



**Submission to the Productivity  
Commission Issues Paper on the Social  
and Economic Benefits of Improving  
Mental Health**

**April 2019**

## **ABOUT CARERS AUSTRALIA**

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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## INTRODUCTION

The Productivity Commission's Issues Paper raises a very large number of questions, many of which are beyond our expertise to address and will be better dealt with by submissions from organisations which specialise in mental health. We have focused our response on those questions which specifically relate to family and friend carers of people with mental health issues.

Estimates vary on just how many mental health carers there are. Our estimates from publicly available data from the ABS 2015 Survey of Disability, Ageing and Carers (SDAC), indicate that there were about 92,900 carers of people with mental health conditions within the scope of conditions identified in the Issues Paper.<sup>1</sup> If autism is added to the scope this number would increase to 104,700. However, the University of Queensland's more intensive and sophisticated analysis of the SDAC identified that 240,000 Australians cared for someone with a mental illness, of which 54,000 were primary carers and 186,000 were secondary carers.<sup>2</sup>

The University of Queensland study also identified that 37.8 percent of primary mental health carers and 18.8 percent of secondary carers provided 40 or more hours of care a week.<sup>3</sup> The study estimated that mental health carers provide the equivalent of at least \$14.3 billion of services to the economy every year based on what it would cost Australian governments to fund the support these carers provide and once the cost of services to mental health carers funded by governments has been subtracted.<sup>4</sup>

As is the case with carers of people with other conditions, mental health carers often provide care at considerable cost to their own wellbeing. This cost includes their health, peace of mind, financial security and the opportunity to pursue their own education, employment and interests.

Carers of people with long term mental health conditions often spend extensive time with the person they care for, providing emotional support, reassurance and, in some cases, behaviour management. Mental health carers may also help those they care for manage finances and communications and attend appointments. They also provide assistance with household tasks including, in some cases, activities of daily living such as personal hygiene, grooming and preparation of meals. However, on average, most of the care provided by mental health carers is devoted to emotional support. A University of Queensland survey of mental health carers in 2016 Identified that the amount of time devoted to different types of caring tasks. Emotional support constituted 68 percent of caring tasks, with practical support and activities of daily living constituting 29 percent and 3 percent respectively.<sup>5</sup>

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<sup>1</sup> Australian Bureau of Statistics (ABS), *Survey of Disability, Ageing and Carers*, 2015, data extracted using Table Builder

<sup>2</sup> Sandra Diminic, Emily Hielscher, Yong Yi Lee, Meredith Harris, Jaclyn Sches, Jan Kealton, Harvey Whiteford, *The Estimated Value of Informal Caring for People with Mental Illness*, University of Queensland, 2017 [https://www.mindaustralia.org.au/sites/default/files/Mind\\_value\\_of\\_informal\\_caring\\_full\\_report.pdf](https://www.mindaustralia.org.au/sites/default/files/Mind_value_of_informal_caring_full_report.pdf), p.xiii

<sup>3</sup> Ibid, p.64

<sup>4</sup> Ibid, p.xiii

<sup>5</sup> University of Queensland *The Estimated Value of Informal Caring for People with Mental Illness: Summary Report*, 2017, page 8

The episodic nature of mental health caring can present particular challenges to accessing services and support.

## RESPONSES TO QUESTIONS IN ISSUES PAPER

- ***Question: Are the disability support pension, carer payment and carer allowance providing income support to those people with a mental illness, and their carers, who most need support? If not, what changes are needed?***

Feedback from mental health carers to Carers Australia is that they find it very difficult to qualify for the Carer Payment and Carer Allowance. While there has been a slight rise in the number of people classified as carers of people with psychological/psychiatric conditions since 2016 (the period for which the public data is available), a very large proportion of carers under this classification will be caring for someone with autism.<sup>6</sup>

To receive Carer Payment and/or Carer Allowance, care must be provided for someone with high care needs. To assess the level of care that is needed, the carer and a health professional each need to complete a questionnaire to measure the support the person needs to undertake basic living activities. Together, the questionnaires make up the Adult Disability Assessment Tool (ADAT) that is applied by Centrelink to determine a person's qualification for either the Carer Payment or Carer Allowance.

The ADAT questionnaires each comprise:

- Division A, covering physical needs, including the person's needs for assistance with mobility and to eat, dress, shower/toilet, communicate
- Division B about cognition and intellectual capacity, and
- Division C about behaviour and mental health, that mostly focus on threatening and harmful behaviour to themselves or others.<sup>7</sup>

The questionnaires are scored and the need for care determined by reaching a minimum score in the health professional questionnaire. The emphasis on meeting a person's physical needs makes it very difficult for the care needs of someone with an episodic mental illness to score a qualifying ADAT. For example, a person who is scored by a professional as sometimes depressed, sometimes withdrawn and sometimes aggressive will get an ADAT of 7, with a minimum score of 8 for Carer Payment and 12 for Carer Allowance required to qualify.<sup>8</sup>

The example below provided by the Department of Social Services (unpublished) illustrates the point.

