

The economic value of informal mental health caring in Australia: summary report

Commissioned by Mind Australia



Summary report

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Sandra Diminic^{1,2}, Emily Hielscher^{1,2}, Yong Yi Lee^{1,2}, Meredith Harris^{1,2}, Jaclyn Schess¹, Jan Kealton³, Harvey Whiteford^{1,2}

1. Policy & Epidemiology Group, Queensland Centre for Mental Health Research.
2. School of Public Health, The University of Queensland.
3. Carer consultant.



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Help, hope and purpose

Overview

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]. However, there are acknowledged gaps in available services for people with mental illness which result in them not always receiving timely support of the type and quantity needed [5].

Therefore informal carers, such as a family member or friend, play a significant role in the care of people with mental illness in Australia, providing a substantial number of hours of unpaid support. 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 would need to be picked up by the formal health and social care systems, at additional cost to government.

Recent reports have estimated the overall value of caring in Australia for carers of individuals with all types of disorders or disabilities [6–8]. The replacement cost of this care was estimated to be \$60.3 billion, which highlights the size of the informal care sector [8]. Until now, there has been no published attempt to establish the value of the care delivered by mental health carers each year, in terms of the unpaid hours of support provided to people with mental illness.

Mind Australia commissioned the University of Queensland (UQ) research team to:

1. profile Australian mental health carers
2. provide an estimate of the value of informal mental health care (replacement cost)
3. estimate bed-based service replacement costs
4. review current government spending on carers.

This information was required to quantify the input of carers into the mental health system, and to describe the support needs of carers to ensure that they can continue to perform their valuable caring roles.

Diminic S, Hielscher E, Lee YY, Harris M, Schess J, Kealton J & Whiteford H. The economic value of informal mental health caring in Australia: summary report. Brisbane: The University of Queensland; 2016.

Summary of methods

Target population

For the purpose of this report, we focused our analyses as closely as possible on 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.

Carers may be of any age, may be a family member, friend or neighbour of the care recipient and do not necessarily live with the person they care for. In-scope mental illness diagnoses included:

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

Note. The following conditions were considered out of scope for our definition of mental illness where they are the care recipient's main condition: autism spectrum disorders, intellectual disability, substance use disorders or neurological disorders (including dementia, stroke and epilepsy).

Data sources

The research team conducted an economic modelling exercise and analyses using data from a range of sources (Box 1). These data sources provided estimates of the number of mental health carers in Australia, weekly hours of care provided, caring tasks typically performed and hourly costs of mental health support workers, which were direct inputs into the replacement cost model. Other sources provided data on the impact of carers on bed-based service use and expenditure on carer support services.

Box 1 – Data sources

- Reviews of published literature on the characteristics of Australian mental health carers, length of hospital stay for people with carers and carers' service use and unmet needs.
- Two national household surveys – the Survey of Disability, Ageing and Carers (SDAC) 2012 [9] and the National Survey of Mental Health and Wellbeing (NSMHWB) 2007 [10].
- A new online survey of carers – the UQ Carer Survey 2016 (see below).
- National award wage rates from the Social, Community, Home Care and Disability Services (SCHADS) award [11].
- A national survey of people with psychosis – the Survey of High Impact Psychosis 2010 [12].
- Key informant interviews with clinicians familiar with the operation of bed-based mental health services.
- Published data on funding of income support payments and support services for carers.

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 research team to fill gaps in previous national surveys, and particularly to elicit additional detail on the mental health caring role (hours of care by caring task). The survey was administered online to 107 carers in April 2016. Participants were recruited from state and territory carer networks and organisations.

Replacement cost model

One of the main aims of the project 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. This approach therefore values caring by estimating how much this informal care would cost if delivered by government-funded services instead of unpaid family and friends.

Note. This is a hypothetical scenario. The intention is never for government to completely replace the care provided by mental health carers. Rather, a replacement cost analysis is a method used to quantify the economic value of informal care, and in turn highlight the importance of carers.

To calculate the annual replacement cost for mental health carers in Australia for the year 2015, we required estimates of:

1. the total number of mental health carers in Australia
2. the total hours of care provided by each mental health carer in a year
3. the cost per hour to replace this care with formal services
4. cost offsets for the estimated current annual government expenditure on mental health carers that might not be required if all informal care was replaced with paid formal care.

These inputs were obtained by combining data from the sources in Box 1.

Key findings

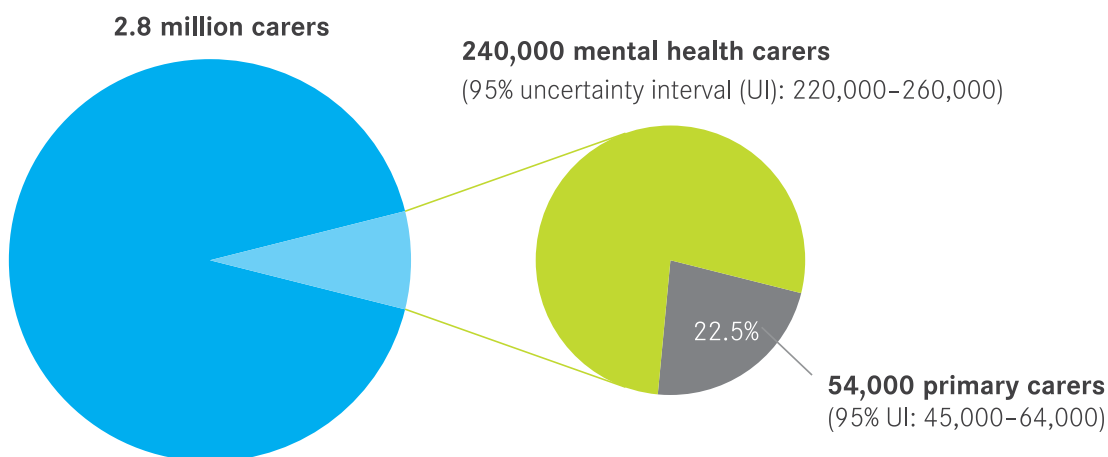
1. An estimated 240,000 Australians care for an adult with mental illness

