MENTAL
HEALTH
COUNCIL OF
AUSTRALIA

Mental Health Carers Report

November 2010

Acknowledgements

The Mental Health Council of Australia (MHCA) wishes to thank the mental health carers who took the time to complete the survey and to the many carers who provided additional comments to their responses. The report would not have been possible without their willingness to comment on how mental illness affects them and the people they care for.

MHCA is grateful to those carers who reviewed the survey in its development stages, providing valuable feedback ensuring it was a relevant and appropriate tool.

MHCA wishes to thank Professor Judy Simpson of the University of Sydney for taking the time to identify any statistical inconsistencies with the survey and Frances Garden who analysed the data received from the many participants.

Finally, the MHCA would like to thank the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) for their generous funding support needed to develop and conduct the survey.

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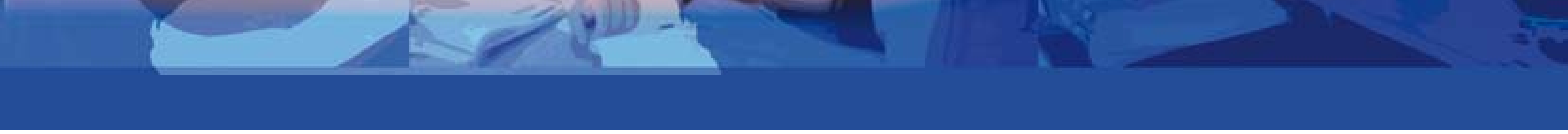


Acronyms and Abbreviations

ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
ASGC	Australian Standard Geographical Classification
CALD	Culturally and Linguistically Diverse
CEP	Carer Engagement Project
FaHCSIA	Australian Government Department of Families, Housing, Community Services and Indigenous Affairs
GP	General Practitioner
MHCA	Mental Health Council of Australia
NGO	Non-government Organisation
NSW	New South Wales
NT	Northern Territory
PHaMs	Personal Helpers and Mentors
QLD	Queensland
SA	South Australia
TAS	Tasmania
VIC	Victoria
WA	Western Australia

Explanatory Terms

Carer	unpaid person who cares for a consumer
Care worker	paid worker who provides services to the consumer
Clubhouse model	provides a comprehensive program of support and opportunities for people with severe mental illness in a non-clinical community setting
Community-based care	non clinical services for the consumer which work towards recovery based care, usually provided by non government organisations or volunteers
Comorbid	more than one illness e.g. a person with schizophrenia and a substance use disorder
Consumer	a person who has a mental illness
Median	a number that separates the highest half of a sample or population, from the lowest half. This means that if seven numbers were ordered from lowest to highest value the middle number would be the 'median'. For example, using the numbers 2, 4, 6, 8, 10, 12, and 14, the number 8 is the median as it is the (phyiscal) middle of this group of numbers.
Mental health services	clinical services, provided by a hospital or mental health clinicians
Recovery-based care	coordinated system of care services provided in the community to assist the consumer to maintain wellness in an atmosphere of hope and to progress to self identified goals.
Respite (for carers)	time away from the caring role, often using care workers to temporarily act in the role of carer

Table of Contents

Foreword

I am delighted to commend to you this report of the first national collection of mental health carer data based on the top 15 issues identified by mental health carers themselves. Quantifiable information about the experiences and lives of carers is in short supply worldwide. Last year when I wrote the foreword for the Mental Health Council of Australia (MHCA) report, *Adversity to Advocacy: the lives and hopes of mental health carers*, the 15 priority issues detailed in the document highlighted the concerns uppermost in carers' minds. This report is different from Adversity to Advocacy. The *Mental Health Carers Report 2010* contains results of a 50 question survey using statistical analysis to enable a clear and accurate record of what is happening to mental health carers throughout Australia. The concerns outlined in Adversity to Advocacy are key mental health carer issues with the data providing added weight and legitimacy to the results.

On reading the Mental Health Carers Report 2010 I find another year has passed when one of the major concerns of carers, 'who will care for my person when I am no longer able to do so', is still not addressed. The provision of comprehensive, coordinated recovery-based services with appropriate long term housing options for consumers would make significant inroads into this ongoing fear and dread of carers.

With this survey report, and the MHCA promise of further mental health carer survey reports, I join with mental health carers throughout Australia in hoping and expecting significant change will be brought about by policy makers and politicians who now have the data to identify and create the changes that are needed.

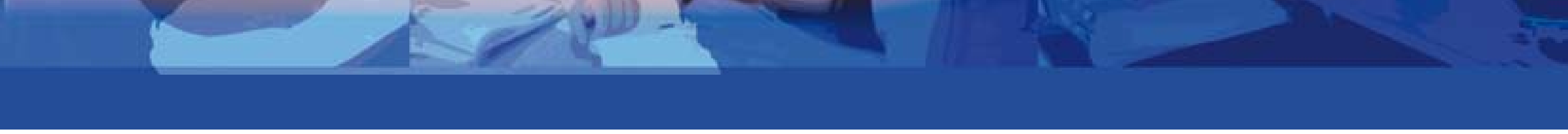
Tony Fowke

Tony Fowke AM

Mental Health Carer

World Federation of Mental Health – President

Mental Health Council of Australia – Board Member



1. Executive Summary and Report Card

The *Mental Health Carers Report 2010* provides the first quantifiable measure of the issues and concerns of Australian mental health carers.

The survey builds on the groundbreaking work of *Adversity to Advocacy: the lives and hopes of mental health carers,*[1] where carers attended 116 workshops nationally to identify the key issues which affected their lives and the lives of the people they care for. Fifteen key issues emerged from the workshops and formed the basis of the 50 question survey completed by 756 mental health carers. This survey is the first of ongoing mental health surveys intended to monitor changes in mental health carers' experiences.

What this survey has revealed is that many carers are ageing and have been caring for a long time. They often care for adult sons and daughters who often live with them, possibly for many years. Carers feel alone and isolated when dealing with the complex issues of living with a consumer who is likely to have other health conditions in addition to mental illness.

The Report Card details the 15 key issues identified in *Adversity to Advocacy*, alongside findings of the *Mental Health Carer Survey 2010* to highlight changes that may have occurred during the last 12 months. It would appear some carers feel their lives have improved during this time, however, there are certainly many areas where significant work still needs to be done.

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[1] MHCA 2009a, *Adversity to Advocacy: The lives and hopes of mental health carers*, MHCA, Canberra.

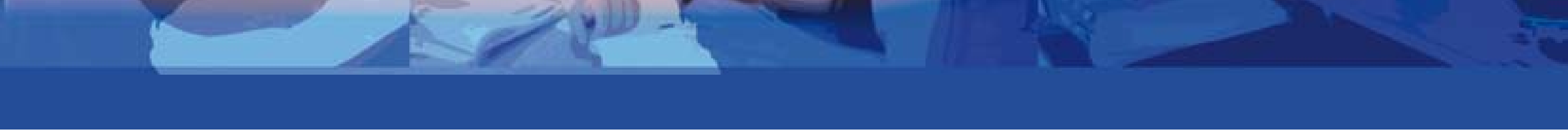
Report Card

Summary of changes in 15 Key Issues since *Adversity to Advocacy*

15 Key Issues	Findings from *Adversity to Advocacy*, 2009	Results of the Mental Health Carers Survey, 2010
Issue 1 **Listen to and respect carers**	*The common view among carers is that they are neither listened to nor respected. The rhetoric of including carers as part of the care 'team' for the consumer is not borne out in reality. Often this leaves carers trapped, excluded, feeling unable to provide adequate care, but also unable to find the services needed for the person they are caring for.*	**Carers reported they felt listened to by GPs and psychiatrists; however a high percentage of GPs and psychiatrists still do not listen to carers. Other health professionals also need to listen to carers more. There is a great need for carers to be included and involved in the consumer caring team. This is still a neglected area.**
Issue 2 **Integrated recovery-based care for the consumer**	*The intolerable stress faced by carers reflects the inadequacy of the care available to consumers. Of particular note here is the common experience faced by carers of lack of integration between different health services, and between health services and other community services such as housing or employment services, and lack of services such as Personal Helpers and Mentors. Recovery is very much an individual matter, assessed in the eye of the beholder. The system is not currently able to provide individualised or tailored approaches to care.*	**Carers across all jurisdictions reported a lack of coordinated, collaborative and consistently reliable recovery-based services for the person they care for. The majority of carers stated they were responsible for the coordination and provision of any recovery-based services for the consumer. The system is heavily reliant on the goodwill and ongoing care provided by carers to fund and resource recovery-based care. A serious attempt to expand nationally available PHaMS and allied program was called for, including consistency in delivery and continuity in quality service provision. Independent accountability measures are required.**
Issue 3 **More and better trained staff at all levels**	*Carers identify inadequate staffing as a key part of current service failure. Access to psychiatry remains extremely limited. Increased access to registered psychology services was not seen as a significant benefit when inadequate workforce numbers impact on availability. Carers report that access to other forms of care, in particular sub acute care, remains a significant issue, particularly in non-metro areas.*	**(Issues 3 and 5 were considered together in the survey.)** **All professions working in mental health, including clinical and non clinical staff, were found to be in need of education and training in carer and consumer issues. Centrelink, police and housing officials were reported by carers as lacking understanding of mental health issues. Carers were concerned about the lack of clinical professionals, particularly outside the metropolitan areas, and indicated the lack of continuity in clinical professional services as a result of staff changes. A national approach to training clinical and non clinical staff in mental health carer and consumer issues is necessary for initial training and within ongoing professional development. Independent accountability measures are required.**
Issue 5 **Carer and consumer education for all professional groups and agencies**	*Many carers feel ignored or patronised by professional groups and agencies. Most carers feel professionals appear to have no understanding of the role of carers, in particular their integral role in the ongoing care of the consumer. There is a real need for increased carer / consumer informed professional development for mental health and other service providers.*	

15 Key Issues	Findings from *Adversity to Advocacy*, 2009	Results of the Mental Health Carers Survey, 2010
Issue 4 **Knowledge and information for carers**	*One of the most debilitating aspects of being a mental health carer is the sense of isolation and helplessness. Knowledge of services such as Commonwealth Carelink is minimal at best. Carelink's understanding of mental health also varies greatly from office to office. Knowledge of peer support options also seems very patchy, with many carers meeting for the first time at the local workshops. Carers reported that the knowledge of how to care for someone with a mental illness was rarely available at first onset of illness.*	***Adversity to Advocacy* reported knowledge and information to carers was lacking. The current survey found a modest improvement in this area. Carers most often sought information from GPs followed by carer services, psychiatrists and their own research. The quality and timeliness of information provision was reported as patchy. Attitudes towards providing information and knowledge to carers have improved in the last 12 months, but remain poor in areas of low service provision. Improving and extending this service is essential for the health and wellbeing of carers and consumers.**
Issue 6 **Support systems, services and processes established for carers**	*The need for more carer led support programs for carers was raised in many workshops. The infrastructure to support carers is generally very weak, with some exceptions. Overall, mental health carer organisations are very poorly resourced. Health services have also generally failed to invest in robust systems to enable engagement with the carer sector. Carers often use their own resources and pay their own way in order to participate in policy and service development activities.*	**Carers commented on the availability and quality of a number of identified support systems and services for themselves. While carers reported an increase in quality and availability in some support services, many carers were unaware of the services available to them or found them not available in their area or inappropriate. Quality staff, flexible and responsive services were reported to be unavailable or unknown to carers in some areas. PHaMS service provision and carer respite need to be combined or work collaboratively to provide better outcomes for carers and consumers.**
Issue 7 **Acute care to be therapeutic and accessible**	*The 2007 Survey of Mental Health and Wellbeing confirmed Australia's inability to lift access to care over the past decade. While the reasons for this are not clear, the impact on carers is very clear. Carers indicate they are commonly faced with providing care to consumers who are acutely unwell, leaving them and the people they care for more vulnerable to the effects of ill health. Carers also considered that acute care (when accessible), was rarely of a therapeutic or recovery oriented nature and often increased the trauma of an acute illness.*	**Carers reported that accessibility of acute care for consumers has remained relatively unchanged. Outside metropolitan areas few services are available. Throughout Australia carers reported that what is available is both hard to access and does not respond to carer need for information and involvement in discharge planning for the person they care for. Carers and consumers seek a significant improvement in availability, responsiveness and inclusiveness within acute care services. Independent external monitoring is needed.**

15 Key Issues	Findings from *Adversity to Advocacy*, 2009	Results of the Mental Health Carers Survey, 2010
Issue 8 **Stigma, discrimination and isolation for carers and consumers**	*Carers and consumers face daily discrimination and stigma. This manifests itself in the realms of employment, housing, health services, schools, in fact all professional agencies. Sometimes even extended family members can look down on people with a mental illness and their carer. This stigma leads to increased isolation with many carers feeling silence is better than reactions from admitting they care for someone with a mental illness.*	**Ninety five percent of carers responded that stigma and discrimination were widespread or existed to some extent. Carers reported a need for stigma and discrimination to be addressed by carer and consumer training for all professionals working with consumers, including clinicians, teachers, Centrelink and housing officials, police and others as well as by wider anti stigma work with all Australians.**
Issue 9 **Accommodation options for consumers at all levels of care**	*Carers report that access to safe, supported housing is a critical problem particularly for consumers with chronic and complex mental health problems. Failure to provide access to housing, or only to unsustainable housing options, leaves consumers very vulnerable to dangers, including worsening health and experiencing violence.*	**Long term safe, appropriate and often supported housing for consumers is paramount. The majority of carers cared for an adult son or daughter who lived with them. Step up/ step down or short term sub acute accommodation was unavailable to the majority of carers. Some excellent supported accommodation programs exist particularly in metropolitan areas but there is far too little in far too few areas. Existing models of housing need to be expanded across Australia.**
Issue 10 **Financial costs to carers**	*In the absence of consumer access to regular mental health care, carers often take on complex and time consuming caring roles including meeting increased costs of transportation or private treatment. The carer role often precludes participation in paid employment leading to significant current and future financial disadvantage for both consumers and carers. Mental health carers are often refused entitlements from Centrelink which, in any case, only partially defray costs incurred, and rarely allow for the level of support and monitoring involved in caring for someone with a mental illness.*	**Little change is reported in this area over the last 12 months. Mental health carers remain disadvantaged both in their current circumstances and also in their future prospects. Significant improvements in support for consumers, including housing and recovery-based care, would impact greatly on the incidental and ongoing financial costs to carers. Many carers stated they were unable to work because of their caring role. Many carers did not receive carer benefits. Carer benefit forms need immediate review to reflect the nature of mental health caring.**
Issue 11 **Physical and mental health of carers**	*Carers do not feel as though their needs are addressed by anyone. Financially they are not in a strong position leaving them isolated and often facing their own deteriorating health without adequate access to the support they need.*	**Seventy percent of carers reported their health was worse as a direct result of being a mental health carer. Wider knowledge and use of a range of already funded services for carers through existing programs is needed to prevent and address the continuing health needs of carers. Subsidised cost of medication and bulk billing for carers is also needed.**



15 Key Issues	Findings from *Adversity to Advocacy*, 2009	Results of the Mental Health Carers Survey, 2010
Issue 12 **Flexible respite options for carers**	*The new respite care program implemented by FaHCSIA has only partially met the needs of mental health carers. Service providers have commonly not understood mental health carers' needs and carers have concerns about respite workers with little or no knowledge of mental illness. As a result, carers do not feel as though respite is a realistic or safe option, and those who try to use the respite services often report problems in finding appropriate options. A possible option suggested by some carers is the co-location of the Personal Helpers and Mentors service for consumers and the respite service for carers within the same organisation (sharing services).*	**FaHCSIA funded respite for carers was generally welcomed by carers who knew of the service. Carers have identified barriers to accessing respite which include a need for a clearer explanation of respite and the benefits of taking respite; consistent and quality trained mental health staff; flexible services; cooperation of PHaMS with respite services; and availability of respite services throughout Australia. An expansion of existing services, a more flexible approach to carer needs, information about existing services and consolidation of carer respite services in all areas of Australia is called for.**
Issue 13 **Privacy and confidentiality issues**	*Carers' rights to be part of the care team are frequently trammelled as they are excluded on the erroneous grounds of privacy and confidentiality. Carers who were aware of Advance Directives for consumers endorsed their implementation to help navigate the privacy and confidentiality minefield.*	**The picture remains one of confusion. A third of carers indicated an extreme or large amount of anxiety because of the lack of necessary information from health professionals. The majority of carers were either not included in the care plan or did not know what a care plan was. Advance directives, nationally applicable guidelines, and carer involvement in care planning would help guide clinicians thorough the minefield of privacy and confidentiality.**
Issue 14 **Early intervention at each episode of care**	*The vast majority of mental health funding remains targeted at acute mental health care. There is only one comprehensive early intervention service for psychosis operating in Australia. Carers are forced to watch consumers wait until their conditions become sufficiently florid to demand the attention of the largely hospital-based acute care system currently in place. This is often despite repeated calls from carers for help and assistance prior to the issues escalating into more dangerous, unhealthy and long lasting situations.*	**Early intervention at each episode of illness is a major concern to carers. Some carers reported an improvement in being listened to and identified clinicians who were open for listening and acting. Nearly a third of carers stated there had been no improvement in the last 12 months. More change in this area is needed to prevent major episodes of illness.**
Issue 15 **Employment options for carers**	*The poor rates of employment or meaningful occupation for consumers means that many carers are also unable to work or unable to work as many hours as they would like. This leaves many carers vulnerable to the negative effects on physical and mental health associated with financial disadvantage.*	**While some carers reported improvement within their existing workplace, more could be done to enable carer employment through a flexible attitude of employers and colleagues. Development of a recovery-based care system for consumers would reduce the need for carers to coordinate care for the consumer and to have the choice to enter the workforce.**

2. Background

Carers play a significant role in the health and wellbeing of the mental health consumers they care for, yet to date limited data has been collected in Australia or internationally to facilitate a better understanding of how the caring role affects carers' own lives as well as coordination and quantification of their lived experiences.

