Invisible care
Access to Carer Payment and Carer Allowance by Victorian carers of a person with a mental illness
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Carers Victoria is the state-wide peak organisation representing those who provide care. We represent more than 700,000 family carers across Victoria – people caring for a person with a disability, mental illness, chronic health issue or someone with age related frailty. The people being cared for could be a parent, child, spouse, grandparent or a friend.

Carers Victoria is a member of the National Network of Carers Associations, as well as the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

Carers Victoria is a membership based organisation. Our members primarily consist of family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.

This report was prepared by Ben IIsley, Policy Adviser, Carers Victoria.

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Invisible Care

Access to Carer Payment and Carer Allowance by Victorian carers of a person with a mental illness

Carers Victoria’s report
August 2013
Foreword

by Professor Allan Fels and Jackie Crowe

It is our pleasure both as Mental Health Commissioners and carers to introduce this timely report on the difficulties that carers of people with mental illnesses experience accessing the very income supports that are meant to help them.

For most Australians who find themselves in a caring role for a family member or friend, daily responsibilities often throw up challenges that can be exhausting emotionally, psychologically and financially. Carer Payment and Carer Allowance are social security payments from Centrelink that are specifically for people in caring roles but carers of a person with a mental illness have long held that it is difficult for them to access these payments.

They have consistently cited several factors that impede their access to the payments. These include the design of the assessment tool used to determine eligibility, consent issues, bureaucratic complexity and difficulties arising from caring for a person with an episodic condition.

These difficulties are well known to mental health carer support groups and carer organisations across Australia; however, the evidence needed to effect real change has been anecdotal and piecemeal. That is until now. This report documents the findings and analysis of a thorough investigation into the issues and experiences of a sample of Victorian carers of a person with a mental illness. The study also developed a method using data from Centrelink and information from a detailed survey for exploring who misses out on Carer Payment or Carer Allowance and why.

Some of the findings will come as little surprise to those carers faced with applying for the payments. The report has value in collecting, confirming and recording these familiar challenges. Other findings may be more surprising, particularly those relating to the extent of the difficulties faced by those caring for a person with a long term psychosocial disability due to a psychotic illness. One of the key findings is that it may often be the combination of several different barriers that prevents carers from applying for the payments or being successful with their applications.

This report attempts to convey the level of feeling that carers of a person with a mental illness have about access to Carer Payment and Carer Allowance. Lack of access to the payments is frequently seen as a deeply symbolic issue by a group who already feel that their role, and its value, often goes unnoticed or is misunderstood within the community.

The lives of carers are, by definition, interdependent with the people with mental illness they support. Many of the challenges faced by people with mental illness also affect their family members. These include the stigma of mental illness, low incomes, social isolation and problems with accessing the services they need. Carers often go to great lengths to mitigate these impacts for their family member of friend when they can. This investigation examines the impacts of caring for a person with a mental illness upon carer workforce participation and financial circumstances, areas that have received relatively little attention in research or policy to date. The report describes the role that carers so often play in providing not just care and support but accommodation, board and social participation.

This report raises several timely questions about social policy. The development of a National Disability Insurance Scheme (now called DisabilityCare Australia) has invigorated debate about the needs and experiences of people with a psychosocial disability. It is hoped that the introduction of the scheme will begin to improve the level of support provided for people with significant disability due to their mental illness. Currently the whole of life and health outcomes for this group remain extremely poor. Support from carers and family members can make all the difference to the recovery, health and dignity of individuals who often struggle to be included in the broader community. One of the more noteworthy findings from this study is that carers and family members of this group face significant and often bewildering difficulties in accessing the income support and recognition they deserve.
The report includes carefully considered recommendations to improve access to Carer Payment and Carer Allowance for those caring for a person with mental illness. We see vast merit in those recommendations.

Professor Allan Fels AO, Chair Mental Health Commission

Jackie Crowe, National Mental Health Commissioner
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<td>ABS</td>
<td>Australian Bureau of Statistics</td>
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<tr>
<td>ADAT</td>
<td>Adult Disability Assessment Tool</td>
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<tr>
<td>ADEC</td>
<td>Action on Disability in Ethnic Communities</td>
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<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
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<tr>
<td>AMHS</td>
<td>Area Mental Health Service</td>
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<tr>
<td>ARAFEMI</td>
<td>Association of Relatives and Friends of the Emotionally and Mentally Ill</td>
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<tr>
<td>BPD</td>
<td>Borderline Personality Disorder</td>
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<td>BoD</td>
<td>Burden of Disease</td>
</tr>
<tr>
<td>CA</td>
<td>Carer Allowance</td>
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<tr>
<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
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<td>Crisis Assessment and Treatment Teams</td>
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<td>CCT</td>
<td>Continuing Care Team</td>
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<tr>
<td>CDA</td>
<td>Child Disability Allowance</td>
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<td>Child Disability Assessment Tool</td>
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<td>Community Mental Health Service</td>
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<td>CPI</td>
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<td>DNCB</td>
<td>Domiciliary Nursing Care Benefit</td>
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<td>FaHCSIA</td>
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<td>Home Based Outreach Service</td>
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<td>Instrumental Activities of Daily Living</td>
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<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
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<td>Mental Illness Fellowship Australia</td>
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<td>MST</td>
<td>Mobile Support Team</td>
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<td>MTAWE</td>
<td>Male Total Average Weekly Earnings</td>
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<td>NDIS</td>
<td>National Disability Insurance Scheme</td>
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<td>Non Government Organisations</td>
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<td>National Mental Health Consumer and Carer Forum</td>
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<tr>
<td>NSMHWB</td>
<td>National Survey of Mental Health and Wellbeing</td>
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<td>PaRC</td>
<td>Prevention and Recovery Care</td>
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<tr>
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<td>Treating Health Professional</td>
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<td>World Health Organisation</td>
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Department of Human Services
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Mental Health Council of Australia
Peninsula Carer Council
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Victorian Carer Consultant Network
Victorian Carer Services Network
Victorian Mental Health Carers Network

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Executive summary

Carers of a person with a mental illness face particular and significant challenges. Not only is the caring role itself a demanding one, it is often poorly understood and undervalued by services and society more generally. The role can also come with significant emotional, health and financial costs to the carer.