In June 2015, there were an estimated 2.8 million informal carers in Australia, of whom 240,000, or 8.6%, were mental health carers meeting our definition (Figure 1). This group comprised 54,000 primary carers and 186,000 other mental health carers.

A primary carer is the person who provides the most informal assistance to the person with mental illness, whereas a secondary carer shares or assists with informal care duties. Primary carers are not limited by their age, their relationship to the care recipient or whether they live with or apart from that person. However, for this project 'primary carers' were restricted to the narrow definition used in the SDAC 2012, that being: required to be confirmed primary carers aged 15 years or more, to reside with their main recipient of care and for their main recipient of care to meet our definition of mental illness.

'Other carers' thus includes people who are secondary carers only, as well as all carers aged below 15 years, primary carers who do not live with their recipient of care and primary carers to a secondary care recipient with mental illness (where their main care recipient has a different condition). Thus our estimate of primary carers is conservative.

Figure 1. Estimated number of mental health carers, Australia 2015



Box 2 describes some key characteristics of the caring role for mental health carers.

Box 2 – Caring role of mental health carers, SDAC 2012

- The majority (99%) of carers provided support to one person with mental illness but 21.7% also cared for at least one other person with another disability type.
- The care recipient was most commonly their spouse/partner (45.8%) or child (31.8%).
- 49.1% of primary carers had been caring for ten or more years.

Key characteristics of mental health carers and their care recipients are shown in Boxes 3 and 4.

Box 3 – Key mental health carer demographics, SDAC 2012

- The majority of mental health carers were female (54.4%), of working age (72.8%), married (53.5%) and living in a capital city (61.2%).
- 14.7% were young carers below 25 years of age.
- More than three-quarters (76.8%) were born in Australia, and the vast majority (92.5%) spoke English at home.
- A substantial proportion (38.4%) of carers were not in the labour force.
- Primary carers had lower levels of educational attainment and employment than the broader carer group.

Box 4 – Key care recipient demographics, SDAC 2012

- Just over half (51.6%) were female, 64.8% were of working age and 59.7% lived in a capital city.
- 25.3% were young people aged 15–24 years.
- Most (80.3%) were born in Australia and only 6.8% spoke a language other than English at home.
- The most frequently reported main disabling conditions were depression (37.4%) and anxiety disorders (18.8%).
- Most care recipients had comorbid conditions (85.3%); the most common were substance use* and physical health problems.

** Not collected in the SDAC 2012; data from the UQ Carer Survey 2016*

Previous estimates of the number of mental health carers in Australia have varied widely. Our profile of carers was drawn from multiple surveys, and in particular relied on the SDAC 2012, a nationally representative household survey. We were able to count and describe not just primary carers, but the wider population of people caring for someone with a mental illness. This profile of mental health carers therefore improves upon previous smaller studies, which focus only on primary carers or those accessing carer services.

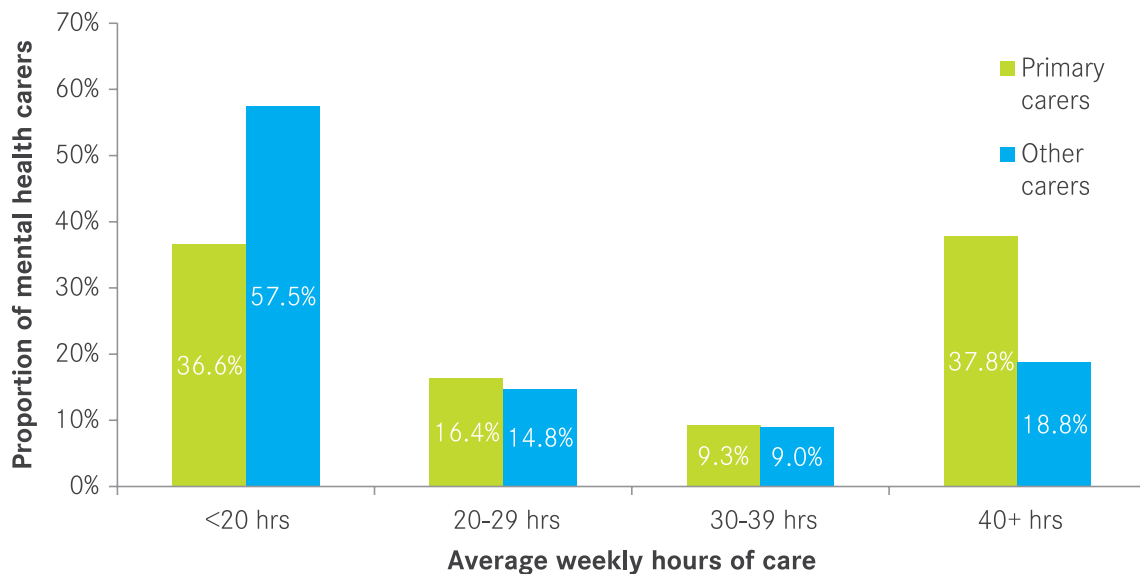
While we used nationally representative household surveys where available, these surveys sometimes miss groups of ‘hidden carers’, who do not identify themselves as a carer, may not engage with surveys and may not be in contact with carer services. This may have been particularly the case for mental health carers from Aboriginal and Torres Strait

