional 59 hours per week. Secondary carers tend to report fewer weekly hours of care; data from the NSMHWB 2007 indicate that this figure is closer to an average of 11 hours per week.

2. Estimated replacement cost of informal care

It is estimated that there were 2.8 million informal carers in Australia in 2015, of whom 240,000 (95% uncertainty interval (UI): 220,000–260,000) are mental health carers. This group comprises 54,000 primary carers (95% UI: 45,000–64,000) and 185,000 'other' mental health carers (95% UI: 167,000–204,000). Nearly half of these carers are aged 45–64 years. Overall, mental health carers provide 208 million hours (95% UI: 181–237) of informal care per year, with roughly equal proportions provided by primary and other carers; this is equivalent to 173,000 FTE formal support workers. The estimated average replacement cost for a primary mental health carer is $129,000 per carer per year, compared with an average cost of $39,000 for other mental health carers. Overall, the total annual replacement cost for all informal mental health carers in 2015 is $14.3 billion (95% UI: 12.4–16.3). After adjusting for cost offsets of $1.1 billion, this figure is $13.2 billion (95% UI: 11.3–15.3).

3. Estimated bed-based service replacement cost

A review of the literature found few studies reporting differences in length of hospital stay for people with a carer. Most of the identified studies found no difference between individuals with and without a carer or family member, while in the few that found a significant difference, patients with a carer tended to stay slightly longer. Results of the SHIP 2010 analysis showed a similar pattern, with no significant difference between people with and without a carer in total nights admitted to hospital for mental health in the past 12 months, after controlling for the effects of diagnosis, alcohol abuse/dependence, comorbid physical health conditions, global functioning, presence of involuntary admissions and private hospital admission. There was a non-significant trend towards individuals with a carer spending more nights in hospital, particularly for the small sample of people admitted to a private hospital.

Key informant interviews with clinicians working in bed-based mental health services provided mixed opinions about the impact of having a carer. The relationship is not straightforward, and depends on the level of engagement and functioning of the carer and the functional level of the care recipient. Qualitative data collected from informants indicated that having a carer may contribute to earlier discharge because there is a stable and supportive environment to which the patient can return. However, if there is tension at home or the carer is not coping well, then this is unlikely. Further, carers may advocate strongly for the needs of their care recipient, leading to a longer stay in bed-based services. Different incentives for discharge in public versus private hospitals may also complicate any relationship between carer status and nights in hospital.

Overall, our analysis indicates that having a carer does not reduce the length of stay in bed-based mental health services and may not have any consistent effect, as it depends on the individual carer-recipient situation. Therefore, we did not model a difference in costs for people with and without a carer admitted to these services.

4. Carer support services and unmet needs

We conservatively estimated that government expenditure on mental health carer services was approximately $1.2 billion in 2015, comprising $1.1 billion in Commonwealth-funded income support payments, $69 million in other Commonwealth-funded services and between $10 million and $46 million in state-funded services. These estimates are conservative because we were unable to locate expenditure data for some programs, and excluded many broader consumer and carer programs that might benefit mental health carers because no specific expenditure data were available.

Results from the SDAC 2012 indicated that the majority of primary mental health carers were not receiving any support, with only 24% receiving Carer Payment and 35% receiving assistance to care for their main recipient of care. A concerning 35% of primary mental health carers did not know what services were available for carers. Around half of SDAC 2012 primary mental health carers reported unmet support needs. Key issues noted by carers across the SDAC 2012, UQ Carer Survey 2016 and the literature included: a lack of information about mental illness, caring and available services; the need for more assistance, such as respite care and emotional support; available services not always meeting the needs of mental health carers; gaps in mental health services for care recipients placing additional burden on carers; poor recognition of carers and exclusion from treatment planning by mental health professionals; and difficulties accessing sufficient financial support.

Discussion

This work provides the first known estimate of the economic value of informal mental health care in Australia. It provides a nationally representative estimate of the number of mental health carers (consistent with our definition of a mental health carer) and primary carers in Australia in 2015. Further, it highlights the substantial hours of support provided by Australian mental health carers for people with mental illness each year. In the process of completing this work, we also identified a number of data gaps and areas for further research.

The estimated annual cost to the government of replacing the support provided by these carers with formal services is substantial, at $13.2 billion in 2015. This is equivalent to 1.7 times the current national expenditure on mental health-related services, which is estimated by the Australian Institute of Health and Welfare to be $8.0 billion in 2013–14. The estimated replacement cost for mental health informal care is also comparatively higher than a previous estimate of the annual replacement cost for all informal carers of $60.3 billion in 2015 (of which mental health carers may comprise about 9%). Compared with previous figures, this work refined replacement cost methods for informal care in Australia to produce a more reliable estimate, particularly for the parameters of average weekly hours of care and hourly replacement costs.

In light of current national expenditure on mental health services, it is unlikely that governments will have the capacity to scale up consumer support services to comprehensively replace the role of informal mental health carers in the foreseeable future. In reality, the preferences of carers, and the people they care for, also need to be taken into account in considering any change to current arrangements. For example, care recipients may value the continuity of care and close personal relationship with their informal carers over formal support services; conversely, they may prefer formal services, which have access to additional training and facilities not always available to informal carers.

It is clear that informal mental health carers add significant economic value to the mental health system. The needs of their care recipients for support appear to be large, with mental health carers providing support and assistance which otherwise might need to be provided at considerable cost to government. By contrast, current government expenditure on support for mental health carers is relatively modest, at $1.2 billion. Continuing to provide this support should be a priority for governments, as well as providing additional services to ensure that mental health carers can continue to perform their role without significant financial disadvantage and psychosocial distress. Improvements in the mental health service system for consumers are also likely to benefit carers, who reported additional burdens from trying to access and coordinate support for their care recipients.

Finally, these results may change over time as current and future mental health reforms are rolled out. Three prominent reforms likely to have some impact on the caring role and access to consumer and carer support services are the National Disability Insurance Scheme (NDIS), the new Carer Gateway and development of an integrated carer support service and the Department of Social Services' review of Carer Payment and Allowance.

Part one

Background and aims

1.1 Introduction

1.1.1 Background

Mental illness is common and is a leading cause of disability burden in Australia [1]. In 2007, it was estimated that mental illness affects 20% of Australian adults aged 16–85 every year [2]. Informal carers, such as a family member or friend, play a significant role in the care of people with mental illness in Australia, providing substantial hours of unpaid support. This support may include assistance with personal care, practical tasks and emotional and crisis support.

The support provided by carers can act as a supplement to, or replacement for, formal mental health support services. Where an informal carer is not available, these support needs may go unmet, leading to poorer functional outcomes for the individual with mental illness. Alternatively, these needs may be met through formal personalised support services provided primarily by the non-government sector, such as state-funded personalised support and the national Personal Helpers and Mentors (PhaMs) program. The availability of a carer to provide support and monitoring may also affect how soon a person is discharged from intensive bed-based mental health services. Future reforms to mental health services, including the introduction of the National Disability Insurance Scheme (NDIS), may affect the availability and coordination of existing supports and therefore the nature of informal caring roles.

Carers often experience significant impacts due to their caring role, including time out of the workforce and negative effects on their physical and mental health [3]. Therefore, a number of programs are funded to provide support to mental health carers to maintain their caring role and provide respite care as needed. An example of these services is the Department of Social Services' Mental Health Respite: Carer Support program [4]. In addition, the Australian Government provides income support payments through Centrelink such as the Carer Payment and Carer Allowance to mental health carers who qualify [5].

Anecdotal and qualitative evidence highlights the significant amount of support that informal carers provide to people with mental illness on an ongoing basis [6]. However, to date there has been no formal attempt to assess the value of the care delivered by mental health carers each year, in terms of providing support to people with mental illness within the Australian mental health system. In the absence of this informal care, the overall functioning and quality of life of people with mental illness who currently have a carer would be poorer; their care needs would either go unmet or need to be picked up by the formal health and social care systems, at additional cost to government.

Recent reports have valued caring in Australia overall, for carers of individuals with all types of disorders or disabilities, emphasising the size of the informal care sector [7–9]. A similar exercise for mental health carers is required to: quantify the input of carers into the mental health support system, in terms of the unpaid hours of support provided to people with mental illness; quantify the full support needs of people with mental illness who currently receive informal care, to guide future planning for formal support services; and describe the support needs of carers to ensure they can continue to perform their caring roles.

1.1.2 Aims

The aims of this project were to:

1. provide a profile of mental health carers and the types of care provided
2. estimate the replacement cost of informal mental health care
3. estimate bed-based service replacement costs
4. review current government spending on mental health carers and unmet support needs.

1.2 Care needs and informal caring

1.2.1 The need for informal care

Mental illness can have a profound impact on individuals, in terms of both clinical symptoms and psychosocial impacts. Individuals with a mental illness experience varying levels of symptoms and associated functional difficulties. These range from mild and transient impacts on mental health and quality of life with little negative effect on daily functioning through to the challenges faced by people with severe and persistent mental illness who have complex, ongoing needs for support. Mental illness is associated with high levels of distress and poorer quality of life. Having a mental illness, particularly a more severe disorder, reduces the likelihood of being in paid employment [10, 11] and completing secondary or tertiary education, [12] and can have significant negative impacts on personal relationships, community connections, motivation and ability to complete regular household activities and self-care and navigation of the complexities of the Australian mental health system. These functional difficulties can persist even when clinical symptoms of the disorder respond to treatment, leading to an ongoing need for support. As the level of severity of mental illness experienced by an individual increases, so too does the need for support [3].

Individuals experiencing substantial impacts resulting from their mental illness require support to function optimally in the community. This support may include: assistance with personal care and household activities; financial management; community engagement; following prescribed treatment; provision of transport; coordinating and attending appointments; advocacy; and emotional and crisis support. These types of support activities can be provided by formal mental health services; alternatively, these support activities may be provided by an informal carer, alone or as a supplement to formal services.

Estimates of the need for support by Australians with mental illness vary. Data from the NSMWHB 2007 indicate that 46% of people with mental illness have a disorder of mild severity, 33% moderate and 21% severe [2]. Further modelling of data from multiple sources has estimated that 1.1% of adults have a severe and persistent mental illness and that one-third of these have complex, multi-agency needs for support, equating to roughly 59,000 adults in 2015 [13]. Children and older adults and those with less severe disorders also have support needs, although those with the most severe disorders are likely to require the highest hours of care and the involvement of multiple service agencies. The national Survey of High Impact Psychosis (SHIP) 2010 recorded interviewer ratings on the Multidimensional Scale of Independent Functioning of the level of formal and informal support received by participants to maintain their role performance across home, work and study domains in the past four weeks. Just under half (43.6%) of adults with psychosis in contact with mental health services were receiving modest, moderate, significant, comprehensive or total support, while the remainder received no or minimal support [11]. Of the total survey sample, 12.3% had received support from a personal support worker and 24.5% from a carer in the past year. Further, 27.5% of participants had unmet needs for services, with 30.5% of these needing further assistance with housing, finances, employment and other practical assistance, and 4.6% requiring additional support for social and leisure needs [11].

The Commonwealth-funded PhaMs program is the most prominent national service providing formal personal support to people with a mental illness. In 2013–14, 18,539 people used the program nationally [14]. Of PhaMs participants, 66% had a mood disorder, 40% an anxiety disorder and 23% a psychotic disorder (individuals could have more than one diagnosis). Slightly more than half of PhaMs recipients lived with family, including parents, a partner/spouse, children or other related persons [14]. If a similar ratio of receipt of personal support to informal care was applied as that found in the SHIP 2010 study (12.3% and 24.5% of participants, respectively), it might be assumed that at least double the number of people using PhaMs nationally receive significant support from an informal carer.

State, territory and the Commonwealth governments also fund other personalised support services for people with mental illness, but limited published data are available on these programs. Data collected for the Disability Services National Minimum Dataset show that 17,909 people with a primary psychiatric disability used state- and territory-administered non-residential support services in 2012–13 and 38,304 used Commonwealth-funded services [15]. This covers a range of service types, including accommodation support, community support, community access, respite and employment services; the majority of service users were accessing employment support.

These data suggest that there are a greater number of people with mental illness and multi-agency support needs than those currently accessing services. Many individuals with mental illness do not currently receive the necessary level of support, and informal carers play a significant role in providing support for those who do.

1.2.2 What is an informal carer?

A carer is a person who provides regular and sustained care or assistance to an older person or someone who has a disability or a long-term health condition [16]. This includes family members, paid helpers such as a care or support worker and volunteers for an organisation. For this report, we focus only on 'informal carers', i.e., family members, friends or neighbours who provide regular and sustained care or assistance to a person on an unpaid basis [17]. This type of care is typically provided in the context of a pre-existing relationship, with demands that go beyond what would normally be expected of the relationship [18]. Carers may be co-resident with the person they care for or provide support while not residing with the care recipient. Unless otherwise stated, the term 'carer' is used in the remainder of this report to refer to an informal carer. It excludes any persons who provide volunteer care services attached to an organisation or who are formally paid for their caring role. However, carers receiving a government benefit such as Carer Payment or Carer Allowance are included in the term 'informal carer'.

The types of caring tasks typically performed by informal carers are diverse, ranging from emotional and crisis support to assistance with practical tasks like housework and personal care tasks such as eating and bathing. Carers provide support to people of all ages who have a range of diagnoses and many different levels of functional impairment or disability. Carers may be classified as 'primary carers' when they are the person who provides the most informal assistance to a person with one or more disabilities or health conditions, or as 'secondary carers' where they share or assist with informal care duties for a person but are not that individual's primary informal carer.

As this report focuses on the replacement costs of caring, we narrowed the scope of 'informal care' to the types of tasks typically performed by a formal sector worker, such as a disability support worker, who would otherwise replace the role of an informal mental health carer. These tasks include, but are not limited to:

- planning collaboratively with the care recipient to identify their goals, skills and strengths
- providing emotional and crisis support
- assisting with personal care, cooking and shopping
- providing transport
- preparing notes, reports and other required documentation for appointments
- attending appointments
- coordinating and communicating with multiple service providers.

1.2.3 Definition of mental health carer

The focus of this report is on informal carers who care for someone mainly because of a mental illness, such as depression or psychosis, or ‘mental health carers’. In order to profile mental health carers and estimate a replacement cost for their care, we first needed to define what a mental health carer is. For the purpose of this report, we have tried to focus our analyses as closely as possible to the following definition:

> *A **mental health carer** is a person who provides regular and sustained informal care to a care recipient whose main health condition is a mental illness, where the care recipient is aged 16 years or over.*

The care recipient either has a primary mental illness diagnosis or does not have a formal diagnosis from a health professional but self-identifies to services as having a psychiatric disability as their main problem. Those without a formal diagnosis would typically be someone whose ability to manage their daily activities and live independently within the community is affected because of a severe functional limitation resulting from mental illness. In-scope mental illness diagnoses include:

- major depression
- bipolar disorder
- anxiety disorders
- schizophrenia and other psychotic disorders
- personality disorders
- eating disorders
- behavioural disorders.

For the purpose of this report, the following conditions were considered out of scope for ‘mental illness’ where they are the care recipient’s main condition: autism spectrum disorder (ASD), intellectual disability, substance use disorder or neurological disorder (including dementia, stroke and epilepsy). However, these disorders are common comorbidities of the above-listed primary mental illness diagnoses and, as comorbidities, may increase the individual’s need for care.

Caring for a person with mental illness aged under 16 years was excluded from the definition due to the substantially different profile of mental and behavioural disorders affecting children. In this group of carers, it is also difficult to clearly separate out the extra responsibilities due to the mental health caring role from the regular responsibilities of parenting [19].

Our definition of a mental health carer is not restrictive of the carer’s age, level of care (primary vs. secondary), living situation (co-resident vs. non-resident) or relationship to the care recipient (family member vs. non-family member).

1.3 Approaches to valuing informal care

One of the central aims of this project was to estimate the value of the informal care delivered by mental health carers in Australia. A number of approaches can be applied to value carers' contributions; this report focuses on the replacement cost method, a way to value the economic impact of caring. To inform the methods of the current project, we reviewed previous studies that estimated a replacement cost for carers. Here, we provide a brief introduction to the replacement cost method and its application to informal carers in previous studies.

1.3.1 Overview of valuation methods

The impact of informal mental health caring can be valued in a variety of ways. Care recipients may benefit from receiving informal care across a range of domains, including improved health and wellbeing, daily functioning, financial and housing stability, social interaction and quality of life. Similarly, carers may experience some benefits, but also negative impacts on their health and wellbeing, quality of life and financial situation from their caring role [20, 21]. Methods are available to measure the subjective burden/benefit of informal caring on carers and care recipients.

Alternatively, informal caring can be valued in terms of its economic impact – how the informal care produces a benefit to the economy in terms of the labour provided; the latter is the focus of the current report. Despite being unpaid, the work performed by informal carers has intrinsic economic value [22]; informal care provided to people with mental illness can act as either a low-cost substitute or as a complement to expensive formal care services [21]. There are, however, difficulties in estimating this value as informal care is a good that exists outside of the competitive labour market [23]. Several approaches are available to estimate the economic value of informal care in the absence of market prices [20, 22, 23]. These approaches generally involve the valuation of total time spent delivering informal care by: 1) measuring the total amount of time spent providing care over a given period; and 2) determining the price of informal care per unit of time, e.g., cost per hour [24]. The methods used to measure informal carers' time are common across all approaches [25]. However, the methods used to determine the price of informal care vary [20, 21].

1.3.2 Time measurement of informal care

Two methods can be used to measure time spent on informal caring: a) the time diary; and b) recall methods.

a) The time diary method requires respondents to systematically record all activities carried out during a specified time period (e.g., a day, week or month) [25, 26]. It is considered the 'gold standard' as data are collected in a structured manner using a relatively short recall period [26, 27]. Unsurprisingly, this method is very costly to both researchers conducting the study and informal carers, who spend significant time and effort completing the diary [21].

b) The recall method is a more practical alternative; it requires carers to recall how much time they spent on various activities over the course of a specified time period (e.g., the past week) [25, 26]. However, the validity of this retrospective method is constrained by several issues, including recall bias and the less structured method of data collection [25].

Most studies use recall questionnaires when measuring informal carers' time, although time diaries have been increasingly used in recent years [24].

Apart from the limitations of these two methods, several important issues need to be considered to ensure valid measurement of time spent caring.

1. Whether the carer is a primary or non-primary carer [25]: primary carers provide the most hours of care and are often responsible for coordinating informal care provided by other carers. It follows that distinguishing between the two carer types is important to ensure an accurate, unbiased estimate of carers' time.

2. Whether the carer is co-resident with the care recipient: this influences the time associated with travelling to the care recipient's place of residence.

3. Whether a care recipient has more than one carer: if there are multiple carers then the caring time needs to be counted for all carers [25].

4. 'Joint production': the time spent on two or more simultaneous activities needs to be allocated proportionally to each [21, 24, 25]. For example, a carer may allocate time spent going for a walk in the park with their care recipient as both personal exercise and a part of their caring duties. Joint production can be measured and adjusted for when using the time diary method but not when using the recall method; this may result in overestimation of total time spent caring [25].

5. Distinguishing 'additional' activities directly related to caring [25]: assuming that all household activities conducted by an informal carer are related to caring can overestimate the time spent caring as some may be 'normal' activities that would be completed regardless (e.g., cooking a meal). The distinction between 'normal' and 'additional' activities is particularly troublesome when carers live with the care recipient or have been providing care for many years [28].

6. Distinguishing between different caring functions: clear distinctions between different caring tasks (e.g., household chores, assistance with mobility, provision of psychosocial support) need to be made when using the replacement cost method, which may assign different formal sector costs to different types of informal care tasks [21, 28].

1.3.3 Determining the price of informal care

There are two broad approaches to costing informal caring time: (1) stated preference approaches; and (2) revealed preference approaches [20, 21].

1. Stated preference approaches, such as contingent valuation and conjoint analysis, involve directly eliciting monetary preferences for informal care through oral or written surveys [21, 23]. These methods involve a direct approach that explicitly asks people to gauge how much they would (hypothetically) value informal caring in monetary units.

2. By contrast, revealed preference methods, such as the opportunity cost and replacement cost methods, use real-life decision data to determine the price per unit (e.g., hour) value of informal care. These data are based on the implicit preferences of informal carers which are deduced from either the choices made by carers or choices made in the market which act as close substitutes of informal care. For instance, a carer who chooses to turn down a job that pays $30 per hour in favour of caring for a close relative implicitly values the time they spend caring for that relative at $30 per hour. In practice, revealed preference approaches are favoured as they are both easier to operationalise and require less restrictive theoretical assumptions than stated preference methods [21, 23].

One revealed preference method is the opportunity cost method, which values time spent delivering informal care according to its next best alternative use; in practice this is usually assumed to be time spent in productive labour [23]. Drummond et al. [23] state that "the value of this production in the home must be at least as great as what could be earned in the labour market, otherwise the homemaker would choose to enter the labour market". It is for this reason that the value of leisure and other unpaid activities is often ignored in favour of measuring productivity losses associated with informal care.

An alternative revealed preference method is the replacement cost. This method attempts to quantify how much it would cost to replace an informal carer with formal services [23]. Caring time is thus valued by matching the market wages of equivalent formal sector workers to different informal care tasks [20, 28]. For instance, time spent doing housework is valued using the wage rate of a professional housekeeper [20, 21]. Calculating the replacement cost of informal carers is relatively straightforward when the following three elements are on hand: (1) a list of the different informal care tasks performed; (2) the time spent on each of these tasks; and (3) proxy values (i.e., prices) for each task. Detailed measurement of the different tasks provided by an informal carer is required. Controlling for time measurement issues such as joint production and the distinction between 'normal' and 'additional' activities (see section 1.3.2) is particularly important when employing the replacement cost method.

1.3.4 Review of previous carer replacement cost studies

We searched the academic and grey literature for carer costing studies and found that the majority did not focus on mental health carers and did not use the replacement cost method; most commonly, studies employed the opportunity cost method. Only two international studies had direct relevance to the replacement cost of informal care for people with mental illness (Table 1). To our knowledge, no study to date has investigated the replacement cost of mental health carers in Australia. Instead, we identified another six Australian studies that conducted a replacement cost analysis for all informal carers or carers of someone with a condition with similarities to mental illness. These studies are described in Tables 1 and 2.

Both mental health caring replacement cost studies were conducted internationally, and both only determined the economic value of informal care for people with schizophrenia. A Spanish study by Aranda-Reneo et al. [29] calculated the replacement value of informal care for people with schizophrenia using data on caring hours obtained from a 2008 national survey (the Survey on Disabilities, Personal Autonomy and Dependency Situations). Replacement costs were calculated with a 2008 baseline year under two alternative scenarios: (1) valuing carer hours using the average cost of public in-home care across three regions of Spain; and (2) using the national wage rate for such care. In addition, the study calculated estimates with and without an arbitrary restriction on the average total hours of care – i.e., excluding any hours of care above a maximum of 16 hours per day. The annual replacement cost across these four permutations ranged from a lower estimate of €27,199 per person (regional wage rate and restricted hours of care) to an upper estimate of €57,494 per person (national wage and no restriction on hours of care).

The English study by Mangalore and Knapp [30] calculated the replacement value of informal care for people with schizophrenia using population survey data (UK Schizophrenia Care and Assessment Program) to estimate the percentage of relatives who provide care in the population and data from another study to estimate the total daily hours spent providing informal care. Both sets of data were combined and valued using the wage rate of an assistant nurse or nursing auxiliary. The study estimated that the total annual replacement cost for schizophrenia carers was £604.1 million nationally.

Several common themes emerge when comparing the broader group of eight identified replacement cost studies (including Australian studies on other informal carers). Firstly, seven of the eight studies relied on time estimates derived from surveys of carers utilising the recall method. An Australian study by Hoenig and Page [31] was the exception – it used time diary data derived from the 2006 Australian Bureau of Statistics (ABS) Time Use Survey. None of the studies adjusted time estimates to account for joint production. Likewise, none of the studies accounted for co-location between carers and recipients in their replacement cost valuations or care recipients who had multiple carers. Four of the eight studies distinguished between primary and secondary carers. The study by Aranda-Reneo et al. [29] limited the valuation of replacement costs to primary carers only, while the remaining three studies calculated separate replacement cost estimates for primary and secondary carers. Only the study by Dewey et al. [32] explicitly calculated replacement cost estimates after limiting the scope of carers' time to additional care directly related to the care recipient's condition.

All except two of the studies in Table 2 used a single, common wage rate to value informal care, regardless of the type of care provided. As one exception, Dewey et al. [32] distinguished between three types of informal care: (1) community-based activities, e.g., completing errands, providing transport, checking up on the patient and shopping; (2) domestic activities, e.g., gardening, home maintenance, housework and meal preparation; and (3) personal activities of daily living, e.g., eating, grooming, bathing, dressing and toilet use. This study valued community and domestic activities using the average hourly wage for an unqualified health care worker in Victoria, while personal care assistance was valued based on the average hourly wage for a nursing employee. The second study, by Hoenig and Page [31], also reported calculating the replacement cost of informal carers by matching appropriate hourly wages for different informal care tasks. However, the methodology for this was not explicitly reported.

Overall, there has been no study to date evaluating the replacement cost of informal care for people with mental illness in Australia. International studies that have calculated replacement costs for mental health care are limited to caring for people with schizophrenia. Direct comparison of replacement cost estimates between these eight studies is inadvisable due to the heterogeneity of methods and diagnostic scope; some studies conducted valuations on all carers while others were limited to specific conditions.

Table 1. Studies reporting on the replacement cost of informal carers

Reference	Title	Location and currency	Base year of valuation estimate	Estimate of the total value of informal care	Time measurement method
Mental health carers (international)					
Aranda-Reneo et al. (2013) [29]	*Informal care of patients with schizophrenia*	Spain - Euros	2008	Annual estimate with restricted hours of care: €27,199–€45,072 per carer Annual estimate with no time restriction: €34,695–€57,494 per carer The lower estimate in each range denotes a replacement cost using the average wage for care across three Spanish regions. The upper estimate is based on the national wage rate	Recall questionnaire
Mangalore & Knapp (2007) [30]	*Cost of schizophrenia in England*	England - British pounds	2004–5	£604.1 million annually	Recall questionnaire
Other carers (Australia)					
Deloitte Access Economics (2015) [9]	*The economic value of informal care in Australia in 2015*	Australia - Australian dollars	2015	The total annual replacement cost is $60.3 billion, i.e., $43.7 billion for primary carers and $16.6 billion for non-primary carers	Recall questionnaire
Access Economics (2010) [7]	*The economic value of informal care in 2010*	Australia - Australian dollars	2010	The total annual replacement cost is $40.9 billion, i.e., $22.1 billion for primary carers and $18.8 billion for non-primary carers	Recall questionnaire
Access Economics (2009) [33]	*Making choices. Future dementia care: projections, problems and preferences*	Australia - Australian dollars	2008	The total cost of replacing family carers with paid carers is estimated to be $5.5 billion annually	Recall questionnaire

Reference	Title	Location and currency	Base year of valuation estimate	Estimate of the total value of informal care	Time measurement method
Access Economics (2003) [34]	*The dementia epidemic: Economic impact and positive solutions for Australia*	Australia - Australian dollars	2002	The total cost of replacing family carers with paid carers is estimated to be $1.713 billion annually	Recall questionnaire
Dewey et al. (2002) [32]	*Informal care for stroke survivors: Results From the North East Melbourne Stroke Incidence Study (NEMESIS)*	Australia - Australian dollars	1997	Total first-year carer time costs for all first-ever-in-a-lifetime strokes estimated to be $42.5 million annually Present value of lifetime carer time costs estimated to be around $331.8 million annually	Recall questionnaire
Hoenig & Page (2012) [31]	*Counting on care work in Australia*	Australia - Australian dollars	2009–10	The imputed value of unpaid care work using the replacement cost valuation method was $601 billion	Time diary

Table 2. Details on time measurement methods in replacement cost studies

Reference	Distinction between primary vs. non-primary carers	Accounts for co-location of carers and recipients	Accounts for single or multiple carers	Adjustment for joint production	Distinction between ‘normal’ vs. ‘additional’ work	Distinction between different caring tasks
Mental health carers (international)						
Aranda-Reneo et al. (2013) [29]	✓	×	×	×	×	×
Mangalore & Knapp (2007) [30]	×	×	×	×	×	×
Other carers (Australia)						
Deloitte Access Economics (2015) [9]	✓	×	×	×	×	×
Access Economics (2010) [7]	✓	×	×	×	×	×
Access Economics (2009) [33]	×	×	×	×	×	×
Access Economics (2003) [34]	×	×	×	×	×	×
Dewey et al. (2002) [32]	✓	×	×	×	✓	✓
Hoenig & Page (2012) [31]	×	×	×	×	×	✓

Part two

Methods

2.1 Overview of data sources

To address the aims of this project, we drew on multiple data sources. These included a number of purpose-designed literature and desktop reviews, four survey datasets and data from key informant interviews, as follows:

- searches of the academic and grey literature on Australian mental health carers
- desktop reviews of government expenditure on carer support services
- two national household surveys – the Survey of Disability, Ageing and Carers 2012 and the National Survey of Mental Health and Wellbeing 2007
- one online survey of carers – the UQ Carer Survey 2016
- a national survey of people with psychosis – the Survey of High Impact Psychosis 2010
- key informant interviews with clinicians familiar with the operation of bed-based mental health services.

Each data source is described in more detail below.

2.1.1 Literature reviews

Profile of carers

A broad search of the academic and grey literature was conducted in order to provide an overview of Australian mental health carers, including number of carers, demographic details, hours of caring and types of care provided. Electronic searches of PubMed, PsycNET, PsycINFO and Google Scholar were undertaken and search results screened at the title and abstract level. The following search terms were used: 'mental health', 'mental illness', 'schizophrenia', 'psychosis', 'carer', 'caregiving' and 'Australia'. The search was limited to studies reporting on Australian data and published in English. In total, 177 resources were found, including 122 academic journal articles and 55 government reports, non-government organisation (NGO) reports, policy submissions and unpublished manuscripts.

A secondary aim of the literature search was to identify datasets that might provide additional unpublished inputs for the replacement cost modelling. The SDAC (2003, 2009) and the NSMHWB 2007 were the most widely reported on datasets and were examined further for unpublished items of relevance to the modelling. Additional national datasets identified in the literature search were also investigated, including the Census of Population and Housing [35], General Social Survey (GSS) [36], Household, Income and Labour Dynamics in Australia (HILDA) Survey [37] and the National Health Survey (NHS) [38]. However, these did not include questions specific to mental health caring, but rather more broadly caring for all long-term health conditions or disabilities (including, but not specifying, mental illness) or problems related to old age. Therefore, access to these datasets was not pursued.

Length of hospital stay

A further brief literature review was conducted to provide an overview of studies reporting on the length of hospital stay for adult mental health patients with and without a carer. Electronic searches of PubMed, PsycNET and Google Scholar were undertaken and search results screened at the title and abstract level. The following search terms were used: 'mental illness', 'schizophrenia', 'psychosis', 'carer', 'caregiving', 'length of stay', 'length of hospital stay', 'hospital discharge', 'psychiatric hospital'. Only seven studies were identified that reported on the length of stay in a psychiatric hospital with respect to the presence of an identified carer or family member.

Carer service use

In addition, a brief literature review was conducted to collate available information about carers' use of support services, barriers to accessing services and their unmet support needs. Electronic searches of PubMed were undertaken and search results screened at the title and abstract level. The following search terms were used: 'psychiatric', 'mental', ‘carer’, ‘caregiving’, ‘Australia’, ‘unmet need’, ‘use’, ‘service’, ‘support’, ‘respite’, ‘help and ‘assistance’. Studies were considered in scope if they: reported on mental health carers in Australia; reported specifically on use of carer services or unmet service needs of mental health carers; and analysed data collected no earlier than 2006 (or, in the absence of information about the year(s) of data collection, were published no earlier than 2006). In addition to studies identified through PubMed, articles identified through the previous literature reviews were scanned and included if relevant. In total, 17 journal articles and reports analysing 15 studies were identified.

2.1.2 Desktop expenditure reviews

Two separate searches were conducted to identify government expenditure on services for mental health carers in Australia. These focused on: a) Commonwealth Government expenditure; and b) expenditure by state and territory governments. Both reviews followed the same broad strategy of accessing relevant Department of Health or equivalent and Department of Social Services or Disability or Communities or equivalent websites to identify relevant programs for mental health carers, supplemented by web searches using the Google search engine. Annual reports, budgets, program guidelines and related documentation were retrieved. Information was extracted regarding expenditure within each program or funding allocation where expenditure was not reported.

2.1.3 Survey of Disability, Ageing and Carers 2012

The Survey of Disability, Ageing and Carers (SDAC) 2012 is a nationally representative survey of households and cared-accommodation establishments (hospitals, nursing homes or hostels with residents of ≥3 months’ duration). The survey was carried out by the ABS between August 2012 and March 2013.

Households were selected from a stratified, multi-stage area sample developed by the ABS. A responsible adult in each selected household completed screening questions to determine the presence of a carer, person with disability and/or person aged 65+ years. Where possible, a personal interview was completed for persons in each of the these three populations; proxy interviews were conducted for children aged <15 years, those aged 15–17 years without parental consent to be directly interviewed and others unable to be interviewed due to language or impairment. Basic demographic and socioeconomic data were collected for all household members via the responsible adult or personal interview. Data were collected by trained interviewers using a Computer-Assisted Personal Interview. Cared-accommodation establishments were selected from a list of in-scope businesses, with the chance of selection proportional to the average number of residents. Occupants were randomly selected within each establishment by a contact person, who completed a questionnaire for each selected individual. The final sample included 27,928 households comprising 68,802 persons (a response rate of 90%) and 999 cared-accommodation establishments with 10,362 persons (response rate of 87%). Overall, the survey covered 79,164 persons, equating to an estimated 2012 resident population of 22,875,200 Australians.

Carers of persons with a core activity limitation (i.e., in mobility, communication or self-care) were identified through the household screening questions or by their care recipient. Respondents who confirmed they were primary carers were asked additional questions about: the care they provided, including the number of people they cared for; whether they lived with each care recipient; their relationship to each care recipient; length of time caring; average hours spent caring each week (<20, 20–29, 30–39, 40+ hours); whether they received Carer Payment; types of assistance provided to their main recipient of care; and their use of, need for and satisfaction with assistance and respite care. Respondents with a disability were asked to indicate their main disabling condition, all disability types, level of core activity limitation and number of carers. Demographic data collected for all participants included their sex, age, marital status, country of birth, main language spoken at home, state/territory of usual residence, area (capital city, balance of state), remoteness (major cities, inner regional, other areas), highest level of education and labour force status. A smaller range of data were collected for cared-accommodation respondents due to the proxy nature of the interview and irrelevance of some household questions.

2.1.4 National Survey of Mental Health and Wellbeing 2007

The NSMHWB 2007 is a nationally representative household survey of Australian adults aged 16–85 years. It was funded by the Australian Government Department of Health and Ageing and carried out by the ABS between August and December 2007.

Households were selected from a stratified, multi-stage area sample developed by the ABS. For each household approached, an interviewer asked a set of household questions to identify all eligible residents. One individual from each household containing eligible residents was then randomly selected using a computerised algorithm and invited to participate in an interview. Younger (16–24 years) and older people (65–85 years) were oversampled to ensure that robust estimates could be drawn for these groups. Interviews took place in respondents' homes using a Computer-Assisted Personal Interview. The interviews were conducted in English by trained lay interviewers and lasted for 90 minutes, on average. The final sample was 8,841 fully responding households (a response rate of 60%), equating to an estimated 2007 resident population of 16,015,300 Australian adults.

The survey instrument was a modified version of the World Mental Health Survey Initiative version of the Composite International Diagnostic Interview (WMH-CIDI), which comprised a series of modules [2]. A 'Caregiving' module commenced by asking respondents if they had any immediate family members with any of the following types of physical health problems (cancer, serious heart problem, senility or dementia, intellectual disability, blindness or paralysis or any other serious chronic physical illness), drug and alcohol problems (not further specified) or mental health problems (depression, anxiety, schizophrenia or psychosis, manic-depression or bipolar disorder or any other serious chronic mental problem) and which family member(s) had each type of problem. Respondents who reported having at least one family member with a health problem were asked how much their life is affected by their family member's(s') health problems (taking into consideration his or her time, energy, emotions, finances and daily activities) – 'a lot', 'some', 'a little' or 'not at all'. Respondents who answered 'a lot' or 'some' were asked further questions about the kinds of tasks they helped their family member(s) with health problems do (help them with washing, dressing or eating, help them with practical things, keeping them company or giving emotional support and other things), and the total time in an average week they spent doing things related to their family member's(s') health problems. Additional questions asked whether family members' health problems caused the respondent embarrassment, caused them to be worried, anxious or depressed and had a financial cost to them.

A 'Demographics' module included questions about respondents' sex, age, marital status, country of birth, main language spoken at home, 'section of state' (major urban, other urban or other [bounded locality, rural balance, migratory]), highest level of education and labour force status.

2.1.5 UQ Carer Survey 2016

The UQ Carer Survey 2016 was a convenience sample survey of Australian adults caring for someone aged 16 years or older whose main condition is mental illness. The survey was purpose designed by the authors to fill gaps in data for this project and was administered online to 107 carers in April 2016.

The UQ Carer Survey 2016 was created in SurveyMonkey, an online survey software tool [39]. Participants were recruited from state and territory carer networks and organisations, including members of Mental Health Carers Arafmi Australia (MHCAA) and the Mental Illness Fellowship in each state and territory. An email invitation containing the SurveyMonkey link was sent to each of these carer organisations to circulate within their networks.

The survey instrument was designed to fill gaps in previous national surveys, particularly the breakdown of hours of care by caring tasks. The demographics section included questions about: carer demographics (age, sex, country of origin, state of residence, language spoken at home, indigenous status); their caring role (number of care recipients, number of years caring, relationship to care recipient, recipient of Carer Payment or Allowance); and care recipient demographic and disability characteristics (age, sex, mental illness diagnosis, other conditions, living situation). The majority of these questions were a modified version of those included in the SDAC 2012 [16] or the Carers Victoria online survey 2011 [40]. The caring relationship section included questions about the average weekly hours of care and types of caring tasks provided by the carer. The content of questions in this section was based on previous caring task studies [41, 42]. Lastly, a psychiatric hospitalisation section included questions about the care recipient's length of stay, the caring role and services received in the week following discharge.

At the end of the UQ Carer Survey 2016, carers were asked: 'If you have any other comments to add about your caring role, please outline below'. This was an optional, open-ended response type, which allowed carers to provide comprehensive qualitative responses about any topic they wished to discuss.

2.1.6 Survey of High Impact Psychosis 2010

The SHIP 2010 is a nationally representative survey of Australian adults aged 18–64 years with psychotic disorders who are in contact with mental health services. It was funded by the Australian Government Department of Health and Ageing and carried out by the SHIP Study Group (see Acknowledgements) between April 2010 and March 2011.

SHIP 2010 consisted of a census of people with psychosis in contact with mental health services. It was conducted in seven mental health catchment areas across five states, with participation from all public mental health services and 86% of mental health non-government organisations in these areas. Eligible participants lived in the area, were in contact with the above services in March 2010 and screened positive for psychosis. Additionally, those in contact with the public mental health services in the 11 months prior who had a recorded diagnosis of psychosis were also eligible. Of 7,955 eligible participants, 4,189 were randomly selected to be contacted for interview and 1,825 completed interviews, a response rate of 44% [11].