Carers of an adult person with a disability, including those with a mental or chronic physical illness or who are frail aged, can receive specific financial supports through the Commonwealth social security system. One of these supports, Carer Payment (adult), recognises that some carers may not be able to support themselves financially without assistance because their caring role prevents them from doing paid work. Carer Payment (adult) is means tested and paid at the same rate as the Age Pension or the Disability Support Pension. On the other hand, Carer Allowance (adult) is a smaller payment in recognition of the caring role and is not means tested.

Carers of a person with a mental illness have consistently reported that they have great difficulties in accessing both these payments. They suspect that these difficulties may be greater than for those caring for a person with a physical disability.

Carer Payment (child) and Carer Allowance (child) are for carers of children with a disability under sixteen years of age. These payments were formally reviewed in 2007. This report is confined to the adult versions of the payments and the terms ‘Carer Allowance’ and ‘Carer Payment’ are used to denote the adult versions.

The longevity of advocacy on this issue suggests that these concerns are still current and that any previous government responses have not been seen as sufficient or effective. Carers Victoria conducted a study to collect evidence to test or validate carers’ anecdotal experiences and, in doing so, contribute to the development of any necessary improvements to the design or implementation of the payments. This report outlines the study’s findings and analysis.

The study used the following method:

1. reviewing previous work in this area
2. designing and conducting a survey of carers of people with a mental illness to gather quantitative and qualitative information about their characteristics, roles and experiences. We intentionally collected data from both those receiving payments and those who were not so that comparisons could be made
3. interviewing a smaller number of carers (individually and in a group) to investigate their issues in more depth and to collect a range of case studies, and
4. requesting specific data from the government about patterns of access to Carer Allowance and Carer Payment.

There were significant limitations with the availability and quality of the Centrelink data. In spite of much goodwill by government staff, it was not possible to provide all of the data requested by Carers Victoria because it had not been collected by Centrelink or could not be reliably cross-referenced between data sources. Carer Payment or Carer Allowance recipient data, which is about the person providing care, could not be cross-referenced with information about the person receiving care. Data limitations may also have contributed to the data request process taking twelve months to complete.

In spite of limitations, this mixed method allowed much useful analysis and triangulation of data between different sources. The key findings of the study are discussed below, followed by a listing of recommendations.

Previous work
Examination of existing literature revealed that problems for carers of a person with a mental illness in accessing Carer Payment and Carer Allowance have been highlighted and documented since the early
development and introduction of these payments in 1997 and 1999 respectively. However, we found that literature documenting government responses to advocacy about any problems with the design or implementation of the payments for this group of recipients is scant.

An enthusiastic response from carers to the study’s request for participation indicates that carers of a person with a mental illness feel very strongly about issues of access to Carer Allowance and Carer Payment. Almost 200 carers voluntarily responded to the electronic survey over a relatively short timeframe. Interviews found that access – and barriers to access – to the payments hold great symbolic importance. For many, the payments represent acknowledgement and understanding of their caring role, for themselves and other carers of people with a mental illness. This was the case regardless of whether or not interview subjects received the payments.

While we know that many individual carers of a person with a mental illness have reported difficulties in accessing payments, little robust analysis has occurred to establish whether carers of a person with a mental illness as a group have reduced access to the payments. The analysis done by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) as part of the Pension Review in 2008 showed that 28% of Carer Allowance recipients cared for a person with a mental or behavioural disorder. Carers Victoria found this analysis to be insufficient for the purposes of this investigation because:

1. The data covers the conditions of adults receiving care of all ages using a very broad category based upon the International Classification of Diseases (ICD-10). The method includes those caring for elderly people with disorders such as dementia. The issues and experiences faced by carers of people with these conditions cannot be assumed to be the same as those faced by carers of adults with other mental health problems.

2. Determining the proportion of Carer Allowance recipients by condition of the person receiving care cannot provide a complete picture of access patterns because different medical conditions or disability types have very diverse levels of prevalence and patterns of severity and care need.

3. 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.

Patterns of access to Carer Payment and Carer Allowance

Our survey findings
The great majority of survey participants identified as carers. Given that the survey was named as being for carers about Carer Allowance and Carer Payment, and that participants self-selected to engage in the survey, this is unsurprising. Nevertheless, it was perhaps more significant that some participants still stated that they did not identify as being a carer.

The largest numbers of participants cared for a son (34%), a partner or spouse (32%) or a daughter (22%). Only 2% identified as a non-family member.
The large majority of survey participants had been caring for several years.

Almost two thirds (63%) of participants cared for a person who was in receipt of the Disability Support Pension (DSP).

Types and amounts of care provided
There was a considerable degree of uniformity in the major types of care activities provided each day by survey participants:

- 87% provided emotional support at least once a day
- 58% provided supervision of household tasks
- 55% provided supervision for safety reasons

- 55% supervised taking of medication
- 44% supervised self-care, and
- 43% supervised eating or drinking.

A very high proportion of participants reported that they also provided advocacy (91%), managed crises (89%), liaised with health professionals (86%), and provided transport to health appointments (79%). The Adult Disability Assessment Tool (ADAT) questionnaire includes relatively few of these activities as evidence of care need.

Carers often also normalised their caring role. 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. In interviews, carers would often not identify the extent of their caring until prompted.

Carer Allowance recipients in our 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’. For Carer Payment recipients, these figures were five hours to over eight hours of care per day respectively. However, any overall averages of this type should be treated with caution because of methodological problems. In addition to the difficulties carers have in estimating the amount of care provided on different days, these figures do not take into account the relative frequencies of ‘good’ or ‘bad’ days, or their degree of how ‘good’ or ‘bad’. When we asked carers about how many ‘good’ or ‘bad’ days they had in a month, on average Carer Payment recipients reported that they had sixteen ‘bad’ days a month; Carer Allowance recipients reported fifteen ‘bad’ days a month. Comments made by carers also made it clear that there was little consensus about what a ‘good’ or ‘bad’ day meant in terms of their experiences or amount of care provided.

Many carers provided housing in addition to support to their family member. This aspect is rarely considered to be a part of the caring role.