Islander or culturally and linguistically diverse backgrounds. The survey methods are also likely to have produced a conservative estimate of the proportion of carers who identify as primary carers due to the way data were collected (see definition of ‘other carers’ on page 4).

2. Mental health carers provide large amounts of unpaid support, often on a fluctuating basis

Primary carers generally provide more support than other carers, and this was reflected in our analysis. Almost 40% of primary mental health carers provided 40 or more hours of care per week on average, and a similar proportion fewer than 20 hours per week. When compared with a small sample of possible, but not confirmed, primary mental health carers, confirmed primary carers provided more weekly hours of care (Figure 2).

Figure 2. Average caring hours for confirmed (n=150) vs. other possible (n=87) primary mental health carers, SDAC 2012



The UQ Carer Survey 2016 provided more detailed estimates of hours of care and caring tasks for a similar population of mental health carers as the SDAC 2012. Data on hours of care from the UQ Carer Survey 2016 were grouped into the same time categories as used in the SDAC 2012, and were used to calculate a weighted average hours of care. On average, primary mental health carers provided 36.2 hours of support per week to their care recipients.

*Combining average weekly hours of care with data on the number of primary carers, we estimated that primary mental health carers in Australia provided a total of **102 million annual hours of care** to their carer recipients in 2015 (95% UI: 81.6–125.1 million).*

Using data from the NSMHWB 2007 sample, which covered a much wider array of mental health carers, we estimated that other carers provide on average 11.0 hours of support per week. The distribution of weekly hours of care was skewed, with most carers reporting very few hours of caring per week.

*We estimated that other mental health carers provided **106 million annual hours of care** to their carer recipients in 2015 (95% UI: 88.8–125.5 million).*

Interpretation and key considerations

Our estimates of average weekly hours of care are smaller than those identified in previously published studies. This may be due to differences in our definition of a mental health carer, which excluded cognitive and behavioural conditions often included in other studies. Past samples recruited through carer organisations are also likely to have captured carers with higher needs who may have been caring for a longer duration, and for more hours per week.

*For all mental health carers, these hours of care are equivalent to **173,198 full-time equivalent (FTE) formal support workers**, assuming that each worker provides 1,201 hours of direct consumer service delivery time per year. In comparison, the whole national mental health non-government organisation workforce was estimated to comprise between 14,739 and 26,494 paid employees, or more than 12,000 FTE employees, in 2010 [3, 4].*

In addition to the time devoted to direct caring tasks each week, carers also reported being ‘on call’ or ‘on standby’ in close proximity to their care recipient so that they can be available quickly if needed (e.g., in a crisis). The majority of UQ Carer Survey 2016 carers reported providing this standby time, estimated at an additional 59.5 hours per carer per week. Since the carer is ‘on call’, they cannot make plans for other activities such as meeting friends, working, engaging in hobbies or travelling. This indirect standby time was not costed in our model due to difficulties in accurately calculating an appropriate replacement value for each hour of carer standby time. A single formal-sector crisis team or emergency department worker would be on standby to provide care to potentially hundreds of possible clients, compared with a one-to-one informal carer and recipient standby relationship. The ambiguities of deriving a precise replacement value for each hour of standby time prevented us from valuing this parameter in our model. However, standby time has a significant impact on carers’ day-to-day lives, even when they are not actively engaged in specific caring tasks. In future, better availability or targeting of crisis support services for people with mental illness, and support and coping strategies for carers, might help to alleviate some of the burden of standby time for mental health carers.

Qualitative feedback provided in the UQ Carer Survey 2016 indicated that, due to the fluctuating and episodic nature of mental illness, many carers had trouble estimating average hours of weekly care. These hours tend to vary from week to week and month to

month, depending on how well the person with mental illness is, with unexpected crisis periods requiring more intensive support. Therefore our data provide an indicative snapshot of caring hours.

3. Most of mental health carers' time is spent on emotional support

Mental health caring tasks were grouped into three categories, consistent with previous studies:

Emotional support and psychosocial care, including:

1. emotional support and encouragement (emotional support and companionship, encouraging and motivating)
2. supervising and monitoring (encouraging or prompting to do things, keeping the care recipient occupied, supervising to prevent wandering/damage)
3. responding to behaviour (managing crises, managing inappropriate behaviours).