The survey included a semi-structured clinical interview, the Diagnostic Interview for Psychosis (DIP), as well as modules on a range of areas, including sociodemographic details, physical and mental health, quality of life, functioning across a variety of domains, service use and unmet needs. Participants were asked whether they had an unpaid carer in the past 12 months who was responsible for looking after them, helping them or taking care of their needs. They were also asked whether they had been admitted to hospital for a mental health problem in the past 12 months and, if so, the number of times admitted and total nights spent in each of four facility types (public psychiatric hospital, public psychiatric unit in general hospital, private psychiatric hospital, other).

Other service data collected included whether staff helped participants to find accommodation on discharge from their most recent hospital admission, number of involuntary admissions for mental health in the past 12 months and number of contacts with psychiatric outpatient and community mental health services in the past 12 months. Main past-year ICD-10 diagnosis was recorded using the DIP. The DIP also includes screening questions for depression (presence of depressed mood or loss of pleasure in past year), ratings on the course of disorder and modules to rate the presence of lifetime diagnosis of alcohol, cannabis or other abuse/dependence.

Participants were asked if they had deliberately tried to harm themselves in the past year. Level of global functioning over the past year was rated by the interviewer on the Personal and Social Performance Scale (PSP). A physical health module recorded if participants had ever been diagnosed with various conditions.

Sociodemographic information collected from participants included their sex, age, country of birth, Aboriginal/Torres Strait Islander status, main language spoken at home and whether they had received the Disability Support Pension (DSP) in the past 12 months.

2.1.7 Key informant interviews

Key informant interviews were conducted with senior clinicians and service managers familiar with the operations of bed-based mental health services. In particular, we sought the views of a small sample of clinicians who had experience of – or were currently working with – adult mental health patients aged 16 years or older. Participants were recruited through the research team's existing professional network, including expert working group members from the NMHSPF and recommendations from other clinicians. Invitations to participate were sent to 23 clinicians, of whom eight volunteered to participate and four completed interviews. Participating clinicians were from Queensland and Western Australia, were all male, aged between 30–65 years and currently working in psychiatric intensive care, acute inpatient, step-up/step-down or residential rehabilitation services. The interviews were conducted by a UQ research officer, either in person or over the phone, and took approximately 10–15 minutes to complete.

The purpose of these interviews was to ask clinicians about their experience of the length of hospital stay and discharge procedures for mental health patients with and without a carer. The interview included questions categorised into two broad sections: demographics and training, and hospitalisation. The demographics and training section included sex, age, training background, experience with mental health bed-based services and current position. The hospitalisation section included open questions about differences in length of stay for patients with and without a carer, differences in duration of stay (if any) and further comments on these estimates with respect to service type or other circumstances.

2.1.8 Summary of data sources

This project drew on multiple data sources, comprising literature and expenditure reviews and survey datasets. The detailed steps in applying the relevant data sources to each of the three project aims are described in the remaining sections of this chapter.

2.2 Profile of mental health carers

Aim 1 was to provide a profile of informal mental health carers in Australia. Specifically, we sought to describe the characteristics of carers and their care recipients, as well their relationship and the characteristics of the caring role, including the hours and types of care provided. To address this aim, we drew upon a literature review and analyses of the three carer survey datasets described in section 2.1 (the SDAC 2012, NSMHWB 2007 and UQ Carer Survey 2016).

2.2.1 Literature review

Number of mental health carers

Forty-one of the 177 resources contained information relevant to the number of carers in Australia. Of these, 23 (or 56.1%) were retained. The other articles and reports were excluded because they did not provide detailed information about mental health carers (n=7) or they only focused on young mental health carers (n=7), culturally and linguistically diverse carers (n=2) or Indigenous carers of people with mental illness (n=2).

The majority of articles and reports (15 out of 23) referred to the same ABS datasets, including the SDAC (2003, 2009) [43, 44] and the NSMHWB 2007. One government report [45], two NGO reports [6, 46] and one journal article [47] collected or reported on other carer datasets. Studies analysing the Centrelink Administrative Database also provided useful data on the number of Carer Payment or Allowance recipients who cared for someone with mental illness. Three reports [40, 48, 49] referred to this database. Finally, published estimates from the SHIP 2010 study [50] were included because, despite its focus on only psychotic disorders, it is a large and nationally representative survey that collected data on caring.

Hours of care

Twenty-one of the 177 resources contained information relevant to the hours of care provided by informal carers in Australia. Of these, 12 studies were retained. The other articles and reports were excluded because they did not provide detailed information about mental health carers (n=7) or only focused on young mental health carers (n=2). The literature was diverse in terms of the data that were collected and reported. There were a number of small-scale studies presenting estimates on average hours of care per week. Few articles or reports (n=3) referred to the SDAC 2003 and 2009 and none referred to the SDAC 2012 or NSMHWB 2007.

Types of care provided

Fourteen of the 177 resources provided information on the types of care provided by informal carers in Australia. Of these, five were retained. The other articles and reports were excluded because they did not provide detailed information about mental health carers (n=4) or only focused on young mental health carers (n=5). One article reported on NSMHWB 2007 data [51], one report utilised SDAC 2009 data [52] and the remaining resources reported on independent data [40, 42, 53]. The SDAC 2003 did not provide a breakdown of care tasks by disability type, and there were no published data from the SDAC 2012.

2.2.2 Survey of Disability, Ageing and Carers 2012

Using data available from the SDAC 2012, respondents were deemed to be mental health carers if they provided care to a care recipient aged 15 years or over[1] whose main disabling condition was reported as one of: Schizophrenia, Depression/mood affective disorders (excluding postnatal depression), Phobic and anxiety disorders, Nervous tension/stress, Attention deficit disorder/hyperactivity, Other mental and behavioural disorders or Mental and behavioural disorders n.f.d. Within this group of all mental health carers,

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[1] The SDAC 2012 provides age in categories only, so a cut-off of 15 years was chosen as the closest to the desired minimum age of 16 years.

additional data were available for a sub-group of ‘confirmed primary carers’ – carers aged 15 years or over who were primary carers, whose main recipient of care met the above criteria and who were co-resident with that main recipient of care.

For comparison, the remaining carers of people aged 15 years or over were grouped into those caring for a recipient whose main disabling condition was an ‘other cognitive/behavioural’ disorder (Autism and related disorders, Mental retardation/intellectual disability, Intellectual and developmental disorders n.e.c., Speech impediment, Alzheimer’s disease, Dementia and Head injury/acquired brain damage) or a ‘physical condition’ (remaining conditions). Additional data for primary carers were also available for these groups. Carers of recipients aged less than 15 years were excluded from the analysis.

Data were obtained from the ABS in the form of a Confidentialised Unit Record File (CURF, May 2014 version). Due to confidentialising procedures, the CURF included data from 77,570 persons, equating to an estimated 2012 resident population of 22,317,168 Australians. Analyses were conducted using Stata version 11 [54]. Person-level and recipient-level data files were merged to obtain estimates for all mental health carers and their recipients. Data were weighted to account for possible selection and non-response biases and for differences between the sample and the Australian population. Jackknife repeated replication was used to calculate standard errors and 95% confidence intervals (CIs) to take account of the complex sample selection procedures. Analyses were descriptive, involving the calculation of proportions.

2.2.3 National Survey of Mental Health and Wellbeing 2007

Using data available from the NSMHWB 2007, respondents were deemed to be mental health carers if they: were aged 16–85 years; reported having a family member with depression, anxiety, schizophrenia or psychosis, manic depression or bipolar disorder or other chronic mental problem; reported that their life is affected ‘a lot’ or ‘some’ by their family member’s(s’) health problems; provided help to their family member(s) with health problems (i.e., help them with washing, dressing or eating; help them with practical things; keeping them company or giving emotional support; and other things); and reported doing things related to their family member's(s') health problems for one or more hours per week.

Data were obtained from the ABS in the form of a CURF (April 2009 version). Analyses were conducted using Stata version 11 [54]. Data were weighted to account for possible selection and non-response biases and differences between the sample and the Australian population. Jackknife repeated replication was used to calculate standard errors and 95% CIs to take account of the complex sample selection procedures. Analyses were descriptive, involving the calculation of proportions and means.

2.2.4 UQ Carer Survey 2016

Respondents were deemed mental health carers if they were: aged 18 years or older; cared for someone aged 16 years or over whose main condition was mental illness; and were not employed to provide their caring role (i.e., formally paid). This does not exclude people receiving a government benefit such as Carer Payment or Carer Allowance. For this survey, mental illness included schizophrenia, schizoaffective disorder and other psychoses; bipolar disorder; major depression; anxiety disorders; personality disorders; eating disorders; and behavioural disorders. It did not include a primary diagnosis of autism spectrum disorder, intellectual disability, substance use disorder or neurological disorder.

Completed survey data were exported from the SurveyMonkey website. Analyses were conducted using SPSS version 22.0 [55]. Analyses were descriptive, involving the calculation of proportions and means. Bootstrapping was used to calculate standard errors and 95% CIs for proportions. A thematic analysis was conducted to summarise the open-ended qualitative data provided by carers, particularly focusing on hours of care.

2.3 Replacement cost of informal care

2.3.1 Overview of replacement cost model

Aim 2 was to estimate the replacement cost of informal mental health care in Australia. The replacement cost approach to valuing informal caring assumes that, in the absence of a carer, the care recipient would need to receive equivalent levels of support from formal mental health or other support services, paid for by the relevant level of government. Our approach to the modelling adopted a national orientation to estimate the annual replacement cost from a government perspective for the year 2015. The definitions of carer and care recipient were as delineated in section 1.2.3 of this report.

To calculate the annual replacement cost for mental health carers in Australia, we required estimates of:

a) the eligible population, i.e., the total number of mental health carers in Australia during 2015

b) the total hours of care provided by each mental health carer in a year

c) the cost per hour to replace this care with formal services

d) cost offsets, i.e., estimated annual government expenditure on mental health carers that would offset the estimated replacement cost.

An economic model was constructed using these inputs to calculate the total annual replacement cost of all informal mental health carers.

2.3.2 Eligible population

We calculated the total number of mental health carers in Australia for the year 2015 using four steps, as described below.

Step 1: Obtain data on the 2015 Australian population

We obtained data on the 2015 Australian estimated resident population from the ABS [56]. We chose to model the following 20-year age groups: youths aged 5–24 years; young working age people aged 25–44 years; older working age people aged 45–64 years; and older adults aged 65 years or more. The rationale for modelling these age groups was twofold: (1) they meaningfully corresponded with different stages of life experienced by informal carers; and (2) they provided sufficiently large sub-samples when stratifying data for different age groups in later steps (e.g., calculating the proportion of informal carers who provide care to a person with mental illness in Step 3). The model did not differentiate between male and female carers as sample sizes from carer surveys at this level of disaggregation were too small for robust estimation.

From our literature review, we identified the SDAC 2012 as the most reliable data source by which to calculate comprehensive estimates of the proportion of informal carers in steps 2 to 4.

Step 2: Calculate the total number of informal carers in the Australian population

The SDAC 2012 was used to calculate the proportion of the total population (n=77,570) who are informal carers for any type of condition, by 20-year age groups. Original estimates from this analysis excluded individuals in the 'establishment population' – i.e., people in residential care or a supervised care facility, who were oversampled in the SDAC 2012. Excluding the establishment population from the denominator would artificially inflate estimates on the proportion of carers in the total population, particularly for the oldest age group, as none of the establishment population were themselves carers. Thus we adjusted proportional estimates for each age group to include the establishment population in the total population denominator. These adjusted proportions were applied to the ABS population estimates from Step 1 to calculate the total number of informal carers in the Australian population, by age group.

Step 3: Calculate the number of carers who provide care to a person aged 16 years or over whose main condition is a mental illness

SDAC 2012 data were used to estimate the proportion of all informal carers (n=7,969) who are mental health carers, by 20-year age groups. Mental health carers who fit the model inclusion criteria encompassed informal carers assisting a care recipient aged 15 years or more[2] whose main disabling condition is a mental illness (see section 2.2.2). The proportion of mental health carers was applied to the total number of informal carers estimated in the previous step to calculate the total number of mental health carers in the Australian population, by age group.

Step 4: Calculate the number of these carers who are primary and non-primary carers

SDAC 2012 data were used to calculate the proportion of mental health carers (n=669) who are primary versus non-primary carers, by 20-year age groups. Ideally, this step would partition the total number of mental health carers into primary and secondary carers. However, the SDAC 2012 only identifies confirmed primary carers aged 15 years or over who are co-resident with their main recipient of care, where their main recipient of care is 15 years or over and has a primary mental illness (main disabling condition). The remaining group thus encompasses secondary carers as well as all carers aged below 15 years, primary carers who do not live with the recipient of care and primary carers to a secondary care recipient with mental illness (but not their main recipient). Based on the structure of the SDAC 2012 dataset, our model was limited to separating the subset of mental health carers into confirmed 'primary' carers and 'other' carers (i.e., secondary carers, carers aged <15 years, non co-resident primary carers and primary carers to a secondary care recipient). Once again, estimates on the proportion of primary and other carers were applied to the total number of mental health carers calculated in the previous step to derive the total number of primary and other mental health carers, by 20-year age group.

2.3.3 Hours of care

The next step in the replacement cost model was to estimate the total annual hours of care provided by mental health carers in Australia. Initial scoping of the literature and available datasets indicated that this variable was not available in exactly this format and would need to be constructed using multiple data sources. Therefore, we calculated the average weekly hours of care per carer using a two-step process, as described below.

Step 1: Estimate the average total hours of care per week for primary and other carers

Estimates were derived for the average weekly hours of care from three separate data sources: the SDAC 2012; the UQ Carer Survey 2016; and the NSMHWB 2007.

Estimates of the average weekly hours of care provided by primary carers were only available from the SDAC 2012 and the UQ Carer Survey 2016. Of these two surveys, the former provides a better estimate of the average weekly hours of care provided by primary mental health carers (n=150) as it is based on a confirmed sample of primary carers and derived from a large, population-weighted survey sample. However, the SDAC 2012 reports average weekly hours of care as a discrete variable – i.e., the proportion of carers falling into each of the following categories for average weekly hours of care: <20 hours; 20–29 hours; 30–39 hours; or 40+ hours. Previous studies [e.g., 9] have applied mid-points to SDAC 2012 categories to calculate a weighted average of weekly hours of care using the proportion of carers in each category (e.g., 10 for <20 hours; 25 for 20–29 hours; 35 for 30–38 hours; 50 for 40+ hours); crude mid-points have generally been chosen in the absence of empirical data. Rather than select somewhat arbitrary mid-points, we were able to refine this method with reference to the UQ Carer Survey 2016. This

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[2] The SDAC 2012 provides age in categories only, so a cut-off of 15 years was chosen as the closest to the desired minimum age of 16 years.

survey recorded average weekly hours of care as a continuous variable. When grouped, the distribution of primary carers (n=50) across time categories was similar to that for primary carers in the SDAC 2012 (see section 3.1.6). Notably, these distributions tend to be skewed, with many carers reporting only a few hours per week and a small proportion of people providing extreme hours of care (e.g., >100 hours per week); thus crude mid-points tend to represent the distribution poorly. Instead, we used the UQ Carer Survey 2016 to calculate mean hours of care for each time category as per the SDAC 2012. From this, a weighted average of the weekly hours of care provided by primary mental health carers in the SDAC 2012 was calculated using SDAC 2012 proportion estimates and UQ Carer Survey 2016 means.

Data on hours of care for other carers required a different approach. The SDAC 2012 only records hours of care for possible primary carers, and the UQ Carer Survey 2016 sample was predominantly primary carers. Preliminary analyses of a sample of possible, but not confirmed, SDAC 2012 primary mental health carers (n=87) and the seven non-primary carers in the UQ Carer Survey 2016 suggested that these carers provide fewer average weekly hours of care than primary carers (see section 3.1.6). However, these estimates were not representative of the other carer population and so could not be used. The NSMHWB 2007 also recorded continuous data on average weekly hours of care. In contrast to the other two surveys, the NSMHWB 2007 includes a much broader sample of mental health carers (n=831), including carers for recipients of all ages, with a primary or secondary mental illness and with unspecified levels of impairment. The question structure is also likely to capture people who would not identify themselves as a carer. It follows that this sample would be more representative of other carers; therefore, we estimated average weekly hours of care for other carers using mean hours of care from the NSMHWB 2007 mental health carer sample.

These estimates encompassed average weekly hours of care provided by the carer. They did not include standby time – i.e., time where the mental health carer is not actively providing care but is ‘on-call’ in the immediate vicinity if a crisis were to eventuate. Standby time was excluded from the model as it is difficult to quantify using a replacement cost approach and deemed beyond the scope of the valuation.

Step 2: Partition the total hours of care provided each week between different caring tasks

Following estimation of the average weekly hours of care provided by primary and other mental health carers, further data were required to split the aggregate weekly hours of care between different informal care tasks. The model classified informal caring tasks into three broad categories: emotional support/psychosocial care; practical tasks; and activities of daily living. Emotional support was further subdivided into: supervising and monitoring; emotional support and encouragement; responding to behaviour (i.e., crisis); and other emotional support. Likewise, practical support was subdivided into: household tasks; health care coordination; literacy and communication; transport; and other practical tasks.

The only data source providing information on the proportional distribution of different care tasks was the UQ Carer Survey 2016. While the survey did collect data on the hours assigned to different care tasks for primary and secondary carers, there were too few observations to calculate reliable estimates for secondary carers (n=7). As such, data on the proportional distribution for all carers (n=94) were used to estimate the proportional distribution of care tasks for both primary and other mental health carers.

It should be noted that the UQ Carer Survey 2016 asked respondents to separately estimate the total average weekly hours of care and the number of hours spent during the week providing each of the informal care tasks outlined above. In the absence of recall bias, the sum of hours reported by respondents for each individual care task should equate with the total average weekly hours of care estimated separately. However, this rarely occurred, with the sum of hours spent assisting with individual care tasks exceeding carers' estimates of the total average weekly hours of care. This observation may be the result of joint production (where respondents conduct two or more simultaneous activities at a time) or recall bias. To account for this discrepancy, the proportion of hours spent on different care tasks was calculated by normalising hours of care for each task relative to the total sum of hours across all care tasks. This produced a sum of the proportional distribution of care tasks of 100%.

Finally, the total annual hours of mental health care were calculated by multiplying estimates of the average weekly hours of care per carer (by care task) by the number of weeks in a year and by the total number of mental health carers in Australia (i.e., the eligible population calculated in the previous section). A fundamental assumption of this approach is that carers maintain their caring role at a similar intensity over the course of the whole year.

2.3.4 Costs of formal care

The third variable required in the modelling of replacement costs was the hourly cost of formal care services to replace informal mental health care in Australia. Costs were sought from a government perspective for the year 2015, including base salaries of formal sector workers, on-costs, organisational overheads and adjustment for consumer service delivery time.

In order to source appropriate hourly replacement costs, two steps were followed. The first was to describe the types of care provided by mental health carers and identify formal services that provide comparable types of support. Where this might comprise multiple service types, an indication of the proportion of hours attributable to different types of care was needed as per section 2.3.3. The second step was to seek average hourly replacement costs for each of these formal services.

Step 1: Identification of replacement services

We explored the types of formal services providing personal support to people with mental illness. The types of roles considered included, but were not limited to: a peer support worker, counsellor, disability support worker, community mental health practitioner, case manager, family engagement worker, employment support worker, recovery worker and PHaMs program worker. We attempted to determine which role or roles would best replace the care tasks typically performed by a mental health carer. After examining several position descriptions, a PHaMs worker appeared to have the best fit to the tasks performed by mental health carers. The main reasons for selecting a PHaMs worker included:

1. The PHaMs program is designed specifically to assist adults (16 years or over) who are living with severe mental illness.
2. A PHaMs worker performs a variety of duties that cover many mental health informal caring tasks. These include, but are not limited to: assistance with practical and everyday tasks (e.g., household chores, shopping, budgeting and using public transport); achieving personal goals; developing better relationships; accessing health and social services; providing one-on-one and ongoing emotional support; advocacy; and assistance to improve economic and social participation.
3. Service providers typically employ a team of PHaMs workers with a range of backgrounds, qualifications and skills. A typical PHaMs team includes a team leader, a peer support worker, a case worker, a cultural broker and an employment worker. Therefore, the duties performed by a PHaMs team encompass many of the other roles listed above.

We attempted to systematically match each type of care task performed by mental health carers (as derived for the UQ Carer Survey 2016 from previous caring task surveys) to the duties typically performed by a PHaMs worker. Table 3 shows the results of this matching; PHaMs workers perform all of the tasks typically performed by mental health carers, except for crisis support or responding to behaviour. In addition, PHaMs workers do not provide assistance with activities of daily living to people with mental illness as often as their other duties. Therefore the majority of care tasks were costed as being replaced by a PHaMs worker, except for responding to behaviour and activities of daily living. A search was conducted for other positions in the mental health system that might appropriately replace these two care categories. The position description of a disability support worker was a good fit for all the listed activities of daily living, and a crisis accommodation worker was deemed a suitable fit for the responding to behaviour category.

Table 3. Matching of mental health carer tasks with typical PHaMs support worker duties and replacement services

Mental health carer task	Duties of PHaMs worker	Replacement service
Emotional support		
Supervising and monitoring: encouraging or prompting to do things; keeping care recipient occupied; supervising to prevent wandering or damage to self/others	✓	PHaMs worker
Emotional support and encouragement: encouraging; motivating; providing intensive emotional support and companionship	✓	PHaMs worker
Responding to behaviour: managing crises; managing inappropriate behaviours	×	Crisis accommodation worker
Other emotional support	✓	PHaMs worker
Practical tasks		
Household tasks: assistance with grocery shopping; preparing meals; housework; property maintenance	✓	PHaMs worker
Health care coordination: supervising or prompting medication; arranging supervision/outside services; assisting and liaising with health professionals; assisting with other aspects of treatment plan	✓	PHaMs worker
Literacy and communication: assistance with managing finances/paying bills; other paperwork; reading and writing; communication	✓	PHaMs worker
Transport: assistance with getting to appointments/workplace	✓	PHaMs worker
Other practical tasks	✓	PHaMs worker
Activities of daily living (ADL)		
Activities of daily living: assistance with personal hygiene and grooming, bathing and showering, dressing, eating, mobility, other ADL	×	Disability suppot worker

Step 2: Identification of hourly replacement costs

Salary rates for each type of worker were identified by:

a) searching job advertisements on the online classifieds websites Seek (www.seek.com.au) and CareerOne (www.careerone.com.au)

b) referring to role descriptions in the national Social, Community, Home Care and Disability Services (SCHADS) award [57].

The following search terms were entered into the CareerOne and Seek websites: 'PHaMs worker', 'crisis support worker', 'disability support worker'. We searched for positions in every state and territory advertised from 2010 onwards. The results of this search are detailed in Appendix 1. Many of the job advertisements listed a SCHADS award level, which provides standardised national rates for employees in the social and community sector. A PHaMs worker was consistently listed at SCHADS Social and Community Services Employee (SCSE) level 4 pay points 1–4, depending upon experience. A disability support worker's salary was more variable and depended upon the person's qualifications and experience and the level of responsibility of the particular job; positions varied more widely from SCHADS SCSE level 2 pay point 1, to level 3 pay point 4. For this reason, a mid-point of SCHADS SCSE level 3 pay point 1 was included in the model. SCHADS has a separate scale for a crisis accommodation employee and advertisements typically listed a crisis support worker at level 1 pay point 1–4.

Based on this search, hourly wage rates for each type of worker were sourced from the SCHADS award, December 2015 version[3] [57]. Table 4 shows the standardised wage rates from the SCHADS award applied to each type of caring task. These wages were multiplied by 38 hours per week and 52.14 weeks per year to obtain an annual base salary for each type of worker.

The rates sourced from the SCHADS national award reflect the hourly wage received by a support worker. However, there are additional costs to government to buy an hour of support time for a consumer. Firstly, the total cost to employ an FTE support worker includes:

1. the base salary or wage paid to the staff member
2. salary on-costs: for superannuation, penalty rates, workers' compensation, long service leave and so on
3. organisational overheads: to cover the costs of administration, human resources, leadership, quality assurance, information technology and communication services, leasing and maintenance of the facilities, vehicles, program evaluation and other activities necessary to deliver a formal support service.

Secondly, an FTE worker is available for a set number of working hours per week and productive weeks per year. They do not provide support for five days per week, 52 weeks per year as some time is spent absent on annual leave, sick leave and public holidays.

Table 4. SCHADS award rate applied to each replacement service

Replacement service	SCHADS award level	Hourly wage rate
PHaMs worker	SCSE level 4 pay points 1–4	$27.62–$29.74
Crisis accommodation worker	Crisis accommodation employee level 1 pay points 1–4	$24.48–$26.27
Disability support worker	SCSE level 2 pay point 1–level 3 pay point 4, mid-point SCSE level 3 pay point 1	$22.17–$26.27 $24.48 (mid-point)

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[3] SCHADS Pay rates change from 1 July each year. The rates used in the cost modelling apply from 1 December 2015.

Thirdly, a support worker does not spend every hour of their productive working weeks delivering support directly to consumers. Their time can be broken down into:

1. 'consumer service delivery time': any time directly attributable to a consumer, including face-to-face support time, writing notes and care planning and liaison on the consumer's behalf
2. 'other time': time spent travelling, in team meetings, in supervision, in training or professional development, conducting research or evaluation or liaising with services generally (not for a specific consumer).

One hour of informal caring provided to a care recipient was deemed to be equivalent to one hour of consumer service delivery time.

We sourced estimates of salary on-costs, organisational overheads, working hours per week, productive working weeks per year and the proportion of time allocated to consumer service delivery time from the NMHSPF [58]. The NMHSPF is a national mental health planning tool which provides benchmarks for the range of services required to deliver adequate mental health care at a systems level[4]. As part of the development of this tool, workshops were held with mental health community support sector stakeholders and consultations conducted with consumers, carers and community sector experts involved in the project working groups, as well as service providers across a number of jurisdictions, to develop best estimates of national average parameters for these services [58]. The parameters sourced from the NMHSPF for a Vocationally Qualified Mental Health Worker (equivalent to a Certificate III- or IV-qualified mental health support worker, such as a PHaMs worker) providing Individual Support and Rehabilitation services are shown in Table 5.

Table 5. Workforce parameters for Vocationally Qualified Mental Health Workers in the NMHSPF

Description of estimate	Value
Salary on-costs	23%
Organisational overheads	20%
Working hours per week (A)	38 hours
Working weeks per year (B)	45.14 weeks (52.14 – seven weeks leave)
Consumer service delivery time (C)	70% of working hours
Annual hours of consumer time per FTE (A × B × C)	1,201 hours

These parameters are comparable with other available estimates, including: 30% on-costs and 60% combined on-costs and overheads from the Assessing Cost-Effectiveness (ACE) in Mental Health and ACE Prevention studies [59–61]; and estimates of working hours per week (38), working weeks per year (44) and consumer-related contact time (72%) from a paper on planning estimates for the mental health community support sector [62].

An hourly replacement cost for informal mental health care tasks, for each type of worker, was calculated using the following steps:

1. annual salary per FTE = annual base salary × (1 + %on-costs) × (1 + %overheads)
2. hourly replacement cost = annual salary per FTE ÷ annual hours of consumer time per FTE.

2.3.5 Cost offsets

The Commonwealth Government currently has significant outlays to provide income support for informal carers who are unable to work due to their caring role. A proportion of mental health carers would qualify for, and currently receive, these support payments. If all of the support currently provided by informal mental health carers were replaced with formal support services, then these outlays would no longer be required. As such, we included them as a cost offset in the replacement cost model.

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[4] The NMHSPF is currently in a user testing phase and should be considered as under ongoing development. However, it provides the best source of nationally agreed service parameters for mental health community support services.

Government spending on carers was sourced from the Department of Social Services's *Annual Report 2014–15* [48]. This is the most up-to-date data on the Department's expenditure. The report outlines the administered outlays for each type of income support for carers, including the Carer Payment, Carer Allowance and Carer Supplement. However, it does not provide a breakdown of payment type by the care recipient's condition (i.e., how many payment recipients were caring for someone with mental illness). These data were instead sourced from the *Invisible Care* report prepared by Carers Victoria [40]. In that report, Carers Victoria conducted an analysis of Centrelink/ FAHCSIA 2011 data which enumerated the number of Carer Payment and Carer Allowance recipients by the first listed medical condition and age of the person receiving care. We extracted the proportion of payment recipients who cared for an adult (16+ years) with a first-listed medical condition of anxiety, major depression, psychotic illness or other mental illness (Table 6).

Table 6. Proportion of carers receiving income support related to an adult care recipient with mental illness

Payment type	Proportion of recipients who are mental health carers
Carer Payment	16.5%
Carer Allowance	16.6%

For Carer Payment and Allowance, these proportions were directly applied to the administered outlays for all carers to calculate estimated 2014–15 expenditure for mental health carers. For Carer Supplement, no data were available from the Carers Victoria study. Carer Supplement is tied to receipt of Carer Payment and/or Carer Allowance[5]; therefore we applied the same proportional estimate to 2014–15 outlays on Carer Supplement as that for Carer Payment (16.5%).

In addition to these support payments, carers are also eligible for Rent Assistance if they pay rent for private accommodation and receive the Carer Payment. The Department of Social Services *Annual Report 2014–15* [48] provides the average fortnightly Rent Assistance paid to eligible recipients of Carer Payment in 2014–15 and the total number of people receiving Carer Payment in 2014–15 (Table 7). The proportion of primary mental health carers receiving Carer Payment who were renting was obtained from the SDAC 2012 (Table 7). We estimated the number of mental health carers eligible for Rent Assistance by multiplying the number of Carer Payment recipients (Table 7) by the proportion who are mental health carers (Table 6) and multiplying this by the proportion who are renters (Table 7). This estimate was then multiplied by the Rent Assistance paid per carer (Table 7, scaled up to one year) to estimate total expenditure on Rent Assistance for mental health carers in 2014–15.

Table 7. Estimates related to Rent Assistance for mental health carers

Description of estimate	Value (SE)
Number of recipients of Carer Payment (all) 2014–15	255,542
Average fortnightly Rent Assistance paid to eligible Carer Payment recipients 2014–15	$123
Proportion of primary MH carers receiving Carer Payment who rent (SDAC 2012)	46.2% (9.8)

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[5] Carer Supplement is an annual lump-sum payment of $600 to assist carers with the costs of caring for a person with a disability or medical condition. All recipients of Carer Payment also receive the Carer Supplement. Recipients of Carer Allowance receive $600 for each eligible person they care for. Recipients of both Carer Payment and Carer Allowance receive $1,200 if they care for one eligible person.

2.3.6 Estimating replacement costs

An economic model was constructed in Microsoft Excel 2013 to calculate the total annual replacement cost of all informal carers who provide care to a person aged 15 years or over whose main condition is a mental illness. The year 2015 was chosen as the baseline year – i.e., the analysis was conducted using the 2015 Australian population and all costs were in 2015 Australian dollars.

As stated above, the total number of primary and other carers was calculated by 20-year age groupings. Similarly, separate estimates were calculated for the average weekly hours of care provided by primary and other carers; these were multiplied by 52 weeks to calculate the total annual hours of care provided by primary and other carers. Total annual hours of care were partitioned, based on the proportional distribution of different care tasks derived from the UQ Carer Survey 2016. The annual hours of care across each individual care task were multiplied by the corresponding hourly replacement cost for each task and then multiplied by the total number of carers, separately for primary and other carers. As a final step, we calculated the total annual replacement cost after deducting cost offsets from total annual replacement cost of primary carers (who are more likely to receive income support due to their more intensive caring role).

In addition to calculating point estimates, an uncertainty analysis was conducted to propagate uncertainty from model input parameters through to the final estimated replacement cost of informal mental health carers in 2015. The uncertainty (i.e., sampling error) of each input variable was recorded as a standard deviation, 95% confidence interval or effective sample size. Ersatz [63], an Excel add-in, was used to conduct a parametric bootstrap analysis that calculated final replacement cost estimates with 95% uncertainty intervals. Full details on the input parameters used in the replacement cost model and their uncertainty are presented in Appendix 3.

2.4 Bed-based replacement costs

Aim 3 was to examine potential cost savings to government of consumers with a carer being discharged early from bed-based mental health services. Data from carer surveys did not provide sufficient information to inform this step. Previous estimates and routine data collections to answer this question are also very limited. Therefore, we combined a literature review with analysis of the SHIP 2010 survey of people with psychosis, as well as key informant interviews with clinicians working in bed-based mental health settings. The aim was to produce case studies on potential cost differences in bed-based services between consumers of these services who do or do not have a carer.

2.4.1 Literature review

A literature review was conducted to provide an overview of studies reporting on the length of hospital stay for adult mental health patients with and without a carer. The topic of interest was any existing patterns of patients staying a longer or shorter time in hospital as a result of having a carer. Details of the search methods are described in section 2.1.

2.4.2 Survey of High Impact Psychosis 2010

Analysis of the SHIP 2010 survey focused on whether there was a difference in number of days spent in hospital for mental health in the past 12 months for participants with or without a carer; participants who had not been admitted in the past year were excluded from the sample. A total number of nights admitted variable was created by summing the total nights spent in each of the four hospital types.

To control for differences between those with and without a carer not directly due to the carer's presence, possible covariates were selected for analysis based on a literature review of factors which drive the cost and length of stay for admitted mental health services [64]. These variables included:

- ICD-10 diagnosis – recoded as non-affective psychosis (schizophrenia, schizoaffective disorder, delusional disorder, other non-organic psychosis) vs. other (mania, depression with or without psychosis, other)
- course of disorder – recoded as continuous disorder (continuous chronic illness with or without deterioration, multiple episodes with partial recovery between) vs. other (single or multiple episodes with good recovery)
- possible comorbid depression – recoded as presence of depressed mood or loss of pleasure in the past month or 11 months preceding that – yes/no
- lifetime diagnosis of alcohol abuse/dependence – yes/no
- lifetime diagnosis of cannabis abuse/dependence – yes/no
- lifetime diagnosis of other abuse/dependence – yes/no
- comorbid physical health condition – recoded as lifetime diagnosis of any of: diabetes, epilepsy, stroke, heart attack, Parkinson's disease or cancer – yes/no
- global functioning – continuous PSP score, with higher scores indicating better functioning
- receipt of DSP – yes/no
- deliberate self-harm in past year – recoded as yes/no
- involuntary admission in past year – recoded as yes/no
- number of outpatient contacts for mental health in past year – summed across all service types, excluding drug and alcohol clinics
- whether staff helped find accommodation on discharge – recoded as yes/no
- age in years
- sex

- country of birth – recoded as Australia vs. other
- Aboriginal or Torres Strait Islander descent – yes/no
- main language spoken at home – recoded as English vs. other.

All analyses were conducted using SPSS version 22.0 [55].

For each potential covariate, a point-biserial correlation (categorical variables) or Pearson's r correlation (continuous variables) was conducted to assess whether the variable had a significant relationship with total nights admitted; variables without a significant relationship were excluded from further analysis. Secondly, point-biserial correlations or phi coefficients were conducted to explore the relationship of each potential covariate with carer status. For significantly related variables, a subsequent analysis of the relationship of that variable to total nights admitted was conducted, grouped separately for those with and without a carer, to explore interaction effects. Thirdly, the relationship between each possible covariate and each other covariate was similarly reviewed. Variables significantly related to multiple other covariates were considered for exclusion from the final model.

An independent-samples t-test was conducted to review the unadjusted relationship between carer status and total nights admitted, separately for private vs. public/other hospitals. This was followed by a linear regression model, including the predictive effect of carer status on total nights admitted controlling for selected covariates.

2.4.3 Key informant interviews

Considering the small sample size of only four participants, no formal qualitative or quantitative analyses were conducted. Instead, we reported on the trend of responses in terms of length of hospital stay for patients with versus without a carer and the insights shared by participants.

2.5 Carer support services and unmet needs

Aim 4 was to review current government spending on mental health carers and unmet support needs. Specifically, we sought to estimate Commonwealth and state/territory government expenditure on carer support, detail carers' use of support services and briefly explore barriers to service use and unmet needs for support. To address this aim, we conducted desktop reviews of published expenditure data, analysis of quantitative data from the SDAC 2012, analysis of qualitative data from the UQ Carer Survey 2016 and a literature review.

2.5.1 Commonwealth expenditure on carer support

We conducted a desktop review to estimate Commonwealth Government expenditure on mental health carer support services for the year 2015. This was in addition to carer payments previously identified in this report, including the Carer Payment, Carer Allowance and Carer Supplement (see section 2.3.5). The first step of this review was to conduct a search on department websites for any national initiatives or programs that target mental health carers. The two key Commonwealth Government department websites targeted were the Department of Social Services and Department of Health, both of which fund national programs for carers of people with mental illness [4, 65]. Once relevant programs were identified, program guidelines, operational manuals and other documentation from these websites were reviewed for recent funding allocation or expenditure data. Most program documentation did not provide this information. Consequently, the search was widened to other websites and reports. A Google search was conducted with the following search terms: 'program name' (e.g., Mental Health Respite: Carer Support or Carers and Work), 'mental health carers', 'support programs', 'services', 'expenditure', 'funding allocated'.

This search yielded the Department of Social Services' report on the proposed Integrated Carer Support Service [66], which outlined recent funding allocation to carer support programs. This included programs specific to mental health carers and programs for all types of carers, including those caring for someone with mental illness (see Appendix 5). Data provided about mental health carer support programs were quite detailed, including the number of carers supported by the program in 2014–15 as well as funding allocated in 2015–16. The number of carers reported was consistent with data in the government's *Community Mental Health Activities (2014–15)* report [14], and funding allocation generally aligns well with subsequent expenditure in previous Department of Social Services annual reports [48]. The more generic carer support programs also provided this level of information; however, the proportion of program users who care for someone with mental illness was not provided. In an attempt to obtain this data, we contacted Carers Australia, which oversees the delivery of some of the national carer support programs, including the National Respite for Carers Program (NRCP) [67]. However, we were unable to obtain further information about the main disabling condition of care recipients for carers using these programs.

A final search was conducted to ensure that we had not missed any relevant carer support programs or any funding data relevant to the programs identified in Appendix 5. The latter was achieved by searching for each program separately with Google.

Expenditure data from the above sources were combined to provide a total estimate for Commonwealth expenditure on mental health carer support, noting areas of uncertainty.

Commonwealth programs deemed out of scope

Apart from the key programs outlined in Appendix 5, the Commonwealth funds several programs that provide some level of support, either directly or indirectly, to mental health carers. These programs were deemed out of scope as they targeted a broader population than just carers and were not focused on the provision of direct respite or practical assistance to carers. Furthermore, no published data were available to indicate the proportion of expenditure for these programs that might benefit mental health carers.

For example, the Children of Parents with Mental Illness (COPMI) national initiative was excluded as it targets all children (0–18 years) of parents with a mental illness, primarily via the development and provision of information and online resources [68, 69], and only some children of parents with mental illness will have caring responsibilities. The COPMI program is funded by the Department of Health; however, it has been announced that the national initiative will no longer be funded after June 2016 [70].

Two other programs funded by the Department of Health target mental health consumers but also acknowledge and highlight the role of the carer. One is the Partners in Recovery (PiR) program, which supports people with severe and persistent mental illness to access the services and supports they need [71]. The PiR worker endeavours to engage the carer throughout this process, as well as provide them with information and resources and link them with services to address their own needs [72]. The other is Mental Health in Multicultural Australia (MHiMA), which advocates for culturally and linguistically diverse (CALD) mental health carers and provides them with a platform to participate in discussions about mental health services and policy input to government [73]. These programs were also deemed out of scope as they provide mainly information and advocacy for carers and, with their primary focus on consumers, there were no data available on the proportion of expenditure benefiting carers.