The social and economic value of these care activities is apparent when the cost of providing them by formal services is considered. Constant supervision of people with a mental illness for safety reasons only occurs in psychiatric hospital acute units and is very expensive. Provision of housing and support is often crucial for the recovery and wellbeing of people with a mental illness, and yet social housing and specialist home-based outreach psychiatric disability support are often in short supply.

Patterns of access to Carer Allowance and Carer Payment

The survey found that 26% of the sample were receiving Carer Payment and 43% were receiving Carer Allowance, with 24% receiving Carer Allowance but not Carer Payment. Of those receiving Carer Payment, 74% also received Carer Allowance. A significant proportion, 36%, reported that they did not receive any Centrelink payments.

Access to Carer Allowance and Carer Payment varied according to:

- medical condition of the person with a mental illness. For example, carers of a person with depression had higher rates of access to the payments than those caring for a person with schizophrenia
- type of relationship with the person being cared for. Spousal carers were more likely to receive payments than parent carers
- gender. Male spousal carers were more likely to receive payments than female spousal carers, and
- cohabitation. Carers who cohabited with the person they cared for were much more likely to receive either Carer Payment or Carer Allowance than those who lived separately.

The survey revealed that mothers of a son or daughter with schizophrenia who lived separately were amongst those least likely to receive Carer Allowance or Carer Payment, even though they often provided significant care to a highly vulnerable population. Further investigation and analysis suggested that this may be due to a combination of factors:
The analysis in this report suggests that the ADAT is particularly insensitive to the care needs of people with long-term psychosocial disability.2

Carers living separately from the person they care for are much less likely to receive Carer Allowance or Carer Payment. Applying for Carer Allowance for those carers living separately requires an extra application form and fulfilment of additional eligibility criteria when compared to coresiding carers. For example, for carers living separately, there is a requirement that ‘the care that relates to the care receiver’s bodily functions or to sustaining the care receiver’s life is received by the care receiver on a daily basis, for a total of at least 20 hours a week’. This eligibility threshold is higher than for those coresiding.

Bureaucratic complexity can bring its own barriers because it provides greater opportunity for misunderstandings and divergent interpretations of the legislation and its guidelines. For example, interpretations of the terms ‘daily care’ and ‘private residence’ in the Social Security Act 1991 are key considerations for all those accessing Carer Allowance, but these interpretations become particularly crucial for those living separately. Some carers reported that they had not applied for Carer Allowance because they had heard from other carers or health professionals that they were ineligible if they lived separately.

Carers of a person with psychosis may be disproportionately affected by any additional barriers associated with living separately. Adults with schizophrenia or other psychotic disorders may be more likely to live separately from their carer than people with other disabling conditions. Population data shows that adults with psychosis are more likely to be unpartnered than other adults in the general population.3 In addition, coresiding with parents may be less sustainable or desirable for people with psychosis than for adults with other types of mental illness or disability.

In Victoria there is a significant population of people with psychosocial disability living in pension-level Supported Residential Services (SRSs).4 Family members continue to provide significant and valuable levels of care for this group, recognising that many SRSs provide inadequate support. The Social Security Act 1991 specifies that Carer Allowance is only for those people caring for a person with disability where the care is provided in a private residence. SRSs are not deemed as private residences, so some carers are ineligible for Carer Allowance regardless of the level and necessity of the care they provide. This creates a systemic inequity. If individuals with a similar psychosocial disability lived in their own home and received a much more appropriate level of formal support, for example from a Home Based Outreach Service (HBOS) from a Psychiatric Disability Rehabilitation Support (PDRS) service or clinical support from a Mobile Support Team (MST), their family member would be eligible for Carer Allowance for providing the same type and amount of daily care as another person caring for a family member in an SRS.

Gender expectations. This issue is much broader than the scope of this study. It is possible that mothers feel more obliged to provide care to their offspring without additional financial support than other family members. They may experience additional stigma in seeking assistance as a result.

What the Centrelink data said

Centrelink data did provide information about access to Carer Allowance and Carer Payment according to the medical condition of the person receiving care. This showed that:

- Of the Victorians aged 16–64 who qualify their carer for Carer Payment, 58% have a physical disability and 27% have a mental illness as their first listed medical condition.
- Of the Victorians aged 16–64 who qualify their carer for Carer Allowance, 52% have a physical disability and 27% have a mental illness as their first listed medical condition.

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2 For a definition and further discussion, see National Mental Health Consumer and Carer Forum (2011). Unravelling psychosocial disability, a position statement by the National Mental Health Consumer & Carer Forum on Psychosocial disability associated with mental health conditions. Canberra: NMHCCF.
Of the Victorians aged 16–64 who qualify their carer for Carer Payment and have a mental illness, 42% have depression, 26% have a psychotic disorder and 16% have an anxiety disorder as their first listed medical condition.

Of the Victorians aged 16–64 who qualify a carer for Carer Allowance and have a mental illness, 37% have depression, 28% have a psychotic disorder and 16% have an anxiety disorder as their first listed medical condition.

Victorian figures were directly comparable to those for Australia as a whole.

These figures by themselves cannot define relative barriers to access for the payments or whether particular groups ‘miss out’ unfairly. The prevalence of depression and anxiety in the population are much higher than those of people with a psychotic disorder. In addition, this data cannot refer to the relative disability severity or level of care provided across different groups of people receiving care and their carers.

It is more informative to compare Centrelink’s payment access figures to population data. Although reliable data about prevalence of psychosocial disability in particular is difficult to come by, we can make the following types of comparisons (using national figures). Given some of the findings of the Carers Victoria survey, we were particularly interested in figures relating to those caring for a person with a psychotic illness:

- 26 484 Australians aged 16-64 who qualify their carer for Carer Payment have a mental illness, 6991 of whom have a psychotic illness.
- 51 193 Australians aged 16-64 who qualify their carer for Carer Allowance have a mental illness, 13 641 of whom have a psychotic illness.
- 339 000 Australians used Community Mental Health Services in 2009-10 (AIHW).
- 3 200 000 Australians had a mental health disorder in the previous twelve months (NSMHWB 2007). Note that this figure is silent about duration of illness or severity of disability or need for care.
- 63 533 people with a psychotic illness received public mental health services in Australia according to the People living with psychotic illness 2011 study. The study does not include those people with psychosis who do not access these services.
- 24.5% of people with a psychotic illness included in the same study identified as having a carer. This is likely to be a significant under report. Many people with a mental illness either do not see their partner or other family member as their ‘carer’, or do not wish to. Even so, this proportion provides an estimate of 15 566 carers of those persons with a psychotic disorder receiving public mental health services, using the conservative figure of 24.5% above. This under-estimate is nevertheless larger than the 13 641 Carer Allowance recipients caring for a person with psychosis. Note that the People living with psychotic illness study also found that a much higher proportion (64.5%) of study participants also disclosed that they had almost daily contact with a family member. It may be assumed that a significant proportion of these family members would be providing daily care even though they have not been identified as a carer by the person with a mental illness.