“Louise is 40 and cares for her older sister, Samantha, who has bipolar disorder. Louise provides hours of emotional support when her sister becomes depressed, to prevent her from self-harming, and is constantly vigilant when her sister becomes manic to ensure she doesn't behave in a risky or reckless manner. Samantha's episodes are

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<sup>6</sup> Department of Social Services, DSS Payment Demographic Data, <https://data.gov.au/dataset/ds-dga-cff2ae8a-55e4-47db-a66d-e177fe0ac6a0/details?q=carer%20payment>

<sup>7</sup> <https://www.legislation.gov.au/Details/F2018L01106>

<sup>8</sup> <https://www.legislation.gov.au/Details/F2018L01106>

unpredictable and Louise is often called unexpectedly when her sister is having a manic episode.

Samantha does not admit there is anything wrong with her mental health and will sometimes decide not to take her medication. Samantha often reacts angrily when prompted to take her medication, so Louise regularly monitors how much of the medication has been taken and adjusts her weekly arrangements accordingly. She knows that when her sister hasn't taken the required medication her own week is likely to be disrupted.

Even though Samantha's bipolar disorder is often quite severe, there are days when she does not experience many symptoms and can function well. As a result, Louise does not score very highly on the assessment and does not qualify for either the Carer Payment or Carer Allowance (adult)."

A Carers Victoria report on mental health carers entitled *Invisible Care Report*, included a survey of carers. While the survey was undertaken in 2013, the ADAT has not changed, so it is still relevant that that nearly all participants reported very high levels of caring activities where needs are not adequately measured by the ADAT. These included advocacy, managing crises, liaising with health professionals, and providing transport to health appointments.<sup>9</sup>

The Department of Social Services undertook a review of the Carer Payment and Carer Allowance application process in 2016-17. Carers Australia understands that a new process and criteria were well developed, which would have better recognised the care needs of people with mental illness, before the project was abandoned in early 2018.

Carers Australia recommends that the project to review the ADAT be progressed, and that an application process with new qualification criteria for Carer Payment and Carer Allowance be implemented.

- **Question: To what extent has the workforce participation of carers increased due to the Australian Government's Carers and Work Program?**

The Carers and Work program is part of the Department of Social Services' (DSS) Community Mental Health Activity Program. It was devised as a small trial program.

This program has had very limited reach as the table below illustrates.<sup>10</sup>

	<b>Funding</b>	<b>Individual Participants</b>
2015-16	\$1.499 million	343
2016-17	\$1.494 million	194
2017-19	\$1.524 million	180
2018-19	\$1.554 million	77**

The Department of Social Services' (DSS) website indicates that only four organisations were providing these services in 2018 (one in NSW, one in Queensland and two in Victoria).<sup>11</sup>

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<sup>9</sup> [http://www.carersvictoria.org.au/Assets/Files/Carers%20Victoria\\_Invisible\\_Care\\_Report\\_2013.pdf](http://www.carersvictoria.org.au/Assets/Files/Carers%20Victoria_Invisible_Care_Report_2013.pdf) pp9-10

<sup>10</sup> Information provided by the Department of Social Services

<sup>11</sup> <https://www.dss.gov.au/our-responsibilities/mental-health/programmes-services/mental-health-respite-carer-support/carers-and-work-service>

There has been no formal evaluation of the program.

The objectives of the program are to:

- develop skills and knowledge to independently achieve their employment goals
- re-engage and be better prepared to start work
- enter or return to employment
- increase their employment participation.

Carers Australia is advocating that such assistance should be available through government funded employment services to all carers seeking employment, including those whose caring role has diminished or ceased, after a period of time out of the workforce due to caring responsibilities - especially those who have been caring for a long time and those whose caring role ceases.

- ***Question: What are some practical ways that workplaces could be more flexible for carers of people with a mental illness? What examples are there of best practice and innovation by employers?***

The capacity of carers to combine work and care and the conditions required to enable them to do so has become a major issue in the carer world in recent years. It is very high up on the policy and advocacy agenda for the International Alliance of Carer Organisations (IACO).

Strong economic and business arguments have been advanced for care friendly work places.