2.5.2 State/territory expenditure on carer support

Due to the fragmented nature of publicly available state/territory data, two alternative approaches were used to identify current expenditure on mental health carer services by state and territory governments.

Approach One

Web searches were conducted in June 2016 for grey literature detailing the existence, state/territory funding and usage of mental health carer support programs. The search focused on three potential data sources: 1) Department of Health (or equivalent) and Department of Human Services/Disability Services/Communities (or equivalent) websites; 2) Google searches; and 3) academic literature searches.

For each state/territory of Australia, searches began at the state/territory Department of Health (or equivalent) website. Each website was scanned for information on mental health services and carer services and 'mental health carer' and 'carer' were input into the website search bar. The same process was used for each state/territory Department of Human Services (or equivalent). Data on programs identified through these websites were pursued as follows:

- In states/territories with dedicated carer support programs, website searches continued for relevant budget papers reporting expenditure on mental health carer services. If necessary, Google searches were commenced to identify funding of these programs using '[program name] budget', '[state/territory] mental health carer funding', '[state/territory] mental health carer expenditure'.
- In states/territories where NGOs were identified as providing mental health carer services, the websites for these organisations were scanned for program descriptions applicable to mental health carers, annual reports and financial statements for the most recent available year. In addition, we checked for equivalent NGOs operating in other states. If identified, the same search process was followed on these interstate organisation websites to find mental health carer programs and expenditure.
- Peak bodies for mental health community services (e.g., Community Mental Health Australia) were identified and their

websites searched for carer-related program information. We also searched the Department of Social Services Carer Gateway website for any relevant information or reports.

A further Google search was conducted using the search terms: ‘mental health carer’, ‘mental health carer services’, ‘mental health carer support’, ‘carer services’, ‘carer support’ (and state/territory name). When further programs or funded organisations were identified, the same methods described above were followed.

Finally, we searched the PubMed database for any academic papers investigating expenditure on mental health carer support programs by state and territory governments. Search terms included: ‘mental health carer’, ‘Australia’, ‘support’, ‘funding’, ‘expenditure’, ‘psychiatric services’, ‘and respite’. This search did not yield any new relevant information.

A minimum estimate of expenditure by state/territory governments on mental health carers was calculated by adding only expenditure clearly linked to mental health carers. Expenditure estimates were converted into constant prices using the June 2015 Consumer Price Index (CPI) [74].

Approach Two

As an alternative method, a top-down investigation was conducted drawing on mental health expenditure data from the Australian Institute of Health and Welfare’s (AIHW) Mental Health Services in Australia website [75]. Mental health NGO expenditure data was provided by service type and state/territory for the most recent year (2013–14). We adjusted these data to 2015 prices using the June 2015 Consumer Price Index (CPI) [74].

Data on expenditure by service type provided by the AIHW for all states and territories was analysed to identify which services would benefit carers versus consumers and therefore which service expenditure was in or out of scope. A range of possible state expenditure on mental health carer NGO services was identified using in-scope expenditure as a minimum and total minus out-of-scope expenditure as a maximum.

Separately, we attempted to identify estimates of the percentage of state mental health expenditure that supported carer services. Firstly, we used data on carer program expenditure in Victoria (identified in Approach One), divided by total state mental health NGO expenditure for Victoria from the AIHW, to estimate a percentage of spending for this state. The AIHW data for Victoria was scaled up proportionally to include residential services, since the state-level breakdown of NGO expenditure from AIHW does not include those services. Secondly, we applied data from the *2010 Mental Health Coordinating Council Sector Mapping Report* for NSW [76] to AIHW total expenditure on mental health NGO services for all states/territories to gain another estimate of the range of state expenditure.

2.5.3 Survey of Disability, Ageing and Carers 2012

Quantitative data from the SDAC 2012 were analysed to explore carers’ reported use of support services, barriers to use, unmet support needs and satisfaction with services. Methods of analysis were as for the profile of mental health carers and are detailed in section 2.2.2.

2.5.4 UQ Carer Survey 2016

For the UQ Carer Survey 2016, de-identified responses to the final open-ended survey question were exported from the SurveyMonkey website and entered into an SPSS data file. A thematic analysis was conducted to summarise the qualitative data provided by carers. Thematic analysis is a common qualitative analytic method which involves identifying, analysing and reporting patterns or themes within data [77].

An iterative process was undertaken to identify key themes in the UQ Carer Survey 2016 qualitative data. An initial reading was conducted by one researcher (EH), undertaking an inductive or bottom-up approach to allow themes to emerge from the data, rather than searching for pre-defined themes. After reviewing the responses, EH identified key themes by organising items relating to similar topics into categories. EH then re-read the qualitative text, line by line, to identify any new themes, identify sub-themes, refine existing themes or identify any items missing from themes. A second researcher (SD) then reviewed the original qualitative data as well as the key themes proposed by EH. This second review identified additional themes and enhanced the existing themes, resulting in a more refined presentation of the patterns embedded in the qualitative data. A final review was conducted by EH by taking each theme separately and re-examining the original qualitative data. Results were presented at an explicit or latent level, where the data is organised into groups and the semantic content summarised.

2.5.5 Literature review

A literature review was undertaken to identify previous work reporting on mental health carer utilisation of carer services and unmet needs for support in Australia. Key data from relevant articles were summarised for three areas: utilisation of carer support services by mental health carers; barriers to using carer services reported by mental health carers; and mental health carers' unmet needs for support services. Details of the search methods are described in section 2.1.

Part three

Results

3.1 Profile of mental health carers

3.1.1 Number of carers

3.1.1.1 Literature review on the number of mental health carers

Estimates from previous studies of the number of mental health carers in Australia ranged widely, from 1% to 15% of all Australian adults aged 15 years and older caring for someone with a mental illness, with or without another disability [3, 51] (see Appendix 2 for full study details). This equates to between 177,900 and 2.4 million individuals [3, 51]. Some articles and reports focused on mental health carers as a proportion of the population of carers for people with any condition in Australia, with estimates ranging from 6.7% to 28.1% (31,800–177,900) of adult carers caring for someone with mental illness [3, 46, 47, 52, 78]. Others focused on recipients of Centrelink Carer Payment or Allowance, with estimates ranging from 11.2% to 28% or between 26,484 and 95,974 payment recipients caring for someone with mental illness [40, 45, 49]. Alternatively, the SHIP 2010 national survey focused on mental health service recipients with a psychotic disorder, with 24.5% of this population reporting having a carer in the last 12 months [50]. This equates to approximately 15,566 individuals [40], assuming a one-to-one relationship of carers to care recipients.

Due to differences in scope, sampling methods and carer definitions, published estimates of the number of mental health carers are inconsistent. Currently no single estimate presents the whole picture about the number of mental health carers in Australia. Many studies only focus on primary or co-resident carers and do not take into consideration family or friends not living with the affected individual, as well as secondary carers who provide informal care to people with mental illness. Another oversight is young carers under 15 years of age, who are often excluded from estimates of mental health carers in Australia. Maybery et al. [79] estimated that 14.4–23.3%, or approximately one in five, children live with at least one parent with mental illness. However, this overestimates the young carer population as not all children living with a mentally ill parent take on caring responsibilities. The SDAC 2003 [78] provides a closer estimate of all young carers, with 170,600 carers (for people with any condition) aged 17 years or younger. This equates to approximately 3.6% of all children and young people in this age range, a portion of which will be young mental health carers.

For comparison, carer samples for existing estimates of the number of mental health carers were assessed on their degree of alignment with our definition of a mental health carer (as described in section 1.2.3). As can be seen in Table 8, none of these populations perfectly aligned with our definition. The SDAC samples (2003, 2009) [3, 52, 78] excluded secondary carers, non co-resident carers and carers under the age of 15 years. The NSMHWB 2007 population [51, 80] did include secondary and non-resident carers; however, it also included care recipients with substance use disorders, which are outside the scope of 'mental illness' for this report where they are the primary condition. Other studies [40, 46, 49] provided estimates from samples that were generally more inclusive of carers, however, their representativeness of the Australian mental health carer population is uncertain. This is particularly applicable to those studies that focused only on Carer Payment or Allowance recipients [45, 49] or a sub-group of mental illnesses [50]. In addition, some studies focused on carers who provide care for someone whose main health condition is a mental illness, while other estimates included carers of people whose primary health condition was another type of disability, but who also had a mental illness.

The differences in survey definitions, sampling and scope also make it difficult to determine any change in the proportion of mental health carers over time. The SDAC 2003 and 2009 surveys provide some of the few comparable estimates, with the number of co-resident primary carers of persons whose main disabling condition was a psychological disability increasing from 6.7% (or 31,800) in 2003 [78] to 9.8% (or 75,500) in 2009 [52].

In summary, previous attempts to enumerate Australian mental health carers have resulted in highly variable results, with little consistency across studies and none that closely approximate our definition of a mental health carer. Despite existing published estimates' poor alignment with the definition, estimates from the SDAC (2003, 2009) and NSMHWB 2007 are the most representative of the Australian mental health carer population. Therefore, we sought to analyse these national surveys further to improve on previous estimates.

Table 8. Alignment of carer samples for published estimates of number of mental health carers with mental health carer definition

Data source	Estimated number of carers	Representative sample of carers	Includes secondary carers	Includes non co-resident carers	Includes carers <18 years	Includes non-family carers	Excludes recipients <16 years	Excludes related disorders[1]	Mental illness as main condition
SDAC 2003 [78]	31,800	✓	×	×	×	✓	×	✓	✓
SDAC 2009 [52]	75,500	✓	×	×	×	✓	×	✓	✓
SDAC 2009 [3]	177,900	✓	×	×	×	✓	×	✓	×
SDAC 2012 [16]	499,400	✓	✓	×	×	✓	×	×	×
NSMHWB 2007 [51, 80]	2,387,710	✓	✓	✓	×	×	×	×	×
Families Caring for a Person with A Disability Study [45]	11.2% of Carer Payment and Allowance recipients	×	×	✓	×	×	×	✓	✓
Survey 17 of the Australian Unity Wellbeing Index [46, 47]	13.9% of all carers	?	✓	✓	×	✓	×	?	✓
SHIP 2010 [50]	15,566 carers of persons with a psychotic disorder	×	×	✓	✓	✓	✓	✓	✓
Pension Review 2008 [49]	28% of Carer Allowance (Adult) recipients (78,009)	×	×	?	✓	✓	✓	×	×
Centrelink Victorian Carer Payment and Allowance data 2011 [40]	Recipients of Carer Payment: 25.5% (26,484)[2] and Carer Allowance (Adult): 26.3% (51,193)[2]	×	?	✓	✓	✓	✓	?	×

[1] Includes primary diagnosis of: autism spectrum disorder (ASD), intellectual disability, substance use disorder or neurological disorder (e.g., dementia, stroke, epilepsy).

[2] Person receiving care aged 16–64 years.

3.1.1.2 Data analysis on number of mental health carers

The SDAC 2012 provides the most recent and detailed nationally representative data on mental health carers in Australia. Using the criteria described in section 2.2.2, we obtained two weighted population estimates from the SDAC 2012 of the number of mental health carers in Australia in 2012:

1. The total number of carers, including carers of all ages, primary and secondary carers, co-resident and non co-resident carers and carers with more than one care recipient where any one of the recipients' main conditions is a mental illness.
2. The number of confirmed primary carers who are aged 15 years or more, reside with their main recipient of care and the main recipient of care's main condition is a mental illness.

Table 9 shows the results of these analyses and their alignment with our mental health carer definition. The SDAC 2012 indicates that 1.0% of the Australian population, or 8.6% of informal carers, are mental health carers. This estimate of 225,421 people in 2012 is the only one available that aligns with all aspects of the mental health carer definition presented in section 1.2.3. Within this group, a smaller subset of 50,828 people were confirmed primary carers. These estimates are not directly comparable with previous analyses of the SDAC 2012 as they focus on carers of people who reported their main disabling condition as one of a number of mental illnesses, rather than on carers of people who have a psychological disability with or without other disability types.

The only other nationally representative carer survey, the NSMHWB 2007, also provided an estimate of the number of mental health carers in Australia (Table 9). Our analysis of this survey suggests that up to 1.5 million Australian adults, or 9.7% of the population and 64.8% of all carers, were mental health carers in 2007. This estimate improved upon previous analyses of the NSMHWB 2007 for this project by excluding people who were only caring for someone with a drug or alcohol problem. It also restricted the carer population to those who assisted their family member(s) across one of several domains and provided this assistance for at least one hour per week on average.[6]

Despite this, there are a number of problems with the way this survey was conducted that limit its utility for enumerating carers. The survey collected very little information about care recipients, and so we were unable to distinguish their age, level of impairment and whether mental illness was their main condition. Comparison of previous published estimates suggests that less than half of these carers would be caring for someone whose main condition (as opposed to any condition) is a mental illness. Further, the questions about caring are broad (see section 2.1) and likely to be over-inclusive of people who would not identify themselves as a carer. Less crucially, the survey also only captures carers aged 16 years or over and those who care for a family member; however, these are the majority of carers. Taking into account the above limitations, the NSMHWB 2007 estimate is less reliable, and the SDAC 2012 estimate of the number of mental health carers is likely to be closest to the true figure.

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[6] Interestingly, a small proportion of people (<3%) reported providing support for family members, but for an average of zero hours per week. When compared with those caring for one or more hours per week, these carers reported similar levels of embarrassment, distress and financial costs associated with caring.

Table 9. Alignment of estimates of number of mental health carers from data analysis with mental health carer definition

Data source	Estimated number of carers	Representative sample of carers	Includes secondary carers	Includes non co-resident carers	Includes carers <18 years	Includes non-family carers	Excludes recipients <16 years	Excludes related disorders[1]	Mental illness is main condition
SDAC 2012	225,421	✓	✓	✓	✓	✓	✓	✓	✓
SDAC 2012	50,828	✓	×	×	×	✓	✓	✓	✓
NSMHWB 2007	1,555,040	✓	✓	✓	×	×	×	✓	×

[1] Includes primary diagnosis of: autism spectrum disorder (ASD), intellectual disability, substance use disorder or neurological disorder (e.g., dementia, stroke, epilepsy).

3.1.2 Carer sociodemographic characteristics

3.1.2.1 Literature review on carer characteristics

We conducted a broad literature search in order to provide an overview of the characteristics of Australian mental health carers. Table 10 shows the range of estimates found in the literature. Demographic data reveal that the majority (63.5%–64.2%) [51, 78] of mental health carers are middle-aged (35–64 years), with the average age being around 57–58 years [6, 81]. Of studies including young carers, only 0.4% to 3% of the total sample were aged 25 years or less [40, 82]. More than two-thirds were female [6, 51, 52] and a similar proportion were born in Australia [3, 51]. Less than 15% [3, 6] spoke a language other than English at home and only 1%–2.3% [6, 81] were of Aboriginal or Torres Strait Islander descent. This is consistent with the 2011 ABS estimate of the national resident Indigenous population, which comprised 2.5% of the total Australian population [83]. It is important to note that most of these estimates were derived from samples of primary carers aged 15 years or older. As a result, they may not be representative of the demographic profile of all mental health carers in Australia, including carers under the age of 15 years and secondary carers.

Table 10. Demographic profile of Australian mental health carers from published studies

Characteristic	Proportion of carers
Gender	
Male	18.4%[6]–35.7%[51]
Female	64.3%[51]–81.3%[6]
Age in years	
Mean	56.96[81]–58[6]
Range	17–90[6, 81]
Country of birth	
Australia	70.9%[3]–77.2%[51]
Other	22.7%[51]–29.1%[3]
Language spoken at home	
English	88.1%[82]–95.5%[6]
Other	4.5%[6]–11.5%[3]
Aboriginal or Torres Strait Islander	
Yes	1%[81]–2.3%[6]
No	97.7%[6]–99%[81]

3.1.2.2 Data analysis on carer characteristics

The sociodemographic characteristics of mental health carers generated from our analyses of the three carer surveys of interest were consistent with those found in the previous literature (Table 11). Importantly, these samples more closely matched our definition of a mental health carer. The SDAC 2012 all carers group (n=669, representative of 225,421 Australian carers) was most aligned with that definition. For comparison, the demographic details of SDAC 2012 confirmed primary carers, participants in the UQ Carer Survey 2016 and the NSMHWB 2007 carer group are also included in Table 11. The SDAC 2012 primary carer and UQ Carer Survey 2016 samples are more representative of primary carers and likely a more intensive caring role (86% of the UQ Carer Survey 2016 sample identified as primary carers), while the NSMHWB 2007 sample is a much broader group of carers and care recipients. Despite its smaller sample size, UQ Carer Survey 2016 participants were remarkably similar to the other survey samples, especially the SDAC 2012 primary carer group; differences included more carers from Queensland and Western Australia, more females and an older age range.

The results show that the majority of mental health carers were female, of working age, married and living in major urban areas. More than three-quarters were born in Australia, and the vast majority (>90%) spoke English at home. The SDAC 2012 was the only survey to include carers under the age of 16 years; nearly 15% of all carers were aged under 25 years, with the youngest respondent being eight years old. Analysis of the UQ Carer Survey 2016 found that 1.9% (SE =1.3) of carers were of Aboriginal or Torres Strait Islander descent; these data were not readily available from the other surveys but are consistent with previous published estimates. A substantial proportion of carers are not in the labour force. SDAC 2012 primary carers had lower levels of educational attainment and employment than the broader carer group.

Table 11. Sociodemographic characteristics of mental health carers in Australian surveys

Characteristic	Proportion of carers (SE)			
	SDAC 2012 carers (n=669)	SDAC 2012 PC (n=153)	UQ Carer Survey 2016 (n=107)	NSMHWB 2007 (n=834)
Gender				
Male	45.6% (2.0)	37.9% (4.4)	11.2% (3.1)	33.4% (2.5)
Female	54.4% (2.0)	62.1% (4.4)	88.8% (3.1)	66.6% (2.5)
Age in years				
Mean	NA	NA	56.5 (1.36)	45.6 (0.6)
Range	8+	15+	20–87	16–84
0–14 years	2.6% (0.6)	NA	NA	NA
15–24 years[1]	12.1% (1.2)	7.6% (2.3)	1.9% (1.3)	8.8% (1.1)
25–64 years	72.8% (1.5)	74.4% (3.9)	69.2% (4.3)	81.7% (1.5)
65+ years	12.5% (1.4)	18.0% (3.4)	29.0% (4.3)	9.5% (1.0)
Marital status				
Married	53.5% (2.0)	63.2% (4.1)	63.6% (5.0)	60.1% (2.8)
Widowed	1.4% (0.4)	1.8% (1.2)	3.7% (1.9)	2.6% (0.6)
Separated/divorced	13.7% (1.4)	17.8% (2.9)	25.2% (4.2)	10.3% (1.2)
Never married	31.4% (2.1)	17.2% (3.6)	7.5% (2.8)	27.0% (2.6)
Country of birth				
Australia	76.8% (2.1)	74.8% (4.5)	81.1% (4.1)	78.4% (2.1)
Other	23.2% (2.1)	25.2% (4.5)	18.9% (4.1)	21.6% (2.1)
Language spoken at home				
English	92.5% (1.4)	91.1% (2.7)	99.1% (0.9)	96.4% (0.8)
Other	7.5% (1.4)	8.9% (2.7)	0.9% (0.9)	3.6% (0.8)
Urbanicity				
Capital city	61.2% (1.9)	48.3% (4.7)	67.6% (4.7)	NA
Balance of state	38.8% (1.9)	51.7% (4.7)	32.4% (4.7)	

Characteristic	Proportion of carers (SE)			
	SDAC 2012 carers (n=669)	SDAC 2012 PC (n=153)	UQ Carer Survey 2016 (n=107)	NSMHWB 2007 (n=834)
Section of state[2]				
Major urban	NA	NA	NA	65.5% (2.5)
Other urban				22.1% (2.3)
Other				12.4% (1.5)
State of residence				
New South Wales	32.2% (2.2)	31.1% (3.6)	16.2% (3.8)	NA
Victoria	26.0% (2.3)	27.0% (3.6)	27.6% (4.5)	
Queensland	19.1% (2.1)	23.4% (3.1)	30.5% (4.5)	
South Australia	10.6% (1.2)	7.9% (1.9)	11.4% (3.3)	
Western Australia	6.9% (1.2)	5.1% (1.5)	11.4% (3.3)	
Tasmania	3.1% (0.5)	3.2% (0.9)	1.0% (1.0)	
Northern Territory	0.5% (0.1)	0.3% (0.2)	1.0% (1.0)	
Australian Capital Territory	1.7% (0.3)	2.0% (0.6)	1.0% (1.0)	
Highest education				
Year 10 or less	30.7% (1.8)	43.0% (3.8)	NA	23.1% (2.3)
Year 11 or 12	19.0% (1.5)	13.7% (2.9)		17.9% (1.8)
Certificate or diploma	31.1% (1.8)	29.7% (4.2)		36.7% (2.5)
Bachelor degree or higher	16.7% (1.9)	13.6% (3.0)		21.8% (1.8)
NA or missing	2.6% (0.6)	NA		0.6% (0.3)
Labour force status				
Employed FT/PT	53.5% (2.1)	40.8% (4.2)	NA	61.6% (2.7)
Unemployed	5.5% (0.9)	5.8% (1.9)		1.7% (0.7)
Not in the labour force	38.4% (2.1)	53.4% (4.5)		36.8% (2.7)
NA (<14 years)	2.6% (0.6)	NA		NA

PC – confirmed primary carers; NA – not applicable.

[1] For the NSMHWB 2007, the minimum participant age was 16 years.

[2] Major urban (population clusters of 100,000 or more people), other urban (1,000 to <100,000 people), other (<1,000 people, migratory).

3.1.3 Care recipient characteristics

3.1.3.1 Literature review on care recipient characteristics

The review of previously published studies found that one-half to three-quarters of care recipients were female, with a mean age of around 44 years [3, 81] (Table 12). Most care recipients had been diagnosed with either depression or anxiety, with or without other mental illnesses [81, 84]. Many also reported a comorbid condition [40, 82], including a drug or alcohol disorder [6], physical disability [6, 84] or intellectual disability [6]. One study reported that 63% of care recipients were on a Disability Support Pension [40].

Table 12. Characteristics of recipients of informal mental health care from published studies

Characteristic	Proportion of care recipients
Gender	
Male	22.6%[81]–54.7%[3]
Female	45.3%[3]–77.4%[81]
Age in years	
Mean	44.27[81]
Range	17–84[81]
Aboriginal or Torres Strait Islander	
Yes	1.2%[81]
No	98.8%[81]
Mental illness diagnosis	
Schizophrenia	14.3%[81]–34%[40]
Bipolar disorder	21%[40]–28.7%[81]
Depression	20%[40]–72%[81]
Anxiety	7%[40]–60%[84]
PTSD/Personality disorder	4%[40]
Comorbidity	
Yes	64.5%[6]–64.6%[82]
No	35.4%[82]–35.5%[6]
Type of comorbidity	
Drug and alcohol	40%[6]
Intellectual disability	16.7%[6]
Acquired brain injury	7.3%[6]
Physical disability	20.1%[6]–30%[84]
Diabetes	7%[84]–15.2%[6]
Receipt of Centrelink payment	
Disability Support Pension	63.1%[40]
Age Pension	14.8%[40]
Newstart Allowance	4%[40]
Youth Allowance	0.7%[40]

3.1.3.2 Data analysis on care recipient characteristics

The characteristics of care recipients differed somewhat, depending on the survey sample (Table 13). A detailed demographic profile was available for care recipients from the SDAC 2012 (n=545). Just over half were female, 80.3% (SE 1.5) were born in Australia, 59.7% (SE 2.0) lived in a capital city and 6.8% (SE 1.1) spoke a language other than English at home. The majority of care recipients were of working age, although around a quarter were young people aged 15–24 years. Compared with their carers, a greater proportion had never been married (49.8%, SE: 2.1), a smaller proportion were employed (28.2%, SE: 2.4) and proportionally fewer had completed post-tertiary qualifications (Certificate or Diploma: 25.4%, SE: 1.9; Bachelor degree or higher: 9.8%, SE: 1.1). Most mental health care recipients had only one carer (79.3%, SE: 1.9). A higher percentage of UQ Carer Survey 2016 care recipients were male, and these recipients tended to be older than SDAC 2012 care recipients.

The most frequently reported mental illness diagnoses were depression and anxiety disorders. One-third of UQ Carer Survey 2016 care recipients had a diagnosis of schizophrenia or other psychosis, but these conditions were reported less frequently in the national surveys. Most care recipients had comorbid conditions alongside their main mental illness diagnosis; the most common comorbidities were substance use disorders and physical health conditions.

Main recipients of care for primary mental health carers in the SDAC 2012 differed from the broader group of SDAC 2012 care recipients (of all mental health carers) in a number of ways. A smaller proportion of main recipients were employed, a much greater proportion were profoundly or severely limited in core activities (mobility, communication and self-care) and a slightly higher percentage had comorbid disabilities. A much greater percentage of these main recipients had a head injury, stroke or brain damage compared with the all care recipients sample. These additional levels of complexity are likely to have been key factors as to why these care recipients met the threshold to be selected into the main recipient-primary carer sub-sample.

Table 13. Characteristics of recipients of informal mental health care in Australian carer surveys

Characteristic	**Proportion of care recipients (SE)**			
	SDAC 2012 all recipients (n=545)[1]	**SDAC 2012 main recipients residing with PC (n=153)**	**UQ Carer Survey 2016 (n=130)**	**NSMHWB 2007 (n=834 carers)[2]**
Gender				
Male	48.4% (2.5)	49.1% (4.6)	64.6% (4.2)	NA
Female	51.6% (2.5)	50.9% (4.6)	35.4% (4.2)	
Age in years				
Mean	NA	NA	41.9 (1.5)	NA
Range	15+	15+	16–84	
15–24 years	25.3% (1.8)	21.5% (3.5)	13.8% (3.0)	
25–64 years	64.8% (2.2)	61.2% (4.2)	73.1% (3.9)	
65+ years	9.8% (1.4)	17.3% (3.5)	13.1% (3.0)	
Labour force status				
Employed FT/PT	28.2% (2.4)	17.1% (2.8)	NA	NA
Unemployed	9.6% (1.3)	7.5% (2.4)		
Not in the labour force	62.2% (2.6)	75.4% (3.3)		
Mental illness diagnosis				
Depression	37.4% (2.4)	33.2% (3.9)	23.3% (3.8)	76.1% (2.1)
Anxiety	18.8% (1.7)	18.1% (3.4)	20.2% (3.7)	70.5% (2.1)
Nervous tension/stress	14.7% (1.4)	19.8% (3.3)	NA	NA
Schizophrenia/psychosis	6.8% (1.2)[3]	9.0% (2.3)[3]	32.6% (4.1)	20.3% (1.9)
Bipolar disorder	NA	NA	7.8% (2.4)	24.1% (2.1)
Borderline personality disorder	NA	NA	10.1% (2.8)	NA
Other mental illness	22.4% (2.0)	20.0% (3.5)	6.2% (2.1)	11.1% (1.4)

Characteristic	Proportion of care recipients (SE)			
	SDAC 2012 all recipients (n=545)[1]	SDAC 2012 main recipients residing with PC (n=153)	UQ Carer Survey 2016 (n=130)	NSMHWB 2007 (n=834 carers)[2]
Core activity limitation level				
Profoundly limited	18.2% (1.8)	45.8% (3.6)	NA	NA
Severely limited	21.4% (1.9)	43.9% (3.7)		
Moderately limited	12.3% (1.5)	2.7% (1.5)		
Mildly or not limited	48.1% (2.7)	7.6% (2.5)		
Has comorbidities				
Yes	85.3% (1.8)	92.0% (2.4)	53.5% (4.7)	NA
No	14.7% (1.8)	8.0% (2.4)	46.3% (4.7)	
Comorbidities				
Substance use disorder	NA	NA	21.5% (3.7)	32.4% (1.9)
Sensory and speech	14.6% (1.7)	26.1% (3.7)	2.5% (1.4)	NA
Intellectual	29.7% (2.1)	34.1% (3.9)	5.0% (2.0)	NA
Physical restriction	42.7% (2.5)	55.1% (4.0)	25.6% (4.0)	76.1% (2.8)
Head injury, stroke or brain damage	7.2% (1.3)	64.4% (3.7)	7.4% (2.4)	NA
Autism	NA	NA	6.6%(2.2)	NA
Other	55.9% (2.0)	28.3% (3.6)	NA	NA

PC – confirmed primary carers; NA – not applicable; MH – mental health.

[1] Excludes five recipients with missing identifier variables.

[2] Represents the proportion of carers who had at least one care recipient with these characteristics.

[3] For SDAC 2012, includes schizophrenia only.

3.1.4 Caring role

3.1.4.1 Literature review on caring role

Data from previously published studies suggest that most mental health carers supported only one care recipient [3, 6], and that the majority had been a carer for ten years or less [6, 40] (Table 14). Most care recipients lived with their carer [81, 82]. Care recipients were most commonly the child [6, 78] or spouse [6, 82] of the carer and, somewhat less frequently, their parent [78, 82]. Approximately one-fifth to one-quarter of carers received Carer Payment and a greater proportion (35%–43%) received Carer Allowance, with some carers receiving both types of payment.

3.1.4.2 Data analysis on caring role

Characteristics of the mental health caring role described in our primary data analysis of the three carer surveys were consistent with those published in previous studies (Table 15). The majority of SDAC 2012 carers only provided support to one care recipient, whereas the majority of carers in the NSMHWB 2007 sample had two or more family members with health conditions. Most commonly, recipients of informal mental health care aged 15 years or more were the carer's spouse/partner or child. Around 50%–60% of primary carers had been caring for ten or more years. Consistent with previous studies, 24% of SDAC 2012 primary carers reported receiving Carer Payment; this figure was lower for UQ Carer Survey 2016 carers (15%). Substantial minorities of the UQ Carer Survey 2016 carer group also reported receiving Carer Allowance (31%) or the Age Pension (16.0%, SE: 3.6), while 43.4% (SE: 4.8) did not receive any Centrelink support.

Table 14. Characteristics of the mental health caring role from published studies

Characteristic	Proportion of carers
Number of care recipients	
One	77.3%[3] –79.2%[6]
Two or more	20.8%[6]–22.7%[3]
Relationship: care recipient is a…	
Parent	13.8%[78]–33.2%[82]
Spouse/Partner	18.4%[6]–41.8%[82]
Child	35.2%[78]–60%[6]
Friend	1.8%[40]
Living situation	
Co-resident[1]	61.4%[6]–66%[40]
Length of time caring	
Ten years or less	53.8%[40]–60.5%[3]
More than ten years	31%[6]–46.3%[40]
Receipt of Centrelink payment	
Carer Payment	20.6%[6] –26%[40]
Carer Allowance (total)	35.2%[6] –43%[40]
Carer Allowance + Carer Payment	19%[40]
Carer Allowance only	24%[40]

[1] These data represent the proportion of care recipients who live with their carer, not the proportion of carers.

Table 15. Characteristics of the mental health caring role from Australian surveys

Characteristic	Proportion of carers (SE)			
	SDAC 2012 carers (n=669)	SDAC 2012 PC (n=153)	UQ Carer Survey 2016 (n=107)	NSMHWB 2007 (n=834)
Number of MH care recipients				
One	99.0% (0.3)	98.2% (1.1)	80.4% (4.0)	62.8% (2.7)
Two or more	1.0% (0.3)	1.8% (1.1)	19.6% (4.0)	37.2% (2.7)
Number of (any) care recipients				
One	78.3% (1.8)	76.2% (4.2)	NA	21.8% (2.6)
Two or more	21.7% (1.8)	23.8% (4.2)		78.2% (2.6)
Relationship: care recipient is a...[1]				
Parent	6.7% (1.1)	10.8% (2.7)	5.4% (2.0)	39.5% (2.4)
Spouse/Partner	45.8% (1.7)	51.5% (4.1)	25.4% (3.7)	17.9% (1.7)
Child	31.8% (1.6)	32.9% (4.2)	54.6% (4.3)	26.7% (2.1)
Other relative, friend or neighbour	6.3% (1.1)	4.8% (1.9)	14.6% (3.1)	49.3% (2.2)
NA	9.5% (1.1)	NA	NA	NA
Co-resident (lives with care recipient)	NA	100%	58.5% (4.3)	NA
Length of time caring[2]				
0–4 years	NA	31.3% (4.1)	20.8% (3.6)	NA
5–9 years		19.5% (3.3)	19.2% (3.4)	
10–14 years		14.1% (3.0)	15.4% (3.1)	
15–19 years		13.6% (2.6)	13.8% (3.0)	
20+ years		21.4% (3.9)	30.8% (4.0)	
Receipt of Centrelink payment				
Carer Payment	NA	23.8% (3.6)	15.1% (4.4)	NA
Carer Allowance		NA	31.1% (3.5)[3]	

PC – confirmed primary carers; NA – not applicable; MH – mental health.

[1] For SDAC 2012, all carers carer-recipient relationship, n=680 because 11 carers cared for two recipients with mental illness (and both dyads are counted here). For NSMHWB 2007, percentages are not mutually exclusive as carers may have more than one care recipient with mental illness.

[2] For SDAC 2012, primary carers n=152 (one response of "does not know" excluded).

[3] Thirteen (out of 33) people receiving Carer Allowance were also receiving Carer Payment.

3.1.5 Types of care provided

3.1.5.1 Literature review on types of care

The majority of relevant literature on types of care provided focused on the proportion of participants performing certain tasks in their caring role (see Appendix 2 for full study details). In the SDAC 2009 [52], 91.7% of co-resident primary carers of someone with a psychological disability (n=75,500) provided cognitive and emotional assistance; 71.4% provided assistance with transport; 54.8% provided assistance with self-care; and 52.1% provided assistance with meal preparation. NSMHWB 2007 estimates [51] were smaller, which could be due to its more inclusive definition of 'carer'. In addition, the SDAC 2009 definition is reliant on the primary carer assisting the care recipient with core activity limitations, which by nature would require these kinds of caring tasks. Of those adult carers of relatives with a mental illness identified in the NSMHWB 2007 [51], 60.4% provided emotional support; 37.8% practical support, e.g., paperwork or housework; and 11.7% help with washing, dressing or eating.

Neither the SDAC 2009 nor NSMHWB 2007 estimates provide any information about the frequency at which these tasks are performed. The Carers Victoria Study [40] presents richer data on the care activities performed daily by proportion of survey participants. Of the total sample of informal mental health carers (n=165), 87% provided daily emotional support; 58% supervised household tasks on a daily basis; and 43%–44% provided daily support for eating or drinking and self-care.

A pattern emerges, with provision of emotional support reported by the majority of mental health carers, followed by practical support (e.g., transportation, managing finances and supervising medications), and lastly smaller proportions providing support for activities of daily living (ADL) (e.g., feeding and dressing). This is somewhat supported by the results of two further studies [42, 53], both of which performed factor analyses on a Caregiving Task survey (n=106–114). The authors found that the key dimensions of mental health caring include, first and foremost, instrumental activities of daily living (e.g., transportation, managing finances and supervising medications), followed by psychosocial care (e.g., managing problem behaviours, providing emotional support and companionship) and, lastly, ADL support.

The main limitations of these studies include the lack of reference to a timeframe, the lack of specificity in the types of care provided and the inconsistency of measures included. For example, the SDAC 2009 and NSMHWB 2007 report on the proportion of carers providing certain types of caring tasks, whereas Jardim et al. [53] asked carers to report on the amount of help provided for certain caring tasks, ranging from 'no help' to 'lots of help'. In order to model a replacement cost, ideally information is needed on the number or proportion of hours that mental health carers provide for each of emotional, practical and ADL support on a daily or weekly basis. To our knowledge, no study to date has published data on hours of care by type of care activity and disability type.

Carer samples for estimates from published studies were assessed on their degree of alignment with our mental health carer definition (see section 1.2.3). In addition, these studies were assessed according to the quality of their definition of type and frequency of care provided. As seen in Table 16, only one study [40] presented a fairly well defined estimate of type and frequency of care. However, even this estimate was flawed for our purposes as, firstly, it only presented the proportion of carers that performed certain tasks on a daily basis. Participants in this study were asked 'which of the following activities do you do in a typical day?', and so the estimate does not provide a breakdown of tasks by time. Secondly, the estimate was drawn from a sample of Victorian mental health carers and therefore may not be representative of all mental health carers in Australia.

Table 16. Alignment of carer samples for published estimates on types of informal mental health care tasks with mental health carer definition

Data source	Types of care provided	Representative sample of carers	Includes secondary carers	Includes non co-resident carers	Includes carers <18 years	Includes non-family carers	Excludes recipients <16 years	Excludes related disorders[1]	Mental illness as main condition	Clear definition provided
SDAC 2009 [52]	91.7% provided cognitive/emotional assistance; 71.4% assisted with transport; 52.1% assisted with meal preparation	✓	×	×	×	✓	×	✓	✓	×
NSMHWB 2007 [51, 80]	60.4% provided emotional support; 37.8% provided practical support; 11.7% provided ADL support	✓	✓	✓	×	×	×	×	×	×

Data source	**Types of care provided**	**Representative sample of carers**	**Includes secondary carers**	**Includes non co-resident carers**	**Includes carers <18 years**	**Includes non-family carers**	**Excludes recipients <16 years**	**Excludes related disorders**[1]	**Mental illness as main condition**	**Clear definition provided**
Carers Victoria online survey 2011 [40]	87% provided emotional support daily; 58% supervised household tasks daily; 43% supervised eating/ drinking daily	×	?	✓	✓	✓	?	?	×	✓
ARAFMI and Carers QLD survey [53]	Instrumental activities of daily living: M=2.41 (SD=1.21) Psychosocial caring: M=2.20 (SD=0.93) Activities of daily living: M=0.22 (SD=0.56)[2]	×	?	✓	×	✓	✓	?	×	×

Data source	Types of care provided	Representative sample of carers	Includes secondary carers	Includes non co-resident carers	Includes carers <18 years	Includes non-family carers	Excludes recipients <16 years	Excludes related disorders[1]	Mental illness as main condition	Clear definition provided
ARAFMI, Carers QLD & MH services survey [42]	Instrumental activities of daily living: M=2.36 (SD=1.42) Psychosocial caring: M=2.23 (SD=0.90) Activities of daily living: M=0.20 (SD=0.42)[3]	✗	?	✓	✗	✓	✓	✗	✗	✗

[1] Includes primary diagnosis of: autism spectrum disorder (ASD), intellectual disability, substance use disorder or neurological disorder (e.g., dementia, stroke, epilepsy).

[2] Amount of caring assistance was assessed on the 18-item Inventory of Caregiving Tasks (ICT). Carers were asked to nominate on a five-point scale (0 = no help to 4 = lots of help) the amount of help provided for each caring task. Higher scores indicate a greater amount of time engaged in caring. A factor analysis was conducted on the ICT, which yielded three distinct factors of mental health caring: instrumental activities of daily living (IADL), psychosocial caring (PC) and activities of daily living (ADL) such as dressing and bathing.

[3] Amount of caring assistance was assessed on the Caregiving Tasks in Caring for an Adult with Mental Illness Scale (CTiCAMIS). For each of the 18 caring tasks, participants were asked to rate on a five-point scale the amount of help (0 = no help to 4 = lots of help). The CTiCAMIS was subjected to a factor analysis which yielded three factors: instrumental activities of daily living (IADL), psychosocial caring (PC) and activities of daily living (ADL) such as dressing and bathing.

3.1.5.2 Data analysis on types of care provided

Mental health carers in all three surveys (SDAC 2012, UQ Carer Survey 2016, NSMHWB 2007) answered questions about whether they assisted their care recipient(s) with various care tasks. These tasks and the proportions of carers performing them are shown in Table 17, grouped by the three broad categories. The UQ Carer Survey 2016 provided the most detail on the sub-types of tasks performed by informal carers. The survey also elicited information about the average weekly hours spent performing different types of care tasks. These are explored in section 3.1.6.