The Mental Health Council of Australia (MHCA), with funding from the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), provided 116 full day workshops throughout Australia during 2008 and 2009. The workshops were developed specifically for mental health carers as part of the Carers Engagement Project (CEP) and were designed to hear their concerns. Points promulgated by carers at those venues were subsequently synthesised into a list of 15 major issues of concern to mental health carers, providing a foundation for the major MHCA landmark report *Adversity to Advocacy: the lives and hopes of mental health carers*.[2]

The fifteen major carer issues were:

1. Listen to and respect carers
2. Integrated recovery-based care for the consumer
3. More and better trained staff at all levels
4. Knowledge and information for carers
5. Carer and consumer education for all professional groups and agencies
6. Support systems, services and processes established for carers
7. Acute care to be therapeutic and accessible
8. Stigma, discrimination and isolation for carers and consumers
9. Accommodation options for consumers at all levels of care
10. Financial costs to carers
11. Physical and mental health of carers
12. Flexible respite options for carers
13. Privacy and confidentiality issues
14. Early intervention at each episode of care
15. Employment options for carers

While carers who attended the workshops had been specifically requested to concentrate their remarks on issues of caring that affected their own lives, they continually highlighted that carers' most pressing concerns were those of consumer care and service provision.

Carers were informed that the MHCA would conduct subsequent ongoing surveys of carers to monitor their changing experiences over time.

Since the initial workshop phase, the MHCA has responded to carers' feelings of neglect by maintaining contact with all who attended, by sending either a letter or email to update them on progress of the project, in addition to providing them with copies of *Adversity to Advocacy*.

More recently, the MHCA created a moderated online forum specifically for mental health carers to talk with each other about the issues that concern them and the people they care for.

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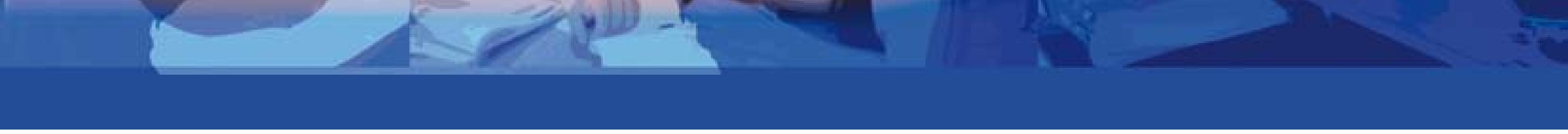
[2] MHCA 2009a, ibid.



The MHCA sent the mental health carers survey for 2010 to all carers who attended the workshops and also distributed it to consumer and carer and MHCA members as well as publicising it on the MHCA website.

This report outlines the results of the initial survey, which is the first measure of carer experiences when navigating the many issues they face while caring for and supporting mental health consumers.

Various compelling comments by carers who completed the survey have been included throughout the report. Carer comments provide a richer context for the presentation of summary findings.

3. Aim

Many reports have been written about the experiences of mental health carers, but, to date, no regular systematic collection of relevant data has been carried out. *Adversity to Advocacy* provided comprehensive national insight to the issues of concern to mental health carers. The MHCA will publish an ongoing survey as part of its commitment to the voice of mental health carers. The ongoing project will provide the opportunity for carers to assess whether their lives are improving, the extent of that improvement, as well as the quality and availability of services available to assist them and the person they care for.

The completed survey and report provides comment and direction on carer as well as consumer services and care to assist policy development, service providers, educational institutions and training managers.

The *Mental Health Survey Report 2010* is the benchmark for recording the lives of mental health carers, against which each successive MHCA report will be measured.

4. Method

The 2010 survey contained 50 questions developed both in response to the 15 major carer concerns identified in *Adversity to Advocacy* and to reflect the direction and content of discussion at the 116 CEP workshops. Forty-three of the questions were analysed using statistical methods, while the remaining seven asked for comments to provide respondents an opportunity to express additional information.

The MHCA distributed surveys to mental health carers in either hard copy or by email depending on their preference. To encourage participation MHCA posted email and website advertisements throughout the relevant sector groups. The MHCA also created an advertising flyer, which it distributed to all of its own members, consumer and carer contacts, as well as to all other interested individuals and organisations. The survey was open to participants for six weeks.

5. Access to specific populations

Over 1,500 mental health carers attended the CEP workshops. 756 carers completed the 2010 survey. Owing to the survey format, only mental health carers with sufficient written English skills were able to respond to either the paper or Internet-based survey.

Both Indigenous workers and the local coordinators who assisted in the CEP workshops agreed that the only way to access the rural Indigenous community experiences was to revisit the communities annually.

> *(The survey) will be an incomplete picture of Indigenous carers' experiences.*[3]

A small number of surveys were received from mental health carers who identified as culturally and linguistically diverse (CALD) or Aboriginal and Torres Strait Islander. This report identifies the need to conduct more targeted work with marginalised groups to gain a better insight into their specific issues.

The survey specifically targeted adults aged 18 years or older. Young carers were excluded from this survey.

6. Survey results

Mental health carers from each state and territory responded to the survey. When these are compared with Australian population data from 2006, it becomes apparent there are similarities between the percentage of mental health carers who responded and the percentage of population in each state and territory, with higher response rates from Tasmania, Northern Territory and the Australian Capital Territory.

State	Survey Sample	2006 Australian Population[4]
	%	%
ACT	3.0	1.6
NSW	31.0	33.1
NT	3.5	1.0
QLD	18.8	19.7
SA	7.4	7.5
TAS	5.0	2.4
VIC	22.7	24.7
WA	8.7	10.0

Table 1 Distribution of survey respondents by state compared to population distribution of Australia (2006 Census population)[4]

To determine the location of respondents, the MHCA used the Accessibility-Remoteness Index of Australia Plus (ARIA+) scores which are a standard Australian Bureau of Statistics (ABS) measure of remoteness[5] to define location. The ARIA map reproduced below is useful in clarifying the relevant classifications which are: major city, inner regional, outer regional, remote or very remote. A 'rural' classification does not exist in that index.

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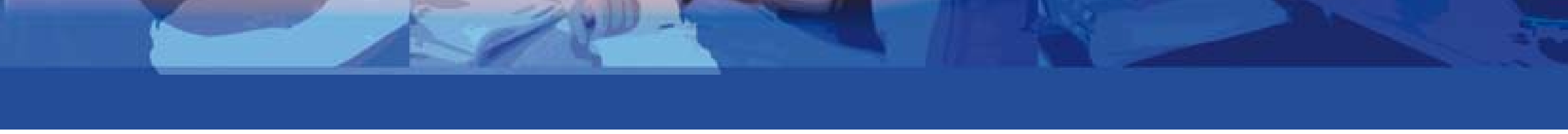
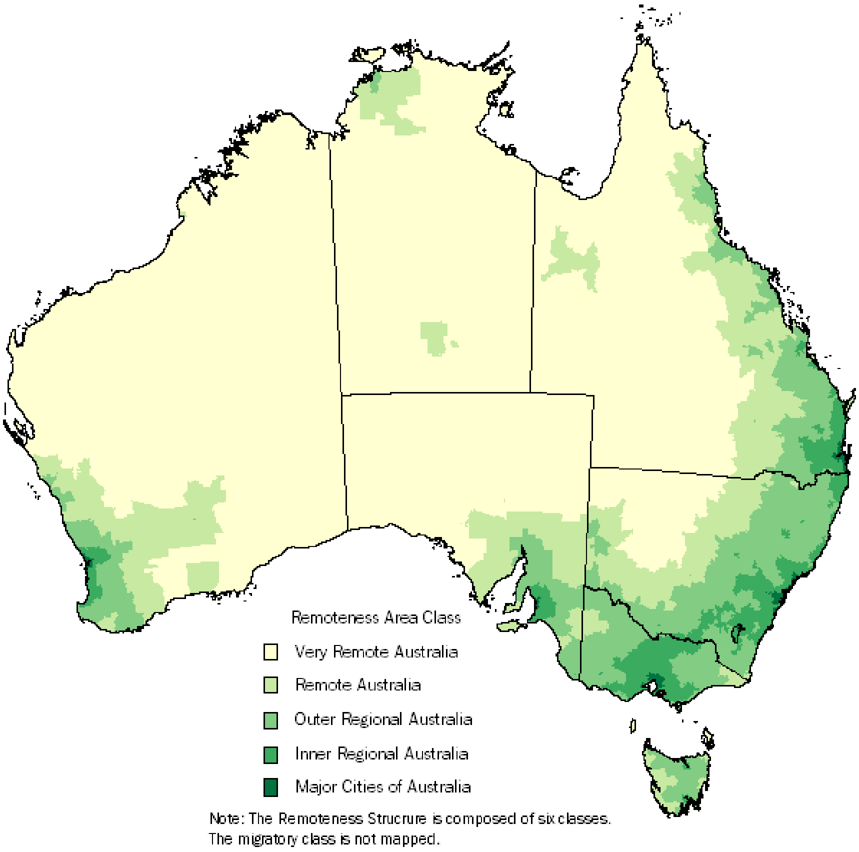
[3] Ibid., p. 83.

[4] Australian Bureau of Statistics, 'Australian Demographic Statistics', December Quarter 2007 (cat. no. 3101.0).

[5] Australian Government, Accessibility-Remoteness Index of Australia Plus (ARIA+).



Map of Australia illustrating the 2006 remoteness structure



While the classification system is important in both standardising data and understanding its implications systematically, some mental health carers living in outer areas or even inner regional areas may consider themselves to be living in rural locations or within the ABS remote classification.

Utilisation of the ARIA classification system reveals that less than half of the mental health carers who responded to the survey lived in major cities, with the majority (52.8%) living in inner and outer regional areas. Australia's vast remote and very remote locations are home to 2.1% of mental health carers who responded to the survey.

Of the 756 total nationwide mental health carer respondents, 615 were female and 139 were male. The youngest respondent was 17 years old (despite the survey being for participants aged at least 18 years) and the oldest was 90, with the mean age being 58. The majority (66.1%) of respondents were over 55 years of age.

English was the main language spoken at home by the majority of mental health carers (95.5%), although a small number of CALD representatives whose main language is not English participated.

A small percentage of respondents (2.3%) identified as being Aboriginal or Torres Strait Islander which is consistent with ABS figures that the national resident Indigenous population in 2006 was 2.5% of the national total.[6]

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[6] Population Distribution, Aboriginal and Torres Strait Islander Australians, 2006

The annual household income of mental health carers varied considerably with 12.6% of carer households earning less than $20,000 annually and 59.4% of households earning less than $60,000. Only 8.9% of households had an income in excess of $100,000 per annum. The median income was $35,000 per household. This compares poorly with the median annual Australian household earnings which reached $66,890 in 2007/2008.[7]

Ninety-two of 340 mental health carers indicated that they spend $100-$200 fortnightly to support the person they care for. It is important to note that 61.4% of mental health carers reported that the consumer had lived with them during the previous 12 months, while only 21.4% indicated that the consumer was living independently. This does not include the remaining consumers living in other situations such as with 'other family' (7.7%) in supported living (9.9%), in an acute care facility/hospital (11.8%), or other accommodation types.

The majority of mental health carers responding to the survey cared for one person, but 20.8% of mental health carers cared for more than one consumer. Sixty percent of consumers were either an adult son or daughter of the carer and 18.4% were partners.

Thirty-one percent of mental health carers reported having been mental health carers for between 11 and 20 years. The median length of time reported caring for a consumer was 10 years with the maximum being 54 years.

Mental health carers reported that most consumers they cared for (64.5%) have more than one disorder, condition or disability and of that group, 40% had a comorbid drug and/or alcohol disorder.

The following table indicates the spread of disorder or illnesses that are comorbid with mental illness.

Disorder, condition or disability	Number of respondents	%
Drug and Alcohol issues	187	40.0
Intellectual disability	78	16.7
Acquired brain injury	34	7.3
Physical disability	94	20.1
Eating disorder	63	13.5
Diabetes	71	15.2
Other	103	22.1

Table 2 What is the nature of the consumer's disorder, condition or disability where more than one exists?

Over 100 mental health carers provided additional comments on this topic, revealing a wide range of conditions and illnesses that are comorbid with mental illness.

While attending the CEP workshops in 2008 and 2009, mental health carers said that they felt isolated and lonely. This was supported by the survey results as 58% of respondents said that they 'always' or 'often' felt alone, with only 14% indicating that they had 'never' or 'rarely' felt alone. When examining this question in terms of location, one third of mental health carers living in remote and very remote areas indicated that they 'never' or 'rarely' felt alone. This result may be distorted because of the small sample size of mental health carer respondents from such locations or could be a reflection of the strong sense of community within those locations.

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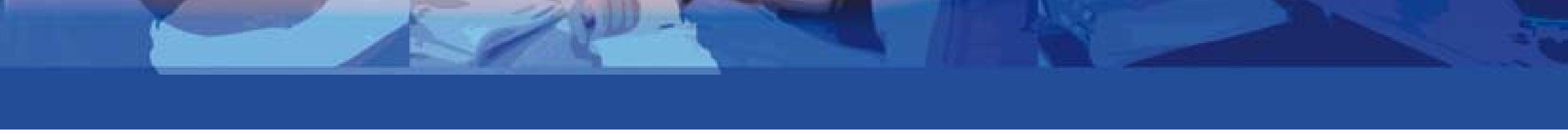
[7] Australian Bureau of Statistics 2009, *Household Income and Income Distribution, Australia 2007-08* (6523.0), ABS, Canberra.



From the data collected, the following picture can be drawn of a typical mental health carer. Many carers are ageing and have been carers for a long time. They often care for adult sons and daughters who most often live with them in the family home, possibly for many years. Mental health carers feel alone and isolated and frequently experience the complex issues of living with a consumer who has other health conditions in addition to mental illness.

Many mental health carers indicated a fear of the future, given the long-term nature of mental illness compounded by their increasing age and ability to care. Many mental health carers are concerned about what will happen to the person they care for after the carer has died.

The issues of concern are complex and involve the consumer and mental health carer's desire that the consumer have lifelong access to safe and appropriate accommodation, companionship, as well as mental health and community services. Mental health carers fear these services and provisions do not exist in the quantity or quality needed at present and when they are no longer able to advocate and facilitate a path on behalf of the consumer, no service or individual will be there to assist. The possibility that there may be a lack of support for consumers after the carer has died is a persistent cause of serious anxiety for many mental health carers.

Carer comments

> *Well thank you for this questionnaire. I hope something positive comes of it for those in need even greater than our own. Just filling it all in is very wearing. As parents we are 80 and 76 and are apprehensive about our son's future when we aren't here.*
>
> *The on-call 24 hour care my husband and I give to our son will be hard to replace. As we get older and less able to care for our son, what quality services are available to replace what we do? His brother and sister help to a limited extent, but will not be willing/able to take on what we are doing.*
>
> *Our middle aged son lives with his ageing and sometimes frail parents (one with Parkinson's disease) as he has no life skills, independence or confidence to live anywhere else. His mental illness prohibits him from living with others and there are not any other appropriate housing choices. Issue: what happens when his parents die and he can't fend for himself? What services are available then, other than aged care for a non-aged care person or public housing which would not help or support his condition?*
>
> *As I am the only person my daughter has, my very deep concern is what is going to happen to her when I can't care for her anymore, when I am not around anymore. There is no one close to her, no one who cares about her. The way things are, she will be totally isolated, especially since her illness has made her paranoid and not accepting of strangers.*

Priority Issue 1 – Listen to and respect carers

At nearly all the 2008 and 2009 CEP workshops, carers identified the following main issues they faced: the lack of respect others had for their caring role; and the unwillingness of clinicians, mental health professionals as well as many people generally to listen to and act on their knowledge of the individuals they care for. Carers indicated that they would like greater recognition for their role and their expertise; to be included in treatment planning; and to work in partnership with mental health service providers and the consumer through open and honest dialogue.[8]

When asked about how much professionals listen to carer concerns the results of the survey were varied with 42% of mental health carers reporting that psychiatrists 'mostly' or 'always' listened to them regarding the health and welfare of the person they care for. Fifty-six percent of mental health carers reported that GPs 'mostly' or 'always' listened.