It is important to note that 1 in 8 Australian employees are carers<sup>12</sup> and that the requirement for people to combine work and care will grow as the population ages and with a growing incidence of some illnesses and disabilities –including mental health problems. If these carers are forced to leave employment because they cannot combine work and care, the costs to the economy will include a growth in social security payments and the loss of productivity and tax revenue. However, if they decide that the financial pressures and long-term reduction in their employability means that they must significantly reduce or cease the amount of care they provide, then there will be a need for more subsidised replacement care to be provided.

From the employer perspective, the advantages of being a carer friendly workplace are well documented.<sup>13</sup> Staff retention, and the high costs of recruitment and training up new employees, features high on the list. The majority of carers are between the working ages of 45–64. Failing to hold onto these experienced workers represents a significant loss of investment to the employer of resources, time and knowledge. Other benefits include high staff morale for those who love to come to work. For carers, work can be the best form of respite from caring. It is well established that carers can become very socially isolated. Work can provide them with the opportunity to socialise with other people and to have an identity and a focus beyond their caring role. In the words of one carer:

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<sup>12</sup> Carers Australia, Work and Care: The Necessary Investment, A Guide for Employers, <http://www.carersaustralia.com.au/storage/workandcare-guideforemployers-2016-logo.pdf>

<sup>13</sup> Carers Australia, Work and Care, *The Business Case for Carer Friendly Workplaces*, , <http://www.carersaustralia.com.au/work-and-care/>

“It’s the opportunity to use my experience and skills, to contribute to my workplace and community, and to enjoy some social life among a wonderful group of supportive colleagues. Very importantly, it gives me the chance to be just me”. (*Helen the person, as well as the loving mother and carer of Ben*)<sup>14</sup>

So what does a carer-friendly workplace entail?

At the most basic level, it involves creating flexible working conditions. This won’t necessarily mean carers work for fewer hours (although sometimes that will be a requirement) but will be able to work flexible hours which fit into their caring needs, as well as options for working from home. It may also involve allowing carers to take a period of time off over and above their normal leave entitlements without losing their jobs, or employers being amenable to the request of carers to drop back to a less demanding job within the organisation.

However, beyond these pragmatic approaches there needs to be ‘buy in’ within the workplace culture, including at a high level. Employers need to send a message to all employees – not just carers - that they understand and value the carers who work for them. This will help to create an environment where carers feel free to disclose their caring responsibilities and can expect a supportive response, including from their co-workers which research shows is very important to working carers. Ideally it should be part of HR policy to identify support services outside the workplace which can help carers to sustain work and care.

However, even against this background mental health carers may struggle more than other carers to access the benefits provided by carer friendly workplaces.

From a workplace perspective, structuring flexibility into jobs works best when carers are caring for people who, except in relatively unusual circumstances, have predictable care needs. Carers of people with unpredictable episodic conditions, especially when these episodes are frequent, may find it harder to plan their working responsibilities around their caring role. Employers may also be more challenged in providing adequate flexibility in these circumstances.

The second problem confronting many mental health carers is the stigma of mental illness. Many families, including carers within those families, find it hard to tell other people that they have a family member with a mental illness. They may feel that to do so would be a form of betrayal of that person. This is especially the case for carers in some CALD communities where, for cultural reasons, the level of stigma is very high.

Moreover, because there is often poor understanding of exactly the kind of care provided, the needs of these mental health carers may not be clearly understood. It is far easier for most people to envisage the level and nature of support needed by people with a physical disability.

- ***Questions relating to education and training***

Carers Australia has a major focus on young carers (those under the age of 25) in our engagement, research and advocacy.

According to the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC), in 2015 there were 213,100 carers between the ages of 15 and 24. Of these, 20,700 were primary carers (those providing the most substantial amount of support). It is estimated

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<sup>14</sup> David Grayson, *Take Care*, Emerald Publishing, 2017, p.xxix

that 61 percent of these young primary carers were caring for a parent. A further 59,100 carers under the age of 15 were identified.<sup>15</sup>

Further analysis of the SDAC revealed that that primary carers aged 20–24 were less likely to have completed Year 12 or equivalent (32 percent) than both non-primary carers (72 percent) and non-carers (80 percent) of the same age.<sup>16</sup> A report by the Australian Institute of Family Studies (AIFS) identified that young carers in Year 9 had significantly lower performance in reading and numeracy compared to their peers.<sup>17</sup>

Unfortunately, it is not possible to identify the proportion of these young carers who cared for someone with a mental health condition from the publicly available data. However, other research into young carers and our own insights from administering the Young Carer Bursary Program indicate that many young carers are caring for someone with a mental health condition as a primary or secondary disability.