As with previous studies, emotional support and psychosocial care tasks were the most commonly reported by mental health carers. Assistance with practical tasks was also commonly provided by carers. Very nearly all primary carers (SDAC 2012 and UQ Carer Survey 2016) provided assistance across these two domains, compared with roughly two-thirds of the complete SDAC 2012 carer sample. Data from the UQ Carer Survey 2016 show that, within the category of emotional support, the most commonly reported care tasks included: encouraging and/or prompting to do things or remember to do things; encouraging and motivating; managing crises; and providing intensive emotional support and companionship. Within the category of practical tasks, the most commonly reported care task was assisting, informing and liaising with health professionals. Most other listed practical tasks were endorsed by significant proportions of mental health carers, including household tasks, health care and services coordination, literacy and communication tasks and transport.

Assistance with ADL was provided by a smaller, but still sizeable, percentage of mental health carers. This proportion was highest for SDAC 2012 primary carers, who need to provide assistance with core activities to qualify as a primary carer. In the UQ Carer Survey 2016 sample, the most commonly reported ADL task assisted with was personal hygiene and grooming.

Detailed analysis of the NSMHWB 2007 (not shown) allowed comparison of the proportion of carers performing different types of caring tasks by the mental illnesses of their care recipients and by whether they also had a family member (the same or a different person) with a drug or alcohol problem or physical health problem. The proportions of carers performing the three categories of caring tasks (emotional, practical, ADL) were fairly consistent across disorder types.

Table 17. Types of care tasks provided by mental health carers in Australian surveys

Type of care task	Proportion of carers (SE)			
	SDAC 2012 carer dyads (n=680)[1]	SDAC 2012 PC (n=153)	UQ Carer Survey 2016 (n=107)	NSMHWB 2007 (n=834)
Emotional support and psychosocial care	68.1% (2.1)	100%	100%	85.2% (2.2)
Encouraging and/or prompting to do things	NA	NA	93.5% (2.4)	NA
Keeping recipient occupied	NA	NA	58.9% (4.7)	NA
Supervising to prevent wandering/damage	NA	NA	30.8% (4.3)	NA
Encouraging and motivating	NA	NA	93.5% (2.4)	NA
Emotional support and companionship	NA	95.4% (2.0)	83.2% (3.8)	NA
Managing crises	NA	NA	88.8% (3.0)	NA
Managing inappropriate behaviours	NA	86.3% (2.9)	57.0% (4.7)	NA
Other emotional support tasks	NA	NA	49.5% (4.8)	NA
Practical tasks	64.1% (2.3)	99.0% (0.9)	98.1% (1.3)	53.5% (2.3)
Grocery shopping	NA	NA	57.9% (4.6)	NA
Preparing meals	10.4% (1.3)	62.5% (4.5)	61.7% (4.9)	NA
Housework	19.2% (2.2)	74.2% (4.8)	60.7% (4.7)	NA
Property maintenance	17.6% (1.8)	58.1% (4.8)	53.3% (5.0)	NA
Supervision/prompting of medication	NA	NA	52.3% (4.8)	NA
Arranging outside services	NA	NA	45.8% (4.8)	NA
Liaising with health professionals[2]	17.6% (1.4)	63.1% (4.5)	82.2% (3.7)	NA
Assisting with treatment plan	NA	NA	50.5% (5.0)	NA
Managing finances	NA	67.5% (4.5)	69.2% (4.5)	NA
Other paperwork	NA	NA	60.7% (4.7)	NA
Reading and writing	23.5% (1.9)	73.0% (4.0)	18.7% (3.9)	NA
Communication	9.5% (1.5)	70.3% (4.7)	44.9% (4.9)	NA
Transport	26.4% (2.2)	81.6% (3.6)	54.2% (4.8)	NA
Other practical tasks	NA	96.4% (1.6)	41.1% (4.7)	NA

Type of care task	**Proportion of carers (SE)**			
	SDAC 2012 carer dyads (n=680)[1]	**SDAC 2012 PC (n=153)**	**UQ Carer Survey 2016 (n=107)**	**NSMHWB 2007 (n=834)**
Activities of daily living	31.9% (2.5)	78.7% (2.8)	61.7% (4.6)	16.3% (1.9)
Personal hygiene/grooming[3]	9.3% (1.2)	34.5% (3.7)	37.4% (4.5)	NA
Bathing/showering	NA	21.6% (3.0)	25.2% (4.1)	NA
Dressing	NA	20.1% (3.1)	12.1% (3.1)	NA
Eating	NA	16.3% (3.6)	25.2% (4.3)	NA
Mobility	28.3% (2.6)	70.3% (3.6)	8.4% (2.7)	NA
Other ADL	NA	6.2% (2.0)	15.0% (3.3)	NA

PC – confirmed primary carers; NA – not applicable.

[1] SDAC 2012 carers includes 669 carers and 680 carer-recipient dyads, including 11 carers counted twice because they had two care recipients with mental illness.

[2] SDAC 2012 estimate is for assistance with health care.

[3] SDAC 2012 estimate is for assistance with self-care.

Information reported by primary mental health carers on their caring tasks was compared with data for primary carers of people with other cognitive/behavioural conditions or a physical condition (Table 18). Nearly all primary carers across the three groups provided assistance with emotional support and practical tasks. Compared with primary physical health carers (but not carers for other cognitive/behavioural conditions), primary mental health carers were significantly less likely to assist with ADL tasks, despite the core activity threshold in the SDAC 2012 required to qualify as a primary carer. Unlike people with physical disabilities, people with a serious mental illness are less likely to experience problems with physical and basic self-care tasks and more likely to require emotional and crisis support, reminders to complete activities, assistance with managing day-to-day life and help to re-engage with the community. Primary mental health carers were also significantly more likely than other cognitive/behavioural condition carers, but not physical health carers, to provide episodic rather than continuous care. This is consistent with the often episodic nature of mental illness (see section 3.1.6.2 for further detail). It is likely that the proportion of carers providing episodic care would be higher in the all mental health carers (including other carers) group, because primary carers needed to be providing care for six months or more to meet the definition.

A similar comparison was conducted for the broader SDAC 2012 all carers group, including secondary and other carers (Table 19). Compared with carers of people with other disorders, mental health carers were significantly less likely to assist their care recipient with practical and ADL tasks, likely due to the different needs of their care recipients. Mental health carers were also much more likely than physical health carers, but not carers of people with other cognitive/behavioural conditions, to provide emotional support to their care recipient.

Table 18. Caring tasks performed by primary carers of people aged 15+ years, by main condition of the main recipient of care, SDAC 2012

Types of assistance provided by primary carer to main recipient of care	Percentage of primary carers [95% confidence interval]		
	Mental illness (n=153)	Other cognitive/ behavioural[1] (n=155)	Physical condition (n=1233)
Emotional support[2]	100%	100%	90.1% [87.9, 92.4]
Practical tasks	99.0% [97.1, 100]	100%	99.0% [98.5, 99.6]
Activities of daily living	78.7% [73.1, 84.2]	76.2% [69.2, 83.2]	**94.0% [92.7, 95.4]**
Provides episodic care (vs. continuous)	25.6% [18.0, 33.2]	**6.5% [3.2, 9.8]**	23.2% [20.6, 25.8]

Note: values are **bold** where 95% confidence intervals are non-overlapping, i.e., significantly different from other types of carers.

[1] Includes: Autism and related disorders, Mental retardation/intellectual disability, Intellectual and developmental disorders n.e.c., Speech impediment, Alzheimer's disease, Dementia and Head injury/acquired brain damage.

[2] Excludes 28 mental health carers, 42 other cognitive/behavioural carers and 303 physical health carers who did not state whether they provided emotional support.

Table 19. Caring tasks performed by all carers of people aged 15+ years, by main condition of the recipient of care, SDAC 2012[1]

Types of assistance provided by carer to recipient of care	Percentage of carer-recipient dyads [95% confidence interval]		
	Mental illness (n=680)	Other cognitive/ behavioural[2] (n=376)	Physical condition (n=3805)
Emotional support	68.1% [63.9, 72.4]	62.5% [57.8, 67.3]	**19.7% [18.2, 21.3]**
Practical tasks	**64.1% [59.5, 68.8]**	82.2% [76.7, 87.7]	86.6% [85.1, 88.1]
Activities of daily living	**31.9% [26.9, 36.8]**	54.6% [48.2, 61.0]	48.9% [46.7, 51.0]

Note: values are **bolded** where 95% confidence intervals are non-overlapping, i.e., significantly different from other types of carers.

[1] Shows carer-recipient dyads, including carers counted twice because they had two or more care recipients.

[2] Includes: Autism and related disorders, Mental retardation/intellectual disability, Intellectual and developmental disorders n.e.c., Speech impediment, Alzheimer's disease, Dementia and Head injury/acquired brain damage.

3.1.6 Hours of care provided

3.1.6.1 Literature review on hours of care

In published studies (Table 20), adult mental health carers report providing on average between 53 and 104 hours of care per week [41, 53, 85–88] (for full study details, see Appendix 2). For many, this time includes periods when they are 'on call' or alert for problems arising with their care recipient. The majority of reviewed studies included all mental health carers, but two focused on sub-groups such as carers of individuals with an eating disorder [86] and mental health carers aged 55 years and older [87]. Compared with other studies, the latter presented a considerably smaller estimate of average hours of care per week (M=53.1) [87]. It is possible that this sample of older spouse carers received more assistance from formal care services in place of informal care. Participants in the Carers Victoria online survey 2011 [40] found it difficult to provide a single estimate of daily hours of care due to the fluctuating nature of mental illness. These carers (n=165) approximated that, on a good day, they would provide on average four hours of care, increasing to over seven hours of care on a bad day.

The SDAC 2003 and 2009 [52, 78] took an alternative approach and recorded average hours of weekly care in categories: (1) less than 20 hours; (2) 20–39 hours; and (3) 40 hours or more. The two surveys were fairly consistent, with 59% (SDAC 2009) to 66% (SDAC 2003) of co-resident primary carers of persons with a psychological disability providing 40 hours or more of care per week. However, these estimates are crude, with the majority of survey participants grouped into the third category.

With the exception of the SDAC 2003 and 2009 data, the main limitation of these studies is the lack of representativeness of included mental health carers, with sample sizes ranging from 20 to 165 people. Despite this, estimates for average hours of care per week were fairly consistent, ranging from 71 to 104 hours per week after excluding Loi et al.s' [87] study of older carers.

To further investigate the gaps in the literature, the carer samples (used for estimates from each study) were assessed on their degree of alignment with our definition of a mental health carer (see section 1.2.3). The results of this assessment are shown in Table 20. In addition, studies were assessed according to the quality of their 'hours of caring' measure. An estimate that captured the 'time spent caring', as opposed to the 'time in contact with' the care recipient, was considered a better measure. An estimate that captured the time spent caring in an hourly rate, as opposed to a proxy measure, was also considered to be of higher quality. As seen in Table 20, five studies [41, 53, 85, 87, 88] presented a good measure of caring hours. The remaining estimates presented fairly poor measures, such as the categorical data included in the SDAC 2003 and 2009. Most carer samples had poorly distinguished between primary and secondary carers, and many were ambiguous as to whether they included care recipients diagnosed with autism spectrum disorders, intellectual disability, primary substance use or neurological disorders. Finally, carers under the age of 18 years were only included in one of the samples [40].

Three studies [41, 53, 88] provided estimates from samples which closely, but not perfectly, aligned with the desired definition of 'carer' and 'care recipient' and which captured a quality measure of caring hours. However, these estimates were from small samples and their representativeness of the Australian mental health carer population is uncertain.

Table 20. Alignment of carer samples for published estimates of hours of mental health caring with mental health carer definition

Data source	Estimated hours of care (per week)	Representative sample of carers	Includes secondary carers	Includes non co-resident carers	Includes carers <18 years	Includes non-family carers	Excludes recipients <16 years	Excludes related disorders[1]	Mental illness as main condition	Good measure of caring hours[2]
SDAC 2003 [78]	66% caring 40+ hours	✓	×	×	×	✓	×	✓	✓	×
SDAC 2009 [52]	59% caring 40+ hours	✓	×	×	×	✓	×	✓	✓	×
SDAC 2009 [3]	55.3% caring 40+ hours	✓	×	×	×	✓	×	✓	×	×
Carers of People with Mental Illness project [85]	104 hours	?	✓	?	?	?	?	?	?	✓
Deakin longitudinal study of eating disorders carers [86]	78.91 contact hours (SD=63.83)	×	✓	✓	×	✓	×	✓	?	×
ARAFMI and Carers QLD survey [53]	71.13 hours (SD=68.96)	×	?	✓	×	✓	✓	?	×	✓
ARAFMI, Carers QLD and MH services survey [41]	90.97 hours (SD=68.65)	×	?	✓	×	✓	✓	?	×	✓

Data source	**Estimated hours of care (per week)**	**Representative sample of carers**	**Includes secondary carers**	**Includes non co-resident carers**	**Includes carers <18 years**	**Includes non-family carers**	**Excludes recipients <16 years**	**Excludes related disorders**[1]	**Mental illness as main condition**	**Good measure of caring hours**[2]
Respite users, ARAFMI and Carers QLD survey [88]	83.07 hours (SD=76.19)	✗	?	✓	✗	✓	✓	?	✗	✓
IMPACCT study [87]	53.1 hours (SD=45.5)	✗	?	✗	✗	?	✓	✓	✓	✓
Carers Victoria online survey 2011 [40]	Daily: 4 hours ‘on a good day’, 7+ hours ‘on a bad day’	✗	?	✓	✓	✓	?	?	✗	✗

[1] Includes primary diagnosis of: autism spectrum disorder (ASD), intellectual disability, substance use disorder or neurological disorder (e.g., dementia, stroke, epilepsy).

[2] Estimates were assessed according to the quality of their ‘hours of caring’ measure. An estimate which captured the ‘time spent caring’, as opposed to the ‘time in contact with’ the care recipient, was considered to be a good measure. An estimate which captured the time spent caring in an hourly rate, as opposed to a proxy measure, was also considered to be a good measure.

3.1.6.2 Data analysis on hours of care

The literature review identified a broad range of estimates for average hours of mental health care, with no existing estimate perfectly suiting our definition of mental health carers, representativeness of the sample and detailed recording of hours of care. The search highlighted that newer SDAC 2012 data were available and that further detail on hours of care could be produced from the NSMHWB 2007 – both nationally representative population surveys. In addition, the UQ Carer Survey 2016 asked carers to record their average weekly hours of care for different types of caring tasks, filling an important data gap on how caring hours are apportioned on average across tasks.

Like previous iterations, the SDAC 2012 recorded average weekly hours of care for primary carers in time categories. Table 21 shows that 38% of primary mental health carers were providing 40 or more hours of care per week and a similar proportion less than 20 hours per week. When compared with a sample of 87 possible, but not confirmed, primary mental health carers, confirmed primary carers appeared to be providing more weekly hours of care on average (Figure 1). A similar graph of average hours of care for these carers combined, stratified by 20-year age group, suggests that older carers (aged 45+ years) provide more weekly hours of care on average than their younger counterparts (Figure 2).

Table 21. Hours of care provided by primary mental health carers, SDAC 2012 (n=150)[1]

Average weekly hours of care	Proportion of confirmed primary carers (SE)
<20 hours	36.6% (4.5)
20–29 hours	16.4% (3.7)
30–39 hours	9.3% (2.6)
40+ hours	37.8% (4.3)

[1] Excludes three participants who responded “don’t know”.

Figure 1. Average caring hours for confirmed (n=150) vs. other possible (n=87) primary mental health carers, SDAC 2012

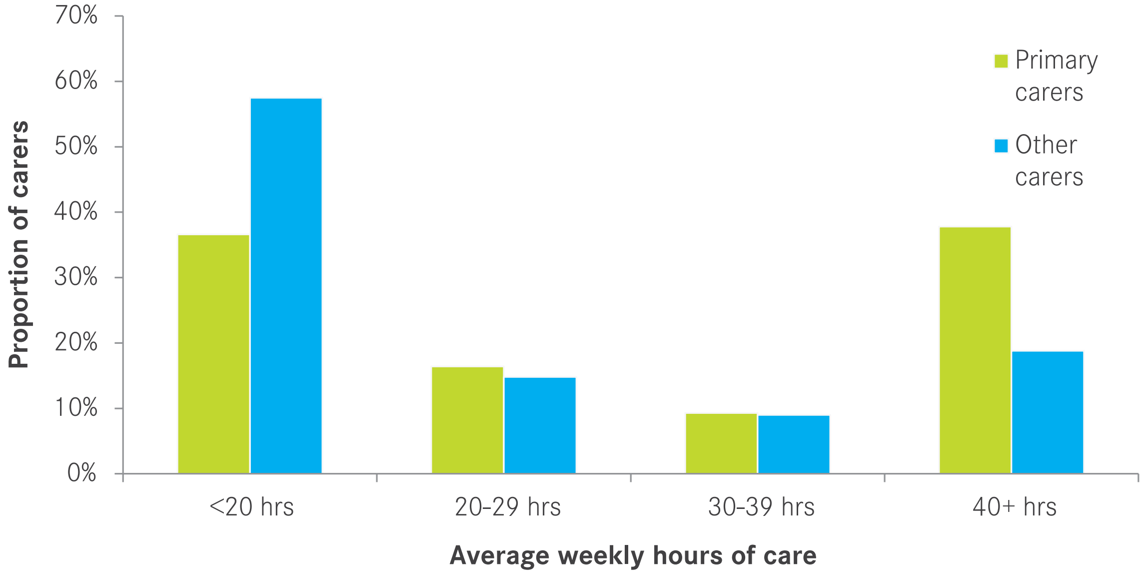
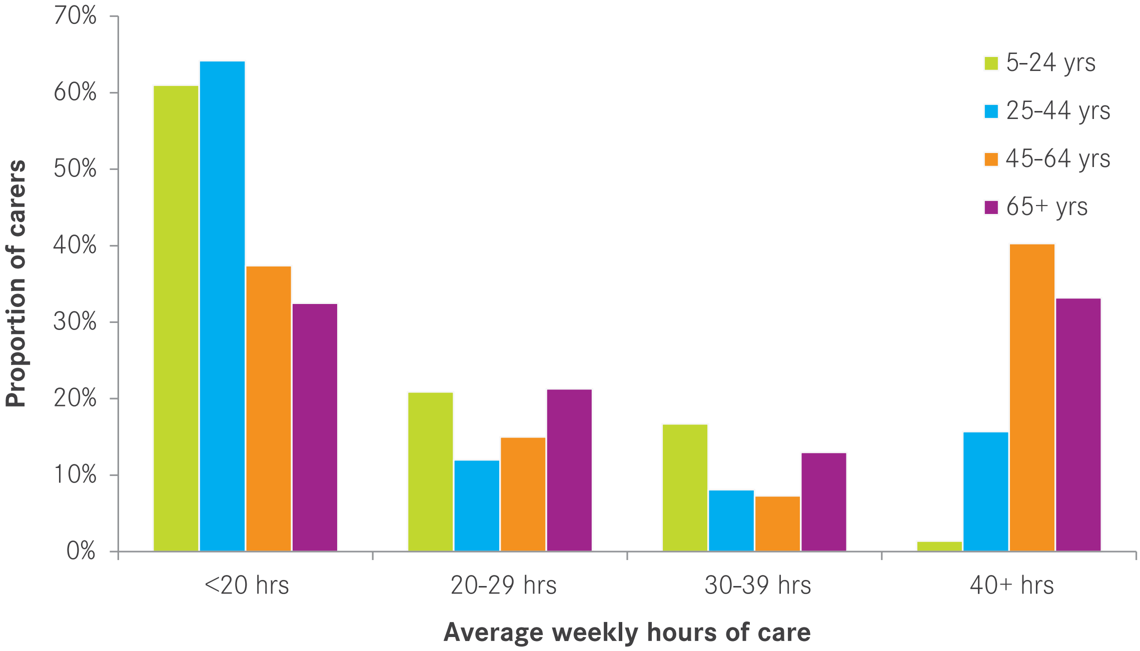


Figure 2. Average caring hours by age group for possible primary mental health carers, SDAC 2012 (n=237)



The distribution of average weekly hours of care was similar for primary mental health carers and primary carers of people with a physical condition (Table 22; Figure 3). Compared with primary carers of people with other cognitive/ behavioural conditions, primary mental health carers were significantly less likely to spend 40 or more hours caring per week. However, this comparison is limited as hours spent caring are likely to vary, depending on the availability of formal support services, and these may differ by the care recipient's type of condition.

Table 22. Hours of care provided by primary carers of people aged 15+ years, by main condition of main recipient of care, SDAC 2012

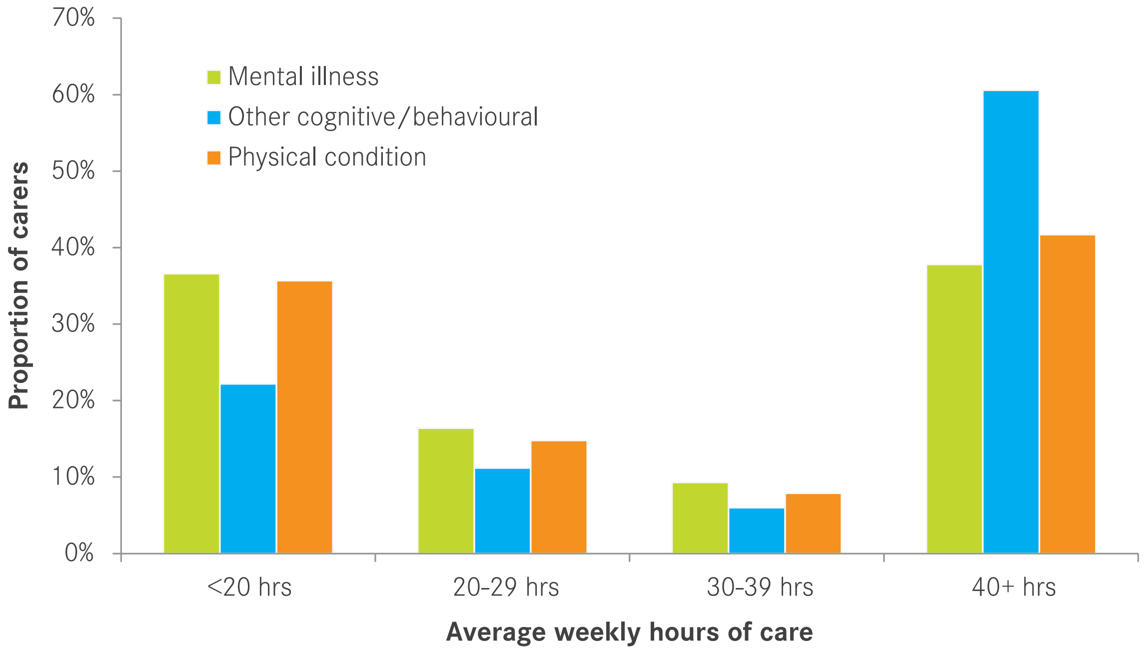
Average number of hours spent caring each week	Percentage of carers [95% confidence interval][1]		
	Mental illness (n=153)	Other cognitive/ behavioural[2] (n=155)	Physical condition (n=1,233)
1–19 hours	36.6% [27.6, 45.5]	**22.2% [15.0, 29.3]**	**35.7% [32.8, 38.6]**
20–29 hours	16.4% [9.0, 23.9]	11.2% [5.8, 16.5]	14.8% [12.5, 17.0]
30–39 hours	9.3% [4.1, 14.5]	6.0% [2.0, 10.1]	7.9% [6.5, 9.3]
40 hours or more	37.8% [29.2, 46.3]	**60.6% [53.6, 67.7]**	41.7% [38.4, 44.9]

Note: values are **bolded** where 95% confidence intervals are non-overlapping, i.e., significantly different from other types of carers.

[1] Excludes three mental health carers, five other cognitive/behavioural carers and 45 physical health carers who responded "don't know".

[2] Includes: Autism and related disorders, Mental retardation/intellectual disability, Intellectual and developmental disorders n.e.c., Speech impediment, Alzheimer's disease, Dementia and Head injury/ acquired brain damage.

Figure 3. Average caring hours for primary carers of people aged 15+ years, by main condition of main recipient of care, SDAC 2012



The UQ Carer Survey 2016 provided more detailed estimates of hours of care for a similar population of mental health carers as the SDAC 2012. Carers participating in this survey provided on average 37 hours of care per week to their main mental health care recipient (Table 23). Most of this sample were primary mental health carers; when secondary carers were excluded, the mean was slightly higher, at 40 hours of care per week. Data on hours of care from the UQ Carer Survey 2016 were grouped into the time categories used in the SDAC 2012 for comparison; proportions of carers and mean hours of care for each category are shown in Table 23. The distribution of carers across these time categories was very similar to that for primary carers from the SDAC 2012.

Table 23. Hours of care provided by mental health carers, UQ Carer Survey 2016

Average weekly hours of care (main care recipient)	Carer estimate (SE)	
	All carers (n=95)[1]	Primary carers (n=84)[2]
Mean	37.16 (3.25)	39.61 (3.50)
Range	1–127	2–127
<20 hours	35.8%(4.9)	33.3% (5.0)
20–29 hours	13.7% (3.4)	11.9% (3.5)
30–39 hours	10.5% (3.1)	10.7% (3.3)
40+ hours	40.0% (5.0)	44.0% (5.3)
Mean hours by category		
<20 hours	8.91 (0.95)	9.77 (0.99)
20–29 hours	22.81 (0.75)	22.65 (0.88)
30–39 hours	31.90 (0.85)	32.11 (0.92)
40+ hours	68.72 (4.24)	68.59 (4.36)

[1] Missing data for five participants, seven outliers excluded who reported 168 hours of care weekly.

[2] Missing data for six participants, ten not applicable (either secondary carer or not sure), seven outliers excluded who reported 168 hours of care weekly.

Average weekly hours of care were also collected by types of caring task, as shown in Table 24. When reporting their hours of care separately against each of these categories, carers produced a sum of hours of care that tended to be higher than the total hours reported in Table 23; this may be due to some tasks overlapping or recall bias. On average, mental health carers spend most of their caring time providing emotional support and psychosocial care, particularly emotional support and encouragement and supervising and monitoring. The third-highest hours of care on average were devoted to assistance with household tasks. Assistance with ADL tasks accounted for only a very small proportion of mental health carers' support time.

Table 24. Hours of care provided by mental health carers, by care task, UQ Carer Survey 2016

Average weekly hours of care (main care recipient)	Carer estimate (n=94)[1]		
	Mean (SE)	Range	Proportion of summed time
Emotional support			
Supervising and monitoring	10.01 (1.87)	0–105	19.2%
Emotional support	12.66 (2.09)	0–105	24.3%
Responding to behaviour	5.32 (1.10)	0–75	10.2%
Other emotional support	7.42 (1.81)	0–105	14.2%
Practical tasks			
Household tasks	8.78 (1.41)	0–70	16.8%
Health care coordination	2.80 (0.56)	0–38	5.4%
Literacy and communication	1.52 (0.23)	0–10	2.9%
Transport	1.43 (0.32)	0–25	2.7%
Other practical tasks	0.63 (0.17)	0–10	1.3%
Activities of daily living (ADL)			
All ADL	1.57 (0.48)	0–36	3.0%
Sum of all care tasks	**52.14 (8.36)**	**0–511**	**100%**

[1] Missing data for six participants, seven outliers excluded who reported 168 hours of care weekly.

UQ Carer Survey 2016 participants were also asked how much time in an average week they spend not actively caring but being ‘on call’ or ‘on standby’ in close proximity so they can be available to their care recipient quickly if needed (e.g., in a crisis). This type of availability can prevent a carer from engaging in other desirable activities, such as working, socialising or going on holiday. The majority of carers (n=85) reported providing this standby time; it was estimated that this was for an additional 59.5 (SE=6.9) hours per week. A small proportion of carers (n=21) had more than one care recipient with a primary diagnosis of mental illness. These carers reported that, on average, they spent 17.6 hours (SE 4.4) caring for their other care recipient(s) with mental illness, with the majority of this time focused on providing emotional support. Finally, 42 of the UQ Carer Survey 2016 carers did not live with their care recipient; 90% of these carers generally drove a car to visit their care recipient, spending on average 2.4 hours (SE=0.4) per week in transit.

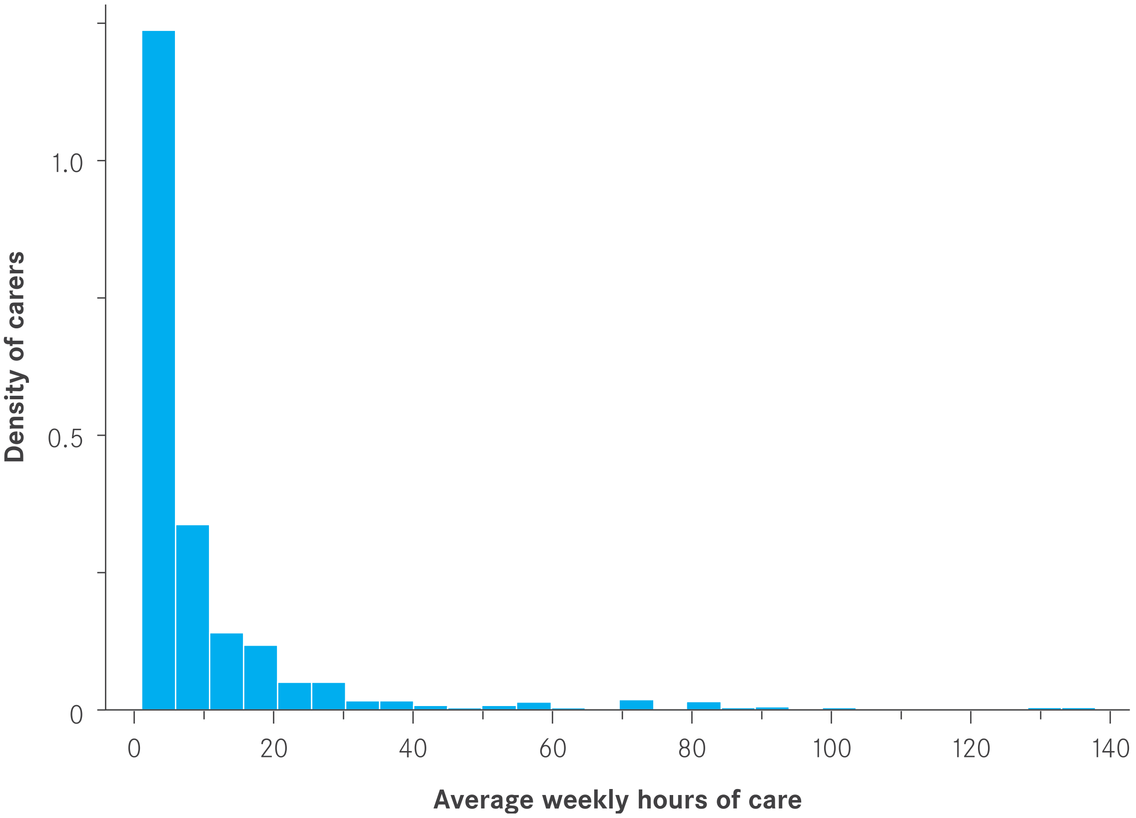
Data from the NSMHWB 2007 sample covered a much wider array of mental health carers, including non-primary carers. On average, these carers reported providing 11 hours of support per week (Table 25). The average weekly hours of care provided by carers supporting family members with different types of mental illnesses was very similar (not shown). Carers who provided assistance with ADL tasks (n=125) reported providing more hours of care on average (M=29 hours, SE: 3.8) than the larger samples of carers who assisted with practical tasks and/or emotional support. The distribution of weekly hours of care was skewed, with most carers reporting very few hours of caring per week and smaller numbers reporting significant hours of care, up to 138 hours per week (Figure 4).

Table 25. Hours of care provided by mental health carers, NSMHWB 2007 (n=831)[1]

Average weekly hours of care	Carer estimate (SE)
Mean	11.0 (0.8)
Range	1–138
<20 hours	82.9% (2.2)
20–39 hours	10.5% (1.6)
40+ hours	6.6% (1.4)
Mean hours by category	
<20 hours	5.0 (0.4)
20–39 hours	24.1 (0.7)
40+ hours	65.9 (4.6)

[1] three outliers excluded who reported 168 hours of care weekly.

Figure 4. Average weekly hours of care provided by mental health carers, NSMHWB 2007 (n=831)



Estimates of average weekly hours of care from these carer surveys are smaller than those generally identified in previously published studies. This may be due to these past estimates relying on small, and possibly less representative, mental health carer samples or differences in the definition of a mental health carer. Samples recruited through carer organisations (rather than representative household surveys) are likely to capture carers with higher needs who may have been caring for a longer duration and for more hours per week.

In qualitative feedback at the end of the UQ Carer Survey 2016, many carers noted that they had trouble estimating average hours of weekly care. The main reason for this was the fluctuating nature of mental illness, as highlighted by the following two carers:

> *"This survey was challenging to answer because the 'hours a day' caring for a mentally unwell person is so intrinsically variable that it is challenging to quantify." [Respondent 21]*

> *"Some questions are difficult to answer specifically eg number of hours for emotional care. This varies very much and relates more to the episodic nature of mental ill health." [Respondent 105]*

Carers explained that, on a good day, their care recipient requires minimal or even no care at all. On bad days, this can increase to almost 24/7 care, particularly if they are on suicide watch or if their care recipient needs to be hospitalised:

> *"…for him it's hard to put into [hours] weekly because some weeks it's a maintenance call and other weeks more. Especially if he is going into hospital he needs support because of his bi-polar." [Respondent 31]*

> *"If my spouse is not doing well, it is a challenging and resource draining day. On his good days/weeks we are without any need for care, aside from the unavoidable assessment and concern on my end, of each moment and action to ensure we are still having a good day." [Respondent 21]*

The time elapsed between the 'good' and 'bad' days appears to be quite variable. One respondent outlined that:

> *"during a relapse my role (which occurs about every 3 years) increases significantly and consumes most of my time each day for a period of 3 months." [Respondent 40]*

Evidently, the care provided by mental health carers is episodic, and the frequency and duration of these care episodes is variable, depending upon the nature of the care relationship, as well as on the care recipient's condition and recovery journey. This is important for further understanding and profiling mental health carers.

3.2 Replacement cost of informal care

3.2.1 Total replacement costs

A flowchart outlining the logic of the economic model is included in Appendix 3, alongside detailed estimates calculated for each step of the modelling, by 20-year age groups.

In June 2015, the population of Australia was 23 million people. We estimate that 2.8 million of these Australians are informal carers for people with any condition, within which 240,000 are mental health carers. The mental health carer group is further sub-divided into confirmed primary carers and other carers. Table 26 shows the breakdown of these population estimates by 20-year age groups; most mental health carers are of working age. Overall, there are an estimated 54,000 primary carers and 186,000 other carers in Australia who meet our definition of a mental health carer (Table 27).

Table 26. Total number of primary and other carers who are mental health carers, by age, Australia 2015

Age	Number of primary carers	Number of other carers	Total number of carers
5–24 years	4,171	31,253	35,424
25–44 years	10,304	55,907	66,211
45–64 years	29,223	76,468	105,691
65+ years	10,424	21,872	32,296

Table 27. Total number of primary and other mental health carers, Australia 2015 (with 95% uncertainty intervals)

Total number of carers	Mean	Lower 95% UI	Upper 95% UI
Primary mental health carers	54,136	44,801	64,350
Other mental health carers	185,532	167,559	204,317
All mental health carers	239,668	219,702	260,395

Separate estimates of the average total hours of informal care provided per week were obtained for primary and other carers. Data from the SDAC 2012 (supplemented by the UQ Carer Survey 2016) were used to calculate this variable for primary carers, who spend an average of 36.2 hours per week (SE: 2.1) providing informal care. By contrast, data from the NSMHWB 2007 were used for the average total hours of care per week for other carers – i.e., 11.0 hours per week (SE: 0.8). Detailed estimates partitioning the total hours of care provided on a weekly basis across different informal care tasks are presented in Appendix 3. Briefly, the proportional distribution of informal care hours across the categories of ‘emotional support’, ‘practical tasks’ and ‘activities of daily living’ was 67.9% (SE: 6.7), 29.1% (SE: 3.0) and 3.0% (SE: 0.9) respectively of total weekly average hours of care. Overall, primary mental health carers provide an estimated 101,938,000 annual hours of care to their care recipients, while other carers provide a total of 106,073,000 annual hours of care. These results are presented in Table 28, along with their associated 95% uncertainty intervals. For all mental health carers, these hours of care are equivalent to 173,198 FTE support workers (each providing 1,201 hours of consumer service delivery time per year).

Table 28. Total annual hours of informal care provided by mental health carers, Australia 2015 (with 95% uncertainty intervals)

Total annual hours of informal care	Mean	Lower 95% UI	Upper 95% UI
Primary mental health carers	101,937,872	81,611,683	125,056,030
Other mental health carers	106,072,649	88,844,981	125,452,086
All mental health carers	208,010,520	181,079,637	237,277,930

We calculated a replacement cost for a PHaMs worker of $83,873 per FTE after making adjustments for on-costs and overheads and $69.85 per hour after adjusting for annual consumer service delivery hours per FTE. The corresponding costs for a disability support worker were $71,337 per FTE and $59.41 per service delivery hour, while the costs for a crisis accommodation worker were $74,207 per FTE and $61.80 per service delivery hour. Combining data on the average total hours of care provided annually by care task and the hourly cost per replacement worker produced an estimated cost of informal mental health care of $129,351 on average per primary carer per year and $39,306 per other carer per year.

Overall, the total replacement cost of informal care provided by Australian mental health carers in 2015 was estimated to be $14.3 billion (95% UI: 12.4–16.3) prior to applying cost offsets to primary carers. Detailed replacement cost estimates for primary and other carers are shown in Table 29.

Table 29. Total replacement cost of informal care provided by Australian mental health carers, 2015, without cost offsets (with 95% uncertainty intervals)

Replacement cost with no cost offsets	Mean	Lower 95% UI	Upper 95% UI
Primary mental health carers	$7,006,741,875	$5,611,117,481	$8,631,637,473
Other mental health carers	$7,290,698,979	$6,081,877,690	$8,629,643,877
All mental health carers	$14,297,440,854	$12,396,886,738	$16,330,942,746

3.2.2 Cost offsets

Estimated government spending on income support payments for mental health carers is shown in Table 30. For the year 2014–15, an estimated $759 million was provided to mental health carers via Carer Payment, and a further $251 million via Carer Allowance. Mental health carers also received support through the Carer Supplement and Rent Assistance payments. Total outlays were estimated at $1.1 billion per year.

Table 30. Estimated Commonwealth Government outlays on mental health carer income support payments, 2014–15

Type of payment	Government spending, 2014–15 (millions)[1]	Proportion of recipients who are mental health carers, 2011[2]	Estimated spending on mental health carers, 2014–15 (millions)
Carer Payment	$4,600.0	16.5%	$759.0
Carer Allowance (adult)	$1,510.0	16.6%	$250.7
Carer Supplement[3]	$0.6	16.5%	$0.1
Rent Assistance[4]	NA	NA	$62.3
Total	$6,110.6	-	$1,072.1

[1] Administered outlays in 2014–15 [48].

[2] Centrelink/FaHCSIA data as at 23 September 2011 [40]. These data report on the proportion of payment recipients who care for an adult (16+ years) with mental illness, including anxiety, major depression, psychotic illness or other mental illness.