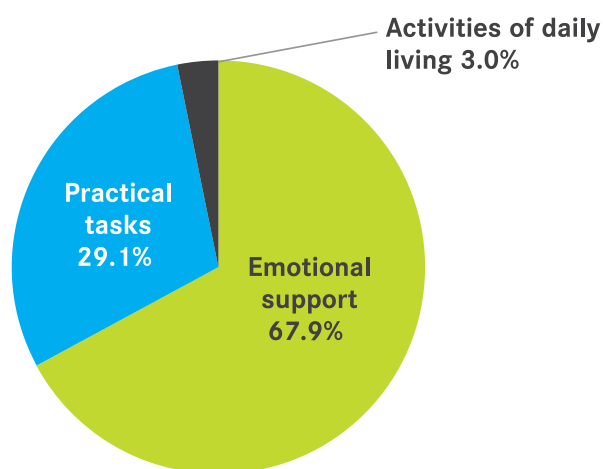
Assistance with **practical tasks**, including:

1. household tasks (grocery shopping, preparing meals, housework, property maintenance)
2. health care coordination (supervision/prompting taking of medication, arranging outside services, liaising with health professionals, assisting with treatment plan)
3. literacy and communication (managing finances, other paperwork, reading and writing, communication)
4. transport, e.g., assistance with getting to appointments/workplace.

Assistance with **activities of daily living (ADL)**, including personal hygiene/grooming, bathing, dressing, eating and mobility.

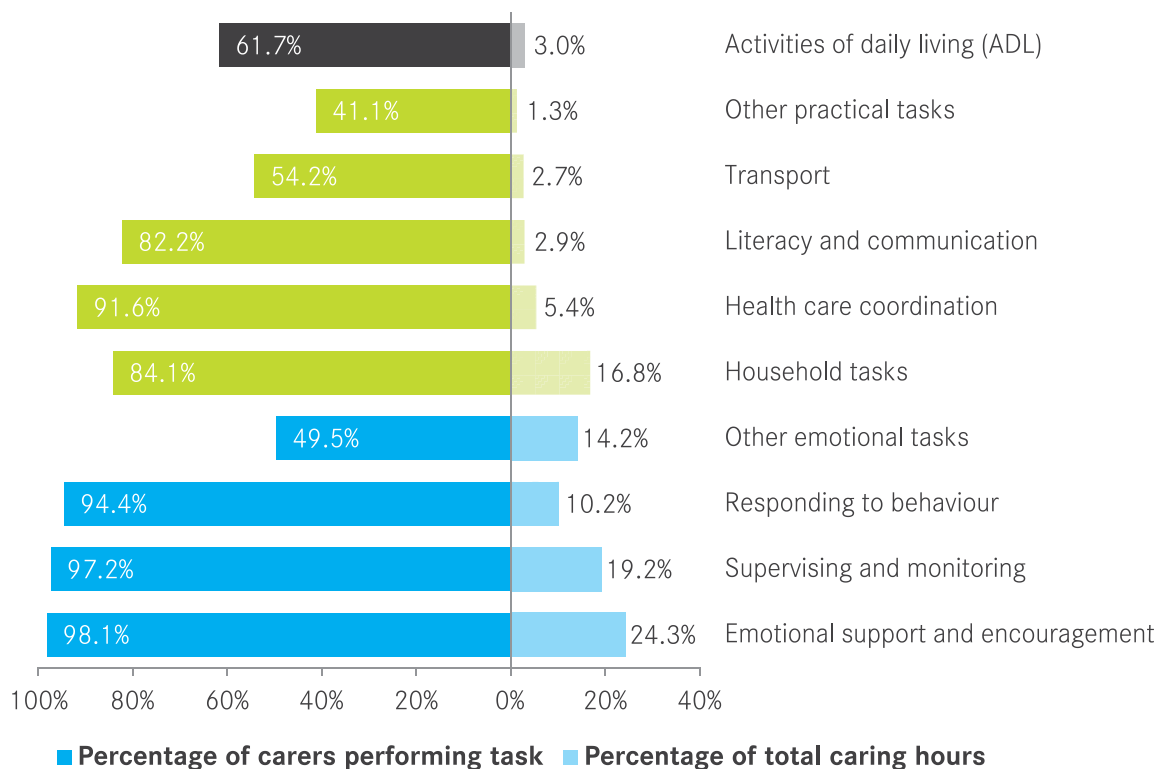
All carers in the UQ Carer Survey 2016 provided assistance to their care recipient with emotional support and psychosocial care, and 98.1% assisted with practical tasks. Assistance with ADL was provided by 61.7% of mental health carers. On average, mental health carers spent most of their care time providing emotional support and psychosocial care (Figure 3). Assistance with ADL accounted for only a very small proportion of mental health carers' support time.

Figure 3. Proportion of total mental health carers' caring time devoted to different types of caring tasks, UQ Carer Survey 2016



A breakdown of tasks within each category is provided in Figure 4. The most frequently reported caring tasks within the emotional support and psychosocial care category were emotional support and encouragement, supervising and monitoring and responding to behaviour; health care coordination was the most frequently reported caring task within the practical tasks category. Average caring time was split across multiple types of tasks, with the most hours devoted to emotional support and encouragement, supervising and monitoring, household tasks and other emotional support tasks.