> *Carers viewed GPs as gatekeepers to accessing assistance in the first instance of mental illness. They also considered GPs to be the first in a line of professionals unwilling or unable to work in partnership with both consumers and carers for better outcomes and wellbeing of consumers.*[9]

Conversely, 17.5% of mental health carers reported that psychiatrists 'never' or 'rarely' listened and another 12.1% indicated that GPs 'never' or 'rarely' listened.

A large number of respondents indicated that psychologists, mental health nurses and community workers were not applicable in relation to this question. Perhaps this is because mental health carers have had little or no access to these groups, hence the lack of mental health carers' involvement. It could also be the case that consumers similarly have little access to this group. Also of interest was the great variation in the percentage of carers feeling listened to depending on the jurisdiction they lived in.

	Always listens	Mostly listens	Sometimes listens	Rarely listens	Never listens	Not applicable	Number of respondents
	%	%	%	%	%	%	
Psychiatrist	20.7	21.3	15.9	9.1	8.4	24.7	668
Psychologist	16.1	12.2	8.5	5.6	5.8	51.9	590
GP	33.0	23.3	14.7	7.1	5.0	16.9	679
Mental Health Nurse	15.7	19.6	12.2	5.6	4.5	42.5	624
Community Worker	22.2	21.8	12.3	4.4	4.0	35.3	643

Table 3 How much do people listen to your concerns about the consumer?

When asked to what degree mental health professionals had made them feel part of the caring team, 39.8% of mental health carers indicated that they 'mostly' or 'always' felt included, while a similar number of mental health carers (34.5%) 'never' or 'rarely' felt part of the caring team. This highlights the inconsistency with which mental health carers are included in consumer care.

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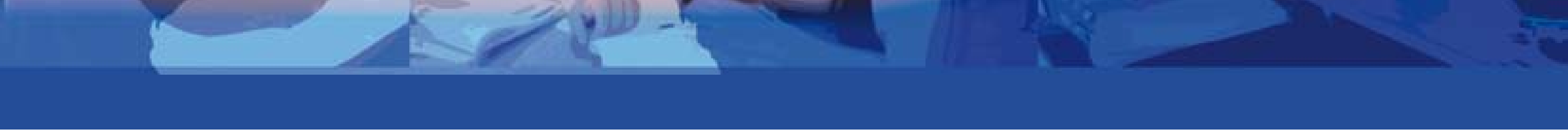
[8] MHCA 2009a, op. cit., p. 21.

[9] Ibid., p. 23.



Carer comments

> *We have been very impressed by the inclusion of us as carers by the team in an inpatient rehabilitation unit our son spent several months in. Prior to that his psychiatrist and community team seemed to ignore our pleas for help for our son.*
>
> *For years, this service practised a carer exclusion ethic. There needs to be better trained staff and more consistency within this service and definitely more accountability. Many of the psychiatrists at the Unit seem to perform selectively and are answerable to no one.*
>
> *The fact that they did not take seriously my concerns, especially following a suicide attempt by my son, resulted in him successfully taking his life soon after being discharged.*
>
> *I never am involved with the caring team. I just pick up the pieces when things go wrong.*

Priority Issue 2 - Integrated recovery-based care for the consumer

Carers attending the 2008 and 2009 CEP workshops strongly supported recovery-based care in the community for those they care for. They also considered that such care was currently supported insufficiently, and thus wanted to see improvements across a range of areas related to recovery. In this context, recovery does not necessarily refer to the absence of a mental illness or its symptoms, but rather to engagement with community and living as well as possible.[10]

Mental health carers were presented with a number of recovery-based care options and asked to indicate which had been available to them during the previous 12 months (Table 4).

It was clear that some mental health carers knew about the availability of Personal Helpers and Mentor (PHaMS) (44.1%); supported employment/training (32%) and day programs (33.6%). Interestingly, just as many, if not more, indicated that these same sources were unavailable or they did not know about them. Clearly, much more work is needed to raise awareness about the services available to mental health carers in their own area.

Most respondents thought the following were either unavailable or did not know of their availability: clubhouse (77.6%), living skills (70.8%), supported employment/training (68.1%), peer support workers (79.2%), and PHaMS workers (55.9%).

	Available	Not available	Don't know	Number of respondents
	%	%	%	
Club House	22.4	41.5	36.1	562
Living Skills	29.3	36.8	34.0	574
Supported Employment / training	32.0	37.5	30.6	579
Personal helpers and mentors (PHaMS workers) / support worker	44.1	29.7	26.2	603
Peer support workers	20.8	40.5	38.7	538
Day program	33.6	32.9	33.6	575
Other	23.1	26.0	50.9	411

Table 4 Were any of the following recovery-based care options available to the consumer during the last 12 months?

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[10] Ibid., p. 25.

Not surprisingly, 77% of mental health carers indicated that they were responsible for organising the majority of care for the person they care for. The medical worker, social worker or case manager organised 10.6% of care with community workers arranging slightly more at 13.9%.

	Number of respondents	%
Medical worker	80	10.6
Community worker	105	13.9
Me or a close family member	582	77.0
Other	124	16.4
Total	756	

Table 5 Who organised the majority of the non-medical care for the consumer in the last 12 months?

Carer comments

Mental health carers provided a significant number of comments on the lack of collaboration within the medical system, other health areas, and the community service area. Many felt a distinct lack of cooperation between different service providers in relating with each other, but also between service providers and themselves as a coordinator of consumer care. Mental health carers often step into the breach and organise, coordinate or provide recovery-based services for the consumer. Without mental health carers, intervention services delivered to the consumer would be ad hoc, uncoordinated or, at worst, would not exist.

The level of commitment by operators of services is mostly very good to excellent. However, we have identified a serious issue with communication, continuity of care and record keeping. Lack of coordination between all levels of mental health workers and associated workers needs to be improved to maintain a better level of safe care for the consumer. This places an unnecessary burden and level of stress onto the primary carer and consumer.

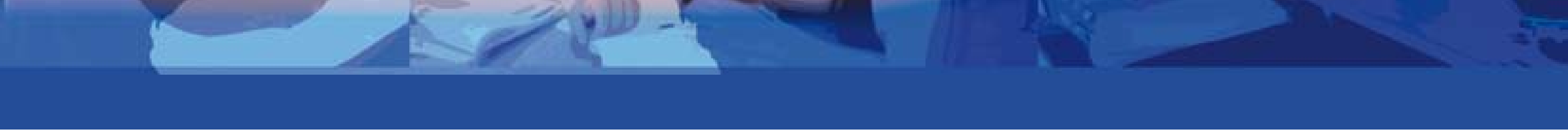
We desperately need more mental health professionals in the community, not more beds. We have enough beds, but resources and staffing levels are very low in community health centres with staff carrying overwhelming burdens. Why is there no new money for the community? When are we going to stop building new beds and instead focus on the 80% of people with a mental illness who live in the community?

All the services are in place for my son and I work hard to keep (them). However whenever I go away for a week, things break down quickly. This is because I am still the central carer.

I am a Personal Helper and Mentor and therefore am involved in the Care Coordination program. There is a big improvement in service provision already, but will improve a lot more if time is spent promoting the program to other services.

Discharge plan was discussed in hospital, but there has been little follow up by the care team i.e. case manager re moving on within the parameters of goals, work etc. Our son would benefit from encouragement to do voluntary or paid work, but his case manager is only interested in regular medication.

We have established a small but reliable informal network of five family members. The treating team does not include or communicate with any of us. I have met the psychiatrist once. We get to pick up the pieces when the wheels fall off basically.



Priority Issue 3 - More and better trained staff at all levels

At almost all of the 2008 and 2009 CEP workshops, carers identified the need for more and better trained staff across the mental health service system. They saw low levels, high turnover and reduced quality of staff as significant impediments to obtaining adequate care for those they care for.[11]

Survey results and discussion of findings are under Priority Issue 5 – Carer and consumer education for all professional groups and agencies.

Priority Issue 4 – Knowledge and information for carers

A theme raised by carers at almost every 2008 and 2009 CEP workshop was the difficulty that they experienced in accessing information and acquiring knowledge required to successfully fulfil their caring role. This included information about 'how to' care as well as information on what services are available for carers and those they care for.[12]

During the last 12 months there appears to have been an improvement in access to information and knowledge for mental health carers. Eleven percent of mental health carers reported that information and knowledge has 'always' been available, with 33.4% indicating that that has 'mostly' been the case. Thirty percent of mental health carers reported it had 'sometimes' been available with the remaining 26.2% saying information was 'never' or 'rarely' available. This seems to be an improvement for mental health carers over what was previously reported at the CEP workshops, and in *Adversity to Advocacy*[13]

	Number of respondents	%
Always	78	10.9
Mostly	239	33.4
Sometimes	211	29.5
Rarely	127	17.7
Never	61	8.5
Total	716	

Table 6 During the past 12 months has the information you needed to help you care for the consumer been easily available?

The ACT reported the largest number of mental health carers (57.2%) stating that information was 'rarely' or 'never' available. This was in contrast to NT mental health carers, with only 27.3% responding in a similar manner.

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[11] Ibid., p. 29.
[12] Ibid., p. 32.
[13] Ibid.

	Always	Mostly	Sometimes	Rarely	Never	Number of respondents
	%	%	%	%	%	
ACT	4.8	9.5	28.6	38.1	19.1	21
NSW	13.8	40.6	21.7	18.0	6.0	217
NT	18.2	18.2	36.4	4.6	22.7	22
QLD	11.6	26.8	34.1	18.8	8.7	138
SA	14.6	25.0	29.2	20.8	10.4	48
TAS	5.9	32.4	35.3	11.8	14.7	34
VIC	5.5	34.8	35.4	15.9	8.5	164
WA	14.5	41.9	22.6	19.4	1.6	62

Table 7 During the past 12 months has the information you needed to help you care for the consumer been readily available, distribution by state

Mental health carers were asked whether the information needed to care for the consumer had been offered at the right time during the previous 12 months. Thirty four percent of mental health carers stated that information had ‘mostly’ or ‘always’ been offered at the right time, while 37.8% of mental health carers said it had ‘never’ or ‘rarely’ been offered at the right time.

	Always	Mostly	Sometimes	Rarely	Never	Number of respondents
	%	%	%	%	%	
ACT	0.0	19.1	19.1	47.6	14.3	21
NSW	10.5	30.1	30.6	20.6	8.2	219
NT	4.6	27.3	18.2	27.3	22.7	22
QLD	8.8	25.7	33.1	19.1	13.2	136
SA	10.4	25.0	31.3	20.8	12.5	48
TAS	5.6	25.0	30.6	19.4	19.4	36
VIC	6.7	30.3	30.3	18.8	13.9	165
WA	11.5	39.3	24.6	18.0	6.6	61

Table 8 During the last 12 months has the information you needed to help you care for the consumer been offered at the right time, distribution by state

When carers were asked where they sourced information to help care for the consumer, a large proportion of respondents indicated GPs (45.5%), carer services (44.8%), the Internet (36.6%) and psychiatrists (35.7%). ‘Other’ was an option when answering the question and a frequent response within that category was ‘own’ or ‘family research’.

	Number of respondents	%
Psychiatrist	270	35.7
Psychologist	154	20.4
GP	344	45.5
Mental health nurse	211	27.9
Community worker	211	27.9
Bilingual worker	6	0.8
Aboriginal worker	7	0.9
Drug and alcohol worker	35	4.6
Pharmacist	132	17.5
Internet	277	36.6
Carer services	339	44.8
Centrelink	137	18.1
Housing	37	4.9
Triage/helplines	54	7.1
Police	58	7.7
Social worker	94	12.4
Counsellor	120	15.9
Other	219	29.0
Total	756	

Table 9 **During the last 12 months where have you sourced information to help you care for the consumer**

Carer comments

> *We are not skilled in dealing with mental illness and we are often at a loss about how to behave effectively, how to help and how to cope when we are worn down by the never- ending nature of the illness.*
>
> *At times, I don't know what questions to ask.*
>
> *Carers feel helpless and fearful when faced with psychosis with no information from the acute care staff on how they should be dealing with this and absolutely no information from anyone on how to look after the consumer after discharge.*

Priority Issue 5 - Carer and consumer education for all professional groups and agencies

Carers attending the CEP workshops recommended consumer and carer education for a broad range of clinicians and professional groups to address their lack of understanding of mental illness and the role of carers.[14]

When asked how well carer and consumer issues are understood by professionals, the responses were varied. Twenty-five percent of respondents indicated psychiatrists understood their issues ‘well’ to ‘very well’, with another 32.2% providing GPs with the same rating. In contrast, 39.4% of respondents indicated psychiatrists understood their issues ‘not at all’ or ‘a little’, compared to 33.2% of GPs. This indicates that mental health carers across the board have quite mixed experiences with service providers.

There were a large number of ‘don’t know’ responses for some professional groups. This was expected to be the case in some categories because not every mental health carer has access to all the professionals on the list. The ‘don’t know’ section may produce information about the mental health carers’ lack of access to that group in terms of information or support. For example, many communities have a pharmacist who is in a good position to help the carer understand the side effects of medication, yet 30.5% answered ‘don’t know’, possibly because of lack of access to this group. Of the remaining 60% of respondents who did access a pharmacist, 25.1% reported that the pharmacist understood ‘not at all well’ or ‘only a little’ of carer and consumer issues.

Adversity to Advocacy reported that Centrelink staff lack understanding when dealing with mental health carer and consumer issues. Of the 63% of mental health carers who responded to the relevant survey question, 44.6% said that Centrelink staff ‘understood a little’ or ‘not at all’ the issues facing consumers and mental health carers. Carers also held similar views of housing officials.

Other notable replies relate to the response of school staff. Only 31% of mental health carers responded to this question, with 23.2% of the response group reporting that school staff understand ‘not at all well’ or ‘a little’ about the issues facing consumers and mental health carers.

Prison staff and court officials also scored poorly on their levels of understanding.

Police are often the only emergency response to an acute and/or urgent situation involving mental illness, thus one would expect mental health carers would have significant contact with them. Of the 494 mental health carers who responded to this question, 34.1% said police understood ‘not at all’ or ’a little’ of the issues of consumers and mental health carers, while 44.9% did not know. Fewer mental health carers in NT (28.6%) and WA (35.7%) responded ‘don’t know’ to the question of how well consumer and mental health carers issues were understood by the police. A possible explanation is the NT and WA have extensive remote and very remote areas and carers in remote areas do not have the option of calling for assistance from anyone other than the police.

The responses by state and territory were quite varied, both within, and between jurisdictions, however caution should be exercised when interpreting these figures given the mostly low response rates in the less populated jurisdictions. The ACT response varied, but of the 52.6% of respondents, 21% reported that the police understood ‘very well’ or ‘extremely well’ mental health carer and consumer issues. In Queensland the scores of understanding ‘very well’ and ‘extremely well’ reached 11.2%, higher than most of the other states. The scores for police understanding carer and consumer issues were low overall, under 10% in NSW, NT, SA, TAS and WA.

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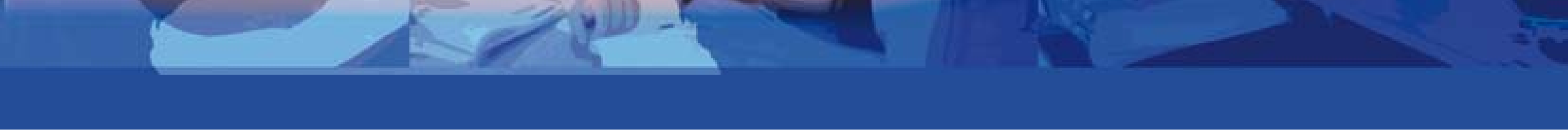
[14] Ibid., p. 36.