[3] For Carer Supplement, the proportion of Carer Payment recipients who are mental health carers was applied to total outlays.

[4] Annual spending on Rent Assistance for recipients of Carer Payment was calculated as the number of Carer Payment recipients who are mental health carers (estimated to be 42,164 recipients), multiplied by the proportion who are renting (46.2%, derived from the SDAC 2012), multiplied by average outlays on Rent Assistance per Carer Payment recipient [48]. Data on the actual number of Carer Payment recipients who received Rent Assistance were not available.

One government payment for carers was not taken into account in the above cost offsets. The Wife Pension is a payment for the female partner of an Age Pensioner or Disability Support Pensioner. New grants of Wife Pension stopped on 1 July 1995. If someone was receiving Wife Pension before that date, they could keep receiving it for as long as they remain eligible or until they transfer to the Age Pension. This payment was not included in the cost offsets because there are no publicly available data on the proportion of payment recipients who are mental health carers. The total number of payment recipients in 2014–15 was small (n=6,612, outlays = $107.6 million) [48] and likely to have had minimal impact on our replacement cost model.

After applying the above cost offsets to the replacement cost model, the total replacement cost for mental health carers reduced to around $13.2 billion per year (95% UI: 11.3–15.3). Detailed replacement cost estimates for primary and other carers with cost offsets applied are shown in Table 31.

Table 31. Total replacement cost of informal care provided by Australian mental health carers, 2015, after applying cost offsets (with 95% uncertainty intervals)

Replacement cost with cost offsets	Mean	Lower 95% UI	Upper 95% UI
Primary mental health carers	$5,934,683,498	$4,539,059,104	$7,559,579,096
Other mental health carers	$7,290,698,979	$6,081,877,690	$8,629,643,877
All mental health carers	$13,225,382,477	$11,324,828,360	$15,258,884,368

3.3 Bed-based replacement costs

3.3.1 Literature review

A brief literature review found few studies (n=7) which reported on the length of stay in a psychiatric hospital with respect to the presence of an identified carer or family member. Studies were inconsistent in terms of the variables collected, including whether the patient was brought into hospital by a family member, whether they live with a family member, carer stress and level of social network (ranging from living alone and financially independent to living with primary family or partner and unemployed) [89–95]. Only two investigations focused specifically on the presence or absence of a carer [89, 90].

Most studies did not find a significant effect. The few studies that did found that length of stay was longer if the patient had a carer [89] or was brought to hospital by a family member [91]. Jacobs et al. [89] found that patients with an informal carer stayed, on average, three days longer in hospital than those patients without a carer. This was significant in the pooled model and for schizophrenia and bipolar disorder patients, but not schizoaffective disorder patients.

This literature review was brief and so only provides a snapshot of the literature on informal carers and their impact on length of stay in psychiatric hospitals. Although our search was not exhaustive, there appears to be very little published literature on this topic.

3.3.2 Survey of High Impact Psychosis 2010

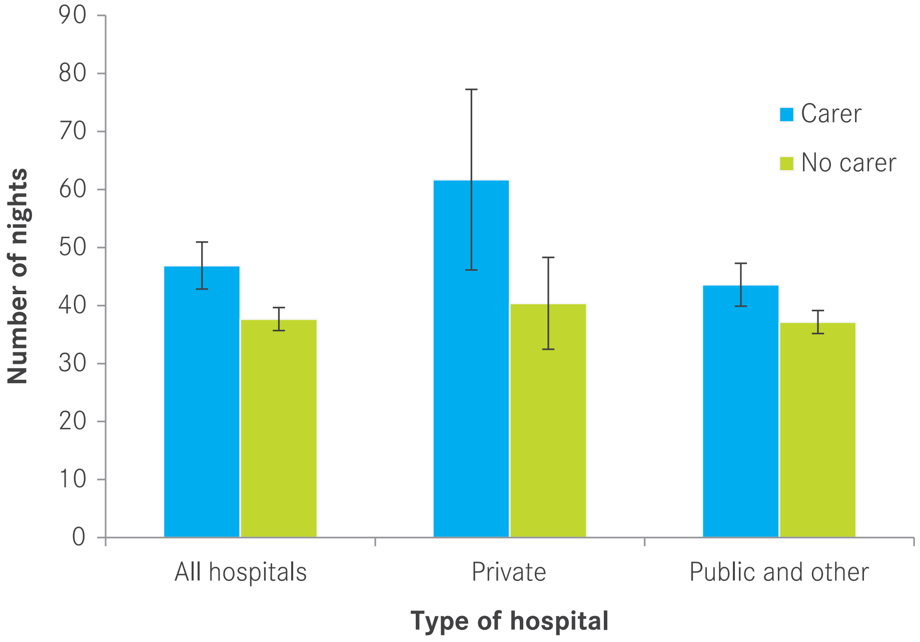
The SHIP 2010 survey included 1,825 participants, of whom 626 had been admitted to hospital for their mental health in the past 12 months. Of this group, 64.1% had one hospital admission and 35.9% had two or more admissions.

Of the 18 possible covariate variables, seven were significantly related to total nights admitted for this group: diagnosis, possible depression, alcohol abuse/dependence, physical health condition, global functioning, involuntary admission and help to find accommodation (see Appendix 4 for detailed results). Global functioning and help to find accommodation were also significantly related to carer status. We considered that needing help to find accommodation on discharge was likely at least partially a direct result of having a carer, who may reside with the care recipient and provide stable accommodation in a family home. Therefore we did not attempt to control for the effects of help to find accommodation on total nights admitted in further analyses. When explored separately for participants with and without carers, global functioning was only related to total nights admitted for those without a carer, $r(451) = -.18$, $p < .001$.

There were significant relationships between some of the six remaining potential covariates, including: diagnosis and possible depression; diagnosis and global functioning; possible depression and alcohol abuse/dependence; possible depression and involuntary admission; and alcohol abuse/dependence and global functioning. Due to its relationship with several other variables, possible depression was excluded from further analyses. The relationships between other variables were modest, and since they capture different domains, they were retained in further analyses.

In the simple model, total nights admitted was significantly higher for participants with a carer (M=46.88, SD=52.80) compared with those without a carer (M=37.66, SD=42.10), t(253.87)=2.05, p=.04, d=0.19, 95% CI [0.34, 18.09]. When broken down for total nights admitted in each hospital type, this relationship was not significant for private or public/other hospitals, although for private hospitals the disparate means and small sample size suggest a trend towards more nights admitted for people with a carer (Figure 5). An outlier was found in the private hospital admission group, which had a significant impact on the model (total nights admitted = 337). This participant was removed from further analyses.

Figure 5. Mean total nights (±1 SE) admitted for mental health in past 12 months for people with psychosis with and without a carer, by hospital type



Only 23 of the participants had been admitted to a private hospital, which was too small a sample to explore the relationship of carer status and covariates within this sub-group. Instead, we included an additional covariate – presence or absence of any private hospital admission – in the main model. Additionally, we ran a regression analysis focused on total nights admitted to non-private hospitals (public or other) to exclude private hospitals altogether. Private admission was significantly related to total nights admitted, $r_{pb}(622) = .08$, $p = .04$, but not carer status. Private admission was also significantly related to involuntary admission, but this variable was retained in the model as it measures a different construct.

A linear regression model was conducted on total nights admitted (sum of all hospital types), including the effects of carer status, diagnosis, alcohol abuse/dependence, physical health condition, global functioning, involuntary admission and private admission. No significant interactions were found, so we reported on the main effects of variables included in the model. The combination of variables significantly predicted total nights admitted, $F(7, 607)=12.11$, $p < .001$ and explained 12.3% of the variance. Alcohol abuse/dependence (Beta = -0.13, $p < .05$), involuntary admission (Beta = 0.27, $p < .001$), private admission (Beta = 0.11, $p < .05$) and global functioning (Beta = -0.11, $p < .05$) all contributed significant effects. After controlling for the effects of these other variables, carer status was no longer related to total nights admitted (Beta = 0.04, $p = .29$).

A secondary analysis was conducted on total nights admitted to public/other hospitals (excluding private hospitals). The same variables were related to total nights admitted to these hospitals, except for physical health condition: diagnosis, alcohol abuse/dependence, global functioning and involuntary admission. A linear regression model was conducted, including these covariates (diagnosis, alcohol abuse/dependence, global functioning, involuntary admission) and carer status. The combination of variables significantly predicted total nights admitted to public/other hospitals, $F(5, 594)=16.93$, $p < .001$ and explained 12.5% of the variance. With the exception of diagnosis, all covariates contributed significant effects to explaining total nights admitted to non-private hospitals: alcohol abuse/dependence (Beta = -0.12, $p < .05$), global functioning (Beta = -0.13,

$p < .05$) and involuntary admission (Beta = 0.29, $p < .001$). Carer status was not a significant predictor of total nights admitted to these hospitals after controlling for the effects of these other variables (Beta = 0.04, $p = .31$).

3.3.3 Key informant interviews

The key informants had varying opinions with respect to length of stay and discharge processes of patients with and without a carer. Nevertheless, they all agreed that the relationship is not as simple as one where recipients having a carer always results in either a shorter or longer stay. This impact, if any, depends on the type of carer, functional level and recovery journey of the care recipient and the caring relationship.

Two informants reported that patients with a carer tend to be discharged sooner than patients without a carer. One informant went on to explain that this is because they have support at home, almost like a continuation of care, including food in the fridge and available medication. The other informant noted that medical staff are typically responsive to carer involvement and to the wants and needs of the family, such as an earlier discharge. Both informants estimated that in acute or subacute mental health facilities, patients with a carer tend to be discharged one-to-two days earlier than those without a carer.

A third informant said that, from a clinical perspective, it is easier to discharge a patient earlier if there is secure base for him or her to go to after hospital. However, if a carer is ambivalent about the person’s recovery, if there is tension at home or if the carer is unable to tolerate the person’s behaviours, this is unlikely to be the case. This informant stressed that stable accommodation is the single most important variable in capacity to discharge. Another informant agreed that an early discharge is contingent upon the carer being engaged and emotionally invested, as opposed to just residing with the care recipient.

Conversely, a fourth informant said that patients with a carer tend to stay longer. They explained that a carer with a high level of involvement usually advocates for the consumer. There tends to be increased pressure on services to produce good care and to produce an acceptable transition plan; this usually translates to longer stays in hospital. Need for carer respite might play a part in longer hospital stays, but this was not often the case in their experience. The informant found it difficult to estimate any time difference because they worked in services with highly variable lengths of stay.

One informant also noted that the patient’s functioning is important to consider. Patients with a carer tend to stay longer than patients without a carer if they have a similar story, e.g., similar functioning and housing situation. However, if a patient does not have a carer and has poor options (e.g., low functioning, temporary housing situation), they would likely stay longer in hospital, or opt to stay longer, than those with a carer.

These key informant interviews provided insight into the complexity of this issue. There is not a direct and straightforward relationship between having a carer and length of stay in bed-based services; it is specific to the individual consumer and their recovery journey, as well as to the level of involvement of the carer and the carer-care recipient dyad. It should be noted that length of stay and discharge practices are likely to differ across states, while the participating informants were only from Queensland and Western Australia. Therefore, their experiences may relate most closely to these state systems.

3.3.4 Summary of bed-based replacement cost findings

These results suggest that having a carer does not significantly reduce the length of stay in bed-based mental health services. Results from the SHIP 2010 analysis are consistent with the very limited studies found in the literature which suggest that carer status has either no effect on length of hospital stay or increases the length of stay. Similarly, our key informant interviews provided a mixed picture as to the impact of a carer, with some clinicians suggesting that if other variables are equal, having a carer enables earlier discharge and others suggesting it has no clear effect or increases the length of stay.

One key informant noted that the impact of having a carer will vary, depending on how engaged the carer is with the care recipient's treatment – some carers may provide extra support to allow a person to return home sooner or remain in the home when they otherwise would be admitted; other carers may advocate for extending the hospital stay to ensure the person is more ready for discharge or help to keep voluntary patients engaged with treatment when they would otherwise discharge themselves early against medical advice. Further, there are different incentives operating in public and private hospital settings. Public hospitals operate under high pressure to discharge patients and are funded on a standard cost for the patient, regardless of how long they stay. In contrast, private hospitals are funded for the full length of stay and have less pressure to discharge consumers quickly. In the latter setting, any influence of a carer may be more pronounced because there is more flexibility for consumers to stay longer if needed.

Our data indicated that having a carer does not reduce the length of stay in bed-based mental health services and may not have any consistent effect on this variable. Therefore we did not model a difference in costs for people with and without a carer admitted to these services.

3.4 Carer support services and unmet needs

3.4.1 Commonwealth expenditure on carer support

The Commonwealth Government funds support for mental health carers through income support payments, mental health carer services and general services for all carers.

3.4.1.1 Carer payments

As outlined previously (see section 3.2.2), an estimated $759 million was provided to mental health carers in the year 2014–15 via Carer Payment, and a further $251 million via Carer Allowance. Mental health carers also received support through the Carer Supplement and Rent Assistance payments. Total outlays were estimated at $1.1 billion per year (see Table 30).

3.4.1.2 Support programs for mental health carers

There are three key support programs funded by the Commonwealth Government that are specifically targeted to mental health carers. The main program is Mental Health Respite: Carer Support (MHR:CS), which provides direct respite care as well as counselling, practical assistance and education for carers of people severely impacted by mental illness [96]. For the year 2015–16, the Department of Social Services allocated $64 million to the MHR:CS program [66]. However, this program supports some carers who are out of scope for this report, including carers of people with autism spectrum disorders and intellectual disability[7] [96]. The $64 million is therefore likely to be an overestimate of expenditure on mental health carers according to our definition (see section 1.2.3).

A second program funded by the Department of Social Services is Carers and Work (CAW), which provides support to carers of people with mental illness to achieve workforce participation, including help with navigating employment service systems, workplace advocacy and connecting with training opportunities [4, 97]. For the year 2015–16, $1.5 million was allocated to the CAW program [66].

Family Mental Health Support Services (FMHSS) is the third key program funded by the Department of Social Services. It provides practical assistance and home-based support to families with children and young people up to age 18 years who are at risk of, or affected by, mental illness [98]. At a 2013 Estimates Hearing for the Families, Housing, Community Services and Indigenous Affairs Portfolio, expenditure projections for FMHSS were at $32.5 million for the year 2015–16 [99]. Only 16–18-year-old care recipients are in scope for this report; however, there were no publicly accessible data on FMHSS users by the age of their care recipient(s).

Combining data for these three programs for the year 2015–16, we estimated total funding allocated to mental health carer programs to be $65.5 million. This estimate only includes funding allocated to the MHR:CS and the CAW programs. It does not include funding allocated to the proportion of FMHSS users who are in scope for this report because we could not disaggregate program utilisation by care recipient's age. The three mental health programs (MHR:CS; CAW; FMHSS) supported a total of 121,075 mental health carers in 2014–15 [66]. Full details on these programs are provided in Appendix 5.

Apart from the three programs above, other Commonwealth-funded programs also provide support to mental health carers, sometimes incidentally. These programs include, e.g., the national COPMI initiative, Partners in Recovery, and Mental Health in Multicultural Australia. These were deemed out of scope for estimating total expenditure on mental health carer support (see section 2.5.1). However, the exclusion of these programs and FMHSS means our estimate of expenditure is likely to be conservative.

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[7] Organisations initially funded to deliver MHR:CS prior to 2011–12 include services for those caring for someone with an intellectual disability, who may comprise up to 25% of carers supported.

3.4.1.3 Support programs for all types of carers

A number of generic carer support programs are inclusive of carers of people with mental illness (for full details, see Appendix 5). All of these programs are funded by the Department of Social Services, with the majority providing direct respite care as well as additional support components such as information and referral assistance [100].

The National Respite for Carers Programme (NRCP) is the main provider of respite in Australia [100] [101]; the Department of Social Services allocated $71.70 million to this program for 2015–16 [66]. However, mental health carers do not appear to be a key focus; we were unable to source data on the proportion of NRCP users who care for someone with mental illness. A one-week Community Care Census [101] found that carers who received respite support under the NRCP mostly cared for older people (81% of care recipients were aged 65 years or over). The predominant reason (68%) for assistance provided was due to 'diagnosed dementia or related condition', with 'other diagnosed conditions, 'diagnosed disability' and 'other conditions' making up 25% of NRCP users [101]. The Census data indicate that few mental health carers utilise the NRCP; most would likely be referred to the MHR:CS program, which may better address the unique and diverse needs of mental health carers [102, 103]. For these reasons, the NRCP was not included in the total Commonwealth expenditure estimate for mental health carers.

Other Department of Social Services-funded carer programs include the Young Carers Respite and Information Services, Respite Support for Carers of Young People with Severe or Profound Disability (RSCYP) and the Young Carers Bursary Programme. These programs explicitly outline 'mental health' as a key focus. An evaluation of the Young Carers Respite and Information Services [104] included a survey of 971 young carers (up to 25 years of age) receiving assistance from 42 Commonwealth and Respite Care Centres (CRCCs) in 2006–7. Of the 971 young carers, 34% reported providing assistance to a person with mental illness[8]. We applied this proportion to the total funding allocated to Young Carers Respite and Information Services for 2015–16, resulting in an estimated funding allocation for mental health carers of $2.8 million. This assumes that all young carers receive a similar quantum of support.

The Young Carers Bursary Programme commenced in 2015 and is an annual bursary of approximately $3,000 per person distributed to young carers (aged 12 to 25 years). Its aim is to help relieve the financial pressure on young carers to undertake part-time employment, in addition to managing their educational and caring responsibilities. The Young Carers Bursary Programme targets a similar group of carers to the Young Carers Respite and Information Services program (students aged up to 25 years) [105]. Therefore we applied the same proportion (34%) to this program's 2015–16 funding allocation, resulting in an estimated $0.42 million dedicated to mental health carers.

The final program, RSCYP, provides support to carers of young people under 30 years of age [106]. Therefore, this program supports a considerable number of carers for recipients aged less than 15 years, who are out of scope for our definition. There is a lack of publicly available data on RSCYP utilisation by care recipient's condition or age. For this reason, the RSCYP was not included in the total Federal funding estimate for mental health carers.

Combining data from the above support programs, we estimated that $3.2 million of Commonwealth funding for mental health carers was provided through services targeted at all carers. This is a minimum estimate, excluding some programs that partially support an unknown number of mental health carers.

3.4.1.4 Summary of expenditure

The final combined estimate for Commonwealth Government expenditure on mental health

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[8] This did not include alcohol and/or drug use or intellectual disability. For this report, intellectual disability included autism, dementia, ADHD and global delay.

carers was $1.14 billion (Table 32). This combines expenditure or funding for carer payments, support programs specific to mental health carers and estimated expenditure on mental health carers who access generic young carer support programs. Due to the exclusion of some programs outlined above, this is a conservative estimate.

Table 32. Estimated Commonwealth expenditure on mental health carers

Program or payment type	Annual government spending on mental health carers
Income support[1]	$1,072,058,377
Support programs specific to mental health carers[2]	$65,447,000
Generic support programs for young carers[3]	$3,204,160
Total	$1,140,709,537

[1] This includes Carer Payment, Carer Allowance, Carer Supplement and Rent Assistance.

[2] This includes Mental Health Respite: Carer Support and the Carers and Work Program.

[3] This includes a proportion of the Young Carers Respite and Information Services and Young Carers Bursary Programme.

3.4.2 State/territory expenditure on carer support

3.4.2.1 Approach One

This approach attempted to map state and territory government expenditure on mental health carer services using published data from each state, but highlighted the difficulty of tracking this expenditure. Each state and their organisations report differently, with no one repository currently existing for funding and utilisation data. Our search therefore mostly relied on published annual reports and financial statements from NGOs. These organisations do not usually report the specific source of their government income or the breakdown of expenditure on each of their services. Frequently, the search yielded total grant income for organisations that service all carers or mental health consumers and carers, making it difficult to discern how much funding benefited mental health carers specifically. Further, counting expenditure at the individual NGO level increases the possibility of missing some funded organisations or programs. The points below summarise the key findings for each state and territory; full details are provided in Appendix 6.

Victoria

- The Department of Health and Human Services offers a dedicated support program for carers, the Mental Health Carer Support Program (MHCSP). This includes a range of services, such as a Carer Support Fund, which provides financial assistance for mental health carers within the clinical mental health system [107]. The most recent data for funding and usage of the MHCSP were from the year 2010–11 ($8.2 million), although this program is still operating [108]. Assuming only CPI increases over time, this figure was adjusted to $8,886,089 in 2015 prices. Tandem, an NGO, is responsible for the administration of the Carer Support Fund and has published expenditure details. In 2014–15, $1,578,954 was brokered through the fund [109]. Applications through the fund are limited to $1,000 per carer per year for each of their care recipients [110].

- Other NGOs provide services that may be used by mental health carers in Victoria. For example:
  - Mind Victoria provides services for mental health consumers and carers in Victoria, including a carer helpline, carer counselling, carer peer support, in-home respite, carer recreation days and carer support groups. There was no published breakdown of their funding allocation by state or by service type [111, 112].
  - Carers Victoria provides mental health carer services and reports the breakdown of Commonwealth versus state funding. However, this number reflects funding for all services, only a portion of which would benefit mental health carers [113].
  - Benetas provides respite services for any carer; a small portion of their funding (which was not available disaggregated by source) would be spent on mental health carers [114].
- Based on available information, it appears that Victoria's dedicated mental health carer support program covers the majority of mental health carer support funded by the Victorian Government. However, it is likely that other organisations not picked up in our search provide general services to carers that may be accessed by a small number of mental health carers.

New South Wales

- New South Wales Health funds the Mental Health Family and Carer Support programs. These programs are offered by five NGOs throughout the state. Some of these organisations solely provide mental health carer support, while others provide support for all carers, and others for anyone affected by mental illness (i.e., consumers and carers) [115]. Each organisation publishes their own data, though few publish utilisation data. Funding data reported by these organisations are for all services, a small percentage of which would be for mental health carers.
- In addition to these NGOs, other large carer organisations are active in the state. For example:
  - Mental Health Carers Arafmi NSW is appointed as the peak body for mental health carers by the NSW Minister of Health. Arafmi reports their grant income but not whether this comes from the State Government or other sources [116].
  - Carers New South Wales provides support for mental health carers, but funding for these initiatives is difficult to disaggregate from available data [117].
- These seven organisations appear to form most of the mental health carer support landscape in New South Wales, particularly given the dedicated program promoted by NSW Health. Other organisations may also provide general carer services that mental health carers may access.

Queensland

- Queensland does not have a dedicated carer support program, though the Department of Communities and the Community Mental Health Branch fund some NGO programs. These are for a broader target group, which includes mental health carers.
- Mental Health Carers Arafmi QLD provides a range of carer support dedicated to mental health carers. Funding information from the State Government for Arafmi was not available through our search methods [118].
- Mind Queensland is also active in the state and offers mental health carer programs. However, as mentioned previously, Mind's funding was not available by state.
- Given that Queensland does not have a dedicated mental health carer funding stream, it is more likely that our search missed the numerous organisations providing services for mental health carers as part of their work.

Western Australia

- Western Australia does not have a dedicated mental health carer support program, so most mental health carer services are provided by carer NGOs. For example:

  - Carers WA provides general carer services, with certain programs aimed at mental health carers. Carers WA publishes their operating grants, but this includes State and Commonwealth funding for all carer services. Only a portion of these grants would go to mental health carers [119].
  - Helping Minds (formerly Arafmi WA) provides dedicated mental health carer services funded by the WA Mental Health Commission. Funding information is better available for Helping Minds, which breaks down expenditure by program for funding received from the Commission. In total, state-funded Helping Minds services that appear dedicated to mental health carers received $966,814 in 2013–14 ($981,421 in 2015 prices) [120].

- Given that Western Australia does not have a dedicated mental health carer program, it is likely that our search missed smaller organisations providing services that mental health carers also use.

Tasmania

- There is not a dedicated program for mental health carers in Tasmania, although the State Government publishes a guide for carers with recommendations for organisations providing carer services. These include:
  - Arafmi Tas (aka Mental Health Carers Tasmania), which provides mostly advocacy and representation programs, and fewer respite, counselling and education services than Arafmi in other states [121].
  - Carers Tasmania, which provides general carer services. Their funding is published as lump sum for grant income, including funding from both Commonwealth and State sources [122].
  - Anglicare, which provides a program called Our Time to support carers of individuals with mental illness and autism spectrum disorders. Anglicare publishes data on their income, 44.7% of which comes from the Tasmanian Government, but this applies to all services. Of all stream funding, 17.7% went to mental health services, but only a portion of this would go to carers (e.g., through Our Time) [123, 124].
- Given that Tasmania does not have a dedicated mental health carer program, it is likely that our search missed smaller organisations providing services that mental health carers also use.

Northern Territory

- The Mental Illness Fellowship of Australia in NT provides Carer Services funded by the NT Department of Health. Utilisation, but not expenditure, data is available for these services [125].
- Carers NT provides services for all carers, including a Mental Health Carers Program. Funding and usage data was not available through our search methods [126].
- Anglicare NT also provides carer respite services that mental health carers may access. Funding from the Territory Government is reported, but not how much of this goes to carer services or specifically mental health carers [127].
- These three organisations, plus Commonwealth programs, appear to make up the majority of the landscape of mental health carer support in the Northern Territory. The lack of a combined, state-wide mental health carer program means that our search may not have identified every service available to mental health carers.

South Australia

- SA Health has hired a carer consultant to be available for phone conversations with any carer looking for support [128]. Other services for mental health carers can be found through multiple state- (and Commonwealth-) funded NGOs. For example:
  - Carer Support provides services for all carers [129]. Their grant income is published, but most of their grant funding

  appears to come from the Commonwealth. Only a small proportion of these total funds would go towards assisting mental health carers.
  - Mind South Australia provides mental health carer support services, but, as noted above, expenditure is reported at the national level.
  - Carers South Australia provides services for mental health carers through funding from the Department for Communities and Social Inclusion, with funding likely coming from the Commonwealth as well. Grant income is published, but not divided by provider [130].
  - Anglicare SA provides carer respite, including specific mental health carer respite [131]. Only total revenue from all sources for all services was available, and only a portion of this would benefit mental health carers [132].
- These organisations, plus Commonwealth programs, appear to make up the majority of the landscape of mental health carer support in South Australia.

Australian Capital Territory

- Carers ACT provides support for all carers and is funded by ACT Health, among other sources. ACT Health funding for mental health carers through Carers ACT can be estimated at $88,776 (10.51% of all income applied to $844,685 in total funding received from ACT Health in 2014–15). Utilisation data are reported for all carers, only a portion of which would be mental health carers [133].

Due to the limitations of the available data, we calculated a low estimate of the minimum amount of expenditure on state mental health carer support by only including expenditure that was clearly linked to mental health carers. This included the Victorian MHCSP ($8.9 million in 2015 prices), Helping Minds programs funded by the WA Mental Health Commission ($981,421 in 2015 prices) and ACT Health funding for mental health carers through Carers ACT ($88,776 in 2014–15). Summing these sources produces a total minimum estimate of state/territory expenditure of $10.0 million in 2015.

3.4.2.2 Approach Two

The second approach used top-down data describing state expenditure on NGO mental health services. Data from the AIHW [75] were provided broken down by service type for 2013–14. We identified the likely target group for each of these service types (Table 33).

Table 33. State/territory expenditure on NGO mental health services by service type, 2013–14

Service type	Expenditure ($'000)	Deemed target group	
		Consumers	Carers
Accommodation services	39,899	X	
Advocacy services	7,018	X	*
Community awareness/health promotion	15,517	X	X
Counselling services	14,077	X	X
Independent living skills support services	70,655	X	
Pre-vocational training services	1,069	X	
Psychosocial support services	160,411	X	X
Recreation services	3,663	X	X
Respite services	6,661		X
Self-help support groups	9,806	X	X
Other and unspecified services	32,671	X	X
NGO residential mental health services	89,116	X	
Total	**450,563**	**X**	**X**

* Although advocacy services do benefit carers in the aggregate, these services were deemed out of scope for our calculations because they largely do not provide immediate benefits to individual carers.

In total, states and territories spent $450.6 million on mental health NGO services in 2013–14. Of this, only respite expenditure was directly related to mental health carers, totalling $6.7 million in in-scope expenditure. Services deemed to be unrelated to support for mental health carers, and therefore out of scope, included accommodation services, advocacy services, independent living skills support services, pre-vocational training services and residential services. Out-of-scope expenditure totalled approximately $207.8 million. Services that likely benefited both consumers and carers included community awareness/health promotion, counselling services, psychosocial support services, recreation services, self-help support groups and other and unspecified services. This grey area expenditure totalled approximately $236.1 million.

We estimated a range of state/territory expenditure on mental health carer services, using in-scope spending as a minimum and in-scope plus grey area spending as a maximum expenditure estimate. This indicated that spending on mental health carer support through NGOs is at least $6.7 million and at most $242.8 million. This is equivalent to $6.9 to $246.5 million in 2015 dollars.

As an alternative approach to the same data, we used other sources to estimate the proportion of total mental health NGO expenditure spent on carers. As outlined in Approach One, the only state for which we obtained a fairly comprehensive estimate of expenditure was Victoria, where $8.2 million was spent on mental health carers in 2010–11. AIHW data on state expenditure indicate that Victoria spent $82.4 million in total on non-residential mental health NGO services during 2010–11. This figure was adjusted up to $100.5 million to include NGO residential services by using the equivalent national figures for 2010–11. Applying the $8.2 million of carer spending to this total produced an estimate that 8.2% of NGO mental health expenditure in Victoria was for mental health carers.

We also drew on NSW-published data from a survey of state mental health community-managed organisations (CMOs) [76]. This survey reported that, of CMO programs whose main funding source was NSW Health, 3% were funded under the Family and Carers Support stream. Further, 10% of programs provided by these CMOs fell under the Family Support and Carers service category. In the absence of other data, and assuming that the proportion of programs equals the proportion of expenditure, we estimated that in NSW approximately 3–10% of NGO mental health expenditure is for mental health carers. This range is consistent with the data from Victoria.

Assuming that all Australian states and territories spend a similar percentage on mental health carers, we estimated that of $450.5 million NGO mental health services funding, $13.5 million (3%) to $45.1 million (10%) was for mental health carers. Adjusted to 2015 prices, this range becomes $13.7 to $45.7 million.

3.4.2.3 Summary of expenditure

In summary, the different approaches provided a range for possible state/territory expenditure on mental health carer support, within which the true value is likely to lie. Approach One yielded an estimate of the minimum amount of expenditure on state mental health carer support of $10.0 million. Approach Two yielded two possible ranges of expenditure: a range based on in-scope service types of $6.9 to $246.5 million and a range based on estimated proportions of individual state expenditure of $13.7 to $45.7 million. We believe the total expenditure is most likely to fall between $10 million and $46 million (Table 34).

Table 34. Estimated state/territory expenditure on mental health carers

Source	Estimated state expenditure on mental health carer support
Approach One: search of state programs	≥$10.0 million
Approach Two: in-scope AIHW-reported expenditure	$6.9 to $246.5 million
Approach Two: estimated proportion of total NGO expenditure	$13.7 to $45.7 million
Overall estimate	**$10.0 to $45.7 million**

3.4.3 Survey of Disability, Ageing and Carers 2012

Primary carers in the SDAC 2012 answered questions about the types of assistance they accessed or needed to carry out their caring role. The proportions of primary mental health carers who reported using key support services are shown in Table 35, alongside equivalent data for primary carers of people with other conditions. As reported earlier, less than a quarter of primary mental health carers received Carer Payment (see Table 15). Further, only around one-third received assistance to care for their main recipient of care, and less than 9% had ever used respite care. These patterns of service use were similar to those for primary physical health carers, but primary mental health carers were significantly less likely than primary carers of people with other cognitive/behavioural conditions to receive assistance or to have used respite care. These data show that substantial proportions of primary mental health carers do not access carer support services. Since the primary carer group generally have a more intensive caring role, it can be assumed that the proportion of all mental health carers (e.g., including secondary carers) accessing support services is likely to be even smaller.

Carers also reported their satisfaction with organised services and barriers to use. One-fifth of primary mental health carers who had used services were dissatisfied with the quality of assistance received. This was significantly higher than dissatisfaction among physical health carers (3%). A small proportion of carers, regardless of service use, were dissatisfied with the range of available services. Perhaps more concerning is that 35% of primary mental health carers reported that they did not know the range of services available for carers, which may indicate a need for better information. Mental health carers who had never accessed respite care mostly reported not wanting or needing the service, while a small proportion indicated that available services were not suited to their needs (Table 36). For primary mental health carers who did not receive Carer Payment, most either did not meet eligibility requirements or thought they would not be eligible. Of the 44% of carers who had not looked at their eligibility, 21% indicated that they had not heard of Carer Payment, again indicating a possible need for better information about services. Other reported reasons for not accessing payments included not identifying as a carer (12%) and pride (10%).

Some primary carers indicated that they needed more support services than they were currently receiving, including for those who did not currently receive assistance (Table 35). Almost half (49%) of the primary mental health carer group reported needing an improvement or more support to assist in their caring role. However, primary mental health carers were significantly less likely than carers for people with other cognitive/behavioural conditions to report a need for more respite care.

Table 36 shows the unmet sources of support identified by primary mental health carers. Financial assistance, emotional support, equipment and training, improved health and respite care were identified as the key areas of unmet support needs for some carers. When primary mental health carers with unmet needs were asked for their main unmet source of support, 33.2% (SE: 5.7) indicated that their main requirement was for more financial assistance, 24.3% (SE: 6.4) more respite care and 13.0% (SE: 5.9) more emotional support. Combined with the data in Table 36, which show that very few carers reported that Carer Payment was not necessary, this suggests that mental health carers would benefit from more accessible regular income support or other financial support (such as brokerage payments).

Table 35. Primary carer use and need for support services, for recipients aged 15+ years by main condition of main recipient of care, SDAC 2012

Primary carer need and receipt of assistance	Percentage of carers [95% confidence interval]		
	Mental illness (n=153)	Other cognitive/ behavioural[1] (n=155)	Physical condition (n=1233)
Use of support services:			
Receives Carer Payment	23.8% [16.5, 31.1]	28.8% [22.4, 35.2]	22.9% [20.2, 25.6]
Receives assistance to care for main recipient of care	34.4% [26.0, 42.8]	**57.3% [49.5, 65.1]**	28.5% [26.0, 31.0]
Has used respite care	8.7% [3.7, 13.7]	**31.4% [24.3, 38.5]**	8.0% [6.6, 9.4]
Satisfaction with services:			
Dissatisfied with range of organised services available to carers[2]	12.5% [6.1, 18.9]	12.2% [4.5, 19.9]	5.7% [4.0, 7.3]
Don't know the range of organised services available to carers[2]	35.0% [24.8, 45.1]	23.6% [14.9, 32.3]	29.4% [26.3, 32.5]
Dissatisfied with quality of assistance received from organised services in last six months[3]	**20.0% [7.5, 32.5]**	4.4% [0, 10.6]	**3.2% [0.9, 5.4]**
Unmet support needs:			
Needs (further) assistance to care for main recipient of care	26.4% [18.2, 34.6]	25.4% [18.1, 32.6]	18.9% [16.6, 21.1]
Needs (further) respite care for main recipient of care[4]	11.6% [5.8, 17.3]	**25.7% [18.8, 32.7]**	9.5% [7.8, 11.2]
Needs an improvement or more support to assist in caring role[5]	49.0% [38.0, 60.0]	**53.0% [43.8, 62.3]**	**35.7% [32.6, 38.8]**

Note: values are **bolded** where 95% confidence intervals are non-overlapping, i.e., significantly different from other types of carers.

[1] Includes: Autism and related disorders, Mental retardation/intellectual disability, Intellectual and developmental disorders n.e.c., Speech impediment, Alzheimer's disease, Dementia and Head injury/acquired brain damage.

[2] Excludes 35 mental health carers, 44 other cognitive/behavioural carers and 335 physical health carers who did not answer.

[3] Excludes 33 mental health carers, 43 other cognitive/behavioural carers and 313 physical health carers who did not answer and 75 mental health carers, 48 other cognitive/behavioural carers and 660 physical health carers who had never received assistance from organised services.

[4] Excludes ten mental health carers, 14 other cognitive/behavioural carers and 94 physical health carers for whom the question was not applicable (may not have answered a previous relevant question).

[5] Excludes 33 mental health carers, 43 other cognitive/behavioural carers and 314 physical health carers who did not answer the question.

Table 36. Primary mental health carer barriers to service use and unmet needs (SDAC 2012)

Primary carer reported barriers to service use and unmet needs	Carer estimate (SE) (n=153)
Barriers to use:	
Main reason primary carer has never used respite care[1]	
Does not need service	58.7% (4.2)
Carer does not want service	12.5% (3.2)
Recipient does not want service	12.2% (3.3)
Available services not suited to needs	6.3% (2.1)
Other reason	10.3% (2.6)
Main reason looking at eligibility did not lead to receipt of Carer Payment[2]	
Did not meet requirements for eligibility	46.6% (7.6)
Dual eligibility (eligible for conflicting payment type)	17.7% (5.3)
Changed mind or decided not necessary	5.0% (2.9)
Other reason	30.8% (5.9)
Main reason primary carer has not looked at eligibility for Carer Payment[3]	
Would not be eligible	43.3% (6.5)
Not heard of it	20.6% (5.1)
Does not think of self as a carer	12.0% (3.9)
Pride	10.0% (4.3)
Dual eligibility (eligible for conflicting payment type)	2.4% (1.4)
Not necessary	0.9% (0.6)
Other reason	10.8% (3.9)
Unmet support needs:	
All unmet sources of support for carers[4]	
More financial assistance	22.2% (4.3)
More emotional support	18.8% (3.5)
More aids/equipment, courses or training for the caring role	15.8% (3.1)
An improvement in carer's own health	15.0% (3.1)
More respite care	14.2% (2.5)
More physical assistance	9.3% (2.3)
None of the above	3.2% (1.5)
Source of support not answered	23.0% (3.9)
No additional support required	38.0% (4.3)

[1] Excludes 17 primary MH carers who had used respite care.

[2] Excludes 104 primary MH carers (67.6%) who received Carer Payment or had not looked at their eligibility.

[3] Excludes 87 primary MH carers (56.2%) who had received or looked at eligibility for Carer Payment.

[4] Percentages will not sum to 100% as carers could endorse more than one item.

3.4.4 UQ Carer Survey 2016

As described in section 3.1.4.2 and Table 15, 15% of UQ Carer Survey 2016 participants reported receiving Carer Payment and 31% Carer Allowance, with the majority of Carer Payment recipients receiving both payment types. In total, 57% of carers received some form of Centrelink payment.

Qualitative data provided by carers participating in the UQ Carer Survey 2016 allowed a more in-depth exploration of the needs of mental health carers. The data provided by these carers centred around a number of themes. These related to carers' unmet needs, health and wellbeing, social outcomes and service utilisation. Specifically, the themes included:

- lack of services and support for carers
- need for respite services or improved accessibility
- lack of understanding or recognition of mental health carers
- financial costs to carers and issues with government payments
- lack of career opportunities for carers
- carers changing their housing situation to accommodate the care recipient
- being 'on call'/on standby for the care recipient
- poor mental and physical wellbeing of carers
- feelings of hopelessness and exhaustion among carers
- the fluctuating nature of mental illness/the mental health carer role
- issues and recommendations for consumer services
- lack of services to support care recipients in rural areas
- older parent carers and their concern about the lack of support after they pass away
- easier access to consumer services in the private sector
- lack of services for consumers forcing additional burden on carers.