The educational disadvantages experienced by young carers include a number of common factors, some of which are heightened in the case of young carers of someone with a mental health problem.<sup>18</sup>

1. Missed school attendance arising from the need to provide care.

**Example:**

“I have been caring for my mother on and off since the age of 12. She has significant caring needs relating to her complex mental illness. As her carer, I am responsible for cooking household meals, cleaning and other domestic duties, shopping, taking care of the pets and making sure that Mum maintains her personal hygiene. Further to this, I provide a large amount of emotional support to Mum, supporting her to attend appointments and she rarely leaves my side at home and reports chronic suicidal ideation. I find that I struggle the most in providing the emotional support to my Mum, as it is emotionally and physically draining on my own wellbeing. I was completing my year 10 certificate in 2014, and although I was able to keep up with the course content, I was unable to meet the attendance requirements. In this time, I also became unwell myself, which increased the burden of caring for my mother as my own mental health was compromised.” *17 year old who cares 40+ hours per week for her Mum who has schizophrenia and bipolar*

2. A high level of anxiety and stress (which can impact on their ability to focus when they are at school or engaged in tertiary studies).

**Example:**

"Mum sleeps a lot because of her tablets and the pain, sometimes she doesn't get out of bed. I have to make our meals all the time so that we eat because Mum forgets and Mum can't do the shopping on her own cause she can't lift the shopping and forgets lots of the

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<sup>15</sup> Australian Bureau of Statistics (ABS), 2015 Survey of Ageing Disability and Carers (SDAC), <https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02015?OpenDocument>, Carers Tables 32.1 and 38.3

<sup>16</sup> Australian Institute of Health and Welfare (AIHW), Australia's Welfare, 2017, <https://www.aihw.gov.au/getmedia/affa1332-0df7-4865-9590-0c60a8aad9e0/aihw-australias-welfare-2017-chapter8-3.pdf.aspx>

<sup>17</sup> Diana Warren and Ben Edwards, Australian Institute of Family Studies, *The Longitudinal Study of Australian Children 2016 Annual Statistical Report*, <https://aifs.gov.au/publications/young-carers>

<sup>18</sup> All case studies extracted from applications for the Young Carer Bursary administered by Carers Australia

things we need. I have to do all the chores at home. Some days I just don't go to school cause Mum isn't well enough and I'm scared when I come home she will be dead." *13 year old who is the only carer for her Mum who has a spinal injury and mental illness*

3. A high level of exhaustion arising from the demands of the caring role which often relate not only to providing care to a parent with disability but also having to take on significant tasks associated with household functioning and the care of siblings.

**Example:**

"It is just Mum, me and my brothers living at home. I have been caring for my family since I was 8 years old. Mum suffers from drug addiction and mental illness.

Because Mum is sick, it is up to me to get my brothers up and ready for school, including making lunches, breakfast, getting them ready and getting them to school. I also have to take them to appointments, clean the house, make dinner. I also care for Mum which includes personal care, and providing heaps of emotional support. I get worried about keeping everyone safe and sometimes I can't sleep from worry and being scared. This year especially I have found it hard to attend school properly because I worry about Mum and need to help her." *14 year old who is the carer for his Mum who has a mental illness and drug addiction*

4. Financial barriers to participating in education.

**Example:**

"Money is very tight for Nana and each year we have to ask around for money to pay for school expenses and it usually takes a while to get everything - like school uniform, books and books to write on, school fees and Outdoor Education is expensive." *15 year old who is the only carer for his grandmother (40+ hours per week) who has a physical disability, a chronic illness, an eating disorder and who is frail aged*

While these barriers to educational participation are not restricted to mental health carers, they often face particular challenges.

As is the case with employed mental health carers, young mental health carers must deal with the stigma associated with mental illness and many are unlikely to reveal their carer status or family situation.

"I have always looked after my Mum. I didn't know I was doing anything special, but now I am 14, I realise that what I do in my home life is different from my friends. I have only told one other friend about my Mum. I am worried people will not understand my situation, or my Mum's illnesses." *14 year old who is the main carer for her mum (21-30 hours per week) who has a physical disability, mental illness and who has attempted suicide and self-harm.*

Another reason young mental health carers may be unwilling to discuss their caring role and seek assistance, particularly in cases where the person they care for has a drug or alcohol problem as well as a mental illness, is the fear that Child Protection Services may be brought in and they will be removed from their family.

There is a great deal which can be done to assist young carers. There are a number of programs available which can provide counselling, peer support and coaching, among other things. There is significant room for more young carer awareness in schools. This includes helping teachers to identify young carers and understanding why they may not be meeting

performance requirements in terms of school attendance, understanding why they struggle to focus on studies and meeting deadlines. Teachers and schools may also be able to provide special assistance to help them keep up with their studies and refer them to community support services. As is the case with employed carers, it is important to support them within the wider culture of educational institutions by acknowledging their contribution to those they care for and the particular challenges they face. It is important that they are better understood and appreciated by their peers as well.