	Extremely well	Very well	Quite well	A little	Not at all well	Don't know	Number of respondents
	%	%	%	%	%	%	
ACT	10.5	10.5	0.0	21.1	10.5	47.4	19
NSW	2.1	7.6	11.8	16.0	18.1	44.4	144
NT	0.0	7.1	14.3	14.3	35.7	28.6	14
QLD	6.1	5.1	6.1	21.2	15.2	46.5	99
SA	2.9	5.9	11.8	26.5	8.8	44.1	34
TAS	0.0	0.0	15.0	10.0	15.0	60.0	20
VIC	0.8	9.8	9.8	14.8	12.3	52.5	122
WA	0.0	4.8	26.2	14.3	19.1	35.7	42

Table 10 How well do you think carer and consumer issues are understood by police, distribution by state

The responses regarding social workers and counsellors was similar, with 20% of mental health carers indicating that employees in those fields understood carer and consumer issues 'not at all well' or 'only a little'.

Of those respondents who indicated that they had accessed triage/helplines when the consumers they cared for were acutely unwell, over half rated the understanding of consumer and mental health carer issues by those providing the emergency response as 'not at all well' or only a 'little'.

Carer services were loosely defined as support groups, information and support and did not refer to any particular service provider or model. Of the 81% of mental health carers who responded, over 51% stated that carer services understood consumer and carer issues 'very well' or 'extremely well' with a further 17% understanding them 'quite well'.

	Extremely well	Very well	Quite well	A little	Not at all well	Don't know	Number of respondents
	%	%	%	%	%	%	
Psychiatrist	8.7	15.8	24.6	19.4	20.0	11.5	670
Psychologist	5.9	15.5	19.9	17.0	12.8	29.0	594
GP	12.0	20.2	27.1	21.3	11.9	7.5	682
Mental health nurse	9.0	19.7	22.0	13.8	9.5	26.0	600
Community worker	10.7	18.1	18.4	13.9	8.4	30.5	570
Bilingual worker	1.4	1.7	1.9	1.7	2.6	90.8	423
Aboriginal worker	0.5	2.1	2.6	1.0	2.1	91.7	422
Drug and alcohol worker	3.3	5.9	11.5	4.8	5.2	69.4	461
Pharmacist	9.5	15.2	19.6	17.4	7.7	30.5	545
Carer services	25.7	25.7	16.9	8.5	4.3	19.0	611
School staff	0.7	2.5	4.5	10.9	12.3	69.2	448
Housing officials	1.1	3.4	6.1	8.5	15.4	65.5	476

	Extremely well	Very well	Quite well	A little	Not at all well	Don’t know	Number of respondents
	%	%	%	%	%	%	
Triage/helplines	4.5	7.3	11.5	14.9	12.2	49.7	469
Centrelink staff	4.2	6.4	17.4	20.8	23.8	27.4	547
Prison staff	0.0	0.7	2.1	3.9	7.8	85.6	436
Court officials	1.1	2.0	6.2	8.1	12.1	70.6	455
Police	2.8	7.2	11.4	17.0	15.6	46.1	501
Social worker	7.8	12.3	17.6	12.5	7.2	42.5	511
Counsellor	7.4	16.1	15.5	13.0	5.6	42.4	502

Table 11 **How well do you think carer and consumer issues are understood by the following professionals?**

Carer comments

> *The support provided to me in a rural area is poor. Our case manager is spread too thin and wanted to help more, but couldn’t because of the workload. We have had to use a private psychiatrist. Fortunately, we can afford it and have private health cover. I feel sorry for those who don’t…*
>
> *After many years trying to get treatment the person I care for was put on a fortnightly injection. Was doing well on it for 2 years, we asked to work with the new doctor, but she ignored our requests and took him off medication and didn’t follow up. He was off medication, not under anyone’s care and is psychotic again. All we can do is wait for him to deteriorate to a point where he has to be scheduled again. What a waste of resources, time and his life and dignity.*
>
> *I think that the Mental Health Crisis Team in our state should be peopled by staff who are interested in working with consumers with a mental health problem. I include hospital emergency staff in that category. Too often, they are dismissive of patients who are in acute need.*
>
> *I can’t speak too highly of the psychiatric and nursing staff at my local hospital.*

Priority Issue 6 - Support systems, services and processes established for carers

Carers attending the CEP workshops in 2008 and 2009 said that they wanted to see more carer services and supports as well as improvements in existing services so that they reflect their requirements. They identified gaps in existing service provision, as well as barriers in accessing existing services and supports. Carers also wanted to see the implementation of services and supports that recognised the value of their work and their needs in undertaking the caring role.[15]

During the CEP workshops, a number of services and support systems were identified. One purpose of the survey was to establish whether access to and quality of the identified services changed over time (Table 12 and 13).

Only 8.5% of respondents indicated they ‘did not know’ of carer support groups or felt they were ‘not required’. Sixty-six percent of respondents indicated carer support groups were ‘mostly’ or ‘always’ available. This is a much higher figure than those determined for other services. For example, carer counselling (40.6%)

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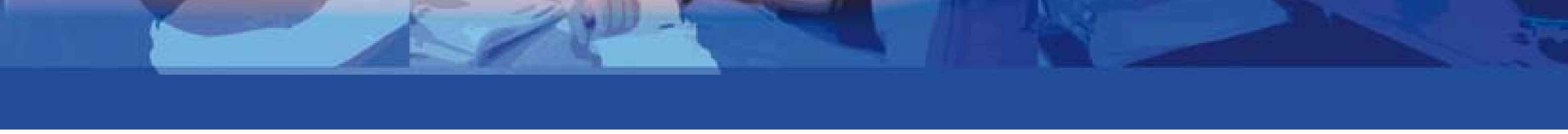
[15] Ibid., p. 39.



or carer respite (28.8%) being either ‘mostly’ or ‘always’ available. Twenty-six percent of mental health carers reported carer counselling was ‘rarely’, ‘never’ or ‘not available’ in their area. They also indicated that carer respite was ‘rarely’, ‘never’ or ‘not available’ in their area (28.4%).

The availability of services to help consumers followed a similar pattern. Pharmaceutical drug information was ‘mostly’ or ‘always’ available (50%), Internet-based services ‘mostly’ or ‘always’ available (41.9%) and information to help the consumer ‘mostly’ or ‘always’ available (35.2%).

	Always	Mostly	Sometimes	Rarely	Never	Not available in my area	Don’t know/ not required	Number of respondents
	%	%	%	%	%	%	%	
Carer support groups	47.8	18.3	11.5	4.2	6.9	2.9	8.5	696
Carer counselling	26.1	14.5	17.8	8.6	14.0	3.1	15.9	648
Carer respite	17.4	11.4	15.7	8.2	16.5	3.7	27.0	648
Pharmaceutical drug information	28.7	21.3	16.4	7.2	7.5	1.1	17.8	628
Information on how to help the consumer	15.8	19.4	26.8	15.2	11.6	1.9	9.3	645
Internet based services	25.4	16.5	15.3	4.7	6.4	1.2	30.5	594

Table 12 Have the following services been available to you over the last 12 months

When asked about the quality of carer support services, 78.6% of mental health carers indicated they utilised carer support groups with 61.2% finding them ‘good’ or ‘excellent’. Two thirds of mental health carers used carer counselling and of that number, 39.1% found the service to have been ‘good’ or ‘excellent’. Forty-eight percent of mental health carers reported they had not utilised carer respite or that it was unavailable. Of the 52.4% of mental health carers who had used carer respite, 28% reported it was ‘good’ or ‘excellent’.

	Excellent	Good	Average	Poor	Very poor	Not available	I haven’t used them	Number of respondents
	%	%	%	%	%	%	%	
Carer support groups	36.2	25.0	9.1	3.5	2.6	2.2	21.4	683
Carer counselling	18.2	20.9	12.4	5.3	6.4	5.2	31.6	637
Carer respite	14.0	14.0	11.1	5.9	7.3	5.9	41.7	641
Pharmaceutical drug information	15.6	30.8	17.7	4.7	5.6	1.8	23.9	623
Information on how to help the consumer	8.2	25.4	22.2	12.9	13.3	3.1	14.9	645
Internet based services	11.9	23.3	19.1	4.4	2.4	1.7	37.3	596

Table 13 Please comment on the quality of the services available to you over the last 12 months

Carer respite services, when compared to carer support groups and carer counselling, did not score highly in terms of either service availability or quality.

Carer respite was found to be the least used and rated either 'not known' or 'not required' (42.9%) in the ACT, while the states and territories which used the services most were NT and WA. Respite care was 'mostly' or 'always' available in WA (42.6%) and VIC (32.6%). TAS (12.9%) and QLD (18.1%) scored least well on respite care being 'mostly' or 'always' available.

	Always	Mostly	Sometimes	Rarely	Never	Not available in my area	Don't know/ not required	Number of respondents
	%	%	%	%	%	%	%	
ACT	14.3	4.8	0.0	14.3	23.8	0.0	42.9	21
NSW	17.9	12.8	16.8	8.2	14.8	5.1	24.5	196
NT	27.3	18.2	4.6	4.6	18.2	9.1	18.2	22
QLD	7.9	10.2	15.0	11.0	19.7	3.9	32.3	127
SA	19.6	10.9	10.9	10.9	10.9	2.2	34.8	46
TAS	3.2	9.7	22.6	9.7	22.6	0.0	32.3	31
VIC	20.8	11.8	18.1	6.3	16.0	2.1	25.0	144
WA	33.3	9.3	14.8	3.7	14.8	5.6	18.5	54

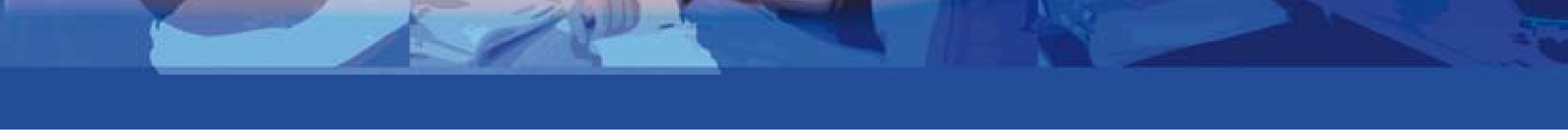
Table 14 Have respite services been available to you over the last 12 months, distribution by state

The number of mental health carers who had used respite care and responded to the question varied considerably from state to state with 32.1% of respondents from NSW and 38.1% from WA reporting respite services were 'good' or 'excellent'. This compared to only 19.1% of QLD respondents. It is difficult to report on the other jurisdictions owing to their low response rates to this question.

A more detailed question on carer respite is outlines in Priority Issue 12 - Flexible respite options for carers.

	Excellent	Good	Average	Poor	Very poor	Not available	I haven't used them	Number of respondents
	%	%	%	%	%	%	%	
ACT	0.0	4.6	4.6	4.6	18.2	4.6	63.6	22
NSW	15.0	17.1	13.4	6.4	7.0	4.8	36.4	187
NT	20.0	20.0	0.0	15.0	0.0	15.0	30.0	20
QLD	10.3	8.7	9.5	7.1	7.1	6.4	50.8	126
SA	13.3	11.1	8.9	6.7	11.1	11.1	37.8	45
TAS	6.9	20.7	10.3	0.0	6.9	6.9	48.3	29
VIC	14.1	15.4	11.4	4.7	6.7	5.4	42.3	149
WA	27.3	10.9	10.9	3.6	7.3	3.6	36.4	55

Table 15 Quality of respite care services available over the last 12 months, distribution by state



Carer comments

> *Imagine how much more effective our support could have been if we had been provided relevant information and education through this journey. Imagine how much less stress there would have been for our family and specifically us as parents. Imagine the benefits to our son in potentially reducing the length of time this journey is taking.*
>
> *The Carer Assist program has been of huge support and information that has made my role a whole lot more effective, enabled me to better understand my son's plight in a non-judgemental way, and thus be better equipped to manage what I am able to do to assist him.*
>
> *I have had no success in accessing carer support services, in particular, carers counselling. After making enquiries at one service, I was referred to another, who referred me back to the first service. If it is this difficult for a carer to access support, I can only imagine how difficult it is for the consumer!*
>
> *I work full-time and am unable to access the excellent carer support organisation in my community. This leaves me feeling incredibly isolated as I'm sure other workers face common issues. Rural living compounds this access issue.*
>
> *One problem with carers support is that it is not for very long. Funding or the lack of it is often the problem.*

Priority Issue 7 - Acute care should be therapeutic and accessible

Ideally, acute or crisis situations can be avoided through early intervention when symptoms first become apparent. As discussed in *Adversity to Advocacy*, carers reported great difficulty in accessing early intervention, increasing the likelihood that acute situations will occur. Carers attending the CEP workshops said that there should be significant improvements in the quality and accessibility of acute care during crises for those they care for.[16]

The survey question relating to acute care asked about the availability of services if the consumer had been extremely unwell during the previous 12 months. The list of services and items defined at the CEP workshops as being of significance to mental health carers in the delivery of adequate acute care for consumers included:

- 24 hour emergency outreach team.
- Quick response from outreach team.
- Consumer activity encouraged and available in acute service.
- No early discharge.
- Discharge plan discussed with carer before discharge, information and assistance offered to carer by acute medical staff.
- 24 hour emergency telephone line.
- Assistance with language and translation.
- Detox services, case worker access when needed and information as to where the consumer has been taken offered within 12 hours.

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[16] Ibid., p. 43.

Most respondents reported they ‘did not know’ if the services listed above were available when the person they cared for was extremely unwell during the previous 12 months. Most respondents (31.8%) reported no acute services were accessed when the consumer was extremely unwell.

In general terms the highest percentage of responses was scored in the ‘never’ or ‘rarely’ available section (27.9%).

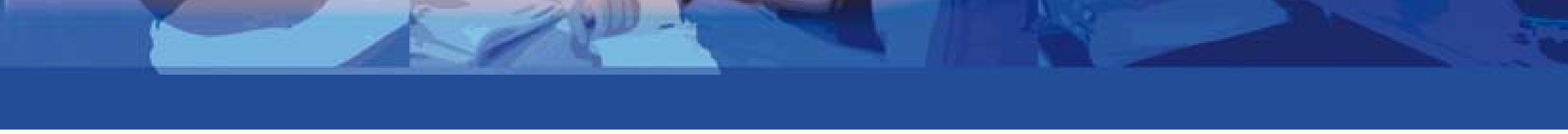
The highest positive score was achieved for the availability of a 24 hour emergency telephone number with 36.7% or respondents finding it ‘mostly’ or ‘always’ available.

Twenty-eight percent of respondents stated they were unaware of the 24 hour emergency outreach team and a further 33.3% stated it was ‘never’ or ‘rarely’ available. Thirty-six percent of mental health carers indicated they did not know whether or not consumer activity was encouraged or available in the acute service with a further 40.4% of mental health carers stating consumer activity in the acute service was ‘never’ or ‘rarely’ available.

Results for both the discharge plan being discussed with carers and information offered by acute medical staff to assist the carer were similar with 38.7% and 41.9% of respondents choosing ‘rarely’ or ‘never’ for these categories respectively. A further 29.4% and 25.2% respectively stated that these services were not known to them.

	Always	Mostly	Sometimes	Rarely	Never	Not known by me	Number of respondents
	%	%	%	%	%	%	
24 hour emergency outreach team	12.6	14.6	11.4	9.0	24.3	28.2	412
Quick response from 24 outreach team	9.5	14.5	12.3	10.0	25.6	28.1	399
Consumer activity encouraged and available in acute service	5.6	13.5	10.6	14.6	20.4	35.5	378
No early discharge	7.8	9.8	11.2	8.1	16.5	46.7	358
Discharge plan discussed with carer before discharge	10.1	9.9	12.0	9.1	29.6	29.4	385
Information and assistance offered to carer by acute medical staff	8.5	13.6	10.8	13.9	28.0	25.2	389
24 hour emergency telephone line	25.7	11.0	7.9	3.9	17.3	34.1	381
Assistance with language and translation	1.6	1.6	0.6	1.0	8.0	87.1	311
Detox services	1.3	2.8	4.1	2.8	13.5	75.6	319
Case worker accessible when needed	9.0	15.2	17.5	15.5	18.2	24.7	401
Information as to where the consumer had been taken offered within 12 hours	19.4	11.5	6.5	4.8	12.6	45.2	356

Table16 When the consumer was extremely unwell during the last 12 months were the following services available?



When asked about the benefit of acute services to the consumer's health during the preceding 12 months, 31.8% of mental health carer respondents stated they had not utilised these services, whilst 34% indicated that such services were 'mostly' or 'always' beneficial. Sixteen percent of mental health carers said acute services were 'never' or 'rarely' beneficial to the consumer's health.

	Number of respondents	%
Always	59	11.1
Mostly	122	22.9
Sometimes	97	18.2
Rarely	49	9.2
Never	36	6.8
No acute services were accessed	169	31.8
Total	532	

Table 17 Were the acute services beneficial to the consumer's health during the last 12 months?

Mental health carers were asked to indicate the distance travelled to access specialised mental health services for the consumer. Most respondents (62.6%) replied that they travelled less than 20km for that purpose, although 6.9% of carers travelled in excess of 200km.