Although all of these themes are important issues relating to the mental health carer role, for this report we have focused specifically on themes related to support services for carers and unmet needs associated with these services.

3.4.4.1 Lack of services and support for carers

A key theme discussed by mental health carers was a lack of services and support available to them, including a lack of: information about mental health conditions; education about the caring role; and assistance with various caring tasks, including daily living and practical tasks in the home. This lack of assistance to help carers support their care recipient was well highlighted by two respondents:

> "*And there is nowhere near enough support for mental health carers*."
> [*Respondent 26*]

> "*As they are my spouse and children (and now my grandchildren are impacted by my daughters' health, and it has fallen to me to provide them with the stability she is unable to) there has been NO supports available*."
> [*Respondent 76*]

A common barrier to services and support was a lack of recognition of the carer role in the mental health system. Respondent 76 alluded to the fact that, because they are a family member, their caring role was somewhat expected and not formally recognised within the health system. Some carers also discussed the lack of information provided to them by doctors and mental health clinicians about their care recipient and the intended treatment plan. One respondent outlined that they were ignored entirely by the medical team that was treating their child:

> "*…we are expected to provide care and support at the drop of the hat and visit as often as we can, as well as do their personal shopping, all without any support for us. We are virtually*

> *ignored by the medical teams (doctors and nurses) and even though we would like to know what is going on with our loved one and we also know the person better than the so called medical team. Yet we have to plead to get any information - why so hard?" [Respondent 3]*

Inevitably this leads to feelings of frustration and disappointment, particularly considering that these carers are the ones who know the care recipient best. One respondent felt that the system had failed them and the person they care for:

> *"Overall it is disappointing and I feel a sense of failure as well as my partner, by not receiving appropriate or any assistance." [Respondent 75]*

3.4.4.2 Need for more respite services or improved accessibility

Another key theme discussed by carers was a need for respite in order to help rejuvenate and energise their own mental and physical wellbeing. Carers mainly discussed their difficulties with accessing respite services in Australia. One respondent outlined that they were not eligible due to their partner's suicidal ideation and another had given up hope altogether that they would ever gain access to respite services:

> *"I gave up asking for respite and services..." [Respondent 26]*

Carers who did use respite services reported that the service did not always provide enough of a reprieve or that they did not receive the service when they needed it most. As outlined by Respondent 33, carers may still be 'on call', even when they receive respite:

> *''I rarely get a break and whenever I do manage to get respite I only get half because of the numerous phone calls from my loved one; I have to answer at least two calls out of many." [Respondent 33]*

This suggests that respite services are not providing the service intended for mental health carers.

3.4.4.3 Lack of services for consumers forcing additional burden on carers

In addition to a lack of services for carers, poor-quality or poorly accessible consumer services were discussed as an additional burden on carers. Carers reported difficulty engaging with consumer services or navigating through the myriad of health care professionals to obtain the correct diagnosis and treatment plan for their care recipient. One respondent discussed how this lack of support for their care recipient placed additional pressure on them, further jeopardising their own mental and physical wellbeing:

> *"The caring role takes an enormous toll on the carer's emotional and physical health especially with no Government support for the caree." [Respondent 14]*

Two respondents discussed that they had particular issues with accessing services for their care recipient during emergency situations, at a time when they needed it most. One respondent even noted how clinicians displaced some of the burden onto them when their care recipient was incorrectly medicated:

> *"When both the pharmacist and the Dr. made an error to medication pack neither would take responsibility or provide support to me whilst the person that I cared for was psychotic." [Respondent 4]*

Most respondents conveyed a sense that if they were not around, their care recipient's situation would not be as hopeful. Their loved one may be at a stable point now, but that would not have been possible without the carer brainstorming new and effective ways to obtain support, ensuring that the care recipient accessed the right services and continually advocating for them in the face of adversity. This is well illustrated by comments made by respondent 87:

> *"Having been very heavily involved in helping her manage her illness which developed when she was [in her late teens], and which was poorly controlled for [several years], her situation is now fairly stable. However, she would not manage without considerable input from her family..." [Respondent 87]*

Carers appear to be filling in the gaps of consumer services in Australia. However, as outlined by one respondent:

> *"I am tired of filling in the gap of the shortfall in services" [Respondent 33].* On top of that, carers *"often don't have the skills to cope with someone who is unwell with mental illness" [Respondent 103]*.

This is not a sustainable system, and more direct support for consumers appears to be needed. Further investment may be required at either the consumer or carer service level in order to take some of the pressure off mental health carers.

3.4.4.4 Issues with government payments

Access to Carer Payment and Allowance appears to be particularly troublesome for carers of people with mental illness. One respondent highlighted complications with getting doctors to recognise that their care recipient is legitimately unwell and requires a great deal of care:

> *"The Dr. that was providing support would not sign a form for Centrelink so that I could receive carers assistance because he said that 'they were well', without consideration that they were well because they were being cared for." [Respondent 4]*

How the doctor describes the care recipient in the Medical Report Form is a critical component of gaining access to these payment types. In addition to dealing with medical staff, the entire process of gaining access to these payments sounds tiresome and unpleasant and may invalidate the severity of the care situation. As outlined by one respondent:

> "*Centrelink requirements for payments are exhausting and the staff seem to treat people with a mental illness as if they are "faking" the illness… feel there is very little compassion from Centrelink*" *[Respondent 49].*

To not be recognised by both medical and Centrelink staff for doing enough caring is hugely disappointing for these carers.

Carers who were not receiving any carer payments had doubts about whether they would be able to sustain their level of care. For example, one respondent stated:

> *"To not be recognised as a carer and thus not obtain any financial assistance means that it is unlikely that I will be able to sustain such a level of care long term" [Respondent 94].*

For those who were accessing these payments, the financial support did not appear to be sufficient. This is troubling considering the amount of support and assistance that mental health carers provide, as highlighted by the following two respondents:

> *"Financial compensation doesn't come anywhere near covering the time spent over many years to create a supportive care program that allows the carer to take a step back into a more supervisory & monitoring role." [Respondent 48]*

> *"There is no way known someone could be employed to fulfil all the jobs that I do for my son that would not cost a lot of money. I only get $120 fortnight for all the work I do and am basically available 24/7 for him." [Respondent 93]*

3.4.5 Literature review

A brief review of the literature found 17 journal articles and reports describing 15 studies on utilisation of carer services by mental health carers, barriers to use of carer services or unmet need for services in Australia. The studies ranged in focus: some evaluated trends on a national scale, while others focused on particular regions, specific recipient disorders or characteristics or specific services. In general, the studies identified a consistent range of use, barriers and unmet need for services for mental health carers. The studies are described in detail in Appendix 7.

3.4.5.1 Use of carer services by mental health carers

Studies reporting on utilisation of services by mental health carers tended to report use of respite care. The most generalisable results are from Harris et al., who identified that 10.9% of mental health carers in the SDAC 2009 had used respite in the past three months [3]. The more recent figures reported from the SDAC 2012 (see section 3.4.3) are lower, due either to system changes or the different definition of 'mental health carer' used. Two other studies with smaller samples of older carers identified use of respite throughout the entirety of the caring and found higher reported usage rates of 36% and 43% [53, 134]. In addition, mental health carers were found to be more likely than carers of people with other disability types to search the internet for information, see a counsellor or psychologist or access a support group and use helplines [135]. The small samples in these studies may not be representative of all mental health carers.

3.4.5.2 Barriers to use of carer services

A range of studies reported on important carer-identified barriers to use of services, though these reported on specific populations (carers of people with borderline personality disorder and older mental health carers). Identified barriers included lack of information or awareness about service availability, lack of flexible or mental health-appropriate services, the financial cost of accessing services and poor past experiences with services [136, 137]. These are consistent with the pattern shown in our analysis of the SDAC 2012 and UQ Carer Survey 2016 data. Ethno-cultural and linguistic minority community carers specifically identified that cultural expectations of the carer to provide family support served as a barrier to accessing services [138].

3.4.5.3 Unmet support needs of mental health carers

The literature review identified a number of unmet needs expressed by carers. Many studies reported an unmet need for carer support services [6, 139, 140]. The Mental Health Council of Australia found that 25.5% of carers reported that carer support groups were at best sometimes available in the past twelve months; 43.5% of carers said carer counselling was at best sometimes available in the past twelve months; only 15.9% said that they did not need to be supported in their caring role [6]. In addition, some studies focused specifically on unmet respite care needs. These studies found that there was a significant unmet need for respite, particularly respite that addresses the needs of, or is flexible enough for, mental health carers [3, 6, 136, 139]. Harris et al. [3] found that 21.2% of mental health carers in the 2009 SDAC reported unmet respite need, which was again higher than found in our SDAC 2012 analysis, using a different carer definition.

In addition, and as described clearly by carers participating in the UQ Carer Survey 2016, the literature showed that lack of consumer services creates a burden for carers, leading to further unmet need for mental health carers. In the Mental Health Council of Australia 2010 Report, carers indicated that many consumer recovery services were unavailable to their care recipients. For example, 29.7% of carers said that PHaMS workers were not available to their care recipient and 36% said living skills services were not available. Three other studies also reported a need for consumer services in order to ease the burden on mental health carers [6, 139, 141]. The most demanding times reported by carers were during acute phases of illness or crisis and at discharge from hospital [6, 142]. Carers reported that during an acute episode of their recipient's mental illness, they had little access to emergency outreach teams, information from acute medical staff or a case worker [6]. Upon discharge, carers were frequently excluded from the discharge plan [6, 141].

Better information sharing and more respect from medical professionals for carers were also identified as key unmet needs. Like the frustrations reported by UQ Carer Survey 2016 carers, multiple studies reported on carers feeling disrespected by medical professionals, both general practitioners and mental health professionals [140, 142, 143]. Carers also indicated unmet need for information about their care recipient's treatment plan [6, 139, 140, 144]. Carers identified that issues of patient confidentiality are complicated and keep them without information to help in their caring role. They often felt that patient confidentiality was taken advantage of as an excuse not to talk to families or involve them in care plans [142].

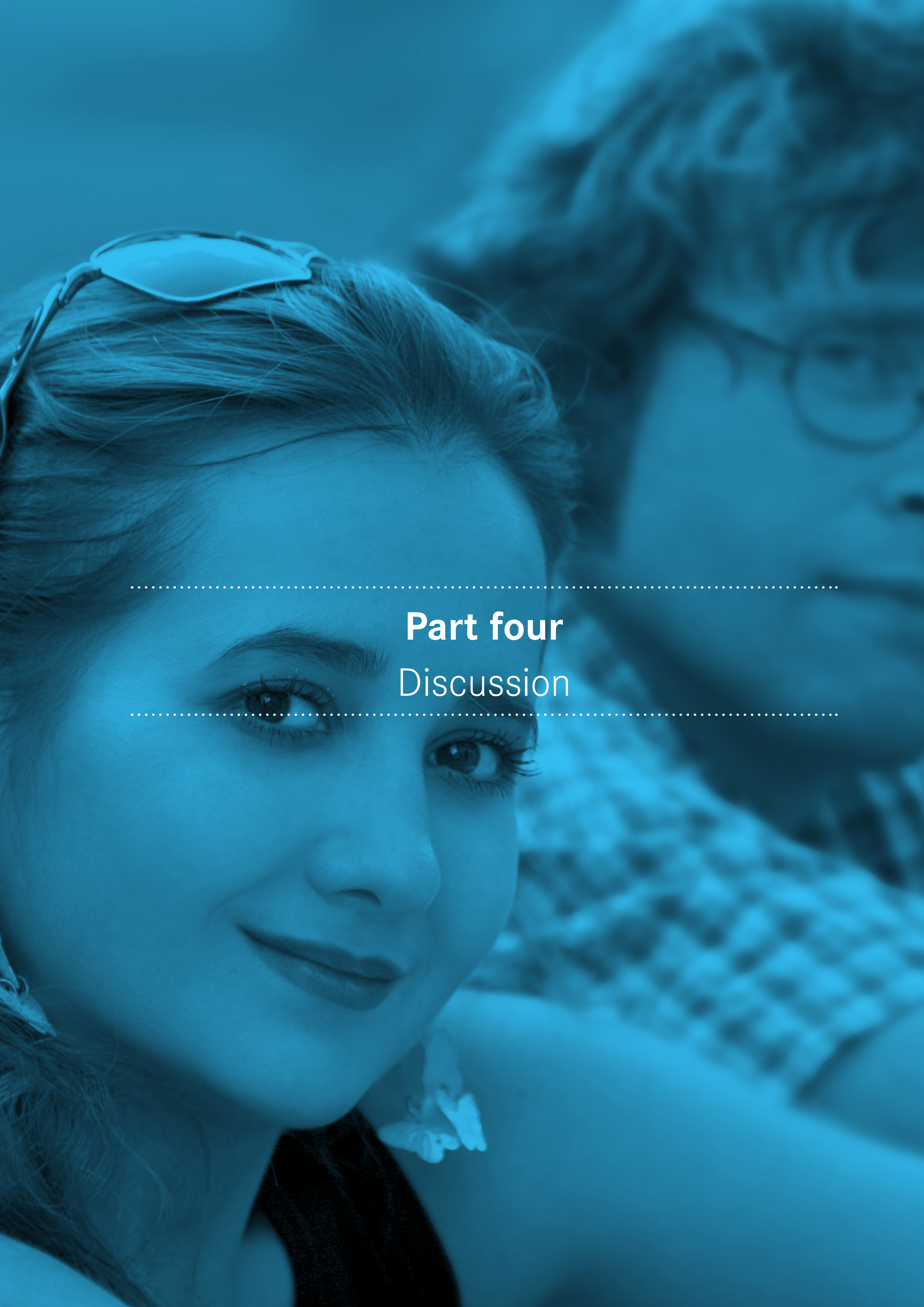
3.4.6 Summary of results

In summary, it is conservatively estimated that the Commonwealth and state/territory governments combined spent approximately $1.2 billion on mental health carer support in 2015. The vast majority of this expenditure was on Commonwealth-funded income support payments for mental health carers, with approximately $78.6 to $114.4 million dedicated to respite care, counselling and other information and practical assistance for carers. Only 24% of primary mental health carers nationally reported receiving Carer Payment, and the majority were not accessing any support services. In fact, 35% reported not knowing about the range of organised services available, and some had not even heard of Carer Payment and therefore had not explored their eligibility.

Mental health carers identified a range of unmet needs for support, although roughly half the primary carer group in the SDAC 2012 indicated that they did not want or need services. For those with unmet needs, key issues noted included:

- a lack of information about mental illness, caring and available services
- need for more assistance, such as respite care and emotional support (e.g., counselling)
- difficulties accessing sufficient financial support
- available services do not always meet the needs of mental health carers
- gaps in mental health services for care recipients place additional burden on carers (e.g., through greater informal support requirements and more carer coordination of outside services)
- poor recognition of carers and exclusion from treatment planning by mental health professionals.

While some carers report needing no assistance (for many reasons, including pride or cultural expectations), the current system of supports for both mental health carers and people with mental illness does not adequately meet the needs of all carers.



Part four

Discussion

4.1 Key findings

This work provides the first known estimate of the economic value of informal mental health care in Australia. It provides a nationally representative estimate of the number of mental health carers, and primary carers, in Australia in 2015, consistent with our definition of a mental health carer. Further, it highlights the substantial hours of support provided by Australian mental health carers for people with mental illness each year.

The estimated annual cost to the Government to replace the support provided by these carers with formal services is substantial, at $13.2 billion in 2015. This is equivalent to 1.7 times the current national expenditure on all mental health-related services, which was estimated to be $8.0 billion in 2013–14 [75]. Similarly, the total hours of support provided by mental health carers equates to 173,000 FTE support workers. In comparison, the whole national mental health NGO workforce was estimated to comprise between 14,739 and 26,494 paid employees, or more than 12,000 FTE employees, in 2010 [145, 146]. Clearly, any attempt to replace the informal support provided by mental health carers with formal services would require a significant scaling up of the mental health workforce and investment.

It is important to compare our results with previous replacement cost modelling, both in Australia and internationally. Previous Australian studies have focused on carers of people with all types of disability, as opposed to mental illness in particular. Deloitte Access Economics conducted the most recent replacement cost model, which selected personal carers and assistants from the Australian and New Zealand Standard Classification of Occupations as the formal replacement service [9]. The hourly replacement cost was estimated to be $31.36, including 15.27% overheads for growth in earnings, on-costs, capital, supervision and administration. The model used average weekly hours of care for SDAC 2012 discrete time categories, with imputed mid-points applied to each category to calculate a weighted mean hours of care for primary carers (ten hours for <20 hours; 29.5 hours for 20–39 hours; 50 hours for 40+ hours). For secondary carers, they applied a value of five hours of care per week in the absence of available data. Using these parameters, Deloitte Access Economics calculated that the replacement value of all informal care in 2015 was $60.3 billion.

Our estimated replacement cost for mental health informal care is comparatively higher than this estimate of the annual replacement cost for all informal carers, of whom mental health carers may comprise 8.6% (according to the SDAC 2012). The current modelling approach refined replacement cost methods for informal mental health care in Australia to produce a more reliable estimate, particularly for the parameters of average weekly hours of care and hourly replacement costs (see section 4.1 for details on these estimates). The model was also able to assign different hours and replacement cost estimates to different types of caring tasks. However, for comparison, if we used imputed means for hours of care as per the Deloitte Access Economics method instead of our data-derived estimates, the replacement cost for mental health carers would reduce from $13.2 billion to $8.0 billion (95% UI: 6.2–10.2). Alternatively, if we used the Deloitte Access Economics hourly replacement cost of $31.36 for all care tasks, the estimated replacement cost would reduce from $13.2 billion to $5.4 billion (95% UI: 4.6–6.4). This estimate is unlikely to be accurate as the lower hourly cost does not take into account sufficient overheads and non-consumer time to reflect the true cost of operating mental health community support services.

Two international studies have investigated the replacement cost of informal carers for people with schizophrenia [29, 30]. The replacement cost of informal care was valued at 27,199–45,072 per carer per year in a Spanish study [29] and £604.1 million in total annually in an English study [30]. Unfortunately, it is difficult to compare these figures with our estimate of the replacement cost for Australian mental health carers. Firstly, these studies are limited to carers of people with schizophrenia rather than capturing carers of people with all kinds of mental illness diagnoses, who may require different levels of support. Secondly, the mental health systems across countries differ, and this would affect both the hourly replacement cost value and how much support carers provide relative to formal services.

The replacement cost estimate focused on the hours of support provided by carers, but excluded additional aspects of the caring role that place significant burden on informal carers. The first is standby time, which is time not spent actively caring but being ‘on call’ or in close connection to the care recipient so that the carer can be available to them quickly if required. Since the carer is ‘on call’, they cannot make plans for other activities such as meeting friends, working, engaging in hobbies or travelling. Carers reported spending an average of 59 hours per week on standby, a significant impact on their day-to-day lives even when they are not actively engaged in providing emotional support or assistance with practical tasks or activities of daily living. The other component is travel time. For carers who do not live with their care recipient, and for formal sector workers travelling to see an individual, travel time is significant. This time was included in the economic model as part of the 30% non-consumer time built into the hourly replacement costs. Hence, the hours of carers’ time spent travelling to and from the care recipient’s house were not separately costed. This burden on non co-resident carers was therefore also excluded from the estimate of total hours of caring provided. The 58% of carers in the UQ Carer Survey 2016 who did not live with their care recipient reported driving 2.4 hours or walking four hours on average per week to and from their care recipient’s home. These standby and travel hours are additional burdens on carers over and above the hours of support enumerated in the replacement cost model.

In contrast with the $13.2 billion replacement cost estimated for informal mental health care, we estimated that national, state and territory governments spent approximately $1.2 billion on mental health carer support in 2015, the vast majority of which was on income support. If this expenditure is theoretically divided among all mental health carers, it equates to $4,470 in income support and $330–$480 in other government support per carer annually. If we assume instead that these supports only apply to primary mental health carers, it equates to $19,800 in income support and $1,450–$2,110 in other government support per primary carer annually. This appears to be good value for governments in comparison with the cost of replacing the large amount of informal care currently provided. However, most mental health carers do not receive Carer Payment or other assistance in their caring role. For some this is by choice, while other carers have eloquently highlighted gaps in current services for both carers and consumers which increase the financial, practical, emotional and health burden on carers. Mental health carers report that they want more support services, in particular services that are flexible enough to meet their often episodic, sometimes crisis-driven, needs.

4.2 Gaps and limitations

4.2.1 Limitations

Replacement cost analysis

The replacement cost analysis was based on the best currently available data on mental health carers in Australia, supplemented by a purpose-designed carer survey to inform estimates where data were lacking. As such, we consider the final estimate to be sound. However, the model relies on certain estimates which, if distorted, would affect the final replacement cost value. We modelled uncertainty around the replacement cost and other key estimates, to take into account the margins of error around each input parameter.

The number of mental health carers was estimated from a nationally representative survey, the SDAC 2012, which specifically sought to identify carers and people with disabilities. We were able to enumerate carers in this survey who met all of our criteria for a mental health carer, thus providing a good estimate of the total number of mental health carers. This estimate may be slightly conservative as the survey identified carers via household key informants and those reported to have a disability. This poses a few problems that may lead to under-identification of carers. If the key informant of the household is a carer, they may not identify themselves as playing that role. If someone other than the key informant is a carer, the informant must recognise his or her caring role. In addition, members of the household with a disability may not identify the role their carer is playing. Literature on the difficulty of identifying carers has reported that, in certain cases, care recipients may be reluctant or unable to recognise and identify their carer [147]. In addition, e.g., due to expectations of family roles, carers may not identify themselves as serving this role [147]. These limitations would influence the identification of carers in the SDAC and may have led to a modest underestimate of the number of mental health carers.

Estimates of the number of primary mental health carers are also likely to be conservative, as the ‘other’ mental health carers group includes some primary carers who did not reach the threshold for the SDAC 2012 primary carer sample. This is because: a) they were aged below 15 years; b) they did not live with their care recipient; c) they provided care to multiple recipients, one of whom had a mental illness, but their main recipient of care had a non-mental health primary diagnosis. Any underestimate of the total number of mental health carers, or number of primary mental health carers, would result in an underestimate of the corresponding total and primary carer replacement costs.

Estimates of the total hours of care provided by mental health carers were based on the best available data but are the input parameters with most uncertainty. In previous studies, reported hours of care for mental health carers have varied widely and have generally been higher than the estimate used in this replacement cost model – in the range of 53–104 average hours per week per carer [41, 53, 85–88], compared with 36 hours for primary carers in our model. However, sample sizes have been small in these studies and the scope also varied, with some estimates including all contact time or standby time, estimated to be more than 50 hours per week in the UQ Carer Survey 2016. Due to the skewed distribution of hours of caring, averages are sensitive to small numbers of carers who report very high weekly hours of care. Although the SDAC 2012 provided a nationally representative sample of carers, hours of care were only available categorically and only for primary and possible primary carers. Therefore we were required to estimate a weighted mean hours of care for primary carers using means for each category derived from the smaller UQ Carer Survey 2016. Primary carers in both surveys reported a very similar distribution across categories and we excluded seven outliers reporting extreme hours of care from the UQ Carer Survey 2016 to reduce their impact on the means. However, this process may have introduced a degree of error into the estimated hours of care. For 'other' mental health carers, the lack of any specific data on hours of care for secondary mental health carers meant we relied on the mean estimated from the NSMHWB 2007. It is not clear how well this estimate aligns with the SDAC 2012 'other' carers sample.

Additionally, the hours of care estimates were collected using recall methods. Recall data are subject to bias, including carers encountering difficulties in retrospective recall of activities and in reliably estimating average weekly hours of care when the care recipient's needs may fluctuate over time [25, 40]. Due to an absence of reliable data, our model did not make adjustments to distinguish between usual care and additional care (i.e., care provided over and above what would otherwise be provided to a care recipient if they did not have a mental illness). The NSMHWB 2007 and UQ Carer Survey 2016 explicitly asked respondents to estimate total hours of care related to the mental illness, but this was not done for the SDAC 2012. Therefore the model assumed that total hours of care reported in all surveys represented additional hours of care. We were also unable to adjust for joint production or overlap between mental health caring tasks and other activities a carer would complete, regardless of their caring role. Under a replacement scenario, a formal support worker would be less likely to benefit from joint production as they would not complete personal tasks while providing paid support to a consumer.

Hourly replacement cost estimates were derived from national award rates and, as such, are reliable. The hourly replacement costs are also dependent on the selection of appropriate replacement workers for each type of caring task and on the adjustments made to base salaries. These adjustment parameters were derived from the National Mental Health Service Planning Framework, where they were developed in wide consultation with the mental health community support sector. As such, they are a good representation of how these services operate. The adjustment for the number of consumer-related hours delivered by each FTE per year assumes that formal sector employees and informal carers operate at similar levels of efficiency [20, 21]; we are aware of no evidence to support or refute this assumption. If carers are more efficient, e.g., due to their intimate knowledge of the care recipient's circumstances, then the replacement cost would be underestimated; if formal support workers are more efficient, e.g., due to their training and experience or access to additional facilities, then the replacement cost would be overestimated.

The final input parameters for the replacement cost model are the cost offsets from government spending on carers. These offsets took into account expenditure on income support payments to mental health carers, but not expenditure on other carer support services. These other services include respite care and group, individual and peer support services provided for family and carers. Some of these services would likely need to be continued even if all informal caring was replaced by formal support services. For example, there is evidence that family psychoeducation and family interventions improve outcomes for people with mental illness [148]. Therefore we did not attempt to offset the cost of these support services in the model.

Estimates of the number of mental health carers receiving income support appear to vary, depending on the source data. Our estimate that mental health carers received $759 million in Carer Payments in 2014–15 was based on a combination of Department of Social Services outlays and Centrelink data on conditions and would be attributable to at least 33,400 carers [149]. In contrast, data from the SDAC 2012 show that 24% of primary mental health carers received Carer Payment, or roughly 13,000 carers. The Centrelink data on conditions relied on the first listed condition on the Medical Report form, which may not always align with the main disabling condition. However, it is more likely, as described earlier, that the SDAC 2012 underestimates the number of primary mental health carers and that some of the 'other mental health carers' group also receive income support payments.

Carer support service analysis

Our estimates of expenditure from state/ territory governments and the Commonwealth on mental health carer support were limited by a lack of available data. Currently, there is no standardised form of reporting or single repository for data on expenditure. Therefore, we had to rely on a desktop review that could at best produce an estimated range of expenditure on carer services. Much of the available expenditure data were broader than our target population of mental health carers. This included, e.g., expenditure on services for carers of people with all conditions or of any age (including recipients younger than 15 years), expenditure on mental health support services targeting both consumers and carers and funding for mental health carer services received from combined sources, including Federal and state governments and other grants. There was generally no information available to deem what proportion of this expenditure would specifically benefit mental health carers. Hence, the final estimates may have missed additional expenditure on mental health carers hidden in these broader programs. Funding for these services is dwarfed by expenditure on income support payments for carers, and the rounded estimate of $1.2 billion would adequately account for some of the uncertainty around these figures.

While data on carer service use from the SDAC 2012 are based on a nationally representative sample, most of the survey questions only related to primary carers and may not reflect the service use and needs of all mental health carers. Given their higher average hours of care and principal caring role, it is expected that primary carers would have greater use and need for support services than other carers. Secondly, much of our analysis of barriers and unmet needs for carer services relied on small sample surveys, both through the UQ Carer Survey 2016 and those identified in the literature review. This limits the generalisability of the results. In particular, the UQ Carer Survey 2016 was limited to a sample of carers already connected to carer organisations or networks. These carers may be more likely to be informed about carer services, to have accessed those services and, importantly, to identify themselves as carers. This survey, and others identified in the literature review, may have missed the needs of carers that do not self-identify or are not currently in contact with carer organisations.

4.3.4 Gaps and areas for further research

There were several gaps in available data that could be improved in future surveys, through further research and improvements in routine data collection.

First, data on hours of care were limited, as discussed above. Further research exploring hours of care for mental health carers would fill a gap in this area. This would preferably include a large and representative carer sample and collect data from both primary and secondary mental health carers, continuous rather than categorical hours of care data and allow adjustments for additional time and joint production. This would best be accomplished through a diary methods study. A new iteration of the ABS Time Use Survey, including detailed data on mental health caring, might be an appropriate method of filling these data gaps. Further research taking into account and exploring episodic fluctuations in the intensity of care over the lifespan of mental health caring would also be valuable.

Second, limited data were available on the impact of caring on care recipients' time spent in bed-based mental health services. The analysis of SHIP 2010 data suggested that there may be different patterns of impact in private hospital settings, but the small sample precluded detailed analysis. The key informant interviews highlighted the complexity of any relationship between carer status and length of stay, but were limited to a small sample from only two states. Further research exploring the impact of having a carer on admissions and length of stay, stratified by functional status of the carer and care recipient and aspects of the caring relationship, would be informative. Exploration of differential patterns across the country based on the current operation of bed-based services would also be useful. Further, including carer status in routine admitted patient data collection would allow detailed analysis using large and nationally representative datasets.

Third, young carers under the age of 15 years were excluded from the SDAC 2012 primary carer dataset and from the NSMHWB 2007 and UQ Carer Survey 2016. This means that limited data were available on the caring relationship for these carers, including how many are primary carers, how long they have been caring for and the hours of care they provide. The SDAC 2012 broader carer sample highlighted that a substantial proportion of all mental health carers are under the age of 25 years. These young carers are of particular interest because their support needs may differ from those of older carers and their caring role can have a significant impact on their educational attainment, employment and socioeconomic outcomes, as well as on their mental health [150]. There are few existing data on young mental health carers. A detailed exploration of the carer and recipient characteristics and caring role for young carers was outside the scope of this report but is an area for future research.

Fourth, our estimates of government expenditure on mental health carer support services were limited by a lack of available data, as noted above. In order to accurately detail total expenditure on mental health carer services by states/territories and the Commonwealth, it would be helpful to have accessible national-level data, e.g., the data provided through the AIHW's Mental Health Services in Australia. There appears to be institutional support behind establishing or further developing existing information systems to allow for ease of data reporting. Work on standardised national reporting for mental health carer services has commenced through progress towards a Mental Health Non-Government Organisation Establishment National Minimum Data Set (MH NGOE NMDS). This dataset proposes to collect nationally consistent data on activity, expenditure and staffing of mental health community-managed organisations that provide any services that fall within the 17 categories agreed upon for the service type taxonomy [151]. Included in this taxonomy are family and carer services, an encouraging prospect for standardised data collection on activity and expenditure for these services. This prospect is further enhanced by the plan for government expenditure to be specifically marked for individual services. In addition, states/territories will be responsible for collecting data from NGOs and submitting aggregates to the AIHW [151]. The roll out of this dataset will be most helpful if data reporting is compulsory and includes specific items on funding source for service types.

Fifth, this study focused on a replacement cost method for valuing mental health informal care. Participants in the UQ Carer Survey 2016 highlighted the financial and opportunity costs of caring for the carer, such as inability to sustain employment while caring, substantial out-of-pocket expenses to support the care recipient and the emotional drain of sustained and intensive caring. These areas are very important but were outside the scope of the current research. However, they should continue to be a focus in future work and would complement the results of this study.

4.3 Implications

4.3.1 Carers provide large amounts of support

The results of this study show that informal mental health carers add significant economic value to the Australian mental health system. The support needs of their care recipients appear to be large, with mental health carers providing support and assistance which otherwise might need to be provided at considerable cost to government. In light of current national expenditure on mental health services, it is unlikely that governments will have sufficient capacity to scale up consumer support services to comprehensively replace the role of informal mental health carers in the foreseeable future.

In reality, the preferences of carers and the people they care for also need to be taken into account in considering any change to current arrangements. For example, care recipients may value having a carer more than accessing formal support services because they may have a close relationship with that carer, receive continuity of care and 'on call' support and the carer has intimate knowledge of their history and current functioning [21]. Alternatively, these individuals may prefer to receive formal support services when available, as there may be fewer complexities in their relationship with employed staff and these staff have access to additional training and facilities not always available to informal carers. Carers may prefer to maintain their involvement in their care recipient's life and be unwilling to stop caring altogether, particularly where they perceive gaps in the support being provided by formal services. Conversely, many carers are under emotional and financial strain from their caring role and would be happy to receive additional support for themselves and their care recipient. If services were scaled up to replace some tasks currently performed by informal carers, it would be important to ensure that the individuals needing support received continuity of care, rather than small amounts of support from many fragmented providers and staff members and needing to re-establish relationships each time.

4.3.2 Government spending on carers is modest

In contrast to the substantial replacement cost of informal mental health care, estimated government expenditure on mental health carers is relatively modest, at $1.2 billion per year. The majority of these funds are directed to income support payments for carers who are unable to work due to their caring role, providing a modest fortnightly income. These payments are only accessible to a minority of mental health carers. The remainder may access other support services, but many are not receiving any formal support in their caring role.

4.3.2 Need for ongoing, expanded carer support services

The provision of carer services such as income support, respite care, information and counselling is important to ensure that carers are supported to maintain their significant caring role, as well as their own health and wellbeing. Despite the current funding of these services, many mental health carers report a lack of awareness about available supports, difficulties in accessing support services at all or that meet their needs (particularly in terms of the availability, appropriateness and flexibility of existing support services) and unmet needs for additional support, both financial and practical. Mental health carers highlight the episodic and unpredictable nature of mental illness, which means support needs to be flexible and available for short- or longer-term periods as required. Maintaining the provision of this support should be a priority for governments, as well as providing additional services to ensure that mental health carers can continue to perform their role without significant financial disadvantage and psychosocial distress, and to address some of the identified unmet needs.

A recurring theme from carers was also that inadequacies in the mental health treatment and support system for their care recipients increased the burden of informal care. Any strategies to increase support for carers should also consider the benefits that may accrue for carers in improving services available to people with mental illness, particularly access to services and coordination of care across multiple providers.

4.3.3 These results may change over time

Mental health services are a constantly-evolving landscape; a range of reforms to carer and consumer services for mental health are currently underway. These reforms are likely to impact on the caring role, as well as the availability and suitability of support services for mental health carers. Three key reforms currently in progress are the National Disability Insurance Scheme (NDIS), the development of the Carer Gateway and integrated services by the Department of Social Services and a review of carer payments.

4.3.4.2 National Disability Insurance Scheme

The NDIS is a social insurance model where the individual consumer is at the heart of the design [152, 153]. It is intended to provide a more individualised and flexible model of health care that is tailored to the person's goals, personal circumstances and support needs [153]. The NDIS includes three tiers. Tier 1 is for all Australians, to meet the costs of their care and treatment. Tier 2 is intended to provide information or referral to services for people with, or affected by, disability. Tier 3 provides tailored and individualised supports for people aged under 65 years with a permanent and significant disability which affects their ability to live an independent life [152]. Tier 3 includes people with a psychosocial disability, which is defined by the National Disability Insurance Agency (NDIA) as impairment attributable to a mental health condition which results in reduced psychosocial functioning [154][9]. The NDIS started in 2013 with four trial sites, and from July 2016 there will be a gradual roll out of the full scheme in all states and territories (except Western Australia). The expectation is that the NDIS will be fully implemented across the nation by July 2019 [153].

Most carer organisations have welcomed the introduction of the NDIS [155, 156]; however, there are some concerns about how carers, particularly of people with mental illness/psychosocial disability, will be included and supported by this new individualised funding model [156]. Carers are not participants of the NDIS and will not receive a separate assessment or an individually funded package of supports [154]. However, carers are not entirely overlooked by the scheme. One of the core aims of the NDIS is to better support the carer to continue their caring role, which may include support with decision making and budgeting, training for carers, respite[10] and group or family therapy [154]. The current level of support provided by a carer is also meant to be considered in the planning process of the participant's Tier 3 support plan [153]. However, for the carer to play a vital role in this planning process, the care recipient has to consent [154]. This approach differs from individualised funding models in other countries [157]. In England, e.g., carers have a legal right to an assessment of their needs and the potential for funding to be allocated independent of their care recipient [157]. This could be particularly

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[9] Not everyone with a mental illness will have a level of impairment that equates to a psychosocial disability. People with a psychiatric disability will be offered support if their impairment affects their capacity for social and economic participation. This psychosocial category does not include autism, intellectual disability or global development delay [127].

[10] Initially, carers were told that respite support was not available through the NDIS. However, since the trial sites started, both the Chair of the NDIA Board and the Assistant Minister for Social Services have publicly stated that respite is part of the NDIS, but they have used the phrase 'supports to sustain informal supports' in the operational guidelines [126].

problematic for mental health carers in Australia, as some consumers from time to time do not identify the contributions of their carer, especially when they are unwell [154, 158, 159]. Both Arafmi Queensland and Carers NSW have recommended that for the roll out of the full scheme, carers should receive a separate assessment of their own needs [155, 156].

Preliminary results from the NSW Hunter NDIS trial site have provided further insight into how carers of people with psychosocial disability will fit into the scheme [152, 155, 160]. Positive experiences reported by carers of all types of NDIS participants include such flow-on effects as the ability to return to work, reduced stress and less financial pressure [155]. Some carers have also been directly supported in their caring role, including domestic assistance and respite [155]; however, the number of carers accessing these direct supports has not been reported. These anecdotal accounts by NSW carers align with many of the findings from the international literature about the benefits of individualised funding models [157].

As well as positive outcomes, key issues specific to mental health carers include: uncertainty about the national roll out and how it will fit in with existing state and Federal mental health funding; anxiety about gaining access to Tier 3 supports, particularly with regard to the episodic nature of mental illness; consumers not fully understanding their carer's support needs; and uncertainty surrounding service accessibility if the care recipient is deemed ineligible [152, 155, 161]. The latter is particularly pertinent for respite services, as many of the key respite services accessed by mental health carers are being transferred to the NDIS funding scheme (see Table 37). It is unclear at this stage whether those found ineligible for Tier 3 funding will miss out on existing Federally-funded community supports [152, 155, 161].

As of March 2016, 6% of NDIS-approved plans were being accessed by participants with a primary psychosocial disability [160]. By 2019, this is expected to increase to 13% (or 57,000) of the total NDIS Tier 3 population [152]; both the RANZCP and the National Mental Health Consumer and Carer Forum (NMHCCF) have identified this as a gross underestimate of the mental illness population that will require assistance from the NDIS [152, 159]. As the full scheme starts to roll out nationally, we will gain a better understanding of how accessible the NDIS is for people with a mental illness, as well as the impact on the NDIS on the caring role.

Table 37. Federal carer support programs transferring to the NDIS Tier 3 funded services

Program name	Current funding source	In scope for NDIS Tier 3 funding
Mental Health Respite: Carer Support (MHR:CS)	DSS	50% in scope [152]
Young Carers Respite and Information Services	DSS	50% in scope1 [152]
Respite Support for Carers of Young People with Severe or Profound Disability	DSS	100% in scope [100]

Note. DSS = Department of Social Services.

[1] Direct respite services provided by this program will transition to the NDIS as the scheme rolls out [162].

4.3.4.3 Carer Gateway and integrated carer support service

In an effort to recognise and sustain the support provided by unpaid carers, the Commonwealth Government has committed $33.7 million over the next four years to design and implement an integrated plan for carer support services (‘the Plan’) [66]. The Plan comes in two key stages. The first is the implementation of a national Carer Gateway, an online resource hub and telephone service which is intended to provide clear, consistent and reliable information for all carers in Australia, regardless of who they care for [66]. A Carer Gateway Advisory Group as well as carer interviews and surveys informed the development of this gateway [135, 163]. One of the key issues identified by carers was difficulty finding the right service when there are so many pathways across the disability, community mental health and aged care sectors [135, 164]. Our analysis also showed that many mental health carers were unaware of the range of available services (see section 3.4.3). The Gateway is intended to help address this by providing a one-stop shop for carers to search for, and connect with, services in their local area. The Carer Gateway launched in December 2015 [164]; however, to our knowledge, there has been no feedback or evaluation data published to date.