Figure 4. Proportion of carers and care time for subtypes of care tasks, UQ Carer Survey 2016



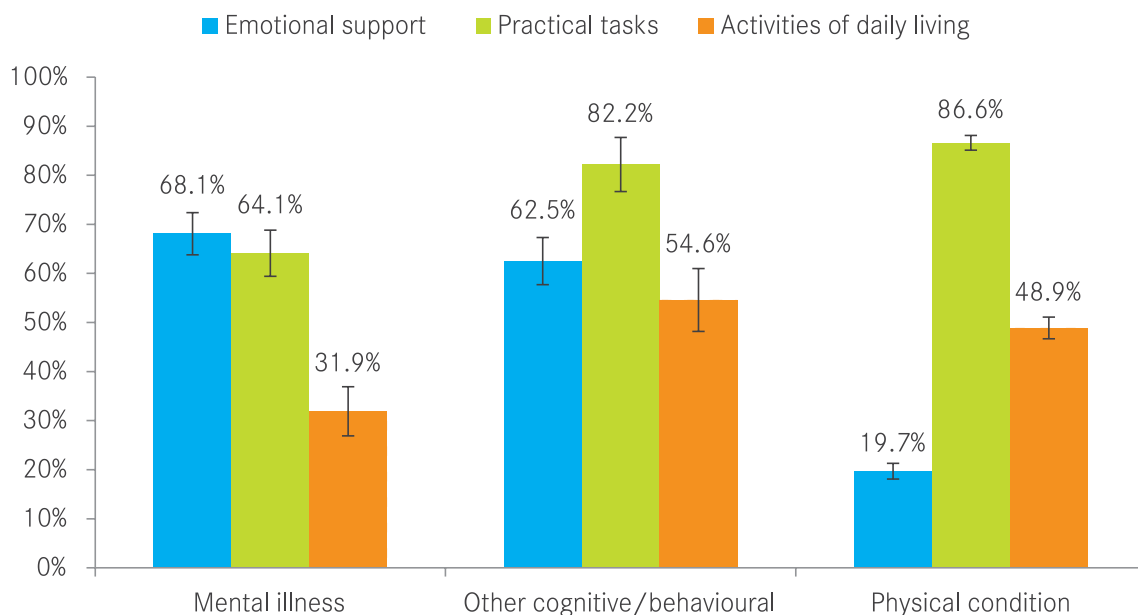
4. Mental health caring differs from other types of caring

We compared the caring role reported by mental health carers with that of carers of adults with other types of disabilities. These were grouped into other cognitive/behavioural conditions (autism spectrum disorders, intellectual disability, other developmental disorders, dementia and acquired brain injury) and physical conditions.

Primary mental health carers were significantly more likely than primary carers of people with other cognitive/behavioural conditions to provide episodic rather than continuous care.

Including all primary and other carers, mental health carers were significantly less likely than carers of people with other disability types to assist their care recipient with practical and ADL tasks (Figure 5). Mental health carers were also significantly more likely than physical health carers to provide emotional support to their care recipient. This is consistent with the symptoms and needs of people with mental illness compared with other types of conditions.

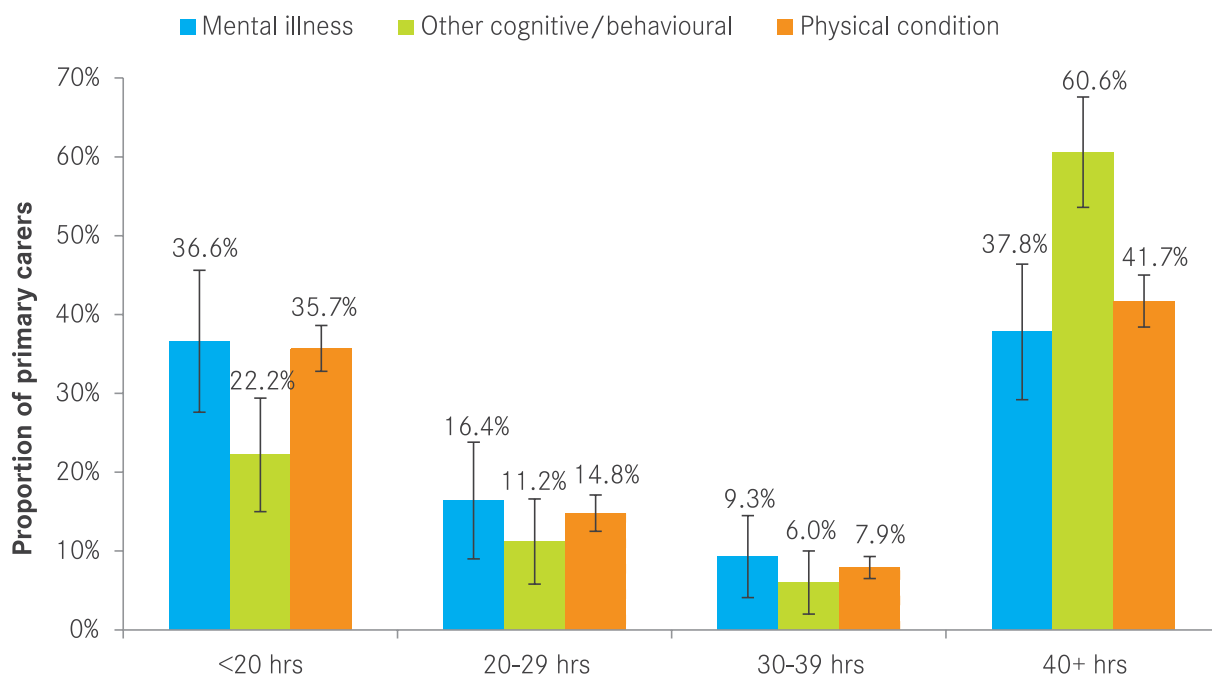
Figure 5. Proportion of all carers of people aged 15+ years performing different types of caring tasks, grouped by care recipient's main condition, SDAC 2012