Carer comments

In our region there are no mental health crisis response teams. We utilise the police.

I did not use local public acute services due to past experiences and detox and rehab services are not available locally. Transported my son to Sydney, myself, 400km away.

Being in rural Australia where there are limited services means greater turnover of workers. Hundreds of miles to travel for specialist services. Why are the rules so hard on us to be able to get help with travel and accommodation and specialist services? Why can't we get help, and why does it take over 100kms before you can get it?

Mental health workers are available locally, however when in need of acute care it takes too long to organise a video link to psychiatrist in order to be suitably placed.

Mental health services were only interested if my son was suicidal. There is a very large range of dysfunction that exists before suicidality that my family have had to live through.

While acute services were beneficial in treating the psychosis i.e. administering medication, the time and energy exerted to have the person I care for admitted to the unit was a long and exhausting process. Discharged early due to shortage of beds and limited follow-up on discharge.

Priority Issue 8 - Stigma, discrimination and isolation for carers and consumers

Carers at the CEP workshops in 2008 and 2009 identified the extremely negative effects of stigma and discrimination that resulted from caring for a person with mental illness. They spoke of discrimination not only against those they care for, but also against themselves, owing to their relationship to a person with mental illness, which is often highly stigmatised.[17]

Most respondents to the survey (56.4%) thought stigma and discrimination 'exist to some extent' in their local communities during the previous 12 months. This was similar for all states and locations. However, a further 39.3% reported stigma and discrimination was 'widespread'. When the results were defined by location the results were strikingly similar for the major cities, inner and outer regional locations.

	Stigma and discrimination are widespread	Stigma and discrimination exist to some extent	Stigma and discrimination do not exist	Number of respondents
	%	%	%	
Major cities	39.5	56.0	4.6	327
Inner Regional	39.9	56.9	3.2	218
Outer Regional	39.4	56.9	3.8	160
Remote/Very Remote	26.7	60.0	13.3	15

Table 18 Extent of stigma and discrimination around mental illness in your local community, by location

Respondents most commonly reported stigma and discrimination were 'widespread' (49.7%) in the wider Australian community during the previous 12 months. This was similar for most states and locations. A further 47.8% of mental health carers stated stigma 'existed to some extent'.

When comparing figures for the local community and the wider Australian community a 10% difference in the degree of stigma and discrimination was recorded. In the former, 39.3% of mental health carers said stigma and discrimination was widespread, but for the latter the figure increased to 49.7%. When mental health carers responded to the proposal that stigma and discrimination 'existed to some extent', the figure reported about the local community was 56.4%, compared to 47.8% for the wider Australian community.

Carer comments

> *My partner wants to hide his mental illness from others. This was extremely hard to me. He was very shamed about his illness.*
>
> *Living in a private rental sounds good, but, even if he could afford it, no-one wants to rent to a person on a pension, let alone someone with a mental illness.*
>
> *I have not told anyone about dad at work, for fear of being judged as I am a community worker supporting people that are disengaged and disadvantaged.*
>
> *Migrants never talk about mental illness, so that my family suppress their needs, that is the worst situation too.*
>
> *Funding is needed in rural community education and support so people can feel less isolated and break down fear and stigma. My daughter is open and honest with people about her condition and has subsequently been discriminated against because of this through fear and lack of opportunities.*

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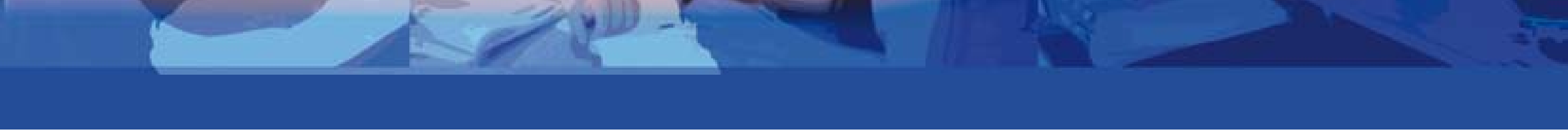
[17] Ibid., p. 45.



Priority Issue 9 - Accommodation options for consumers at all levels of care

Carers at many of the 2008 and 2009 CEP workshops raised the matter of accommodation for the person they care for as a major concern. This reflects the significance of housing as an issue for people with mental illness. Rates of mental illness in the homeless population are high, and people with mental illness may face a range of additional barriers in maintaining stable housing as explored in detail in the MHCA *Home Truths: mental health housing and homelessness in Australia*[18] report. Many carers who attended the workshops had those they care for living with them. In some cases this was not an ideal situation for either carer or consumer, but the lack of other accommodation options meant that accommodation and support provided by the carer was the only thing keeping the consumer from homelessness.[19]

The majority (61.4%) of mental health carers reported the person they cared for lived with them during the previous 12 months and a further 7.7% that the person they care for resided with other family members. This was similar for all states and locations. During the last 12 months, 21.4% of respondents indicated the person they cared for was living independently, while a further 11.1% spent time in an acute care facility or a hospital. Less than one percent of mental health carers reported that the person they cared for had spent time in a step up/step down facility; around one percent in prison or hostel accommodation; and two percent in a group home. In the previous 12 months, one percent of mental health carers were unsure where the consumer lived and 3.3% of mental health carers reported the consumer lived on the street.

	Number of respondents	%
With me	464	61.4
With other family	58	7.7
Independently	162	21.4
Supported independent living	75	9.9
Group home	15	2.0
Hostel	11	1.5
On the street	25	3.3
Public unsupported accommodation	40	5.3
Private unsupported accommodation	49	6.5
Acute care facility/hospital	84	11.1
Step up/step down facility	6	0.8
Prison	9	1.2
Residential rehabilitation	21	2.8
Unsure	10	1.3
Other	68	9.0
Total	756	

Table 19 Where has the consumer lived during the last 12 months?

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[18] MHCA 2009b *Home Truths: Mental Health, Housing and Homelessness in Australia*, MHCA, Canberra.

[19] MHCA 2009a, op.cit.,p. 49.

A further question was asked to ascertain if mental health carers were aware of alternative accommodation for consumers in their local area.

Several mental health carers thought that the question could be misleading because although mental health carers were aware of a variety of accommodation options in their area the size of the waiting list to access them was excessively long. Demand for safe and appropriate accommodation for mental health consumers far exceeded supply.

The majority (44.4%) of respondents were unsure of the accommodation options available for consumers in their area during the previous 12 months.

The question had a poor response rate overall. For example, only 25 mental health carers responded to the option of a step up/step down facility being available in their area, which could indicate a lack of knowledge of the terminology and/or a paucity of this type of accommodation. During the CEP workshops, many mental health carers had not heard of the term or known of a service that offered short-term accommodation for consumers when they became unwell or after discharge from an acute service. Mental health carers who knew of step up/step down facilities as well as those who were introduced to the concept at the CEP workshops considered the service greatly beneficial.

	%	Number of respondents
Supported independent living	14.2	107
Group home	5.7	43
Hostel	4.1	31
Step up/step down facility	3.3	25
Public unsupported accommodation	9.0	68
Private unsupported accommodation	13.6	103
Residential rehabilitation	5.7	43
Unsure	44.4	336
Total		756

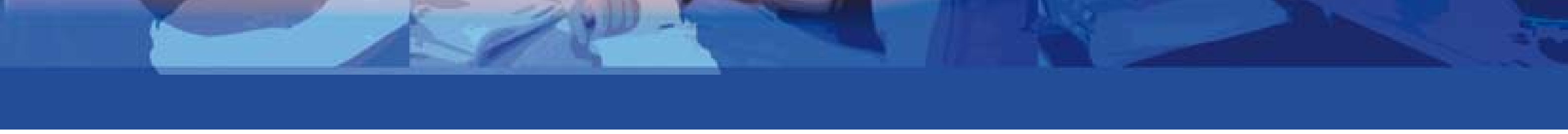
Table 20 Which of the following accommodation options were available in your area during the last 12 months?

Carer comments

Housing is a huge issue. If I put my daughter out on the street she would get housing, but because I won't do that she will probably never be considered needy.

Appropriate accommodation is one of the major issues in our area (rural), we have limited supported and semi-supported accommodation. Public housing made available to mental health clients, in the main, is not appropriate in that it is in blocks or small estates that have other residents that leave mental health clients very vulnerable to exploitation, with little or no monitoring.

There is no available facility between the acute care facilities and re-entering normal society. Is it too difficult for an unwell person to manage the pressures of living out in society and navigate the services available on their own.



It's a black hole. Most of our concerns are whether our son can live alone (or part of a group house) as he has slid backwards before in such a setting. The stigma of Centrelink and difficulty in getting independent accommodation while not having full-time employment means most options collapse, and he remains at home.

My son has Schitzo-Affective Bipolar Disorder and cannot live independently. Like so many others, if there is no family to support them, they are homeless (and it is very tough on families).

I have bought this unit to leave in trust for my son when I die as I along with other carers fear for our children future. The unit is called an Investment property by Centrelink.

Priority Issue 10 - Financial costs to carers

Carers of people with a mental illness may face a range of associated financial burdens, some of which may be expenses related directly to provision of care itself, such as those for medication, medical appointments and transportation. Other costs might pertain to the behaviour of those in their care when that person is unwell and cover such things as damage to property, fines, and financial commitments. The financial burden on many carers is considerably greater because they have to give up or reduce paid employment as a result of their caring responsibilities. Research indicates that one-third of those providing primary care for elderly or disabled people live in households with incomes falling into the poorest one fifth of households in Australia. A 2006 survey found that 44 percent of carers of those with mental illness reported that their financial situation worsened when those they care for experience a relapse. While carer support payments and allowances are available from Centrelink, carers often report that these are difficult to access and insufficient.[20]

Of the 340 respondents who answered the question referring to the amount of money they spent on the consumer the following information was received. The median amount spent on the person they cared for fortnightly was $100. Some mental health carers provided independent living accommodation for the person they cared for at their own expense, by either purchasing or renting. Other mental health carers reported paying for medication and other essentials. Considering that the majority of mental health carers responding to this survey care for an adult son or daughter and 61.4% of mental health carers reported that the person they cared for lived at home, it appears mental health carers are providing substantial financial and other support.

	Number of respondents	%
$0-$24	41	12.1
$25-$49	29	8.5
$50-$99	77	22.7
$100-$199	92	27.1
$200-$499	82	24.1
$500+	19	5.6
Total	340	

Table 21 Median fortnightly costs for the carer for the consumer

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[20] Ibid., p. 52.

	Not applied for	My application has been rejected	Am an existing recipient	Not used	Number of respondents
	%	%	%	%	
Carer payment	42.4	4.7	20.6	32.3	635
Carer allowance	35.7	6.9	35.2	22.2	681
Travel costs to remote hospital	44.6	0.7	3.5	51.2	605
Carer accommodation costs to access remote hospital	44.7	0.5	2.0	52.8	599

Table 22 **Have you applied for any of the following during the last 12 months?**

Carer comments

> *We have had to travel over 700km each way weekly for appropriate and necessary support. I feel for those who can't afford to do this.*
>
> *Our son required specialist psychologist therapy that was not available in our area and we had to travel 180kms for 2 years to access this therapy on a weekly basis, then monthly, all at a significant personal financial cost to us.*
>
> *Consumer has had to move to city to access proper care. Carer had to buy unit in city to care for them. Father has to stay on farm to work.*
>
> *After receiving a bequest after my father's death, my husband and I bought a tiny unit for our son which gave him security and helped his mental state, but it was at considerable financial cost to ourselves. We are now debarred from getting the age pension for 5 years as the unit we bought for our consumer comes under gifting rules.*

Priority Issue 11 - Physical and mental health of carers

The experience of caring for a person with mental illness can have major negative health impacts on carers, especially as carers frequently end up neglecting their own health requirements. The focus of carers and clinicians is often entirely centred on consumer health, while carer needs are often not considered. Carers attending the CEP workshops in 2008 and 2009 discussed various negative impacts on their health arising from their caring role, and suggested a range of strategies[21]

Carers were asked in the survey to comment if their mental or physical health had been affected by being a mental health carer. Nearly half (45.5%) of mental health carers reported their health was 'slightly worse' and a further 25.1% reported their health was 'much worse' as a result of being a mental health carer. Thus over 70.6% of mental health carers reported a deterioration of their health as being a direct result of caring for someone with a mental illness.

	Number of respondents	%
My health is much worse	181	25.1
My health is slightly worse	328	45.5
There has been no change to my health	149	20.7
My health is slightly better	39	5.4
My health is much better	24	3.3
Total	721	

Table 23 **As a result of being a mental health carer do you consider your physical or mental health has changed during the last 12 months?**

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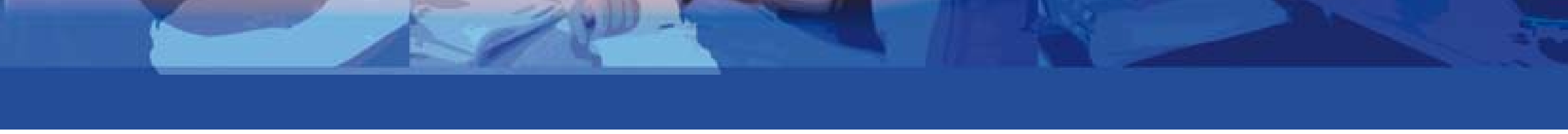
[21] Ibid., p. 60.



A number of mental health carers reported taking various medications as part of their coping strategy: sleeping pills 27.8%, anxiety medication 31.9% and antidepressants 37.1%. Most mental health carers paid, to some extent, for medication, with roughly half having paid full costs and half making subsidised payments. Less than one percent of mental health carers received free medication.

The coping strategy most accessed by mental health carers was counselling (56.7%). This strategy had the highest rate of service provided at no cost to the carer (24.6% free). However, 14.4% of mental health carers reported paying 100% of the costs themselves, with 17.7% indicating that they received a carer subsidised service.

Of the 37.8% of mental health carers who used massage as a coping strategy, 28.7% paid the full cost, while 5.3% reported receiving a free carer service.

A quarter (25.5%) of mental health carers used the gym/exercise as a coping mechanism, but less than one percent received it as a free carer service.

Just under half of mental health carers (47.9%) used a holiday as a coping strategy, and while 4.7% received it as a free service or subsidised cost, a further 43.3% reported paying the full cost themselves.

Thirty seven percent of mental health carers utilised respite/time out as a coping strategy. After counselling, this was the most utilised free carer service, with 16% accessing this as a free service extended to mental health carers.

Further information relating to this section is contained in Priority Issue 12 - Flexible respite options for mental health carers.

	100% of cost	Subsidised cost	Free carer service	Not used	Number who responded
	%	%	%	%	
Sleeping pills	16.3	11.5	0.6	71.7	547
Anxiety medication	16.0	15.9	0.4	67.8	555
Anti depressants	18.2	18.9	0.7	62.1	565
Counselling	14.4	17.7	24.6	43.3	589
Massage	28.7	3.8	5.3	62.2	547
Acupuncture	7.4	1.6	0.0	91.0	487
Gym membership	22.0	2.7	0.8	74.5	522
Respite / time out	12.0	9.6	16.0	62.5	544
Holiday	43.3	3.1	1.6	52.1	580
Other	25.4	1.1	3.7	69.8	378

Table 24 Please indicate which of the following coping strategies or services you have used during the last 12 months?

Carer comments

> *We care around the clock 100% of the time and this can be VERY stressful and exhausting for everyone. We are glad when he is having a good day. He only feels safe living with us so we look like being cohabitants for some time to come*
>
> *The health system does not understand under what stress a carer lives and what it does to the carer's health.*
>
> *It is the consumer's situation that causes me the most anxiety. My life would be made easier if I could see good rehabilitation, training and employment options for the person I care for.*
>
> *One son has lived with us since he got sick and wherever we go he comes along, not that we mind as we got used to it, but at times it gets you down.*

Priority Issue 12 - Flexible respite options for carers

Various forms of respite are essential in assisting carers continue their caring role, by giving them a break from responsibilities and a chance to take some time for themselves. The are several types ranging from emergency respite if carers are unable to care because they themselves are unwell or they need to assist another family member, to planned respite from a few hours to several days in length. Respite can also involve assistance with housework or other tasks. Some providers are flexible and innovative in their provision of creative respite options, such as massages and other 'treats' for the carer, while others operate under very strict guidelines with respect to eligibility and available services. In some cases the carer and consumer can take respite together. Research indicates that carers consider respite care to be very important.

While carers who attended the CEP workshops recognised the possibilities and value of respite, they raised concerns about access and the quality of services when available. Flexibility was a significant concern for many carers as representatives from certain groups, such as CALD and young carers, found accessing appropriate respite particularly difficult.[22]

FaHCSIA provides mental health carer respite on a national basis. The service providers vary from state to state and within states. The service is not integrated with the PHaMS service for consumers.