The second stage of the Plan involves designing a new national service (‘integrated carer support service’) that provides better coordinated and more streamlined carer services [66]. In doing so, this new national service is intended to increase the wellbeing of carers, and at the same time reduce the risk of the caring role ending. The draft concept model published in May 2016 proposes eight key services to be delivered at both a local and national level, including: awareness; information; intake; education; peer support; needs identification and planning support; and counselling [66]. A multi-component service has also been proposed where a single package of interventions will be delivered, including carer mentoring, respite support and financial support[11] [66]. Services that hold the most promise in helping carers are those that use a variety of interventions [165].

Overall, the integrated carer support service sounds promising [166]; however, it is too early to comment on what kind of impact it will have on carers. The Government only recently distributed a draft service concept for the public to review and provide feedback on [66]. This co-design process has been warmly welcomed by carers as it has provided them with the opportunity to have a say in the development of this future service model [166]. There is nothing outlined in the current draft service concept that pertains specifically to mental health carers. There is also little detail about how the integrated carer support service will fit in with existing state and territory services, other than that it will build on the strengths of existing systems [66]. The service delivery model is the next phase in the design process [66], and it is expected to provide a much more detailed layout of what this carer support service will include and how it will be rolled out across the nation. It is also important to keep in mind that, with the changing political landscape in Australia, planning for this support service may be discontinued.

4.3.4.4 Review of Carer Payment and Allowance

The Department of Social Services is currently undertaking a review of the assessment process for the Carer Payment and Allowance [167]. This review commenced in July 2015, and the Government intends to implement changes by 1 January 2018 [167]. The following carer-related qualification criteria are under review: the amount and nature of care provided by the carer; nature of care required by the care recipient; and the methods of capturing care required and provided [167]. RANZCP has been invited to provide input into this review process.

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[11] While access to multi-component support is proposed to occur at a local level, financial support may be delivered through the Federal Government payments. It is not the intention that financial support under this model would replace income support payments accessed through the Department of Social Services.

In a recent submission to the Department of Social Services, the RANZCP outlines some key concerns and recommendations for carer payments with respect to carers of people with mental illness [168]. Its main concern is that the current assessment process is too heavily geared toward carers of people with a physical disability [168]. In particular, it does not take into consideration that mental illness is episodic, and so questions about the caring role need to be redesigned to reflect this, e.g., '*how is the person when they are at their worst or at their best?*' [168]. The unique caring profile of mental health carers is supported by our findings outlined in Section 3.1. In particular, the qualitative data from the UQ Carer Survey 2016 highlight that the role of mental health carers fluctuates, with both 'good' and 'bad' periods, mirroring the course of recovery for those living with mental illness (see Section 3.1.6).

The RANZCP also has concerns about the Medical Report form, which is typically completed by the treating health professional and requires consent from the care recipient to release their medical information [168][12]. Some people with psychosocial disability lack insight about their condition and the amount of support provided by their carer, particularly when they are unwell [154, 158, 168][13]. For this reason, the College recommends that the Medical Report form should include an additional question which informs practitioners about the consumer's level of insight [168]. Another oversight, which should be included in the Medical Report form, is a section about risk of self-harm or suicidal ideation. During these periods, carers typically provide additional care up to almost 24 hours a day, as identified in the qualitative data of the UQ Carer Survey 2016 (see section 3.1.6). Finally, the RANZCP strongly recommends that the Department implements an accompanying guide to carer payments to assist both the carer and health practitioners [168]. Mental health carers should also be encouraged to keep a record of their caring activities, and there should be ongoing dialogue between the department and the carer, considering the episodic nature of their caring role [168].

These concerns are supported by a carer payment analysis conducted by Carers Victoria, which found that the assessment process is insensitive to those with long-term psychosocial disability [40]. Carers Victoria highlight particular issues with the Adult Disability Assessment Tool (ADAT), a questionnaire which carers are required to fill out about their care recipient's level of functioning, if their care recipient is aged 16 years or over [169]. Questions in the ADAT are more relevant to those who cannot feed, dress or bathe themselves [40]. As seen in our analysis of the 2012 SDAC and UQ Carer Survey 2016 (see Table 17), fewer than half of mental health carers perform these bathing, dressing and eating activities of daily living (ADLs) on a regular basis. There is a lack of questions in the ADAT about emotional care or prompting or supervision of practical tasks [5], which are tasks more commonly performed by mental health carers, as seen in section 3.1.5. Carers Victoria recommends alternative tools to be incorporated into the ADAT, including psychosocial disability assessment tools which cover the need for emotional care [40]. Their analysis of survey data identified that those most disadvantaged against receiving Carer Payment or Allowance are mothers of a son or daughter with schizophrenia who live separate from their adult child [40]. Carers Victoria propose that it is likely harder to demonstrate that you provide constant care, particularly with respect to ADL support, when you do not live with your care recipient [40]. Eligibility criteria and assessment procedures for non co-resident carers, particularly for those caring for someone

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[12] The Medical Report form is a component of the Adult Disability Assessment Tool (ADAT), which is typically completed by the treating health professional. Both the Medical Report form and ADAT questionnaire have to be completed in order for a carer to be deemed eligible for the Carer Payment or Carer Allowance.

[13] Carers Victoria interviewed carers about the assessment process. On some occasions, the person with mental illness would not consent to disclosure of information and their treating health professional would refuse to complete the form.

with schizophrenia, should be a focus of the Department of Social Services's review.

4.3.5 Conclusion

This report has shown that mental health carers provide a large amount of support, with an estimated replacement cost of $13.2 billion. However, estimated government expenditure on carer support services is modest. Carers report a need for better accessibility to services, as well as development or expansion of services that better meet the requirements of their episodic caring role. A number of reforms are in the pipeline that will likely have an impact on the caring role, as well as on the availability and suitability of support services for mental health carers and their care recipients. It is too early to comment on the extent of their impact, but it is clear from this report and other publications that mental health carers have a unique caring profile, and that this needs to be considered in the planning process of these reforms. Psychiatrists, mental health organisations and carer support groups have already started to, and will continue to, champion the extensive role of mental health carers during the planning and implementation of these reforms.

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Appendices

Appendix 1: Formal support service costs

Table A1.1. Summary of job advertisements for possible mental health caring replacement services

Source	Year	Staff type	FTE staff price	Salary on-costs
1. PHaMS job ads				
Mind Australia	Feb 2016	Community Mental Health Practitioner – PHaMs	Health Professionals and Support Services Award 2010 CMHP 2/1. This equates to $26.87. SA CMHP 2/4. This equates to $30.06 per hour, dependent on qualifications and experience	17.5% Leave loading[1]. Salary packaging up to $15,899 per year
Schizophrenia Fellowship of NSW	Jan 2016	PHaMs recovery support worker	SCHADS level 4	9.5% super and 17.5% annual leave loading[1]
Prahran Mission	Jan 2016	Community Mental Health Practitioner – PHaMs	$54,570–$59,164	?
Mallee Family Care	Jan 2016	PHaMs Employment Case Worker	$48,328–$60,541, dependent on qualifications and experience	Superannuation and salary packaging up to $15,834 (tax free)
Inner South Community Health	Jan 2015	PHaMs worker	Community Health Centre – Social and Community Service Employees Social worker class 2. Equates to $1,106.10/or community development worker class 2. Equates to $893.60	Salary packaging available up to $15,900 per year (tax free)
Health Staff Australia	Oct 2013	PHaMs support worker	SCHADS modern award – Level 4	Salary packaging available up to $16,050 per year
JobCo	June 2013	PHaMs employment support worker	$41,000–$45,000 (Labour Market Assistance Industry Award 2010). Pay point depends on experience	?
Schizophrenia Fellowship	May 2013	PHaMs recovery support worker	SCHADS level 4. Pay point depends on experience	?
Catholic Care NT	Feb 2013	PHaMs community support worker	$50,615 (SCHADS level 5.1)	9% superannuation + 17.5% leave loading[1]
UnitingCare	July 2012	PHaMs community support worker	$47,506	9% superannuation.[1] Salary packaging up to $16,050 per year
Richmond Fellowship of the ACT	?	PHaMs recovery worker	$43,403–$44,493	14% superannuation.[1] Salary packaging up to $16,050 per year (tax free)

Source	Year	Staff type	FTE staff price	Salary on-costs
2. Other positions in the mental health system				
NEAMI	Jan 2016	Community Rehabilitation and support worker	\$53,627–\$58,919 (CSD level 2)	?
Aftercare	Jan 2016	Mental Health Support Worker	SCHADS level 3. Equates to \$25.09–\$26.81	9.5% superannuation and 17.5% leave loading[1]
Mind Australia	Jan 2016	Family engagement worker	Health Professionals and Support Services Award 2010 - QLD - CMHP 2/1. Equates to \$26.87 an hour or \$1007.63 per week	?
Ashfield (via Career One)	Jan 2016	Employment support worker	\$57,149–\$59,812 (CSD Level 3)	?
CODA	Sept 2012	Disability support worker	Social, Community, Home Care and Disability Services Industrial Award 2010. 2.1 (\$22.55 per hour) or 3.1 (\$25.09 per hour)	?
Breakaway	?	Disability support worker	Disability Support Workers Award State (DSWA) Level 3 Pay point 1 (\$24.48 per hour)	?
Healthcare Australia	Mar 2016	Disability support worker	\$30.00–\$40.00 per hour	?
VIC Department of Health and Human Services	Mar 2016	Disability support worker	\$43,085–\$52,755, depending on qualifications	?
NEAMI	Sept 2013	Peer support worker	CSD Level 2 from \$50,500–\$54,396 pa	?
Aftercare	Mar 2016	Peer support worker	SCHADS Level 3. Ranges between \$25.09–\$26.81	Salary packaging (up to \$15,899 (tax free) per year), 9.5% superannuation, leave loading of 17.5%1
?	Mar 2016	Mental health case manager	\$36–\$40 per hour	?
St Vincent de Paul Society	Mar 2016	Case manager	\$30.06 per hour	13% superannuation + salary sacrifice[1]
?	Jan 2016	Crisis accommodation worker	SCHADS Award, Social Stream level 4. Pay ranges between \$28.34–\$30.39	?

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[1] Additional cost on top of the base salary rate.

Appendix 2: Literature review

Table A2.1. Summary of studies reporting on number of mental health carers

Data source	Methodology	Sample	Estimated number of carers	Limitations
SDAC 2003 [43]	The ABS conducted the SDAC 2003 from June to November 2003. The survey scope was persons in urban and rural areas in all states and territories, living in private or non-private dwellings Psychological disability includes: mental illness; nervous or emotional condition; and head injury, stroke or other brain damage which results in mental illness or nervous and emotional condition Question about caring ('03,'09,'12): '*Could you please tell me if anyone in (the household or outside household) helps or supervises another member of (the household) who has a long-term health condition or disability, or is elderly?*'	Co-resident primary carers (aged 15 years and over)[1] of people with a psychological disability	**31,800** co-resident primary carers cared for someone with a psychological disability. This disability type caused the most problems for main recipient of care [78] As many as **150,000** Australians are the primary informal carer for someone with a mental illness [53][2] There are approximately **110,000** Australian informal carers of loved ones living with a mental illness [41][2]	Does not include primary carers under the age of 15. Also, does not include mental health carers who are not co-residents but would still be considered the primary carer The SDAC 2003 categorises severity of disability according to core activity limitations (communication, mobility and self-care). Most people with a psychological disability may not experience limitations in these activities to any great degree Questions rely on the respondent to identify themselves as a carer. Family members who are carers sometimes do not identify as one because they normalise their role Inconsistent estimates in the literature [41, 53, 78]

Data source	Methodology	Sample	Estimated number of carers	Limitations
SDAC 2009 [44]	The ABS conducted the SDAC 2009. The survey scope was persons in urban and rural areas in all states and territories living in private or non-private dwellings Same definitions as the SDAC 2003	Co-resident primary carers (aged 15 years and over)[1] of people with a psychological disability	**75,500** co-resident primary carers cared for someone with a psychological disability. This disability type caused the most problems for main recipient of care [52] **177,900** (or **28.1%**) co-resident primary carers were providing care to a person with a psychological disability, with or without other disability. This is equivalent to **1%** of Australians aged 15 years or older [3]	Does not include primary carers under 15 years. Also, does not include mental health carers who are not co-residents but would still be considered the primary carer. Harris et al.'s [3] paper focused on any disability type of main recipient of care, as opposed to ABS resources, which focused on main recipients of care who found psychological disability to be the most problematic disability type People who provided emotional support would not have qualified as carers in SDAC 2009 unless they also provided practical assistance Questions rely on the respondent to identify themselves as a carer
SDAC 2012 [16]	The SDAC 2012 was conducted throughout Australia from 5 August 2012 to 2 March 2013. The scope of SDAC 2012 was persons in both urban and rural areas in all states and territories, living in both private and non-private dwellings Same definitions as SDAC 2003 and 2009	Co-resident carers of people with mental and behavioural disorders. Carers aged less than 15 years were included	Of the total co-resident carers, **499,400 (or 26.1%)** were caring for someone with a mental and behavioural disorder [16]	The category of mental and behavioural disorder includes dementia, intellectual and development disorders and autism and related disorders Does not include mental health carers who are not co-residents but would still be considered the primary carer The number of Australians caring for someone with a psychological disability has not been analysed

Data source	Methodology	Sample	Estimated number of carers	Limitations
NSMHWB 2007 [80]	The NSMHWB 2007 survey is a nationally representative survey conducted in the latter part of 2007 by trained interviewers from the ABS. Survey respondents were identified from a stratified multistage probability sample of households Mental illness includes: alcohol or drug problem, depression, anxiety, schizophrenia or psychosis, manic depression or bipolar disorder Question about caring: '*Do any of your immediate family members have any of the following problems?*' If so, '*would you say that their health problems affect your life a lot, some, a little, or not at all?*' If it affected their life 'a lot' or 'some', this person was deemed a caregiver	3,434 people aged 16–85 years indicated they had at least one relative with a chronic mental illness	Of the 3,434 respondents, **1,309 (or 38%)** were caring for a relative with a mental illness (with or without a physical disorder). This equates to **15%** of Australian adults caring for a relative with a mental illness (or nearly **2.4 million** individuals) [51] Carers Victoria modelled carer numbers using NSMHWB 2007 estimates and found a comparable figure. Total number of carers caring for persons with mental illness (with or without physical conditions) – **2,247,072** [40]	Does not include carers under the age of 16 years or non-family member carers Carer status was determined by impact on the respondent's life and did not take into account tasks performed or hours of caring per week Estimate includes those caring solely for family member(s) with a primary substance use disorder. This group is out of scope for the current project Does not provide fine-grained detail about the spectrum of characteristics or levels of care provided by family members
Families Caring for a Person with a Disability Study (FCPDS) [45]	A random sample of 5,000 people (aged 18 years or over) receiving Carer Payment and/or Carer Allowance in June 2006 was selected from the Centrelink Administrative Database. Computer-assisted telephone interviewing (CATI) was used to collect information from carers Carers were asked about the care recipient's primary medical diagnosis or disability. Carers' responses were categorised into five major categories in the National Community Services Data Dictionary: physical, intellectual/learning disability, psychiatric, sensory/speech, acquired brain injury	The analysis was based on data from 1,002 carers in the 2006 database (aged 18 years or over). This sample was deemed representative compared with the total population of carers that received government assistance in 2006	**11.2%** (or 128) of people being cared for had a psychiatric disability 1,140 care recipients in total were reported by the 1,002 carers. Carers could discuss up to three people they care for in the interviews [45]	Does not include carers under the age of 18 years. Does not include carers not eligible for Carer Payment or Allowance The estimate is for proportion of care recipients rather than carers The estimate is relative to the carer population in Australia but not the Australian population as a whole The estimate does not exclude caring for people under 16 years: 4.1% of the people being cared for were aged 0–4 years and 22.7% were 5–12 years

Data source	Methodology	Sample	Estimated number of carers	Limitations
Survey 17 of the Australian Unity Wellbeing Index [46]	Approximately 11,000 questionnaires were distributed to a random sample of carers (aged 18 years or over), as identified by the Carers Australia database. Question about caring: '*Which category best describes the main conditions of the person you care for? Chronic fatigue, aged and frail, disability, mental illness, two conditions*'	The analysis was based on data from 3,314 carers aged 18 years or over	**13.9%** (or 466) of the sample reported that the main person the cared for had a mental illness [47]	Does not include carers under the age of 18 years The representativeness of this sample is uncertain The estimate is relative to the carer population in Australia but not the Australian population as a whole
SHIP 2010 [50]	SHIP 2010 is survey of psychosis which generated a national probability sample from seven catchment areas, including inner-city, urban and rural setting Question about caring: '*In the last 12 months, have you had a carer who is responsible for looking after you, helping you, or taking care of your needs? Not a paid professional*'	1,825 adults with psychosis aged 18–64 years completed face-to-face interviews This sample is representative of adults with psychosis aged 18–64 years and in contact with public mental health services	**24.5%** (or 447) reported that they had a carer in the past 12 months [50] This proportion provides an estimate of **15,566** carers of those persons with a psychotic disorder receiving public mental health services [40], assuming a one-to-one relationship between number of carers and care recipients	Only focuses on those living with a psychotic disorder. It does not include Australians living with non-psychotic disorders, nor carers of people with psychosis who are not accessing public mental health services The estimate is derived from the care recipient's perspective and is likely to be an underestimate. Many people with a mental illness do not recognise their family member as their carer

Data source	Methodology	Sample	Estimated number of carers	Limitations
Pension Review 2008 [49]	As part of the pension review report, Carer Allowance was accessed from the Centrelink Administrative Database at June 2008. They investigated the first listed medical condition for care receivers, mapped to the current version of the International Classification of Diseases (ICD-10), as reported by Carer Allowance recipients. These include nervous system, circulation, musculo-skeletal, neoplasms, congenital, endocrine/metabolic and mental/behavioural disorders	Recipients of the Carer Allowance (adult) at June 2007. There are no carer age restrictions for eligibility of these payments	In 2006–7, 278,602 people were receiving the Carer Allowance (Adult). Of these, **28%** cared for a person with a mental or behavioural disorder [49]	The ICD-10 categorisation of mental/behavioural conditions is very broad. It includes dementias that are associated with ageing and developmental disorders such as autism and people with acquired brain injury Conditions of the person receiving care are categorised according to the first medical condition listed in the application form. This may not correspond to their main disability type
Centrelink Victorian Carer Payment and Allowance data 2011 [40]	Carers Association Victoria investigated how many Victorians accessed the Carer Payment and Carer Allowance in 2011. In particular, they were interested in carers of persons with a mental illness Carer Payment and/or Carer Allowance were accessed from the Centrelink Administrative Database at 23 Sept 2011	Recipients of the Carer Payment and Carer Allowance (adult) at 23 Sept 2011. There are no carer age restrictions for eligibility of these payments	**26,484** (or **25.5%**) of Australians aged 16–64 who qualify their carer for Carer Payment have a mental illness, **6,991** of whom have a psychotic illness. **51,193** (or **26.3%**) of Australians aged 16–64 who qualify their carer for Carer Allowance have a mental illness, **13,641** of whom have a psychotic illness [40]	Conditions of the person receiving care are categorised according to the first medical condition listed in the application form. This may not correspond to their main disability type

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[1] The SDAC primary carer is the person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least six months and be provided for one or more of the core activities (communication, mobility and self-care).

[2] This estimate was not based on a secondary analysis of the SDAC 2003. The authors listed this estimate in their introduction, along with citing the ABS.

Table A2.2. Summary of studies reporting on types of care provided

Data source	Methodology	Sample	Types of care provided	Limitations
SDAC 2009 [44]	The ABS conducted the SDAC 2009. The survey scope was persons in urban and rural areas in all states and territories, living in private or non-private dwellings Carers were asked about the types of activities they performed to assist their main recipient of care	Co-resident primary carers (aged 15 years and over) of persons with a psychological disability[1]	Of those co-resident primary carers caring for someone with a psychological disability (75,500) (main disability type), **69,200 (or 91.7%)** provided cognitive and emotional assistance; **57,300 (or 75.9%)** provided communication assistance; **53,900 (or 71.4%)** provided assistance with transport; **41,400 (or 54.8%)** provided assistance with self-care; and **39,300 (or 52.1%)** provided assistance with meal preparation [52]	Does not provide a timeframe. It would have been more useful to provide care activities performed daily by proportion of survey participants, or the hours spent performing each care activity Does not include primary carers under the age of 15 years. Also, does not include mental health carers who are not co-residents but would still be considered the primary carer
NSMHWB 2007 [80]	The NSMHWB 2007 survey is a nationally representative survey conducted in the latter part of 2007 by trained interviewers from the ABS. Survey respondents were identified from a stratified multistage probability sample of households Carers were asked about the types of activities they performed in the course of caring for their relatives with mental illness	1,309 people aged between 16 and 85 years indicated they were caring for at least one relative with a chronic mental illness	Carers indicated that their role involved keeping their relatives company or giving them emotional support (**60.4%, 95%CI = 56%–64.8%**). Many also spent time helping them with practical things like paperwork, getting around, housework or taking medications (**37.8%, 95%CI = 33.8%–41.8%**). Much less common was the provision of help with things like washing, dressing or eating (**11.7%, 95%CI = 9.1%–14.4%**)[51]	Does not provide a timeframe. It would have been more useful to provide care activities performed daily by proportion of survey participants or the hours spent performing each care activity

Data source	Methodology	Sample	Types of care provided	Limitations
Carers Victoria online survey 2011 [40]	Carers Association Victoria investigated how many Victorians accessed the Carer Payment and Carer Allowance in 2011. They also recruited carers for participation in an online SurveyMonkey questionnaire about issues to access to Carer Allowance and Carer Payment. They asked carers about the types of care and how frequently carers performed these tasks	165 Victorian carers of a person with mental illness responded to the electronic survey. 73% of the sample were between the ages of 36–65. Only five participants were under the age of 25	**99%** of respondents reported that they provided emotional support; **99%** reported they provided encouragement and motivation; **91%** provided advocacy on behalf of care recipient; **90%** provided paperwork on behalf of care recipient; **89%** provided support for managing crises; **87%** supervised household tasks; **79%** provided support for transport to health appointments; **66%** provided support with eating and drinking Frequency: **87%** of carers reported providing emotional support at least daily; **86%** reported providing encouragement and motivation; and **58%** supervised household tasks at least daily. Only **43%** of participants provided supervision of eating and drinking on daily basis [40]	Sample included carers from Victoria only

Data source	**Methodology**	**Sample**	**Types of care provided**	**Limitations**
ARAFMI and Carers QLD survey [42, 53]	A questionnaire package was posted to 700 carers, who included 500 ARAFMI members and 200 randomly selected carers from Carers Queensland's mental health carer member database Amount of caring assistance was assessed on the Caregiving Tasks in Caring for an Adult with Mental Illness Scale (CTiCAMIS). For each of the 18 caring tasks, participants rated on a five-point scale the amount of help (0 no help to 4 lots of help)	Informal carers of an adult with a mental illness recruited through ARAFMI and Carers Queensland	106 informal carers. Mean age 58.33 (SD=10.86). The factor analysis produced three distinct factors measuring activities of daily living (ADL), (dressing, bathing, toileting), instrumental ADL, (IADL, e.g., grocery shopping, paying bills, preparing meals) and psychosocial caring (PC) activities (supervising to prevent wandering, prompting to do things, providing emotional support) [53]. Mean ICT scores IADL = **M=2.41, SD=1.21** ADL = **M=0.22, SD=0.56** PC = **M=2.20 SD=0.93** 114 carers of adults with a mental illness (mean age = 58.69, SD=10.57) who completed questionnaires at time 1 and 12 months later (time 2). An additional 13 participants were recruited by staff in the two mental health services. Caring tasks involved in caring for an adult with mental illness fall into three psychometrically sound dimensions: instrumental, activities of daily living (ADL) and psychosocial care [42]. Mean ICT scores (Time 1): IADL = **M=2.36, SD=1.42** ADL = **M=0.20, SD=0.42** PC = **M=2.23, SD=0.90**	Small sample size (n=106–114) from Queensland only Does not provide a timeframe. It would have been more useful to provide care activities performed daily by proportion of survey participants or the hours spent performing each care activity

[1] The SDAC primary carer is the person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least six months and be provided for one or more of the core activities (communication, mobility and self-care).

Table A2.3. Summary of studies reporting on hours of mental health caring

Data source	Methodology	Sample	Estimate of number of hours of care	Limitations
SDAC 2003 [43]	The ABS conducted the SDAC 2003 from June to November 2003. The survey scope was persons in urban and rural areas in all states and territories, living in private or non-private dwellings Psychological disability includes: mental illness; nervous or emotional condition; and head injury, stroke or other brain damage which results in mental illness or nervous and emotional condition Average current weekly hours was recorded in three categories: (1) less than 20 hours, (2) 20–39 hours, (3) 40 hours or more	Co-resident primary carers (aged 15 years and over) of people with a psychological disability[1]	31,800 co-resident primary carers caring for those with a psychological disability (main disability type) reported average current weekly hours: Less than 20 hours → 5,200 20–39 hours → 4,700 **40 hours or more → 19,000** This equates to two-thirds (or 66%) of this group caring 40 hours or more a week [78]	Does not include primary carers under the age of 15 years. Also, does not include mental health carers who are not co-residents but would still be considered the primary carer People who provided emotional support would not have qualified as carers in SDAC 2003 unless they also provided practical assistance Questions rely on the respondent to identify themselves as a carer. Family members who are carers sometimes do not identify as one because they normalise their role
SDAC 2009 [44]	The ABS conducted the SDAC 2009. The survey scope was persons in urban and rural areas in all states and territories, living in private or non-private dwellings Same definitions as the SDAC 2003 Average current weekly hours was recorded in three categories: (1) less than 20 hours, (2) 20–39 hours, (3) 40 hours or more	Co-resident primary carers (aged 15 years and over) of people with a psychological disability[1]	Of the 75,500 co-resident primary carers assisting people with a psychological disability (main disability type), **59%** provided care for an average of 40 hours or more a week to their main recipient [52] Of the co-resident primary carers of main recipients with a psychological disability (EPC=177,900), with or without other disability, more than half (**55.3%**, **95%CI = 52.0%–58.6%**) spent **40 hours per week** or more providing care to main recipient [3]	Does not include primary carers under the age of 15 years. Also, does not include mental health carers who are not co-residents People who provided emotional support would not have qualified as carers in SDAC 2009 unless they also provided practical assistance Questions rely on the respondent to identify themselves as a carer. Family members who are carers sometimes do not identify as one because they normalise their role

Data source	Methodology	Sample	Estimate of number of hours of care	Limitations
Carers of People with Mental Illness project [85]	Project conducted by Mental Health Council of Australia (MHCA) in partnership with the Carers Association of Australia. Respective focus groups of carers and mental health service providers were conducted in each state/territory	A total of 76 mental health carers participated in the focus groups. Does not report age of carers	Individual carers on average contribute **104** hours per week caring for a person with mental illness. For many carers this time includes periods they are 'on call' for problems arising with their care recipient [85, 170]	Small sample size (n=76) The representativeness of this sample is uncertain
Deakin longitudinal study of eating disorders carers [86]	A self-report, quantitative questionnaire approach was utilised. Carers of people with an eating disorder completed three self-report questionnaires over a period of nine months (initial, four-and-a-half and nine months)	42 Australian carers of those with an eating disorder. Mean age 45.79 (SD=11.84)	Carers reported an average of **78.91 (SD=63.83)** hours of contact with the person with an eating disorder per week, with one hour (SD=1.24) per week of direct treatment commitments [86]	Small sample size (n=42) Hours of 'contact' is too broad. This would likely include time with the care recipient that doesn't involve care tasks Findings not representative of all mental illnesses
ARAFMI and Carers QLD survey [41, 53]	A questionnaire package was posted to 700 carers, which included 500 ARAFMI members and 200 randomly selected carers from Carers Queensland's mental health carer member database	Informal carers of an adult with a mental illness recruited through ARAFMI and Carers Queensland	106 informal carers of an adult with a mental illness recruited through ARAFMI and Carers Queensland. Mean age 58.33 (SD=10.86). Caring hr/week: **M=71.13, SD=68.96** [53] 114 informal carers of an adult with a mental illness recruited through QLD ARAFMI and Carers Queensland. Mean age 58.69 years (10.57). Hours per week in caring: **M=90.97 h (SD=68.65) Range 1–168 h**. [41, 42]. This sample includes an additional 13 participants that were recruited by staff at two mental health services	Small sample size (n=106–114) from Queensland only

Data source	Methodology	Sample	Estimate of number of hours of care	Limitations
Respite users, ARAFMI and Carers QLD survey [88]	The effectiveness of respite care was examined using a respite care group and comparison group with pre- and post-respite assessment and three-month follow-up. Participants were asked about their caring environment, including hours of care per week	20 informal carers of an adult with mental illness. Participants were recruited through ARAFMI (Brisbane) and Carers Queensland. Mean age 61.50 + 12.66	Caring hr/week **M=83.07, SD=76.19** [88]	Very small sample size, (n=20) from Queensland only
Improving Mood through Physical Activity in Carers and Care-recipient Trial (IMPACCT) study [87]	For this cross-sectional study, the inclusion criteria were that: 1. the participant was a carer aged 55 years or older 2. the participant was living at home with the patient, who was 60 years or older 3. the participant was providing support to the patient	202 older (55 years and older) informal co-resident carers in Australia. 11.9% (or 24 people) were caring for someone with mental illness, such as schizophrenia and depression. Mean age 67.4 (6.9)	Hours of caring per week of carers caring for patients with mental illness: **M=53.1, SD=45.5** [87]	This study only focused on older informal carers (≥55 years) who were caring for older participants (≥60 years) Also, does not include mental health carers who are not co-residents but would still be considered the primary carer Small MH carer sample size (n=24)
Carers Victoria online survey 2011 [40]s	Carers Association Victoria investigated how many Victorians accessed the Carer Payment and Carer Allowance in 2011. They were interested in carers of persons with a mental illness. They also recruited carers for participation in an online SurveyMonkey questionnaire about issues to access to Carer Allowance and Carer Payment	165 Victorian carers of a person with mental illness responded to the electronic survey. 73% of the sample were between the ages of 36–65. Only five participants were under the age of 25	Carer Allowance recipients in the survey provided an average of approximately **four hours of care a day 'on a good day'**, increasing to over **seven hours of care 'on a bad day'** [40]	Sample included carers from Victoria only Issue with the estimate's reliability. Survey participants reported that it was difficult for them to reliably estimate how many hours of care they typically provided in a day. This can be seen as a function of the fluctuating nature of the need for care by the person with a mental illness

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[1] The SDAC primary carer is the person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least six months and be provided for one or more of the core activities (communication, mobility and self-care).

Appendix 3: Replacement cost model

Figure A3.1. Flowchart representing the logic of the replacement cost model

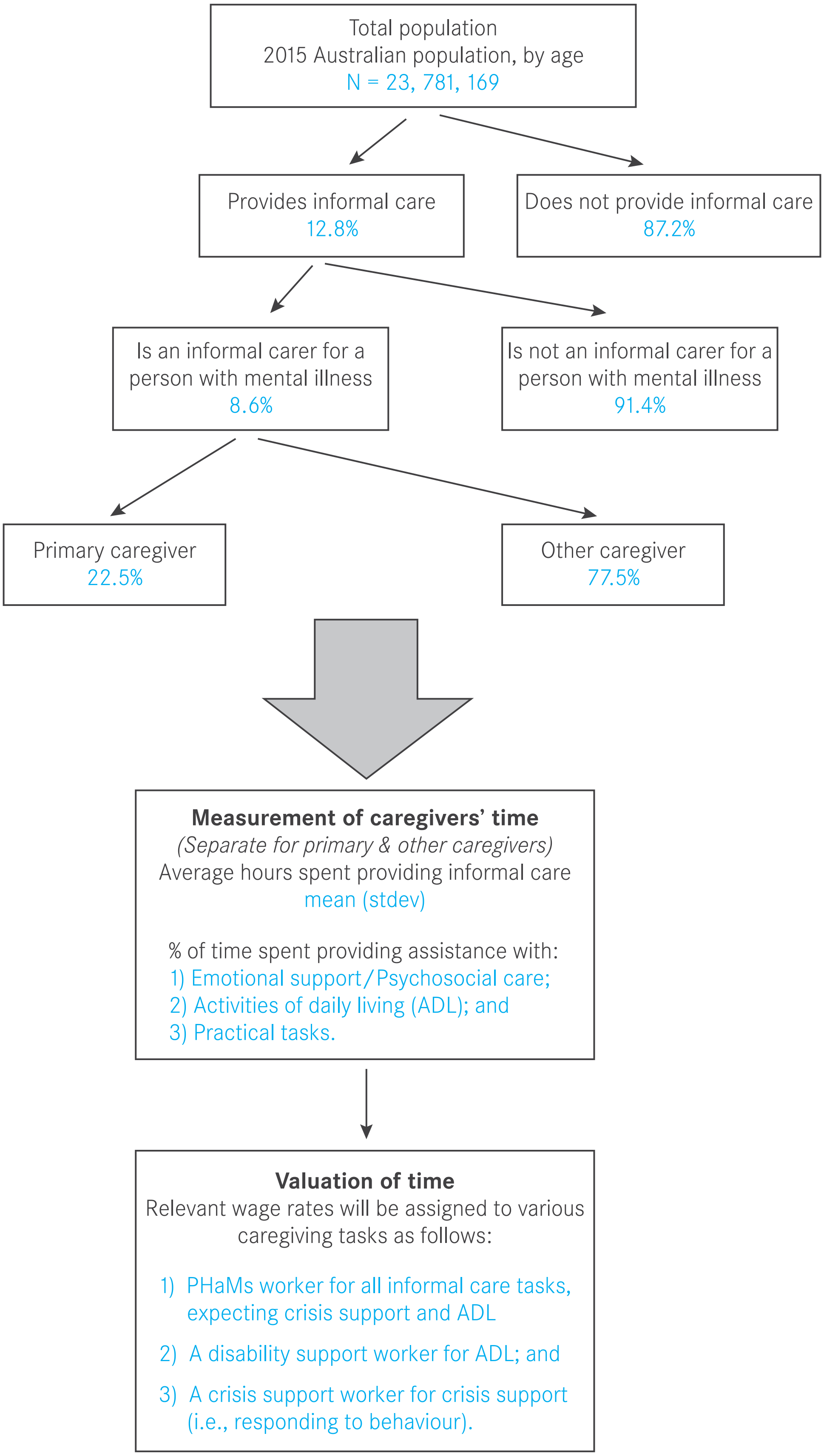

Table A3.1. Input parameters and uncertainty for replacement cost model

Input variable	Parameter value and uncertainty	Uncertainty distribution	Source
2015 Australian population (by 20-year age groups)	5–24 years: 6,070,956 25–44 years: 6,741,269 45–64 years: 5,859,004 65+ years: 3,569,556	Not applicable	ABS 2015
Proportion of informal carers in the population, after adjusting for the established population[1] (by 20-year age groups)	5–24 years: 5.0% (SE: 0.2) 25–44 years: 10.3% (SE: 0.3) 45–64 years: 19.7% (SE: 0.3) 65+ years: 18.5% (SE: 0.4)	Beta	SDAC 2012
Proportion of informal carers who care for a recipient with mental illness, aged 15+ years (by 20-year age groups)	5–24 years: 11.6% (SE: 1.3) 25–44 years: 9.6% (SE: 0.8) 45–64 years: 9.2% (SE: 0.5) 65+ years: 4.9% (SE: 0.6)	Beta	SDAC 2012
Proportion of 'primary' carers among mental health carers (by 20-year age groups)	5–24 years: 11.8% (SE: 3.7) 25–44 years: 15.6% (SE: 2.9) 45–64 years: 27.6% (SE: 3.3) 65+ years: 32.3% (SE: 4.5)	Beta	SDAC 2012
Proportion of 'other' carers among mental health carers[2] (by 20-year age groups)	5–24 years: 88.2% (SE: 3.7) 25–44 years: 84.4% (SE: 2.9) 45–64 years: 72.4% (SE: 3.3) 65+ years: 67.7% (SE: 4.5)	Beta	SDAC 2012
Average total hours of care provided during the week[3]	Primary carer: 36.2 hours (SE: 2.1) Other carer: 11.0 hours (SE: 0.8)	Lognormal	SDAC 2012 NSMHWB 2007
Proportional distribution of informal caring tasks (by three broad categories of informal care tasks)	Emotional support: 67.9% (SE: 6.1) Practical tasks: 29.1% (SE: 3.0) Activities of daily living: 3.0% (SE: 0.9)	Conditional beta	UQ Carer Survey 2016
Proportional distribution of informal caring tasks related to emotional support (by specific care tasks)	a) Supervision and monitoring: 19.2% (SE: 3.6) b) Emotional support: 24.3% (SE: 4.0) c) Responding to behaviour: 10.2% (SE: 2.1) d) Other emotional support: 14.2% (SE: 3.5)	Conditional beta	UQ Carer Survey 2016

Input variable	Parameter value and uncertainty	Uncertainty distribution	Source
Proportional distribution of informal caring tasks related to practical tasks (by specific care tasks)	a) Household tasks: 16.8% (SE: 2.7) b) Health care coordination: 5.4% (SE: 1.1) c) Literacy and communication: 2.9% (SE: 0.4) d) Transport: 2.7% (SE: 0.6) e) Other practical tasks: 1.2% (SE: 0.3)	Conditional beta	UQ Carer Survey 2016
Proportional distribution of informal caring tasks related to activities of daily living (by specific care tasks)	a) All activities of daily living: 3.0% (SE: 0.9)	Conditional beta	UQ Carer Survey 2016

[1] The unadjusted proportion of informal carers, which excluded the established population (i.e., people in residential care or a supervised care facility) was (0.0503, 0.1026, 0.1971, 0.1890). The proportion of people in the established population within the total population was (0.0001, 0.0004, 0.0015, 0.0190). The adjustment was calculated as the ‘array of unadjusted proportions’, multiplied by ‘1 minus the array of proportions for the established population’.

[2] The SDAC 2012 distinguished between confirmed ‘primary’ carers and ‘other’ carers. The latter group included informal carers who are: secondary carers; carers aged below 15 years; non co-resident primary carers; and primary carers for a secondary care recipient with mental illness.

[3] The average total hours of care provided during the week for primary carers was based on discrete data from the SDAC 2012 on the proportion of people who report one of the following categories for total average weekly hours of care: <20 hours; 20–29 hours; 30–39 hours; 40+ hours. The proportion of primary carers in each discrete time category was (36.6%, 16.4%, 9.3%, 37.8%) with effective sample sizes of (55, 25, 14, 56). We converted these discrete data into a continuous variable (expressed as a mean and standard deviation) by using means for each discrete time category derived from the UQ Carer Survey 2016: (9.77 hours, 22.65 hours, 32.11 hours, 68.59 hours). Using a Dirichlet distribution to calculate the arithmetic mean of these mid-points, weighted according to the proportion of respondents in each discrete time category, resulted in a continuous variable of the average total weekly hours of care among primary carers – i.e., a mean of 36.2 hours (SE: 2.1).