Evidence shows that people with a psychotic illness will often have significant levels of psychosocial disability and corresponding care needs. Comparison with population data from different sources strongly suggests that access levels of Carer Payment (adult) and/or Carer Allowance (adult) for carers of a person with a mental illness may be disproportionately low in relation to the population of people with a mental illness and their carers.

These figures are of particular concern for those caring for a person with significant and enduring psychosocial disability due to a mental illness.

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6 This figure for Carer Allowance recipients also includes the great majority of Carer Payment recipients because most Carer Payment recipients also receive Carer Allowance – see section 6.3.
Centrelink data was also used to test our survey findings in regard to the relationship between access to payments and coresidency:

- The proportions of Carer Allowance and Carer Payment recipients who live separately from the person they care for are low across all medical conditions of the person needing care. 10% of Victorian Carer Allowance recipients and 9.4% of Victorian Carer Payment recipients live separately. Victorian figures are comparable to national ones. The figure relating to Carer Allowance may be seen to be particularly low because, in contrast to Carer Payment, eligibility allows for care to be provided either in the carer’s private residence or that of the person receiving care.

- The scope of this study cannot verify the reasons why numbers of non-coresiding carers receiving payments are proportionately low. Anecdotal evidence suggests that many people do need, and receive, significant levels of care even though they live apart from their carer. If so, this suggests that carers who live apart from their family member may be unfairly disadvantaged because of systemic barriers.

- The proportions of Carer Payment and Carer Allowance recipients caring for a person with a mental illness who live separately are broadly similar to those for recipients caring for a person with other disability types. The exception is those recipients caring for a person with an intellectual disability, who are even less likely to live separately than other payment recipients.

- The proportions of payment recipients living separately are again an inadequate guide to patterns and equity of access. For example, some cohorts of carers may be more likely to live separately than others. Any additional barriers to accessing payments correlated with living separately would affect these cohorts more than others. Parent carers of an adult with schizophrenia can be seen as an example of such a cohort.

- Gender seems to be a factor. Only 5.8% of Victorian Carer Payment recipients caring for a male live separately as compared with 13.1% caring for a female. For Victorian Carer Allowance recipients, the equivalent figures are similar: 6.1% and 14.1%.

Centrelink data shows that there are 12,263 people in Australia receiving Carer Payment but not receiving Carer Allowance. Given that eligibility for Carer Payment requires recipients to provide constant care in the home of the person with a disability, it is reasonable to assume that Carer Payment recipients are ineligible for Carer Allowance if:

- the person they care for is expected to have a disability for six months, but not twelve months, or
- the Carer Payment recipient was found to have a sufficient ADAT score to qualify for Carer Payment but an insufficient score to qualify for Carer Allowance. This would mean that they scored between 25 and 30 points in total and/or between 10 and 12 points from the Medical Report.

Either reason may be seen to be the result of administrative factors rather than due to a clear policy direction. The ramifications for the individuals concerned are significant. The espoused rationale for Carer Allowance is to recognise care provided, and these Carer Payment recipients are providing constant care. Carer Payment, being means tested, is only allocated to those carers on very low incomes. It is difficult to establish a reasonable rationale that denies Carer Allowance to this group based upon need. It may be that this group is accidentally victim of a broader policy agenda to use ADAT thresholds to limit the numbers of people accessing Carer Allowance, possibly because of a need to contain rising recipient numbers.

It is noted that, as a result of the Carer Payment (child) Review 2007, Carer Payment (child) recipients are now automatically eligible for Carer Allowance (child).

**Carers and the application process**

Many participants in the study perceived that the assessment processes for Carer Payment and Carer Allowance are biased towards those caring for a person with a physical disability. They felt strongly that the rules, questionnaires and language used in the application process are not a good fit for their circumstances. Some carers abandoned the application process based upon this perception.
The carer application form asks carers to provide information about the needs of the person they care for based upon a 'good day, not a bad day'. In the project survey, participants were also asked to estimate how much and what types of care they provided on a 'good', 'bad' and 'typical' day. Unprompted comments included on the survey made it clear that many found the question difficult to answer or meaningless. For some, the caring activities varied according to how symptomatic the person with a mental illness was but the amount of care remained the same. This was either because the underlying functioning difficulties of the person remained constant or because some caring activities were only possible on a 'good day', when the person with a mental illness was functioning better. Some carers we interviewed saw reference to this in the application form as evidence of discrimination against those caring for a person with an episodic condition. It is well known that many psychiatric conditions are by nature episodic or fluctuating.

The first of three main sections of both application forms refers to the 'day to day care needs' of the person with a disability. These refer to Activities of Daily Living (ADLs) such as mobility and self-care. The forms do refer to the fact that support can include prompting or supervision, which is highly relevant to the role played by carers of a person with a mental illness. Many of the study participants were unaware of this feature of the assessment process and so did not complete this part of the form and missed out on potential points which may have helped their eligibility. ADLs such as shopping, cooking or cleaning are not included. Instrumental Activities of Daily living (IADLs) such as paying bills, making phone calls, using transport independently, shopping and cooking and so on are also not included.