The distribution of average weekly hours of care was similar for primary mental health carers and primary carers of people with a physical condition, but 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 (Figure 6). Note that 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. Figure 6 does not include standby time, data for which were only available for mental health carers.

Figure 6. Average caring hours for primary carers of people aged 15+ years, grouped by care recipient's main condition, SDAC 2012



5. It would cost \$13.2 billion to replace informal mental health care with formal support services

As explained on page 3, one of the key aims of this project was estimating the economic value of informal mental health care via a replacement cost valuation. The main steps for calculating the annual replacement cost for mental health carers in Australia are outlined in Figure 7.

Detail on costing methods

A Personal Helpers and Mentors (PHaMs) or equivalent support worker was deemed to be the most closely related formal support service to informal caring, and therefore was used to determine the hourly formal service cost to 'replace' informal mental health

care. Caring tasks not typically performed by PHaMs workers, including crisis support and assistance with activities of daily living (feeding, dressing and so on), were costed as a crisis accommodation worker or disability support worker, respectively.

Support workers were costed using a base wage from the SCHADS award, with additional workforce parameters sourced from the National Mental Health Service Planning Framework (NMHSPF) [13]. These calculations produced a total cost per FTE staff member, including overhead costs, and a cost per support hour (Table 1).

Table 1. Workforce parameters for support workers

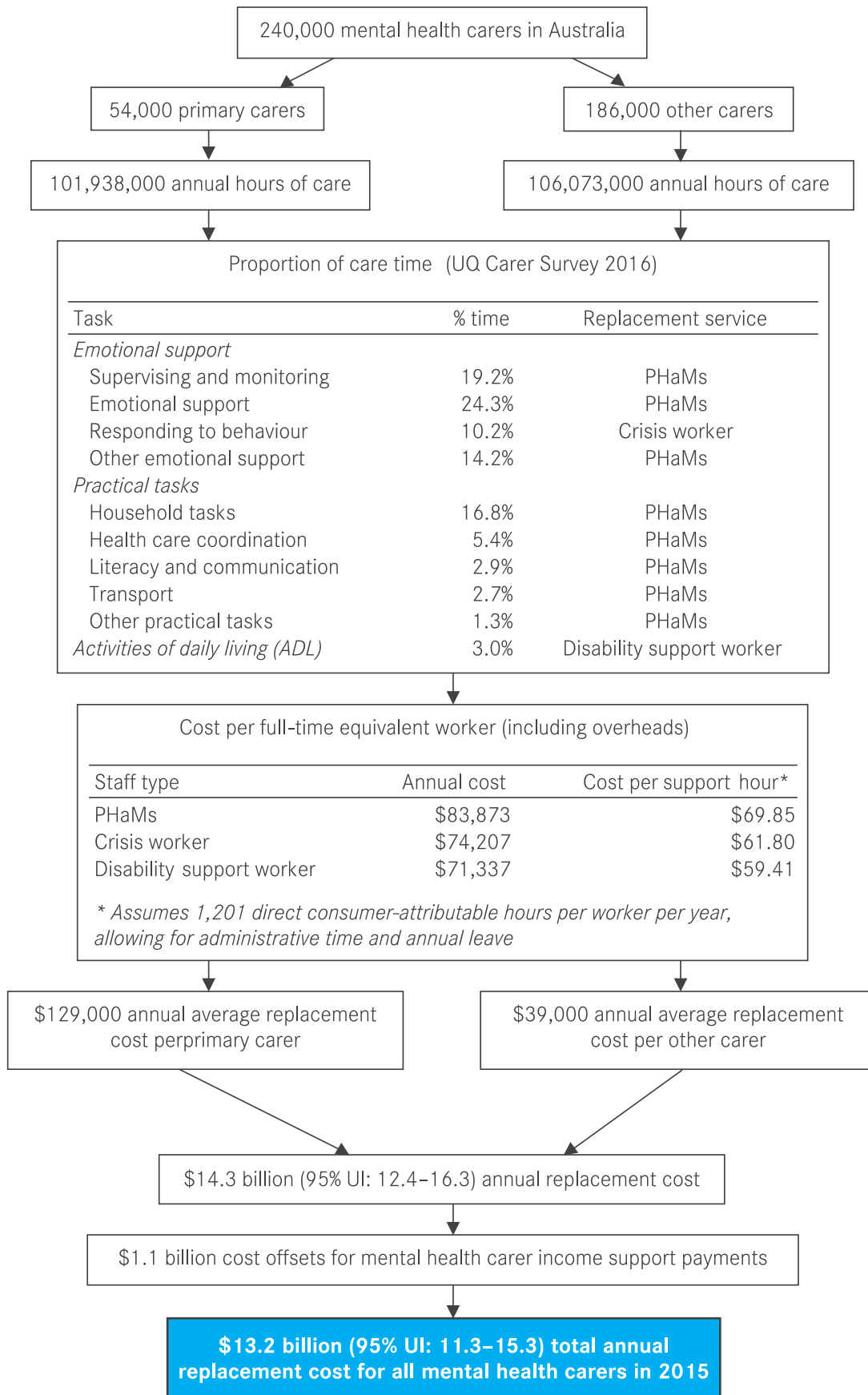
Salary on-costs	23%
Organisational overheads	20%
Working hours per week (A)	38 hours
Working weeks per year (B)	45.14 weeks (52.14 – seven weeks leave)
Consumer-attributable service delivery time (C)	70% of working hours
Annual hours of consumer time per FTE (A × B × C)	1,201 hours