Table A3.2. Calculating the number of mental health carers in the 2015 Australian population

Age	2015 Australian population	Informal carers in the population	Mental health carers
5–24	6,070,956	305,323	35,424
25–44	6,741,269	691,691	66,211
45–64	5,859,004	1,153,165	105,691
65+	3,569,556	661,668	32,296
Total	**22,240,785**	**2,811,847**	**239,623**

Table A3.3. Number of primary and other mental health carers in the 2015 Australian population

Age	Number of primary carers	Number of other carers	Total number of carers
5–24	4,171	31,253	35,424
25–44	10,304	55,907	66,211
45–64	29,223	76,468	105,691
65+	10,424	21,872	32,296
Total	**54,122**	**185,501**	**239,623**

Table A3.4. Data on average weekly hours of care provided by informal mental health carers

Average total weekly hours of care	Used in the model?	Mean	SE
NSMHWB 2007 (n=831)	Yes – Other carers	11.0	0.8
SDAC 2012 - Primary carers (n=150)	Yes – Primary carers	39.6	2.1
UQ Carer Survey 2016 - All carers (n=95)[1]	No	37.2	3.3
UQ Carer Survey 2016 - Primary carer (n=84)	No	39.6	3.5
UQ Carer Survey 2016 - Other carer (n=7)	No	13.2	4.1

[1] This includes primary carers, other carers and three people who were unsure about their carer status. One person skipped the carer status question altogether.

Table A3.5. Proportional distribution of average weekly hours of care among primary carers

Activity description	Hours	%
1. Emotional support/psychosocial care	**26.9**	**67.9 %**
a) Supervising and monitoring	7.6	19.2%
b) Emotional support and encouragement	9.6	24.3%
c) Responding to behaviour	4.0	10.2%
d) Other	5.6	14.2%
2. Activities of daily living	**1.2**	**3.0%**
a) All activities of daily living	1.2	3.0%
3. Practical tasks	**11.5**	**29.1 %**
a) Household tasks	6.7	16.8%
b) Health care coordination	2.2	5.4%
c) Literacy and communication	1.2	2.9%
d) Transport	1.1	2.7%
e) Other	0.5	1.2%
Total hours of care	**39.6**	**100.0%**

Table A3.6. Proportional distribution of average weekly hours of care among other carers

Activity description	Hours	%
1. Emotional support/psychosocial care	**7.5**	**67.9%**
a) Supervising and monitoring	2.1	19.2%
b) Emotional support and encouragement	2.7	24.3%
c) Responding to behaviour	1.1	10.2%
d) Other	1.6	14.2%
2. Activities of daily living	**0.3**	**3.0%**
a) All activities of daily living	0.3	3.0%
3. Practical tasks	**3.2**	**29.1 %**
a) Household tasks	1.8	16.8%
b) Health care coordination	0.6	5.4%
c) Literacy and communication	0.3	2.9%
d) Transport	0.3	2.7%
e) Other	0.1	1.2%
Total hours of care	**11.0**	**100.0%**

Table A3.7. Hourly replacement cost for each informal care task

Activity description	Formal sector worker	Hourly replacement cost
1. Emotional support/psychosocial care		
a) Supervising and monitoring	PHaMs worker	$69.85
b) Emotional support and encouragement	PHaMs worker	$69.85
c) Responding to behaviour	Crisis accommodation worker	$61.80
d) Other	PHaMs worker	$69.85
2. Activities of daily living		
a) All activities of daily living	Disability support worker	$59.41
3. Practical tasks		
a) Household tasks	PHaMs worker	$69.85
b) Health care coordination	PHaMs worker	$69.85
c) Literacy and communication	PHaMs worker	$69.85
d) Transport	PHaMs worker	$69.85
e) Other	PHaMs worker	$69.85

Table A3.8. Weekly average replacement value for each informal care task on a per carer basis

Activity description	Cost per primary carer	Cost per other carer
1. Emotional support/psychosocial care	**$1,717**	**$522**
a) Supervising and monitoring	$485	$148
b) Emotional support and encouragement	$614	$187
c) Responding to behaviour	$228	$69
d) Other	$360	$109
2. Activities of daily living	**$65**	**$20**
a) All activities of daily living	$65	$20
3. Practical tasks	**$735**	**$223**
a) Household tasks	$426	$129
b) Health care coordination	$136	$41
c) Literacy and communication	$74	$22
d) Transport	$69	$21
e) Other	$31	$9
Total weekly cost per person	**$2,488**	**$756**

Table A3.9. Total annual replacement cost per mental health carer

Age	Primary carers	Other carers	All carers
5–24	$129,351	$39,306	$49,908
25–44	$129,351	$39,306	$53,318
45–64	$129,351	$39,306	$64,203
65+	$129,351	$39,306	$68,369
Average	**$129,351**	**$39,306**	**$59,644**

Table A3.10. Total calculated annual replacement cost with no cost offsets

Age	Primary carer)	Other carers	All carers
5–24	$539,524,294	$1,228,426,799	$1,767,951,093
25–44	$1,332,812,305	$2,197,470,185	$3,530,282,490
45–64	$3,780,046,984	$3,005,621,333	$6,785,668,317
65+	$1,348,376,397	$859,704,126	$2,208,080,522
Total	**$7,000,759,979**	**$7,291,222,443**	**$14,291,982,422**

Table A3.11. Cost offsets applied to primary carers

Type of government payment	Government spending in 2014–15	Proportion who care for an adult with mental illness	Expenditure on those caring for adults with mental illness
Carer Payment	$4,600,000,000	16.5%	$759,000,000
Carer Allowance (adult)	$1,510,000,000	16.6%	$250,660,000
Carer Supplement	$614,815	16.5%	$101,444
Rent Assistance	N/A	N/A	$62,296,933
Total	**$6,110,614,815**	-	**$1,072,058,377**

Appendix 4: SHIP 2010 analysis

Table A4.1. Relationship between variables of interest

Variable 1	Grouped by	Variable 2	Statistic	Degrees of freedom	Significance
Total nights admitted	NA	Diagnosis	$r_{pb} = -.09$	622	$p = .03$
		Course of disorder	$r_{pb} = .01$	622	n.s.
		Possible depression	$r_{pb} = -.10$	622	$p = .01$
		Alcohol abuse/dependence	$r_{pb} = -.12$	622	$p = .004$
		Cannabis abuse/dependence	$r_{pb} = -.02$	622	n.s.
		Other abuse/dependence	$r_{pb} = .05$	622	n.s.
		Physical health condition	$r_{pb} = .08$	622	$p = .04$
		Global functioning	$r = -.13$	622	$p = .001$
		DSP[1]	$r_{pb} = .06$	572	n.s.
		Self-harm[2]	$r_{pb} = -.07$	616	n.s.
		Involuntary admission[3]	$r_{pb} = .26$	615	$p < .001$
		MH outpatient contacts[4]	$r = .06$	542	n.s.
		Help to find accommodation[5]	$r_{pb} = .27$	584	$p < .001$
		Age	$r = .01$	622	n.s.
		Sex	$r_{pb} = .06$	622	n.s.
		Country of birth	$r_{pb} = .02$	622	n.s.
		Indigenous status	$r_{pb} = .04$	622	n.s.
		Main language	$r_{pb} = -.03$	622	n.s.
		Private admission	$r_{pb} = .08$	622	$p = .04$
Carer status	NA	Diagnosis	$\Phi = -.04$	1	n.s.
		Possible depression	$\Phi = .01$	1	n.s.
		Alcohol abuse/dependence	$\Phi = .06$	1	n.s.
		Physical health condition	$\Phi = .04$	1	n.s.
		Global functioning	$r_{pb} = -.13$	622	$p = .001$
		Involuntary admission[3]	$\Phi = -.01$	1	n.s.
		Help to find accommodation[5]	$\Phi = .09$	1	$p = .04$
		Private admission	$\Phi = .07$	1	n.s.
Total nights admitted	Carer status	Global functioning	N) $r = -.18$	451	$p < .001$
			Y) $r = .02$	167	n.s.
Diagnosis	NA	Possible depression	$\Phi = .23$	1	$p < .001$
		Alcohol abuse/dependence	$\Phi = .03$	1	n.s.
		Physical health condition	$\Phi = .07$	1	n.s.
		Global functioning	$r_{pb} = .15$	624	$p < .001$
		Involuntary admission[6]	$\Phi = .03$	1	n.s.
		Private admission	$\Phi = .05$	1	n.s.

Variable 1	Grouped by	Variable 2	Statistic	Degrees of freedom	Significance
Possible depression	NA	Alcohol abuse/dependence	$\Phi = .11$	1	$p = .01$
		Physical health condition	$\Phi = .05$	1	n.s.
		Global functioning	$r_{pb} = -.02$	624	n.s.
		Involuntary admission[6]	$\Phi = -.13$	1	$p = .001$
		Private admission	$\Phi = .10$	1	$p = .01$
Alcohol abuse/ dependence	NA	Physical health condition	$\Phi = .02$	1	n.s.
		Global functioning	$r_{pb} = -.12$	624	$p = .003$
		Involuntary admission[6]	$\Phi = .04$	1	n.s.
		Private admission	$\Phi = -.01$	1	n.s.
Physical health condition	NA	Global functioning	$r_{pb} = -.06$	624	n.s.
		Involuntary admission[6]	$\Phi = .04$	1	n.s.
		Private admission	$\Phi = .06$	1	n.s.
Global functioning	NA	Involuntary admission[6]	$r_{pb} = -.07$	617	n.s.
		Private admission	$r_{pb} = .01$	623	n.s.
Involuntary admission	NA	Private admission[2]	$\Phi = -.12$	1	$p = .002$
Total nights admitted to non-private hospitals	NA	Diagnosis	$r_{pb} = -.10$	607	$p = .01$
		Course of disorder	$r_{pb} = .01$	607	n.s.
		Possible depression	$r_{pb} = -.11$	607	$p = .005$
		Alcohol abuse/dependence	$r_{pb} = -.10$	607	$p = .01$
		Cannabis abuse/dependence	$r_{pb} = -.01$	607	n.s.
		Other abuse/dependence	$r_{pb} = .07$	607	n.s.
		Physical health condition	$r_{pb} = .07$	607	n.s.
		Global functioning	$r = -.15$	607	$p < .001$
		DSP[7]	$r_{pb} = .05$	559	n.s.
		Self-harm[2]	$r_{pb} = -.08$	601	n.s.
		Involuntary admission[3]	$r_{pb} = .29$	600	$p < .001$
		MH outpatient contacts[8]	$r = .03$	528	n.s.
		Age	$r = -.01$	607	n.s.
		Sex	$r_{pb} = .03$	607	n.s.
		Country of birth	$r_{pb} = .01$	607	n.s.
		Indigenous status	$r_{pb} = .04$	607	n.s.
		Main language	$r_{pb} = -.03$	607	n.s.

NA – not applicable; r_{pb} – point-biserial correlation, a measure of the strength of association between a dichotomous and continuous variable; Φ – phi coefficient, a measure of the strength of association between two dichotomous variables; r – Pearson's correlation, a measure of the strength of association between two continuous variables.

[1] 52 participants missing (8.3% of cases).

[2] 8 participants missing (1.3% of cases).

[3] 9 participants missing (1.4% of cases).

[4] 82 participants missing (13.1% of cases).

[5] 40 participants missing (6.4% of cases).

[6] 7 participants missing (1.1% of cases).

[7] 50 participants missing (8.2% of cases).

[8] 81 participants missing (13.3% of cases).

Appendix 5: Commonwealth-funded carer support

Table A5.1. Federal-funded support programs for mental health carers

Name of program	Program description	Target population	Funding source	Funding allocated (2015–16)	Number of carers supported (2014–15)	Data source
Mental Health Respite: Carer Support (MHR:CS) [96]	MHR:CS provides a range of flexible respite options (in-home or out-of-home) for carers of people severely impacted by mental illness. In addition to direct respite care, the program offers family support options, including counselling, practical assistance, social inclusion activities, case management and education. The aim of services is to provide support for the carer and their family, to help them maintain their caring role	Carers of people severely impacted by mental illness, including people caring for someone with autism spectrum disorder and intellectual disability[1]	Department of Social Services	$63.974 million	40,644	[66]
Carers and Work (CAW) [4]	CAW provides intensive support to mental health carers to address barriers to achieving workforce participation. Assistance may take the form of carer confidence building, assistance with navigating employment service systems, workplace advocacy, connecting with training or work experience opportunities and assisting carers to manage family problems	Carers of people with mental illness	Department of Social Services	$1.473 million	5,243	[66]

Name of program	Program description	Target population	Funding source	Funding allocated (2015–16)	Number of carers supported (2014–15)	Data source
Family Mental Health Support Services (FMHSS) [98]	FMHSS provides early intervention support to assist vulnerable families with children and young people who are at risk of mental illness. This includes: assessment and identification of needs; practical assistance and home-based support; linking with other relevant services	Families with children and young people up to age 18 years who are at risk of, or affected by, mental illness[2] Only 16–18-year-old care recipients are in scope	Department of Social Services	$32.5 million	75,188	[14, 99]

Table A5.2. Federal-funded support programs for all types of carers

Name of program	Program description	Target population	Funding source	Funding allocated (2015–16)		Number of carers supported (2014–15)	Data source	Mental health carer estimate
National Respite for Carers Program (NRCP) [100]	The NRCP supports and assists primary carers of people who are unable to care for themselves because of frailty or a disability The National Carer Counselling Programme (NCCP) provides short-term counselling, emotional and psychological support services for carers in need of support Carer Information Support Services (CISS) provide a coordination pathway for carers to access services and other forms of support that are most appropriate to their individual needs and circumstances Carer Directed Respite Care (CDRC) allows carers to take a break from their caring role and gives them a greater say and more control over the design and delivery of respite services provided to them and the person(s) they care for. This allows carers to make choices about the types of respite services they access and the delivery of those services, including who will deliver the services and when	Primary carers of people who are unable to care for themselves because of frailty or a disability. In particular, frail aged Australians (aged 65 years and over), people with dementia and people with terminal illness are the key focus of this program	Department of Social Services	Short-term or emergency respite	$60.298 million	59,699	[66]	NRCP was not included in Federal expenditure on mental health carers Data from the 2008 Community Care Census [101] indicates that most NRCP users care for elderly people (65+) with dementia
				National Carers Counselling Programme (NCCP)	$4.886 million	6,461		
				Carer Information and Support Service (CISS)	$3.958 million	34,152		
				Carer Directed Respite Care (CDRC)	$2.553 million	482		

Name of program	Program description	Target population	Funding source	Funding allocated (2015–16)		Number of carers supported (2014–15)	Data source	Mental health carer estimate
Young Carers Respite and Information Services [162]	Young Carers Respite and Information Services assists school-aged carers with a significant caring role who need support to complete their secondary education or the vocational equivalent due to the demands of their caring role Direct respite and education support component assists students up to and including 18 years of age with a significant caring role to access respite and age-appropriate educational support. Delivered by the Commonwealth Respite and Carelink Centres (CRCCs) Information, referral and advice services supports students with a significant caring role up to and including 25 years of age with information, advice and referral services, including referral to counselling	Students aged up to and including 25 years of age who provide care and support for a person(s) with chronic illness, disability, mental illness, alcohol or other substance dependence or who is frail and aged	Department of Social Services	Direct Respite	$1.7 million	4,633	[66]	Young Carers Respite and Information Services was included in the Federal expenditure on mental health carers Survey of 971 young carers (up to 25 years) accessing these services reported that 34% were caring for someone with mental illness [104]
				Educational support	$5.893 million			
				Information and Referral	$0.596 million	2,782		

Name of program	Program description	Target population	Funding source	Funding allocated (2015–16)	Number of carers supported (2014–15)	Data source	Mental health carer estimate
Respite Support for Carers of Young People with Severe or Profound Disability (RSCYP) [106]	The RSCYP provides immediate and short-term respite for carers of young people with a severe or profound disability whose needs are not being met through existing state or territory government initiatives The program is delivered by the national network of Commonwealth Respite and Carelink Centres (CRCCs)	Carers of people under 30 years and those experiencing significant stress in caring for a person under 65 years. These carers provide care for a person(s) with chronic illness, disability, mental illness or who is frail and aged Only care recipients aged 16 years or older are in scope	Department of Social Services	$7.939 million	5,347	[66]	RSCYP was not included in Federal expenditure on mental health carers There was a lack of publicly accessible data about RSCYP users and their care recipient's main condition and age

Name of program	**Program description**	**Target population**	**Funding source**	**Funding allocated (2015–16)**	**Number of carers supported (2014–15)**	**Data source**	**Mental health carer estimate**
Young Carer Bursary Programme (YCBP) [105]	The YCBP aims to help relieve the financial pressure on young carers to undertake part-time employment, in addition to managing their educational and caring responsibilities It is an annual bursary of approximately $3,000 per person that was/will be distributed to young carers in 2015, 2016 and 2017	Carers aged 12 to 25 years who care for someone with disabilities, chronic illness, mental illness or serious substance abuse problems. Carers must be studying an approved course, e.g., secondary school, TAFE, apprenticeship, undergrad university	Department of Social Services	$1.235 million	300 (2015 calendar year)	[66]	YCBP was included in the Federal expenditure on mental health carers YCBP is targeting a similar carer population as the Young Carers Respite Services. Therefore, the same proportion (34%) was applied

Appendix 6: State-/territory-funded carer support

Table A6.1. State-/territory-funded support programs for mental health carers

Name of program/ provider	Funding source	Description	Target population	Funding allocated	Number of carers supported	Data sources
Victoria (VIC)						
Mental Health Carer Support Program (MHCSP)	Department of Health & Human Services, State Government Victoria	Provides carer support workers, planned respite support for carers, support and education programs, carer consultants and the Mental Health Carer Support Program brokerage fund	Mental health carers	2010–11: $8,200,000	2010: 3,000 (excludes use of carer support groups, counselling and training; data not available on these)	[107] [108]
Carer Support Fund (part of MHCSP)	Department of Health & Human Services, State Government Victoria	Provides discretionary financial assistance for mental health carers (through application) to ease direct and indirect costs relating to caring. Fund applications are limited to $1,000 per carer and care receiver per year	Mental health carers	2014–15: $1,578,954 with $149,198 rollover	Data not available	[109] [110]
Mind Victoria	Multiple, including Commonwealth and Victorian Governments	Offers a range of mental health services, including family and carer support services. Carer services include education and a helpline	Mental health consumers and carers	Revenue for all of Mind for rendering services 2014–15: $56,759,328	2014–15: 1,807 carers supported by all of Mind	[111] [112]

Name of program/ provider	**Funding source**	**Description**	**Target population**	**Funding allocated**	**Number of carers supported**	**Data sources**
Carers Victoria	Multiple, including Commonwealth and Victorian Governments	Provides general carer services, including services aimed at mental health carers. Mental health carer services include counselling, respite, education and information	All carers	State brokerage income 2014–15: $585,359.23 State Government grants 2014–15: $3,819,401 (for all services)	Data not available	[113, 171]
Benetas Respite Services	Multiple, including Commonwealth, Victorian Government and clients	Benetas, a member of Anglicare Australia, provides respite services for all carers. This organisation focuses on aged care	All carers, though tailored towards carers of aged people	Total grant and client income 2014–15: $94,292,249		[114, 172]

Name of program/ provider	Funding source	Description	Target population	Funding allocated	Number of carers supported	Data sources
New South Wales (NSW)						
Family and Carer Mental Health Support Programs	NSW Health	Funds five NGOs to provide education and training, support and advocacy and peer support groups for carers	Mental health carers	Data not available	Data not available	[115]
		Carer Assist provides education for mental health carers	Mental health carers	Data not available	Data not available	[173]
		Parramatta Mission (UnitingCare Mental Health) provides mental health carer services for Western Sydney, Nepean Blue Mountains, Northern Sydney and Central Coast Regions. The organisation in general provides a range of social services	Mental health carers	2014–15 total government funding: $19,121,950	Data not available	[174]
		Aftercare provides family and carer education support (FACES) in addition to services for individuals with mental illness	Mental health carers	2014–15 NSW Government grants: $4,921,680 (for all services)	Data not available	[175]
		Mission Australia provides a range of support services in northern NSW, including support for mental health carers	Mental health carers	2014–15 state and local government funding: $99,684,335	Data not available	[176]
		CentaCare provides a range of support services for western NSW, including mental health carer support	Mental health carers	2014–15 NSW funding: $3,576,856 (for all services)	2011–12: 300 families	[177]
Arafmi NSW	Multiple sources, including Commonwealth and NSW State Government	"Peak body for NSW mental health carers", appointed by NSW Minister of Health	Mental health carers	Grant income (not specified government): $365,514	Data not available	[116]

Name of program/ provider	Funding source	Description	Target population	Funding allocated	Number of carers supported	Data sources
Carers NSW	NSW Department of Family and Community Services, DSS	Carer support program includes recognition, support services and resources for carers of people with mental illness. They also direct people to the MHFCSP of NSW	Mental health carers	Total government grant revenue 2014–15: $8,603,721	Data not available	[178, 179] [117]
Queensland (QLD)						
Arafmi QLD	Jerendine and Coolibah Family support respite, lifestyle support and carer connect funded by Dept of Communities Disabilities Services; carer support funded by community mental health branch	Provides mental health carer support, including: telephone support, skills development, support groups, respite for families, counselling, community awareness and education and mental health information Family Support Programs aim to increase the viability of the family unit, increase community inclusiveness and break down the isolation of the family. This includes Respite Support programs The Carer Connect program provides individualised support for carers by addressing their needs	Mental health carers	Data not available	Data not available	[118]
Mind Queensland	Multiple, including Commonwealth and State Governments	Offers a range of mental health services, including family and carer support services. Carer services include education and a helpline	Those affected by mental illness, including carers and consumers	Revenue for all of Mind for rendering services 2014–15: $56,759,328	2014–15: 1,807 carers supported by all of Mind	[111, 112]

Name of program/ provider	**Funding source**	**Description**	**Target population**	**Funding allocated**	**Number of carers supported**	**Data sources**
Western Australia (WA)						
Helping Minds (formerly Arafmi WA)	WA Mental Health Commission	Provides carer rest and respite, counselling and support, as well as education and advocacy for carers	Mental health carers			[120, 180]
		Family and Carer Support: programs available include counselling, support groups, information sessions and education	Mental health Carers (mostly in Metro Area)	2013–14: $1,121,340		
		Young People Support: support for young carers, mostly delivered through schools	Young mental health carers	2013–14: $426,692	2013–14: 332	
		COPMI	Children of parents with mental illness	COPMI 2013–14: $86,006		
		Kimberly/Broome Family and Carer Support: regionally focused family and carer support programs include working with family support workers	Mental health carers	2013–14: $133,046	2013–14: 43	
		Pilbara Family and Carer Support: regional focused family and carer support, including focused support for young Indigenous carers	Mental health carers	2013–14: $138,346	2013–14: 22	
		Statewide 1800 phone: provides hotline services, particularly focused at rural areas where no other support is available	Rural mental health carers	2013–14: $14,004		
		Carer Advocacy: advocacy represents carers at multi-agency meetings, particularly those in complex circumstances	Mental health carers in complex circumstances	2013–14: $96,668	2013-14: 322	
		Residual funds		2013–14: $158,058		

Name of program/provider	Funding source	Description	Target population	Funding allocated	Number of carers supported	Data sources
Carers WA	Multiple funding sources, including WA Mental Health Commission and local governments	Provides a range of support services for all carers, including information and education, counselling, policy and research	All carers	2014–15 Operating grants from government sources: $3,984,325	Data not available for mental health carer services	[119, 181]
Mental Illness Fellowship WA	WA Mental Health Commission and others (local and commonwealth)	Well Ways program provides family education on mental illness, services available, ways to improve communication, recovery and practical insight	Mental health carers	2014–15 total Mental Health Commission funding for all services: $2,172,347	2014–15: 400+ carers and families	[182, 183]
Tasmania (TAS)						
Arafmi Tas (aka Mental Health Carers Tasmania)	Department of Health and Human Services, TAS	Family/Carer Representation & Participation Programs help to get carers represented in organisations to enable the needs of carers to be brought to light The Caring Voices Network creates a platform for grassroots voices impacted by mental illness	Mental health carers	Data not available	Data not available	[121]
Carers Tasmania	Multiple, including Carers Australia, DSS, Dept of Premier and Cabinet TAS, and DHHS TAS	Provide support to carers of individuals with any condition. Support includes information and advice, carer support and wellbeing checks, counselling, mindfulness and therapeutic groups, support specialised for young carers, policy and research and support groups	All carers	Total grant income 2014–15: $1,695,904	Data not available	[122]

Name of program/ provider	Funding source	Description	Target population	Funding allocated	Number of carers supported	Data sources
Our Time (Anglicare provided)	DHHS?	Provides assistance to family members and friends supporting someone with a mental illness or ASD. Provides respite, education and resources for carers (charges $10 per week)	Mental health carers and carers of people with ASD	2013–14: income $60.09 million, 44.7% from TAS Government grants; 17.7% of stream funding went to all mental health services	Data not available	[123] [124]
Northern Territory (NT)						
Mental Illness Fellowship of Australia NT Carer Services	NT DoH	Provide respite, individual group and peer support, training and education and information, advocacy and referral services for mental health carers in NT.	Mental health carers	Data not available	2014–15 carers in contact with Carer services team: 1800	[125, 184]
Carers NT		Provides services for all carers. Include Mental Health Carers Program which provides education and training and also involves carers in working groups and advocates for their representation on government and NGO committees. The organisation also provides respite for carers	Mental health carers	Data not available	Data not available	[126]
Anglicare NT Carer Respite Service	NT Government	Provide carer respite for carers of aged people and people with disability (including mental illness)	All carers	2014–15: $12,728,944.60	120 carers (only some mental health carers)	[127, 185]

Name of program/ provider	Funding source	Description	Target population	Funding allocated	Number of carers supported	Data sources
South Australia (SA)						
Carer consultant	SA Health	One carer consultant has been hired at SA Health to liaise with carers and carer organisations	All carers	Data not available	Data not available	[128]
Carer's Hope and Recovery Team Program (through Carer Support)	DSS and SA Department of Communities and Social Inclusion	Provides support for mental health carers, including a hotline and specific mental health carer events and workshops	Mental health carers	Grant income – Operational $3,108,400.65 Grant income –Brokerage $2,602,284.64 (2014–15)	Carer Support calls 2014–15: 122 CHART team respite 2014–15: 880 bookings	[129, 186]
Mind South Australia	Multiple, including Commonwealth and State Governments	Provides a range of services for people with mental illness, including family and carer services. For carers, Mind provides counselling and peer support, respite, recreation days, carer education and support groups. A Carer Helpline is also available	People affected by mental illness, including consumers and carers	Revenue for all of Mind for rendering services 2014–15: $56,759,328	2014–15: 1,807 carers supported by all of Mind	[187] [111, 112]
Carers SA	Majority of funding from Commonwealth and State governments	ARAFMI Service provides carers of people with mental illness with information and activities	Mental health carers	Income from grants 2014–15 (not specified government): $5,830,746	2014–15: 128	[130]
Anglicare SA Carer Respite	Multiple State and Government departments	Respite services provided for carers of people with mental illness, psychiatric disability, autism or an intellectual disability	Carers of people with a range of mental and neurological diagnoses	Revenue for all services and from all sources 2014–15: $118,076,754	Data not available	[131, 132]

Name of program/provider	Funding source	Description	Target population	Funding allocated	Number of carers supported	Data sources
Australian Capital Territory (ACT)						
Carers ACT	ACT Health among others	Provide counselling and support, carer advocacy, respite, information and advice for mental health carers. The organisation provides services for all types of carers	Mental health carers	10.51% of total income spent on mental health carers. $844,685 of funding came from ACT Health (2014–15)	Caring families supported 2014–15: 5,058	[133]

Appendix 7: Literature on unmet needs

Table A7.1. Literature review of carers' service use and unmet needs

Data source	Methods	Sample	Key relevant findings	Notes
Coker et al., 2015 [144]	Analysis of data collected pre- and post-psychoeducation program. Data collected through semi-structured interview using the Carers' and Users' Expectation of Services tool. Post-program evaluation took place after July 2012	39 consumers and 38 carers who participated in the Building Family Skills Together Mind program, a behavioural family therapy program aiming to improve communication in families with a member with mental illness, delivered through Mind Australia. CALD and Indigenous carers included; majority of carers female and in middle or late adulthood, most common consumer diagnosis was depression and most common relationship between consumer and carer was partner/spouse	Needs: information and involvement in treatment, education on mental illness, financial needs; still want more support from services after psychoeducation program (44%); desire to improve relationships	

Data source	Methods	Sample	Key relevant findings	Notes
Coomber et al., 2013 [86]	Multi-pronged self-report survey given at three times throughout a nine-month period to the same sample; includes questions about carers' needs self-assessment. Participants recruited through multiple means: advertisements on eating disorder organisation websites, newspapers, radio ads, distribution of flyers at carer support groups, questionnaire mail-outs through hospital-based eating disorder services and via non-profit eating disorder organisation; date of data collection not specified	56 carers at time one, 45 at time two, 43 at time three (some dropout between each survey administration)	Needs: consistently moderate levels of unmet total needs identified by carers across all domains	Unmet needs taken from a total need scale summing the scores from measures of needing information, professional support or support for self and information from GPs; higher scores indicate more support and information obtained, lower scores indicate need
Harris et al., 2015 [3]	Evaluating service demand ("willingness and/or ability to seek, use and in some settings pay for services"), data gathered from the household component of the 2009 Survey for Disability Ageing and Carers, a nationally representative survey conducted through trained interviewers via computer-assisted personal interviews. Data used to define the service utilisation and unmet need for services	Primary informal carers of people with a psychological disability (weighted n=177,900)	Carer-reported use: 10.9% of carers used respite in the past three months. Carer-reported service needs: 21.2% of carers reported unmet respite care need	Data only available for last three months; respite service term may be unfamiliar to respondents and lead to underreporting

Data source	Methods	Sample	Key relevant findings	Notes
Healthdirect Australia, 2015 [135]	Mini focus groups, in-home immersions and in-depth phone interviews with carers for qualitative data. Carers for qualitative research were recruited through Carer Recruitment Australia, which utilises databases and networks for advertisement and contacts. Quantitative data were recruited through survey dissemination to AMR social research project panellists	Qualitative: 134 carers, five mental health. Quantitative: 1,205 all carers (number mental health carers unknown)	Use: mental health carers more likely to Google for information or see a counsellor or psychologist or use a support group; more likely to use helplines, compared with carers of other types of disability, alcohol/drug abuse disorder, chronic illness or aged and frail	
Jardim et al., 2010 [53] Jardim et al., 2014 [188]	Participants recruited through ARAFMI QLD and Carers QLD, questionnaire package sent to 500 ARAFMI members and 200 randomly selected from Carers QLD mental health carer database took questionnaire on demographics, caregiving context and carer adjustment. Year of data collection not specified	106 carers of an adult with mental illness, 80% female, 67% partner of the consumer; 35% of consumers had psychotic disorder, 30% had mood disorder	Use: 36% of respondents had used respite care at some point during their caring experience; respite care users were more likely to reside with their recipient than non-users; users were more involved in ADL, instrumental activities of daily living and psychosocial caring Barriers to use: care recipient reluctance, no services available, carer reluctance, lack of info Needs: half of participants identified improvements necessary to respite care: increased availability and access, improved suitability, including more competent staff and services that are more appropriate for consumers with multiple diagnoses and the like and greater number of options	Done through carer organisations, which limits generalisability because the carer population that accesses these organisations may have different characteristics from those who do not belong to these groups

Data source	Methods	Sample	Key relevant findings	Notes
Jeon et al., 2007 [136] Jeon et al., 2006 [134]	Carer sample collected by requesting mental health professionals distribute information and directions for participation to carers; data collected through semi-structured in-depth interviews and self-completed questionnaires	Older family carers (age >65) of people with severe mental illness in Sydney area (mental health professionals and respite service providers were also interviewed), 21 carers, 14 female; most care recipients had schizophrenia	Use: nine carers used respite Needs: identified poor quality and insufficient time in respite as reason for not using or dissatisfaction with respite; carers were almost unanimous in expressing lack of access, particularly in lack of flexible and timely respite; carers do not see respite as a service for themselves but for their recipient; lack of knowledge of respite services; 12/21 expressed need for some form of respite Barriers to care include: lack of knowledge and understanding of respite care by carers and MH professionals, lack of help-seeking by carers for their own wellbeing, carers' negative experiences with mental health services, lack of service flexibility, lack of mental health specific respite availability	Older carers unlikely to accept services, particularly those that are unknown or unfamiliar to them
Kokanovic et al., 2006 [138]	Purposive sampling used to identify key informants from a range of community organisations. Semi-structured interview with each informant; year of data collection not specified	Total sample: n=20; five mental health carers of each of the following backgrounds: Polish, Croatian, Bosnian, Chinese in Perth, WA identified as key informants	Use: barriers = cultural expectations, belief that there are not quality services available, acceptance of services only as last resort, stigma; practical/material support seen to threaten the culturally expected role of carer Needs: easier communication with medical professionals (improved information about diagnosis, and so on, which frequently requires interpreter); information about mental illness, social support, respite, culturally-/linguistically-specific helplines	

Data source	Methods	Sample	Key relevant findings	Notes
Lakeman, 2008 [141]	Inpatient participants were recruited through researcher attending community meetings of acute inpatients and those interested were encouraged to seek out one of the researchers. Contacts were attempted with all people receiving case management services. Service users invited to nominate carers. Instrument was a three open-ended question self-report survey. Many inpatient participants opted to have the project officer complete the survey with their declarative statements. Survey investigated the obstacles to, benefits of and possible improvements to family participation	41 consumers and 53 carers from hospital; 86 consumers and 33 carers from community	Needs: information on treatment and discharge plans, greater continuity of case managers, increased consultation with doctors	
Lawn & McMahon, 2015 [137]	Survey delivered through SurveyMonkey to all states/territories in 2011; respondents recruited through survey advertisement through 29 consumer and carer mental health networks	Family carers of people with borderline personality disorder across Australia (n=121); most respondents female, disproportionate respondents from rural areas	Needs: 62.3% stated wanted to access support but couldn't, barriers included "not being taken seriously by service providers" (60.5%), "lack of carer support available" (56.6%) and "financial cost of accessing services as a carer" (37.3%); carer support groups of mixed helpfulness; 35.9% (n=14/39) said that during times of crisis they did not get a response to their request for help from health professionals	Discussion suggests that carers of people with bipolar disorder have specific needs and need tailored carer support; bipolar disorder could be primary or secondary diagnosis of care recipient. May not generalise to carers of people with other mental disorders

Data source	Methods	Sample	Key relevant findings	Notes
McAuliffe et al., 2009 [139]	Participants recruited through giving information to all staff of adult mental health service, organisations providing carer and consumer support and through advisory groups and posters in psychiatric inpatient units. Focus groups asking "what are the experiences and support needs of carers/families that provide care to people with a serious mental illness receiving services from the adult mental health service?"; conducted over 12-month period, although start date not specified	31 carers of 24 people with severe mental illness, 23 have schizophrenia; majority of carers female, majority over 55, large majority parent of consumer and living with consumer	Needs: improved information/communication from mental health professionals, psychoeducation and support, access to rehabilitation and structured activity for care recipient (would help recipient and carer), greater access to respite care, guidance in planning for future	
McCann & Bamberg, 2016 [189]	Interpretive phenomenological analysis used to analyse semi-structured interviews; participants recruited from mental health program providing services	30 carers of older adults with functional, organic and age-associated psychiatric disorders, who had not attended support group and were in the caring role for a maximum of three years	Needs: improved cultural competence, increased carer participation in decision-making, regular information about relative's care and treatment, education and training on illness and behaviour management, carer support groups	The specific scope of psychiatric disorders of the consumers is not specified
Mental Health Council of Australia, 2012 [140]	Mental Health Council of Australia circulated survey through networks, open late 2011–early 2012; questions were all optional, and an alternative version of the survey was available to young carers; consultation workshops were held with Indigenous carers and the survey was translated for CALD carers	508 carers, 72 young carers, 48 CALD carers	Needs: respect, inclusion in treatment plans, better access to recovery-based care in the community for consumers, information, education, better availability/information about services, secure and stable housing for consumers, financial support, flexibility in respite options	

Data source	Methods	Sample	Key relevant findings	Notes
Mental Health Council of Australia, 2010 [6]	Sample reached through sector groups, interested individuals and organisations. Fifty-question survey developed through interaction with carers and identification of broad needs through the Carer Engagement Project workshops conducted by the MHCA in 2008 and 2009. The survey probed further the concerns identified in the workshops. The survey was conducted in 2010	756 mental health carers, Targeted adults 18+. 52.8% live in inner and other regional areas. Given the need for written English proficiency to complete the survey, the results will not be representative of the Indigenous and CALD carer populations. Response rates per state were somewhat proportional to state population, though there were more respondents from TAS, NT and ACT. Majority of respondents were over 55 years of age and large majority were female. 60% of care recipients were children of the carer	Carer-reported service needs: • integrated recovery-based care for consumer: carers indicated that many services were not available in their areas (i.e., 29.7% said PHaMS workers were not available to their care recipient, 36% said living skills services were not available, 40.5% said peer support workers were not available, 41.5% said club house services not available, 37.5% said supported employment/training not available, 32.9% said day programs were not available and 26% said other support options were not available); 77% of carers indicated they were responsible for organising the majority care of their recipient in the past 12 months • improved knowledge and information for carers: 26.2% reported rarely or never having the information they needed, including 'how to' caring information or information on services, easily available • Support and services for carers: 26% said carer counselling was rarely, never or not available in their area • Better availability of acute care services: lack of availability or awareness of services for when consumer is very unwell, lack of information offered for discharge plan	

Data source	Methods	Sample	Key relevant findings	Notes
			• Better accommodation options for consumers • More and flexible respite options: 17% said the service they needed from respite care was unavailable; flexibility a particular concern for CALD carers and young carers • Better information sharing with mental health services regarding the consumer’s treatment plan; 20% of carers said information on what to expect from their recipient’s mental illness was never available • Better employment options for carers	
Outram et al., 2015 [143]	Ethnographic qualitative approach, semi-structured interviews; participants recruited through dissemination of information through carer organisations and networks. Interviews were conducted between September 2010 and December 2011	13 carers of people with schizophrenia from regional NSW	Needs: clarity in communication of diagnosis and information on schizophrenia; respect in communications from GPs and mental health clinicians	

Data source	Methods	Sample	Key relevant findings	Notes
Shankar & Muthuswamy, 2007 [142]	Three focus groups held in each of three regions of Sydney, NSW. Participants also asked to complete an Experience of Caring self-report questionnaire, including questions on socio-demographics, social networks, health and ways of coping, before participating in the focus group. The focus group asked "what are some of your experiences as a caregiver?", "what has been your experience of the mental health services in your area?" and "what are your suggestions on how your needs can be better met?". Ten participants were interviewed separately, due to constraints in attending the focus group	Carers of people with mental illness (considered a carer if co-resident, provide ongoing support and maintain regular contact) in Sydney area, n=36 (26 ARAFMI carer group members, ten non-members). Large majority of carer sample were women, mostly mothers of recipient, over age 50. The sample poorly represents spouse and sibling carers as well as CALD carers. The majority of care recipients had schizophrenia. 38% of care recipients lived independently	Carer-reported support needs: more caregiver support during crisis phase, information/advice for discharge and better follow-up care for consumer, more respect from mental health professionals, including improvement of issues surrounding confidentiality ("little incentive to work with families") *Elderly caregivers: (n=9 over 65) help in setting up services for their recipient when they die	Although not the biggest sample, relatively diverse; analyses between experienced and non-experienced carers suggest that caregiver needs are too diverse to be strongly helped by current family education and support programs and need more tailored programs

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[1] Those accessing support from a MHR:CS initially funded prior to 2011–12 include those caring for someone with an intellectual disability.

[2] A formal diagnosis of mental illness is not required to access services.

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