The second section refers to the cognitive function of the person receiving care. Although this section might seem to be highly relevant to those caring for a person with a mental illness and/or psychosocial disability, participants expressed disappointment that the questions did not seem to make any reference to distress or symptoms of psychosis, whether active (hallucinations, delusions, thought disorder) or negative (flattened affect, reduced motivation). Cognitive problems associated with long-term psychosocial disability such as difficulty in making either simple or complex decisions are not assessed. The questions listed on the form closely resemble those used in a mini–mental assessment tool that is designed to assess the cognitive function of people with dementia rather than people with other conditions.

The third section of the form refers to the behaviour of the person with a disability. There are three main criticisms of this section relevant to carers of a person with a mental illness:

- The behaviours listed do not include those most relevant to people with a psychosocial disability such as those relating to social functioning and self-management.
- The form asks about the frequency of particular behaviours rather than the frequency or intensity of the care required to manage them. An obvious example here refers to self-harm. The form asks how often the self-harm occurs rather than how often the vigilance and supervision occurs to prevent it. This seems to be inconsistent with the approach taken in the 'Day to day care needs' section in which the functioning of the person with a disability corresponds much more closely with the care activity required.
- The ADAT scoring system as applied to the possible behaviours of a person with a mental illness does not adequately reflect the level of care required or probable impacts upon the carer.

Qualitative data from the survey and interviews suggested that the Medical Report part of the application form was particularly problematic for carers. One of the clear findings was that success of an application was dependent upon involvement of a Treating Health Professional (THP) who:

- knew the carer and understood their role in relation to the person with a mental illness. This was not a given because it is the THP of the person with a mental illness who must fill in the Medical Report. Some carers reported that their family member did not have a regular THP themselves, for example, because of staff turnover within a public mental health service or because of difficulties in developing a relationship with the same GP within a practice
- understood the possible financial impacts of caring
- understood the purpose and application processes of Carer Payment and Carer Allowance, and
- sympathised with carers, either in general or specific terms, receiving the payments.
Centrelink collects the reasons for unsuccessful payment applications within its ‘Common Events’ database. This confirmed that, for Carer Allowance (including both Child and Adult versions and all medical conditions of person needing care), 34% of rejections occurred because their THP score was less than the required 12 points. For Carer Payment, the respective figure was much lower: only 8% of Carer Payment applications were unsuccessful because of a failure to reach the required THP score of 10 points. This finding may warrant further investigation. One possible explanation is that there are initial screenings or self-selection processes that occur for Carer Payment applicants which prevent carers who might score lower on the ADAT from applying. Another possibility is that the difference between needing to score 12 points for Carer Allowance and 10 points for Carer Payment is a highly potent one in terms of determining application success.

Some carers reported that they had not applied for Carer Allowance or Carer Payment because the process required consent from the person with a mental illness. This became a barrier because they did not want to offend their family member or cause conflict within their relationship. They were certain that the person with a mental illness would not accept that they had, or needed, a ‘carer’. Others wished to avoid the process because they knew that dealing with health professionals and assessments was stressful and caused a deterioration of their family members’ mental health. On some occasions, the person with a mental illness would not consent to disclosure of information and their treating health professional would refuse to complete the form. Further investigation revealed inconsistencies in policy and its application in this area. Advice from the Commonwealth Department of Human Services indicated that it is possible for a health professional to complete and sign the form without the consent of the person with a mental illness. However, this is unclear from the design and wording of the form. At the same time, there has been at least one recent appeal case in which a carer of a person with a psychotic illness was refused Carer Allowance because treating health professionals were unable to sign the form without the consent of the patient. This area of law and practice is complex and highly sensitive; however, it is clearly an area that requires more attention. Currently some carers of people with psychosis are systematically and unfairly excluded from access to Carer Allowance or Carer Payment.

Access to information about Carer Payment and Carer Allowance

Many of the carers who participated in the survey and interviews stated that they had been caring for a number of years before they became aware of Carer Payment or Carer Allowance. Others were still confused as to the difference between the two payments, both in terms of purpose and eligibility.

The survey was able to provide useful data about the sources of information used by carers to become aware of the payments. Word of mouth from friends or carer support groups or information derived from an individual’s own research or knowledge were reported as being the most common sources of awareness of the payments. These sources were used more commonly than Centrelink directly or from health or community support services. This set of findings highlights the importance of providing accurate information in the community about eligibility for Carer Payment and Carer Allowance because:

- carers may need to come across information informally before they access Centrelink information. By the time many carers approach Centrelink they are likely to be already aware of Carer Allowance or Carer Payment unless they are existing customers of Centrelink services
- mental health and primary health services are an imperfect source of information about Carer Payment and Carer Allowance, and
- perceptions in the community and amongst carers about eligibility for Carer Payment and Carer Allowance can create an important dynamic that affects access. That is, if carers of a person with a mental illness believe that they are unlikely to be successful in applying for payments, they are less likely to apply. This in turn reinforces the original community perception.

There were a range of different attitudes towards Centrelink about access to information. Many carers were angry that they had been unaware for so long about Carer Allowance and Carer Payment, particularly if they were existing Centrelink customers or their family member already received the Disability Support Pension. These carers had an expectation that Centrelink staff and processes would
actively inform them they might be eligible for greater assistance. Other carers had lower expectations, realising that they would only receive information from Centrelink if they requested it.

In particular, many carers expressed frustration that the carer application forms were no longer readily available to download from the internet. Many carers were also unaware that ADAT scores were weighted, or if they were, did not know how they would find out about the relative weights of questionnaire responses. For many, this unavailability of information created a view that access to the payments was mysterious and disempowering.

Carer experiences of Centrelink

Similarly there were a broad range of experiences of, and corresponding attitudes towards, Centrelink more generally. Some felt upset that they had been treated badly, with Centrelink staff making disrespectful or dismissive remarks or providing inaccurate information. There was a common view that Centrelink staff did not understand the impacts of mental illness on individuals and lacked appreciation of the value and particular experience of caring for a person with a mental illness. For some, negative experiences of Centrelink were sufficiently discouraging for them to decide not to follow through on applying for a payment they may have been entitled to.

There were also many carers who were highly motivated, resilient and determined to access the payments they felt they deserved and were entitled to. Interviews highlighted that many of these carers were well informed about eligibility for the payments and had received support and encouragement from health professionals or advocates. These carers were also more likely to reapply if their application was unsuccessful.