Carers were asked in the survey if they used respite services. Over two thirds (69.2%) of mental health carers reported they required respite services. The remaining carer respondents reported they did not require respite services. Thirteen percent of mental health carers who did require respite services indicated that they were 'unaware' of the availability of such services, or carer respite service were 'unavailable' in their area. Six per cent of carers did not know what respite services are.

A further 17.2% stated the service they needed from respite care was unavailable. Fourteen percent of mental health carers could not use respite because they felt they could not leave the consumer with a respite worker.

Of the 25.8% of mental health carers who used respite, 20.6% used it sometimes and 5.2% used it regularly.

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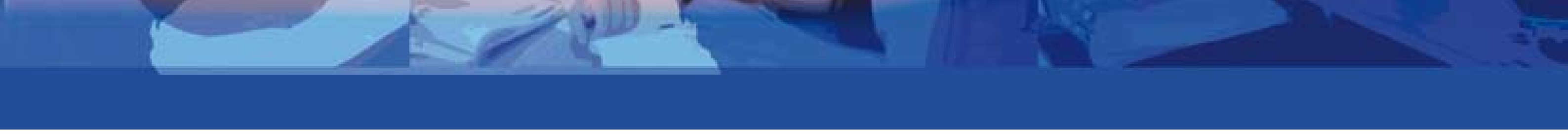
[22] Ibid., p. 64.



	%	Number of respondents
I do not know what carer respite services are	6.2	47
I am not aware of any carer respite services being available	9.5	72
Carer respite is not offered in my area	4.0	30
What I need from respite care is not available	17.2	130
I could not leave the consumer with a respite worker	14.3	108
I do sometimes use carer respite services	20.6	156
I use carer respite regularly	5.2	39
I do not need carer respite services	30.8	233
Total		756

Table 25 Do you ever use carer respite services?

Carer comments

> *I would like information about respite. Carers need to be followed-up post discharge because carers are often too stressed and burnt out to seek it out. Plus, there are so many different support services in the community doing similar things it becomes totally confusing. I would love to have paid respite on a regular basis to have a break and re-energise.*
>
> *My consumer attended a five-day holiday which I later discovered was my respite, but I had to go to work every day due to only two weeks notice of the holiday being given, so I didn’t really feel like it was respite.*
>
> *I need respite less than I need to see better recovery programs for people with mental illness.*
>
> *Respite for us would be for our son to be in supported accommodation, so as we could support him, but not be all consumed.*
>
> *Respite services have been available, but not for mental health carers. Even if this was made available, my partner would not accept someone coming in to our home to provide support, such is the nature of his illness.*
>
> *Amount of time available to each carer is limited, on the other hand all those years with no help are like a bad dream, so I am very grateful for the help I have had.*

Priority Issue 13 - Privacy and confidentiality issues

Many carers reported at the 2008 and 2009 CEP workshops that privacy and confidentiality controls presented significant impediments to them providing care and to the overall quality of care that was provided. They said that clinical service providers and other mental health workers often use 'privacy and confidentiality' as an excuse to exclude them from the care of the person they care for. Privacy and confidentiality are also used as excuses to prevent information-sharing between services.[23]

Carers were asked if privacy and confidentiality issues were a barrier between themselves and mental health professionals when seeking the information the carers needed to care for the consumer. Thirty-four percent of mental health carers stated that they were 'always' included and privacy and confidentiality issues did not exclude them from the information they needed to provide proper consumer care. A further 43.1% indicated that they were included 'some of the time' or included and excluded 'some of the time'. Another 22.5% stated they were 'always' or 'mostly' excluded because of privacy and confidentiality issues.

	%	Number of respondents
I was always included	34.4	226
I was included some of the time	18.6	122
I was sometimes included and sometimes excluded	24.5	161
I was mostly excluded	13.7	90
I was always excluded	8.8	58
Total		657

Table 26 During the last 12 months were the privacy and confidentiality of the consumer used by staff to exclude you from information you needed to be able to provide proper care?

Sixty two percent of mental health carers 'mostly' or 'always' received the information they required about the consumer's medication and prescribing routine, with 22.6% reporting they 'rarely' or 'never' received the information.

On the question of side effects of medication, 46.4% of mental health carers reported they 'mostly' or 'always' received the information, with 34.6% stating they 'rarely' or 'never' received it.

Mental health carers responded less well to the question of information being available to them on how to care better. Forty-nine percent reported they 'rarely' or 'never' received the information, although 30.7% indicated that they had 'mostly' or 'always' received it.

Information about what to expect from the mental illness was 'rarely' or 'never' received by 40.2% of mental health carers, while the same amount of carers (41.3%) said that it was 'mostly' or 'always' available.

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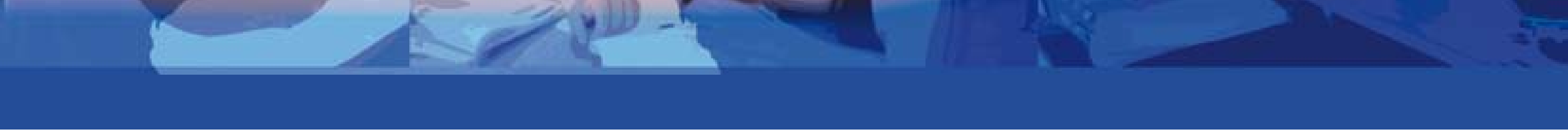
[23] Ibid., p. 66.



	Always	Mostly	Sometimes	Rarely	Never	Number who responded
	%	%	%	%	%	
Consumer medication and prescribing routine	40.6	21.5	15.4	8.1	14.5	657
Medication side effects	24.6	21.8	19.0	13.7	20.9	642
What to expect from the mental illness	19.1	22.2	18.6	19.4	20.8	635
How to care better	11.9	18.8	19.9	19.9	29.5	628

Table 27 Please comment on the availability of information about the consumer's medication and illness during the last 12 months

Carers were asked to comment if anxiety was caused by the lack of disclosure to them of information concerning the health and welfare of the person they cared for. Lack of disclosure by mental health professionals concerning consumer health and welfare caused 77.5% of mental health carers some degree of anxiety, ranging from a 'small amount' (19.8%), 'moderate amount' (24.1%), 'large amount' (20.1%), to an 'extreme amount' (13.6%).

	%	Number of respondents
None	22.5	156
Small amount	19.8	137
Moderate amount	24.1	167
Large amount	20.1	139
Extreme amount	13.6	94
Total		693

Table 28 How much concern and anxiety about the consumer's health and welfare have you experienced because of the lack of disclosure by mental health professionals involved in consumer care?

To establish the amount of engagement with mental health professionals a very practical question was asked, 'were you included in the planning of the consumer care plan'. In response to this question, 44.2% of carers reported they had not been included in the consumer care plan and an alarming 16.9% of mental health carers did not know what a care plan was.

	%	Number of respondents
Yes	38.9	264
No	44.2	300
I do not know what a care plan is	16.9	115
Total		679

Table 29 Were you included in the planning of the consumer care plan?

Carer comments

> *I am frustrated by not being 'fully in the loop' due to the privacy conditions. I am not allowed to be told of the state of my daughter's health and feel I cannot report to our GP as anything I say will need to be passed on to my daughter. This would destroy the essential trust that has been built up between my daughter and I over the years.*
>
> *Confidentiality seems to be the biggest issue when caring for a consumer over the age of 18. Even when presented with a primary carer authorisation form I have met scepticism from the GP and doubt over whether the consumer is capable of giving informed consent.*
>
> *This only happened (more openness) since my daughter's last episode. Before that time, communication was a nightmare! It has made such a difference! We have moved on to much more stable health and care for my daughter.*
>
> *We were included in care plan only because we refused to accept the person we care for be discharged to us until the discharge plan was discussed with us and we were included in the planning.*
>
> *The care plan put together with the community worker was terrific - we were really involved.*

Priority Issue 14 - Early intervention at each episode of care

Carers at many of the CEP workshops called for early intervention when signs and symptoms of mental illness first appear. Not a single carer at any of the workshops reported they had been able to access early intervention services for those they care for at the onset of an episode of ill health.[24]

A question was asked in the survey to discover if carers had accessed in the last 12 months any early intervention services for the person they care for. The highest response (78.3%) was received from mental health carers where the person they cared for had been unwell during the last 12 months. Of these respondents 37.3% were 'quite satisfied' with the early response from the mental health service, while 28% were either 'quite dissatisfied' or 'extremely dissatisfied' with the response, with only 6.9% being 'extremely satisfied'.

	%	Number of respondents
Extremely satisfied	6.9	46
Quite satisfied	27.3	181
Not satisfied or dissatisfied	16.1	107
Quite dissatisfied	10.8	72
Extremely dissatisfied	17.2	114
The consumer has been well during the last 12 months	21.7	144
Total		664

Table 30 If the consumer was unwell during the last 12 months how satisfied were you with the response from mental health services in order to prevent an acute episode of illness?

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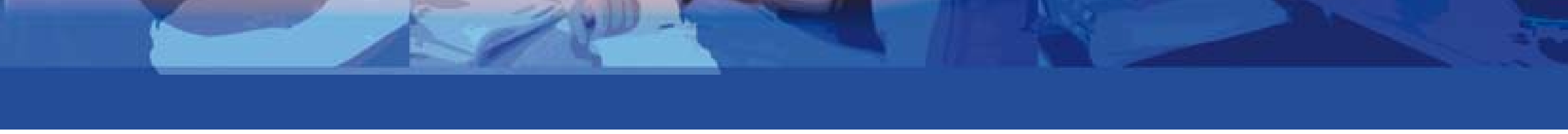
[24] Ibid., p. 69.



Carers were asked if access to early intervention had improved and if it had, who did they consider was responsible for that improvement. Over a quarter (27.2%) of mental health carer respondents indicated that there had been no improvement in early intervention care for the consumer. This was the highest score achieved for this question.

Where there had been an improvement, mental health carers reported that psychiatrists (16.1%) and GPs (16.9%) had been responsible for the improvement. Case managers and community workers scored 8.7% on responsibility for the improvement. Mental health nurses and psychologists scored 9.1% and 7.1% respectively. Aboriginal workers and bilingual workers were accessed by only a small percentage of mental health carers. The response to the individual groups of workers varied because carers may not have had access to those groups.

	%	Number of respondents
There has been no improvement	27.2	206
Psychiatrist	16.1	122
Psychologist	7.1	54
GP	16.9	128
Mental health nurse	9.1	69
Community worker	8.7	66
Aboriginal worker	0.3	2
Bilingual worker	0.3	2
Drug and alcohol worker	0.8	6
School staff	1.1	8
Police	0.9	7
Case manager	8.7	66
Other	23.5	178
Total		756

Table 32 **If there has been an improvement during the last 12 months in access to early intervention care for the consumer, who was responsible for that improvement**

Carer comments

Confidentiality for the consumer becomes an issue when they are not well enough to explain their symptoms. Carers need to be more involved with medical professionals at the beginning of the illness.

When my son was extremely unwell, I could not get anyone to treat him. I was repeatedly told that “unless he is suicidal or about to harm someone there is nothing we can do” and if you took him to hospital “they would not treat him but would send him home.” Consequently, he got a lot worse and then went missing. After being a missing person for over eight weeks he was admitted to hospital “extremely unwell”. He had been living on park benches and under bridges for a lot of that time.

Unfortunately, nobody listened until my son was once more admitted to hospital as an involuntary patient.

In country areas the police are the only ones available. There is no early intervention care.

Priority Issue 15 - Employment options for carers

The proportion of people aged 15 to 64 with caring responsibilities who are employed is lower than the proportion in the general population (63% compared to 73%). For primary carers, this rate is even lower: only 48% of primary carers are involved in the labour force, and they were more likely to be working part-time. Among women carers aged 30 to 64 years, over half are not in the paid labour force, compared with less than a third of women non-carers in that age group. Almost two fifths of all women aged between 30 and 64 are in paid employment, compared with 20% of women primary carers aged 30 to 64.[25]

Carers were asked in the survey to comment on the attitude of the workplace to them as mental health carers. A third of respondents reported that they were retired (33.7%) or not in the workforce (21.2%). Similarly in response to the improvement in workplace flexibility to assist the carer, 33.5% of mental health carers reported they were retired, with a further 21.4% stating they were not in the workforce.

Of the remaining mental health carers who were in the workforce (54.9%), 22.2% either 'agreed' or 'strongly agreed' that the workplace was more understanding of their needs over the last 12 months. 'No change' was reported by 16.5% and 6.5% either 'disagreed' or 'strongly disagreed' with the statement: in the last 12 months my workplace was more understanding of my needs as a mental health carer.

	%	Number of respondents
Strongly agree	9.0	63
Agree	13.2	92
No change	16.5	115
Disagree	3.3	23
Strongly disagree	3.2	22
I am not in the workforce	21.2	148
I am retired	33.7	235
Total		698

Table 33 Please comment on the statement "In the last 12 months my workplace was more understanding of my needs as a mental health carer"

A further question was asked to ascertain if the improved understanding had resulted in greater flexibility in the workplace for mental health carers. Of the 45.1% of respondents who were in the workforce, 18.5% reported an improvement in flexibility, 20.4% reported 'no change' and 6.2% 'disagreed' or 'strongly disagreed' that flexibility within the workplace had improved over the previous 12 months.

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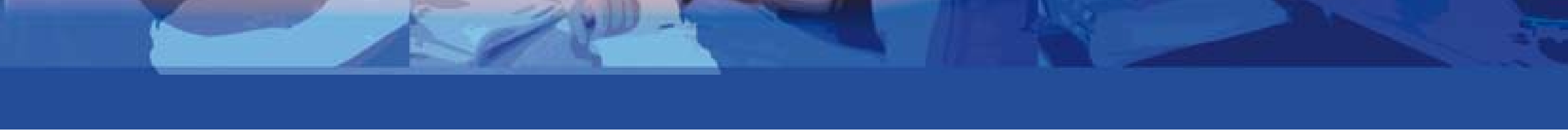
[25] ABS 2008, A profile of Carers in Australia (ABS Cat. No. 4448.0) ABS, Canberra; and NATSEM 2008, Commonwealth Financial Planning Women Carers in Financial Stress Report, Carers Australia, Canberra, cited in MHCA 2009a, op. cit.



	%	Number of respondents
Strongly agree	7.1	49
Agree	11.4	79
No change	20.4	141
Disagree	2.9	20
Strongly disagree	3.3	23
I am not in the workforce	21.4	148
I am retired	33.5	232
Total		692

Table 34 Please comment on the statement "In the last 12 months the flexibility within my workplace to assist me as a mental health carer improved"

Carer comments

I am very fortunate to work in the public sector and 'family care' is highly regarded. I have worked in the same field in the private sector and believe I would not have kept my job if I had as much time off.

My workplace was very flexible in allowing me to change to part-time work.

I had to take leave from my work place to care for my son and my work place will (not) have me return. I am currently on a carer pension and looking for work now my son is recovering. It is difficult at my age.

I have not advised my workplace of my carer situation due to stigma.

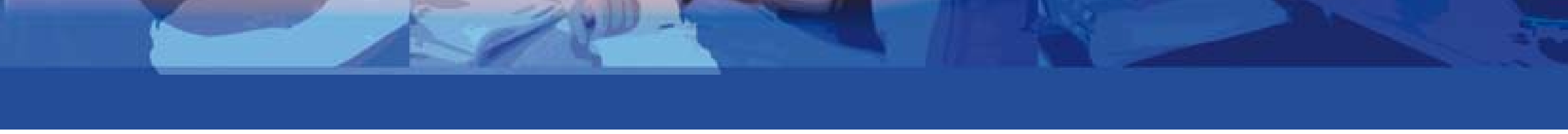
At the time I became a carer for my daughter I was working. Because of the commitment and difficulty of the illness I found it impossible to work and cope with carer responsibilities. I took all my leave and then retired to focus on caring.

I am unemployed. I worked in a corporate environment but when my son became ill and the stress associated with that and work changed how I viewed my life forever. I now only want mundane jobs where there is little stress associated with the role. So my life had changed dramatically as well.