The cost offset was the estimated government expenditure on Centrelink income support for mental health carers in 2015. This included:

- Carer Payment
- Carer Allowance
- Carer Supplement
- Rent Assistance for carers receiving Carer Payment.

This income support was subtracted from the final replacement cost model. Expenditure on other carer support services such as respite care and counselling was not included in the cost offset as many of these services would still be required for families, even under a total replacement scenario.

Figure 7. Schematic overview of replacement cost model



*Overall, the total annual replacement cost for all informal mental health carers in 2015 was **\$14.3 billion**. After adjusting for \$1.1 billion offset in Centrelink payments, this figure was **\$13.2 billion**. This is how much it would cost governments to replace all of the caring tasks currently provided by mental health carers with formal mental health support services, such as PHaMs or disability support workers.*

Interpretation and key considerations

To put this in context, the total replacement value of \$13.2 billion is equivalent to 1.7 times the current national expenditure on all mental health-related services in Australia, including hospital, clinical outpatient and psychosocial support services. Total national expenditure on these services was estimated to be \$8.0 billion in 2013–14 [14]. These figures highlight the significant value provided by carers, in terms of providing support for people with mental illness.

Carers have previously reported their family members being discharged early from hospital where there is a stable home and carer available to support the person with mental illness. If early discharge is associated with having a carer, this would be a cost saving to government from caring and should be considered in the replacement cost model. To explore this, we combined a literature review with analysis of the SHIP 2010 survey and key informant interviews. The data indicated that having a carer does not reduce the length of stay in bed-based mental health services, and

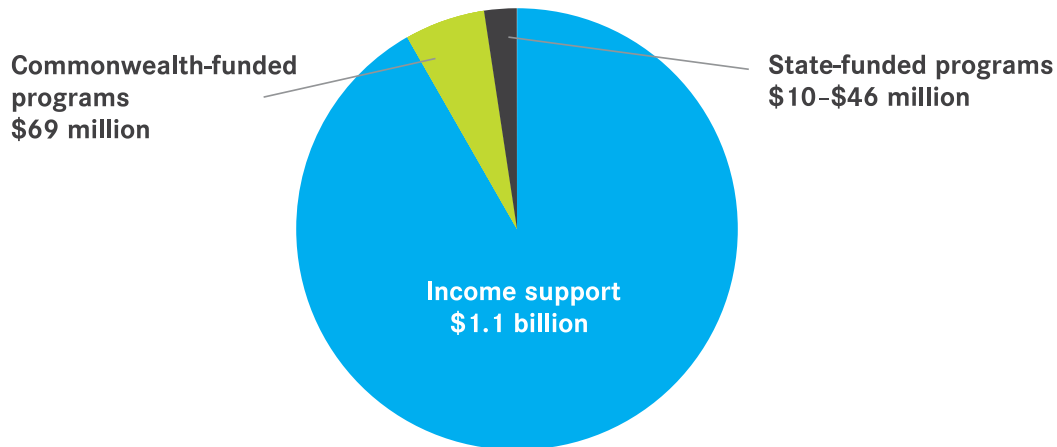
may not have any consistent effect one way or the other. The impact, if any, of a carer is likely to depend on how engaged the carer is with the care recipient's treatment, how well the carer is coping and the carer-care recipient relationship. Therefore we did not model a difference in hospital costs for people with and without a carer.

In comparison with previous estimates of the replacement value of all informal care in Australia (\$60.3 billion) [8], our estimated replacement cost for mental health informal care is higher. Our modelling approach was able to refine replacement cost methods for informal mental health care in Australia to produce what we believe is a more reliable estimate.

6. Conservatively, \$1.2 billion is currently spent on support for mental health carers

In contrast to the substantial economic value of informal mental health care (\$13.2 billion), estimated government expenditure on mental health carers is relatively modest. We conservatively estimated that government expenditure on mental health carer services was approximately \$1.2 billion in 2015. This includes \$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- and territory-funded services (Figure 8). These other Commonwealth- and state-funded support services include, e.g., respite care, information, counselling and practical assistance.

Figure 8. Government expenditure on mental health carer services



Note. These estimates are conservative because we were unable to locate expenditure data for some programs, and excluded some broader consumer and carer programs that might benefit mental health carers because no specific expenditure data were available on the portion directly linked to mental health carers.