Analysis of the range of Centrelink experiences by carers found the following relevant factors:

- Individual Centrelink staff variations. Some staff were extremely understanding and helpful, others dismissive and unhelpful.
- Individual carer variations. Carers are highly diverse, with different personality types and a broad range of skills in dealing with complex systems. Carers also find themselves in quite different contexts when they are applying for payments. Some carers explained that they were unable to cope with dealing with Centrelink because they were already distressed because of traumatic events and the challenges of their caring role. Others were exhausted by their experiences of the mental health system. For these carers, any perceived insensitivity by Centrelink's staff or procedures was seen as indicative of a larger set of discriminatory and marginalising attitudes within society.
- Support and advice by a third party can be highly beneficial. Support from Centrelink social workers, when available, was particularly valued.

Our survey asked carers if they had been unsuccessful in applying for Carer Payment or Carer Allowance and, if so, whether they were given a reason why. The majority (59.3%) of unsuccessful Carer Payment applicants said that they had not been given a reason why, and 46.2% of unsuccessful Carer Allowance applicants stated likewise.

Many carers expressed gratitude and relief in relation to receiving Carer Allowance and/or Carer Payment.

Financial impacts of caring

We asked participants about any financial difficulties they might have faced in the past year. Understandably, given the sensitivity of this topic, the response rate to this issue was lower than that for other areas.

- 64% of respondents reported that they had been unable to pay utility bills on time
- 58% had asked for financial help from friends
- 32% had been unable to heat or cool their home
- 29% had been unable to pay their rent or mortgage on time
26% had gone without meals, and
23% had asked for material help from a community organisation.

Carer Payment recipients were more likely to have encountered financial difficulty than the general sample of survey participants.

Over 40% of respondents to a question about their levels of financial concern stated that they were very or extremely concerned about their financial situation. This figure rose to 50% of Carer Payment recipients. For non-coresiding carers, 45% were very or extremely concerned about their financial situation. This suggests that coresiding is not a simple indicator of financial difficulty.

Financial hardship of carers can be understood to be a result of a combination of the impacts of caring on paid employment and direct financial costs associated with caring for a person with a mental illness.

Impacts of caring for a person with a mental illness on workforce participation
Consistent with previous studies about carers and patterns of paid employment, our survey of carers of people with a mental illness showed low levels of workforce participation. Only 29% of survey participants who received Carer Payment had any paid employment. The figure was 53% for those receiving Carer Allowance but not Carer Payment.

Significant numbers of survey respondents said that they had changed to a job with lower pay and responsibility because of their caring role, or had to leave a job, or needed to work fewer hours, or had not applied for a job because of their caring responsibilities.

One of the more important findings from the study was that the employment of many carers of a person with a mental illness was adversely affected because of stress associated with the caring role or other negative impacts upon their health. While this finding may not be surprising to those familiar with caring for a person with a mental illness, this represents an additional consideration for those interested in policies to support carers in paid employment. Many studies concerned with the more general population of carers depict balancing care and employment as a spatial-temporal ‘juggling act’ in which difficulties are primarily practical and concern the challenge of needing to be in two places at once. While this understanding certainly applies to carers of a person with a mental illness, particularly those who need to provide vigilance and supervision of a family member, there is often also a demand upon the personal resources of the carer in terms of energy, resilience and wellbeing. Many carers talked about their own anxiety, depression and lack of sleep which in turn affected work performance and capability. This additional finding may be significant for designing supports for the workforce participation of carers of a person with a mental illness.

Direct financial costs
The study gathered information about the direct costs of caring for a person with a mental illness. The survey asked participants about how they spent their Carer Allowance if they were in receipt of it. Interview subjects also provided qualitative data about how carers conceptualised their costs. Here are some broad themes that emerged:

- As the lives of people with a mental illness and their carers are interdependent, costs are almost always pooled. The reality of this is that carers pay for or subsidise many of the costs of disability. Carers rationalise this on the grounds that they have more capacity to pay, either in terms of organisational and budgeting skills, or because they have higher incomes than their family member.
- A great number of carers provided accommodation and board for their family member. Co-coresiding carers did this directly by providing rent free accommodation and providing meals. Carers did not usually identify this as a distinct cost to themselves. Non-coresiding carers often paid or contributed towards rent payments and providing meals or buying food for their family member with a mental illness.
- Carers reported that Carer Allowance was almost always added to general household income and spent accordingly. Very few carers reported that they spent it exclusively on themselves or for recreation. This finding is consistent with Carers Allowance being used as a de facto cost of disability or cost of caring supplement.
Below are some examples of specific ways in which survey respondents reported that they spent Carers Allowance:

- petrol or travel to medical appointments
- medications or support services
- utilities, including telephone. Study participants explained that bills were often larger because of their family member’s mental illness. For example, some people with a mental illness were too preoccupied to minimise use of energy while others had lifestyles that were more energy intensive, such as staying up at night, and
- fines paid on behalf of the person with a mental illness. Common examples were public transport fines or paying off unrealistic purchases.
Recommendations

Recommendations have been formulated with regard to the following principles:

- fairness
- clarity
- minimising unnecessary legislative change
- administrative feasibility
- minimising costs and 'waste', and
- avoiding unintended consequences.

The recommendations cover a number of areas, processes and areas of responsibility, and so have been organised accordingly.

1. Recommendations to improve data collection

   Carers Victoria recommends that improvements are made to Commonwealth Government data collection and analysis to allow for a more rigorous evaluation of the effectiveness and equity of Centrelink payments. These should include:

   1.1 That the recording and listing of the medical conditions of people assessed in the Carer Payment (adult) and Carer Allowance (adult) Medical Report are reworked and rationalised to create a comprehensive classification system across all conditions.

   1.2 That improvements in government data collection and handling are made to allow correlation between the characteristics of carers and the persons they care for.

   1.3 That data is collected to allow analysis of Carer Allowance (adult) and Carer Payment (adult) Grant Rates by characteristics of applicants and the persons they care for.

2. Recommendations to improve awareness of Carer Allowance (adult) and Carer Payment (adult)

   2.1 Within the community

   Carers Victoria recommends that the Commonwealth Department of Human Services (DHS) considers the distribution and targeting of information about Carer Allowance (adult) and Carer Payment (adult) specifically for carers of a person with a mental illness. Particular attention should be given to those who may not have existing contact with Centrelink or specialist mental health services.