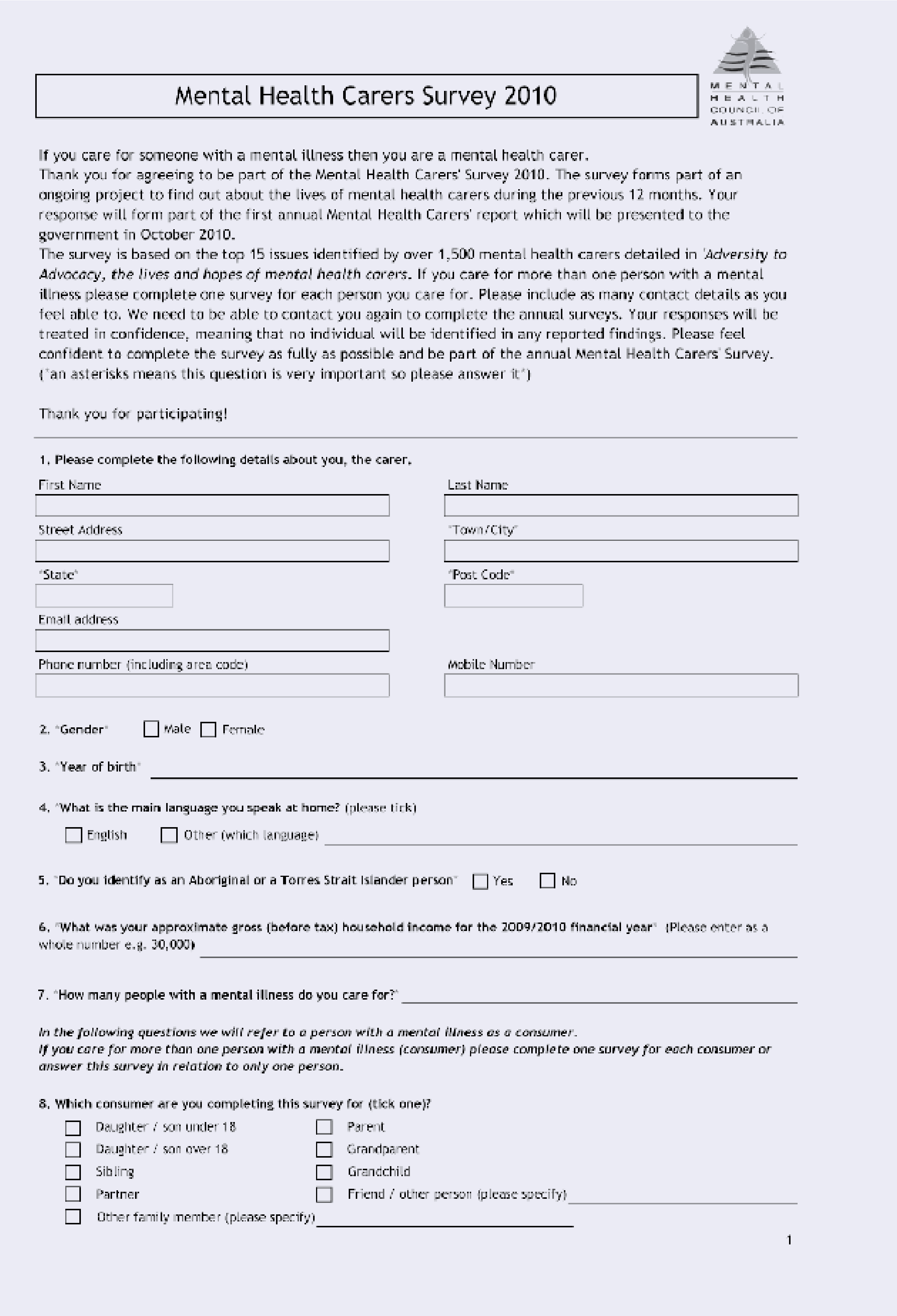
Conclusion

The survey results demonstrate the lives of mental health carers generally remain focussed on the person they care for, particularly their lack of access to timely and appropriate services. Mental health carers' own concerns are generally poorly addressed and while there were some small improvements in experiences since Adversity to Advocacy was published, there is still a long way to go to improve the lives of mental health carers.

Unfortunately, neither Adversity to Advocacy nor this Mental Health Carers Report 2010 actually answer the question that is so pressing for mental health carers: who will care for the person I care for when I am no longer able? However, this report does shine a spotlight on the areas of most urgent attention for mental health carers. The MHCA will continue ongoing surveys of mental health carers to monitor the changes, for better or worse, that mental health carers experience. The results will be used to advocate, where possible, for better lives for mental health carers.



Appendix A



Mental Health Carers Survey 2010

MENTAL HEALTH COUNCIL OF AUSTRALIA

If you care for someone with a mental illness then you are a mental health carer.
Thank you for agreeing to be part of the Mental Health Carers' Survey 2010. The survey forms part of an ongoing project to find out about the lives of mental health carers during the previous 12 months. Your response will form part of the first annual Mental Health Carers' report which will be presented to the government in October 2010.
The survey is based on the top 15 issues identified by over 1,500 mental health carers detailed in *'Adversity to Advocacy, the lives and hopes of mental health carers*. If you care for more than one person with a mental illness please complete one survey for each person you care for. Please include as many contact details as you feel able to. We need to be able to contact you again to complete the annual surveys. Your responses will be treated in confidence, meaning that no individual will be identified in any reported findings. Please feel confident to complete the survey as fully as possible and be part of the annual Mental Health Carers' Survey.
(*an asterisks means this question is very important so please answer it*)

Thank you for participating!

---

1. Please complete the following details about you, the carer.

First Name	Last Name
Street Address	*Town/City*
State	*Post Code*
Email address	
Phone number (including area code)	Mobile Number

2. *Gender* ☐ Male ☐ Female

3. *Year of birth* ____________________

4. *What is the main language you speak at home? (please tick)

☐ English ☐ Other (which language) ____________________

5. *Do you identify as an Aboriginal or a Torres Strait Islander person* ☐ Yes ☐ No

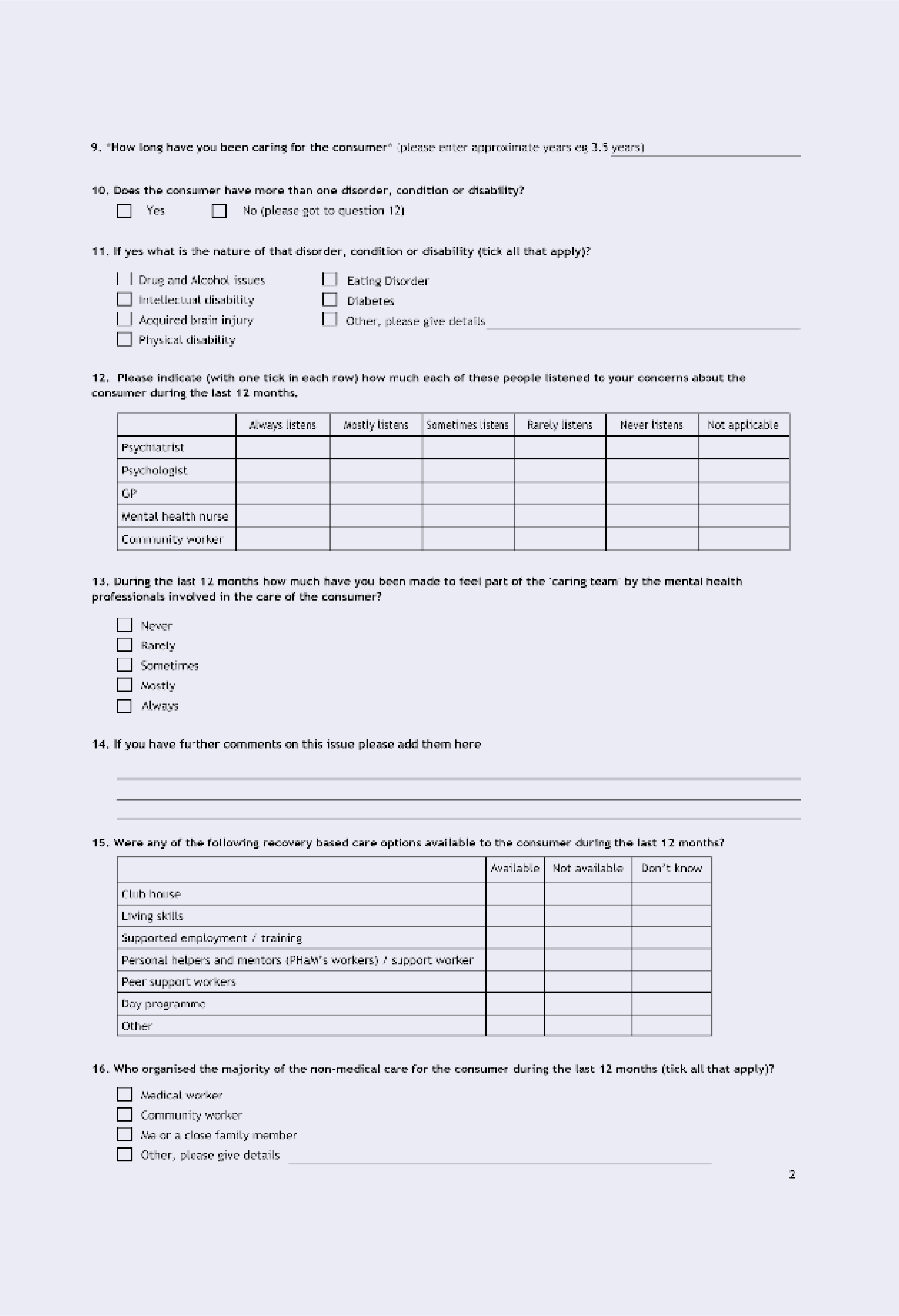
6. *What was your approximate gross (before tax) household income for the 2009/2010 financial year* (Please enter as a whole number e.g. 30,000) ____________________

7. *How many people with a mental illness do you care for?* ____________________

In the following questions we will refer to a person with a mental illness as a consumer.
If you care for more than one person with a mental illness (consumer) please complete one survey for each consumer or answer this survey in relation to only one person.

8. Which consumer are you completing this survey for (tick one)?

☐ Daughter / son under 18
☐ Daughter / son over 18
☐ Sibling
☐ Partner
☐ Other family member (please specify) ____________________
☐ Parent
☐ Grandparent
☐ Grandchild
☐ Friend / other person (please specify) ____________________



9. *How long have you been caring for the consumer* (please enter approximate years eg 3.5 years) ____________

10. Does the consumer have more than one disorder, condition or disability?

☐ Yes ☐ No (please got to question 12)

11. If yes what is the nature of that disorder, condition or disability (tick all that apply)?

☐ Drug and Alcohol issues
☐ Intellectual disability
☐ Acquired brain injury
☐ Physical disability
☐ Eating Disorder
☐ Diabetes
☐ Other, please give details ____________

12. Please indicate (with one tick in each row) how much each of these people listened to your concerns about the consumer during the last 12 months.

	Always listens	Mostly listens	Sometimes listens	Rarely listens	Never listens	Not applicable
Psychiatrist						
Psychologist						
GP						
Mental health nurse						
Community worker						

13. During the last 12 months how much have you been made to feel part of the 'caring team' by the mental health professionals involved in the care of the consumer?

☐ Never
☐ Rarely
☐ Sometimes
☐ Mostly
☐ Always

14. If you have further comments on this issue please add them here

____

____

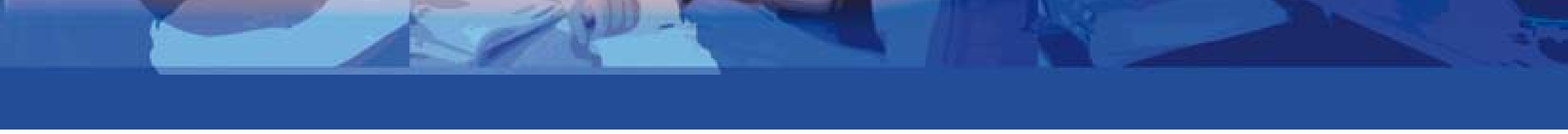
____

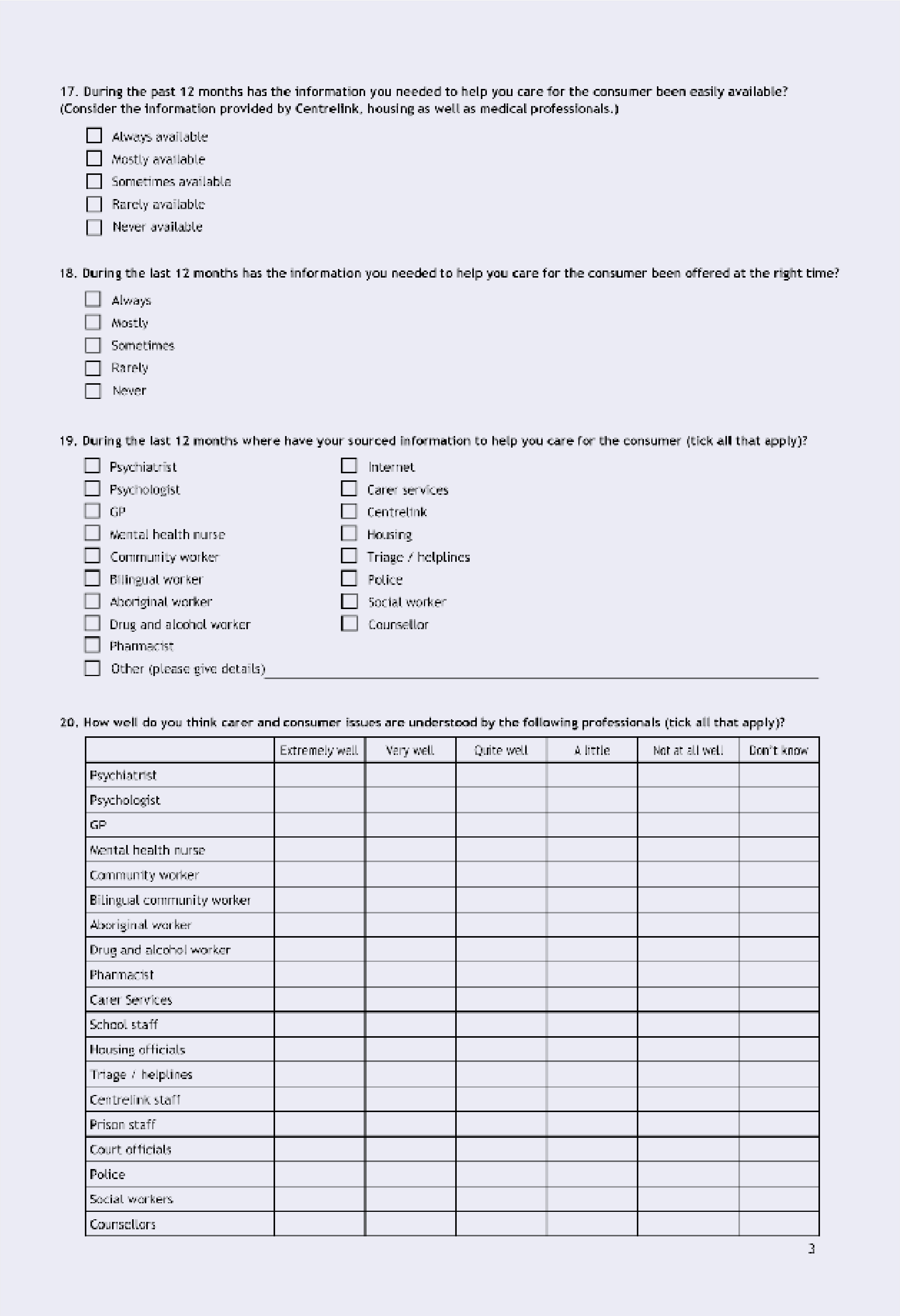
15. Were any of the following recovery based care options available to the consumer during the last 12 months?

	Available	Not available	Don't know
Club house			
Living skills			
Supported employment / training			
Personal helpers and mentors (PHaM's workers) / support worker			
Peer support workers			
Day programme			
Other			

16. Who organised the majority of the non-medical care for the consumer during the last 12 months (tick all that apply)?

☐ Medical worker
☐ Community worker
☐ Me or a close family member
☐ Other, please give details ____________





17. During the past 12 months has the information you needed to help you care for the consumer been easily available? (Consider the information provided by Centrelink, housing as well as medical professionals.)

☐ Always available
☐ Mostly available
☐ Sometimes available
☐ Rarely available
☐ Never available

18. During the last 12 months has the information you needed to help you care for the consumer been offered at the right time?

☐ Always
☐ Mostly
☐ Sometimes
☐ Rarely
☐ Never

19. During the last 12 months where have your sourced information to help you care for the consumer (tick all that apply)?