7. Not all mental health carers are accessing support services or feel their needs are addressed

The SDAC 2012 indicated that the majority of primary mental health carers were not receiving any support, with only 23.8% receiving Carer Payment and 34.4% receiving assistance to care for their main recipient of care. More detailed data from the UQ Carer Survey 2016 participants showed that 43.4% of mental health carers did not receive any form of Centrelink support.

*A concerning **35.0% of primary mental health carers did not know what services were available** for carers. A small proportion had not heard of the Carer Payment and therefore had not explored their eligibility.*

*Around **half of primary mental health carers reported unmet support needs.***

Key issues with carer support services noted by carers across the SDAC 2012, UQ Carer Survey 2016 and the literature are noted in Box 5.

Box 5 – Key issues with mental health carer support services

- A lack of information about mental illness and carer support services.
- The need for more assistance, such as respite care and emotional support.
- Available services do not always meet the episodic caring needs of mental health carers.
- Gaps in mental health services for care recipients place additional burden on carers.
- Poor recognition of carers and exclusion by mental health professionals from treatment and discharge planning and discussions about recovery.
- Difficulties accessing sufficient financial support.

This report highlights a need for better disseminating information about support services to mental health carers. Carers report needing more appropriate and flexible support services to match their unique caring profile and the episodic and unpredictable nature of mental illness. Services originally developed for carers of people with other types of disabilities may not be directly suitable or transferable to the needs of mental health carers.

Other carer needs

Qualitative data from the UQ Carer Survey 2016 expanded upon a number of the issues in Box 5, as well as poor carer mental and physical wellbeing, feelings of hopelessness and exhaustion and carers changing many aspects of their lives to accommodate the care recipient, including their careers, finances and housing. The take-home messages from these

responses were that “... *there is nowhere near enough support for mental health carers*” and that carers are “... *tired of filling in the gap of the shortfall in services*”.

Another recurring theme from carers was 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.

Prioritising provision of carer support services would do much to ensure that mental health carers can continue to perform their role without significant financial disadvantage and psychosocial distress. It would also do much to address some of their identified unmet needs.

Implications

This work provides the first known estimate of the economic value of informal mental health care in Australia. The results of this study show that informal mental health carers add significant economic value to the Australian

mental health system, and that improvements to services for people with mental illness and their carers are warranted. A summary of the key findings is shown in Box 6.

Box 6 – Key messages

1. An estimated 240,000 Australians care for an adult with mental illness.
2. Mental health carers provide large amounts of unpaid support, often on a fluctuating basis.
3. Most mental health carers' time is spent on emotional support.
4. Mental health caring differs from other types of caring.
5. It would cost \$13.2 billion to replace informal mental health care with formal support services.
6. Conservatively, \$1.2 billion is currently spent on support for mental health carers.
7. Not all mental health carers are accessing support services or feel their needs are being addressed.

This study also highlighted a number of areas where a lack of good-quality data led us to make necessary assumptions. These areas could be improved by further research and data collections (Box 7).

Box 7 – Areas for further research

- More detailed data collection on hours of care for a large and representative sample of mental health carers, such as an ABS Time Use Survey or diary methods study, considering the episodic nature of mental health caring.
- Routine recording of carer status in bed-based mental health service datasets to allow detailed analysis of large samples on the relationship between caring and service utilisation.
- More detailed profiling of young carers below 25 years of age, whose support needs and caring impact are likely to differ from older carers.
- Implementation of the Mental Health Non-Government Organisation Establishment National Minimum Dataset to improve available data on mental health carer support service expenditure and access.
- Exploration of the financial impact of caring on mental health carers and the opportunity costs, which were outside the scope of this study.

A number of reforms in the pipeline (Box 8) will likely have an impact on the mental health caring role, as well as on the availability and suitability of support services for 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.

Box 8 – Summary of current and future reforms

- *National Disability Insurance Scheme (NDIS)*
 - Carers are not participants of the NDIS and will not receive a separate assessment or an individually funded package of supports.
 - One of the core aims of the NDIS is to better support the carer to continue their caring role, which may include training for carers, respite and group or family therapy.
 - Preliminary results indicate some positive outcomes for carers: ability to return to work, reduced stress and less financial pressure.
 - Key issues for mental health carers include uncertainty about the national roll out, anxiety about access to Tier 3 supports and uncertainty surrounding service accessibility if the care recipient is deemed ineligible.
- *Carer Gateway and integrated carer support service*
 - Commonwealth Government has committed \$33.7 million over the next four years to design and implement an integrated plan for a carer support service.
 - Stage One: implementation of a national Carer Gateway or online resource hub. The Carer Gateway launched in December 2015; however, no evaluation data published to date.
 - Stage Two: designing a new national service ('integrated carer support service') that provides better coordinated and more streamlined carer services. A draft concept model was published in May 2016 for public feedback. There is nothing in the draft service concept pertaining specifically to mental health carers.
- *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.
 - The Royal Australian and New Zealand College of Psychiatrists (RANZCP) has been invited to provide input into this review process.
 - Concerns have been raised about the current assessment process being too heavily geared towards carers of people with a physical disability.

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1300 286 463

Carer Helpline

1300 554 660

info@mindaustralia.org.au

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Mind Central Office | 86-92 Mount Street
PO Box 592 | Heidelberg VIC 3084

Mind Australia Limited ABN 22 005 063 589