   2.2. Within the agencies of the Department of Human Services (Commonwealth)

   Carers Victoria recommends that the DHS investigates opportunities to identify carers of a person with a mental illness through existing income support programs and initiatives. For example, there are opportunities to engage with family members who accompany Disability Support Pension (DSP) applicants or recipients to Centrelink interviews or are mentioned as supports in the context of the Under 35 DSP initiative.

   2.3 Within Commonwealth Government mental health services

   Carers Victoria recommends that the Department of Health and Ageing (DoHA) and Department of Families, Housing Community Services and Indigenous Affairs (FaHCSIA) seek opportunities to promote awareness and good practice in relation to Carer Payment (adult) and Carer Allowance (adult) through the design and administration of its programs and services. Examples of opportunities in this regard include: mental health practice nurses, Personal Helpers and Mentors program (PHaMs), new employment fuscused PHaMs, Day to Day...
Living programs, Partners in Recovery (PIR), Medicare Locals, and service coordination funding.

2.4 Within Victorian Government funded mental health services
Carers Victoria recommends that the Victorian Government supports improvements to increasing awareness about Carer Allowance (adult) and Carer Payment (adult) within state funded mental health services. Examples of support include:

- inclusion and promotion of information about the payments within funded training to services and practitioners, and
- liaison with Commonwealth DHS to improve access to information about the payments within Victorian services.

Key professionals for engagement are Area Mental Health Service (AMHS) staff working as carer consultants, those in Continuing Care Teams (CCTs), Mobile Support Teams (MSTs), and Psychiatric Disability Rehabilitation and Support (PDRS) service staff.

3. Recommendations to improve the practice of health professionals in Carer Allowance (adult) and Carer Payment (adult) application processes
Carers Victoria recommends that the Commonwealth Government seek opportunities to promote the following amongst health professionals in mental and primary health environments:

- awareness of Carer Payment (adult) and Carer Allowance (adult), their value and application processes
- good practice regarding completing the Medical Report for the person receiving care. This will require engagement with both the carer and the person with the condition, sometimes separately, and
- education about the use of appropriate Medicare items to support good practice.

4. Recommendations about Centrelink workforce development

4.1 Carers Victoria recommends that Centrelink staff:
- are trained, equipped and updated to provide accurate information about Carer Allowance (adult) and Carer Payment (adult)
- are instructed to encourage possible applicants to apply for Carer Allowance (adult) and/or Carer Payment (adult) except in circumstances where a person is very clearly ineligible, and
- receive training that includes specific information about the nature, value and impacts of caring for a person with a mental illness.

4.2 Carers Victoria also recommends that access to Centrelink social workers is improved through expansion of their numbers and distribution.

5. Recommendations about Centrelink processes
Carers Victoria recommends that:
- all application forms relevant to Carer Allowance (adult) and Carer Payment (adult) are made available online
- in the event of an unsuccessful application for Carer Allowance (adult) and/or Carer Payment (adult), specific reason should be automatically given to the applicant, and
- to avoid confusion and possible duplication of effort, that administrative processes ensure Carer Payment (adult) applications found to be ineligible because of, for example, the
income and assets test or 'constant care' requirement, remain in process for Carer Allowance (adult).

6. Recommendations to change design and wording of application forms

There are some favourable changes that can be made to application forms for Carer Allowance (adult) and Carer Payment (adult) without amending the ADAT or changing the legislation. One option is to include an additional section in the application forms for carers of a person with a mental illness. This would have the advantage of explicitly including carers of a person with a mental illness in the assessment process. Although this option has merit, it was not pursued in this report because it could be unworkable for the many people who care for a person with more than one disability type. For equity, carers of persons with each disability type would effectively need their own tool, adding to complexity and possible confusion.

Some more straightforward changes to improve the experience of applicants caring for a person with a mental illness are suggested below:

- Consider changing the order of the questions in the carer application and Medical Report forms so that the initial experience of the form is not dominated by questions about care for a person with a physical disability.
- Insert an introductory sentence to the Carer application form that the ADAT is intended to assess the needs of people with all disability types, including psychiatric, and that it is important that carers complete all questions in the form. The Medical Report form provides a useful precedent for this.
- Provide more emphasis that supervision or prompting are included in response to questions about 'Day to day care needs'. This could be achieved by a larger font size, repetition or rephrasing.
- Avoid confusion about consent conditions by grouping Question 4 of the Medical Report with Question 18 and providing an explanation that it is not always essential that the person receiving care consents to release of medical details if the Treating Health Professional provides a reason.
- Changes to the ‘Carer Allowance Questionnaire carer not living with the person being cared for’ form:
  - The final paragraph of Question 13 should be removed. Its emphasis and repetition is unnecessarily discouraging of carers of a non-physical disability or medical condition.
  - Question 18 would be improved by explicitly referring to support for a person to attend essential medical appointments.

7. Recommendations to amend the Adult Disability Assessment Tool (ADAT) Determination 1999

7.1 As recommended by the House of Representatives Standing Committee on Family, Community, Housing and Youth report on the Inquiry into better support for carers (Recommendation 20), Carers Victoria also recommends that the definition of Treating Health Professional for application to Carer Allowance (adult) and Carer Payment (adult) be expanded to include appropriately registered social workers and psychologists.

As well, Carers Victoria recommends:

7.2 That an expert panel be assembled to review the ADAT with regard to its appropriateness for those caring for a person with a mental illness.

7.3 That the panel revise the ADAT to assess the need for support for a person’s social functioning, self-management and decision making.

7.4 That the panel revise the ADAT to include the need to support a person to attend essential medical appointments.
7.5 That the panel revise the cognitive function component of the ADAT to include common signs of psychosis.

7.6 That the panel reviews the wording of the carer assessed cognitive function section of the ADAT to achieve a more empirical basis. Here are some examples of revised questions:

Does the person you care for appear to:
1. have difficulty in understanding what you say?
2. have difficulty in understanding what other people say?
3. have difficulty in communicating what they feel, want or need? (e.g. by speaking, using sign language and/or a communication aid)?
4. become confused, unsure or unaware about where they are?
5. become confused, unsure or unaware about whether it is morning, afternoon or night?
6. have difficulty remembering or recalling what happened today?

7.7 That the panel revise the behaviour section of the ADAT to assess the frequency of care, supervision or intervention required in relation to specified behaviours.

Examples of improved wording for the carer component.

Does the person you care for:
1. need supervision to ensure they do not wander away or run away from home?
2. need supervision or the use of specific strategies because they show signs of aggression or distress?
3. need supervision to ensure they do not harm other people?
4. need supervision to prevent them from damaging property?
5. have sudden or unexpected changes of mood e.g. laughing or crying?
6. need support or encouragement to interact with other people?
7. need monitoring because they deliberately harm themselves, or intend to?

And for the Medical Report component.

Does the person you care for:
1. show signs of depression?
2. need help to remember or organise? (Instead of ‘show signs of memory loss?’ This then also includes people with thought disorders)
3. require help or encouragement with maintaining social interactions and relationships? (Instead of ‘Withdraw from social contact?’)
4. need supervision, vigilance or monitoring to ensure own safety or that of others? (Instead of ‘Display aggression to self or others?’ Aggression does not cover self-harm sufficiently)
5. require monitoring and strategies to help manage unusual behaviours? (Instead of ‘Display disinhibited behaviour’), and add
6. need intervention or support because of psychological distress?

7.8 That the panel review and make necessary adjustments to the ADAT scoring system with regard to:
- the probable impacts upon the carer of different answers. Some scores that relate to caring for a person with a mental illness may be too low, and
7.9 That the panel review the utility and impacts of the following phrase in the 'Carer Payment and/or Carer Allowance Caring for a person 16 years or over' form, and consider removing or rewording it:

*If the condition is episodic or only apparent at certain times (less than once a day), the carer and THP must respond as if the care recipient is NOT experiencing an episode or flare-up of the disability/condition (a “good day”, not a “bad day”).*

Carers Victoria recommends that the panel have regard to this item’s:

- possible different utility and meaning for different cohorts of applicants
- potential for the phrase to unintentionally discourage potentially eligible carers from applying
- difficulties that applicants may have in applying the instruction, and
- possible redundancy of the instruction given that applicants are also required to provide ‘constant’ or ‘daily’ care under the Social Security Act 1991.


8.1 Carers Victoria recommends that the Act be amended to provide automatic eligibility for Carer Allowance (adult) to Carer Payment (adult) recipients on the following grounds:

- **Equity.** Carer Allowance (adult) is provided in recognition of the caring role.
- **Need.** Carer Allowance (adult) is commonly used by households and individuals to assist with meeting the costs of caring and disability. These costs also apply to Carer Payment (adult) recipients.
- **Simplicity.** Automatic eligibility is consistent with the purposes of both Carer Payment (adult) and Carer Allowance (adult). Non-eligibility causes confusion within the community about the purpose of the respective payments and additional complexity for the administration.
- **Consistency.** Changes made to the Carer Payment (child) legislation provide automatic eligibility to Carer Allowance (child) for Carer Payment (child) recipients.

8.2 Carers Victoria recommends that the Guide to Social Security Law avoids unnecessary administrative complexity by applying a uniform approach to interpreting the 'likely to be permanent' disability requirement of the Act across Carer Allowance (adult) and Carer Payment (adult). This would be achieved by reducing the qualification period for Carer Allowance (adult) to caring for a person who is likely to have a disability from twelve months or more to six months or more.

8.3 To improve access to Carer Allowance (adult) by carers of a person with a mental illness, Carers Victoria recommends that amendments are made to the Act to remove the requirement that non-coresiding Carer Allowance (adult) applicants are assessed according to care ‘that relates to the care receiver’s bodily functions or to sustaining the care receiver’s life is received by the care receiver on a daily basis’. The wording of this is ambiguous and applies a higher threshold of care than that for coresiding Carer Allowance (adult) applicants. The policy rationale for such a distinction is unclear, and may have been inherited from the previous design of the Domiciliary Nursing Care Benefit.

8.4 Carers Victoria recommends that the definition and interpretation of ‘personal care’ be reviewed to allow for broader interpretations of supervision, vigilance and support for people with a mental illness. Monitoring and crisis management by telephone should be considered as fulfilling the ‘daily care’ requirement for Carer Allowance (adult) when it is a component of a predominantly face-to-face caring relationship.
8.5 In order to avoid unintended barriers for some Carer Allowance (adult) applicants caring for a person with a psychiatric disability within pension-level Supported Residential Services, Carers Victoria recommends that the definition and application of ‘private home’ be reviewed and amended with regard to:

- The intent of the legislative distinction between private and non-private homes.
- The unintended consequences and negative impacts of the distinction for some carers of people with a psychiatric disability and the people they care for.
- The level of care provided within different non-private homes or classes of accommodation.
- The assessed level of care required for a particular individual, as per ADAT.
- The source of funding for the care component of a non-private home and whether it is government funded or not.

8.6 In order to improve transitions between care, training and paid employment for Carer Payment (adult) recipients, Carers Victoria recommends that the ‘25 hour rule’ described in the Guide to Social Security Law be reviewed with regard to:

- The rule’s effectiveness, necessity and value in assessing the ‘constant care’ requirement for Carer Payment (adult) applicants and recipients. This requirement is already assessed through the ADAT and the payment is means tested.
- Possible unintended inequities for carers in education or training, or those with longer travel times for geographical reasons.

8.7 Carers Victoria recommends that Question 18 in the Carer Allowance Questionnaire form (Carer not living with the person being cared for) and the Guide to Social Security Law be amended to more explicitly recognise the personal support provided to people with a disability to attend essential medical appointments and services as evidence of care.

8.8 Carers Victoria recommends that the Guide to Social Security Law be amended to provide further clarity and guidance about consent issues in relation to the Medical Report component of the ADAT. In particular, consideration should be given to the circumstance when a person with a mental illness does not consent to disclosure of personal information for the purpose of their carer applying for Carer Allowance or Carer Payment. Guidance will need to take into account existing legislation relevant to health records, confidentiality and duty of care.