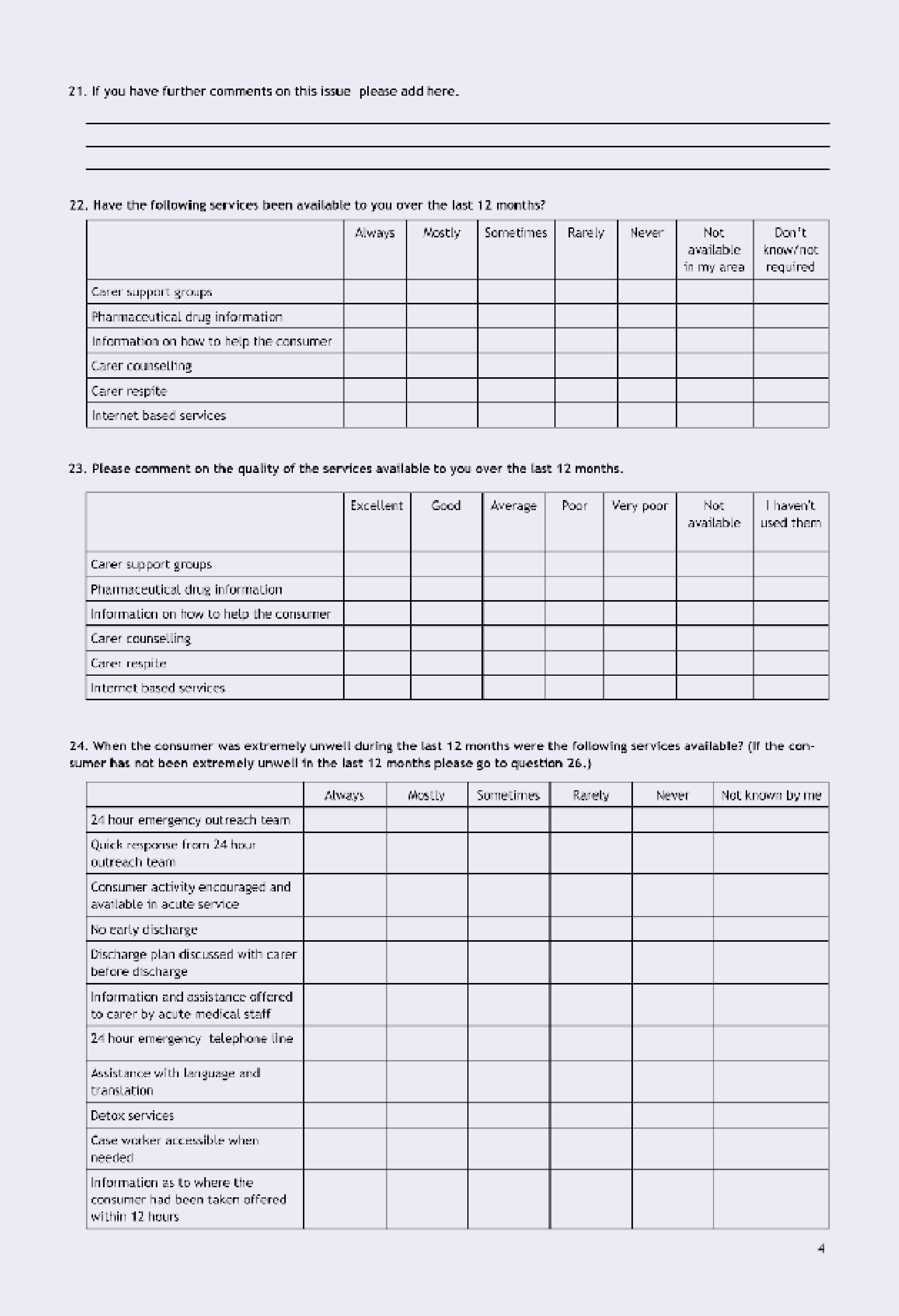
☐ Psychiatrist
☐ Psychologist
☐ GP
☐ Mental health nurse
☐ Community worker
☐ Bilingual worker
☐ Aboriginal worker
☐ Drug and alcohol worker
☐ Pharmacist
☐ Other (please give details)________________________________

☐ Internet
☐ Carer services
☐ Centrelink
☐ Housing
☐ Triage / helplines
☐ Police
☐ Social worker
☐ Counsellor

20. How well do you think carer and consumer issues are understood by the following professionals (tick all that apply)?

	Extremely well	Vary well	Quite well	A little	Not at all well	Don't know
Psychiatrist						
Psychologist						
GP						
Mental health nurse						
Community worker						
Bilingual community worker						
Aboriginal worker						
Drug and alcohol worker						
Pharmacist						
Carer Services						
School staff						
Housing officials						
Triage / helplines						
Centrelink staff						
Prison staff						
Court officials						
Police						
Social workers						
Counsellors						

3



21. If you have further comments on this issue please add here.

22. Have the following services been available to you over the last 12 months?

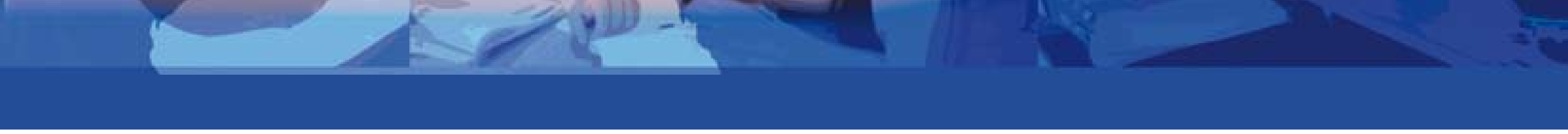
	Always	Mostly	Sometimes	Rarely	Never	Not available in my area	Don't know/not required
Carer support groups							
Pharmaceutical drug information							
Information on how to help the consumer							
Carer counselling							
Carer respite							
Internet based services							

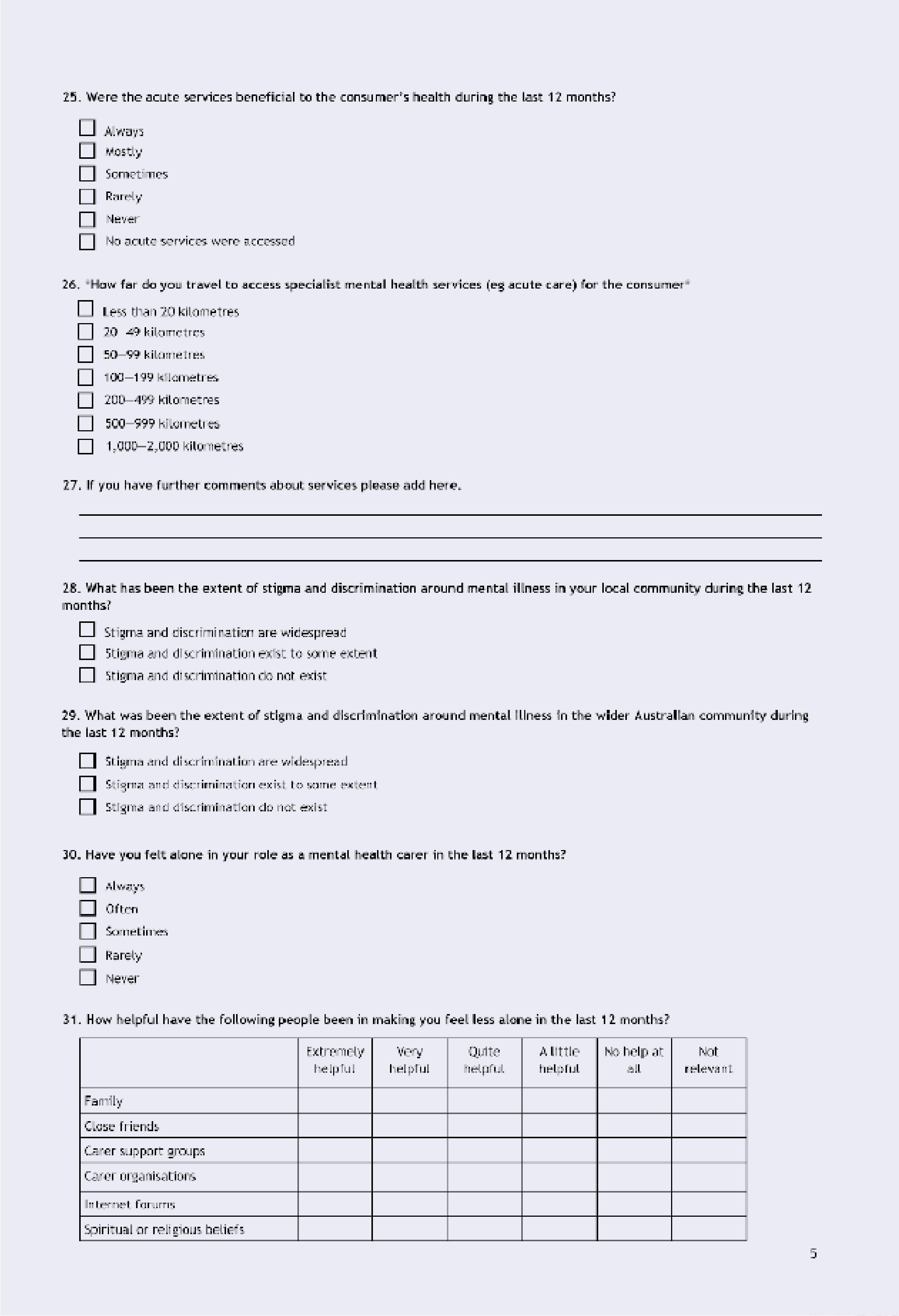
23. Please comment on the quality of the services available to you over the last 12 months.

	Excellent	Good	Average	Poor	Very poor	Not available	I haven't used them
Carer support groups							
Pharmaceutical drug information							
Information on how to help the consumer							
Carer counselling							
Carer respite							
Internet based services							

24. When the consumer was extremely unwell during the last 12 months were the following services available? (If the consumer has not been extremely unwell in the last 12 months please go to question 26.)

	Always	Mostly	Sometimes	Rarely	Never	Not known by me
24 hour emergency outreach team						
Quick response from 24 hour outreach team						
Consumer activity encouraged and available in acute service						
No early discharge						
Discharge plan discussed with carer before discharge						
Information and assistance offered to carer by acute medical staff						
24 hour emergency telephone line						
Assistance with language and translation						
Detox services						
Case worker accessible when needed						
Information as to where the consumer had been taken offered within 12 hours						





25. Were the acute services beneficial to the consumer's health during the last 12 months?

☐ Always
☐ Mostly
☐ Sometimes
☐ Rarely
☐ Never
☐ No acute services were accessed

26. "How far do you travel to access specialist mental health services (eg acute care) for the consumer"

☐ Less than 20 kilometres
☐ 20–49 kilometres
☐ 50–99 kilometres
☐ 100–199 kilometres
☐ 200–499 kilometres
☐ 500–999 kilometres
☐ 1,000–2,000 kilometres

27. If you have further comments about services please add here.

____

____

____

28. What has been the extent of stigma and discrimination around mental illness in your local community during the last 12 months?

☐ Stigma and discrimination are widespread
☐ Stigma and discrimination exist to some extent
☐ Stigma and discrimination do not exist

29. What was been the extent of stigma and discrimination around mental illness in the wider Australian community during the last 12 months?

☐ Stigma and discrimination are widespread
☐ Stigma and discrimination exist to some extent
☐ Stigma and discrimination do not exist

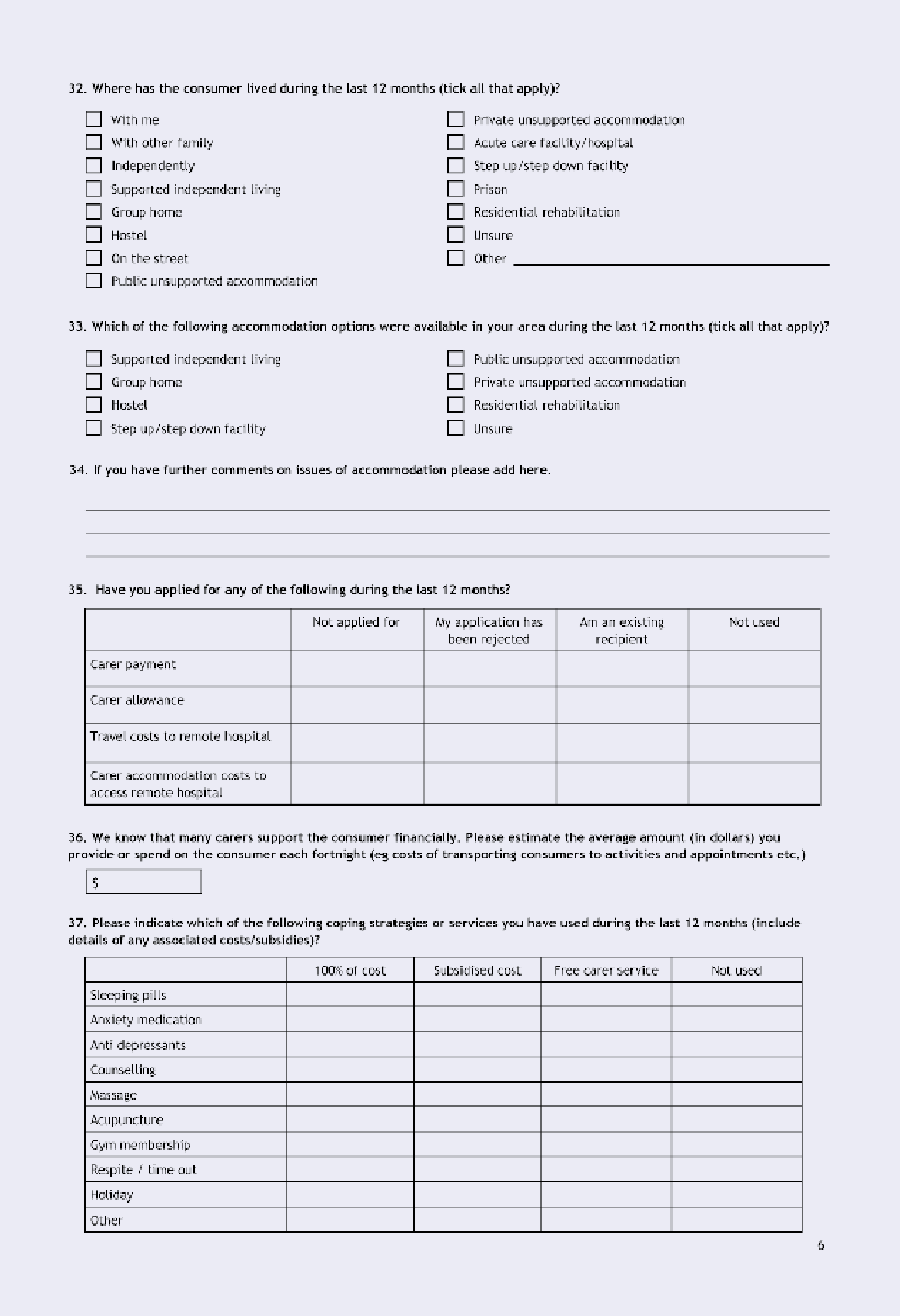
30. Have you felt alone in your role as a mental health carer in the last 12 months?

☐ Always
☐ Often
☐ Sometimes
☐ Rarely
☐ Never

31. How helpful have the following people been in making you feel less alone in the last 12 months?

	Extremely helpful	Very helpful	Quite helpful	A little helpful	No help at all	Not relevant
Family						
Close friends						
Carer support groups						
Carer organisations						
Internet forums						
Spiritual or religious beliefs						

5



32. Where has the consumer lived during the last 12 months (tick all that apply)?

☐ With me
☐ With other family
☐ Independently
☐ Supported independent living
☐ Group home
☐ Hostel
☐ On the street
☐ Public unsupported accommodation
☐ Private unsupported accommodation
☐ Acute care facility/hospital
☐ Step up/step down facility
☐ Prison
☐ Residential rehabilitation
☐ Unsure
☐ Other ____________________

33. Which of the following accommodation options were available in your area during the last 12 months (tick all that apply)?

☐ Supported independent living
☐ Group home
☐ Hostel
☐ Step up/step down facility
☐ Public unsupported accommodation
☐ Private unsupported accommodation
☐ Residential rehabilitation
☐ Unsure

34. If you have further comments on issues of accommodation please add here.

____

____

____

35. Have you applied for any of the following during the last 12 months?

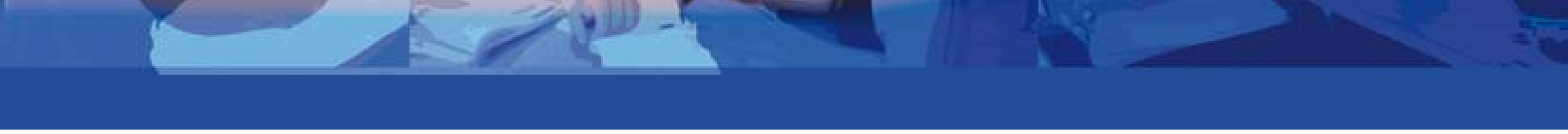
	Not applied for	My application has been rejected	Am an existing recipient	Not used
Carer payment				
Carer allowance				
Travel costs to remote hospital				
Carer accommodation costs to access remote hospital				

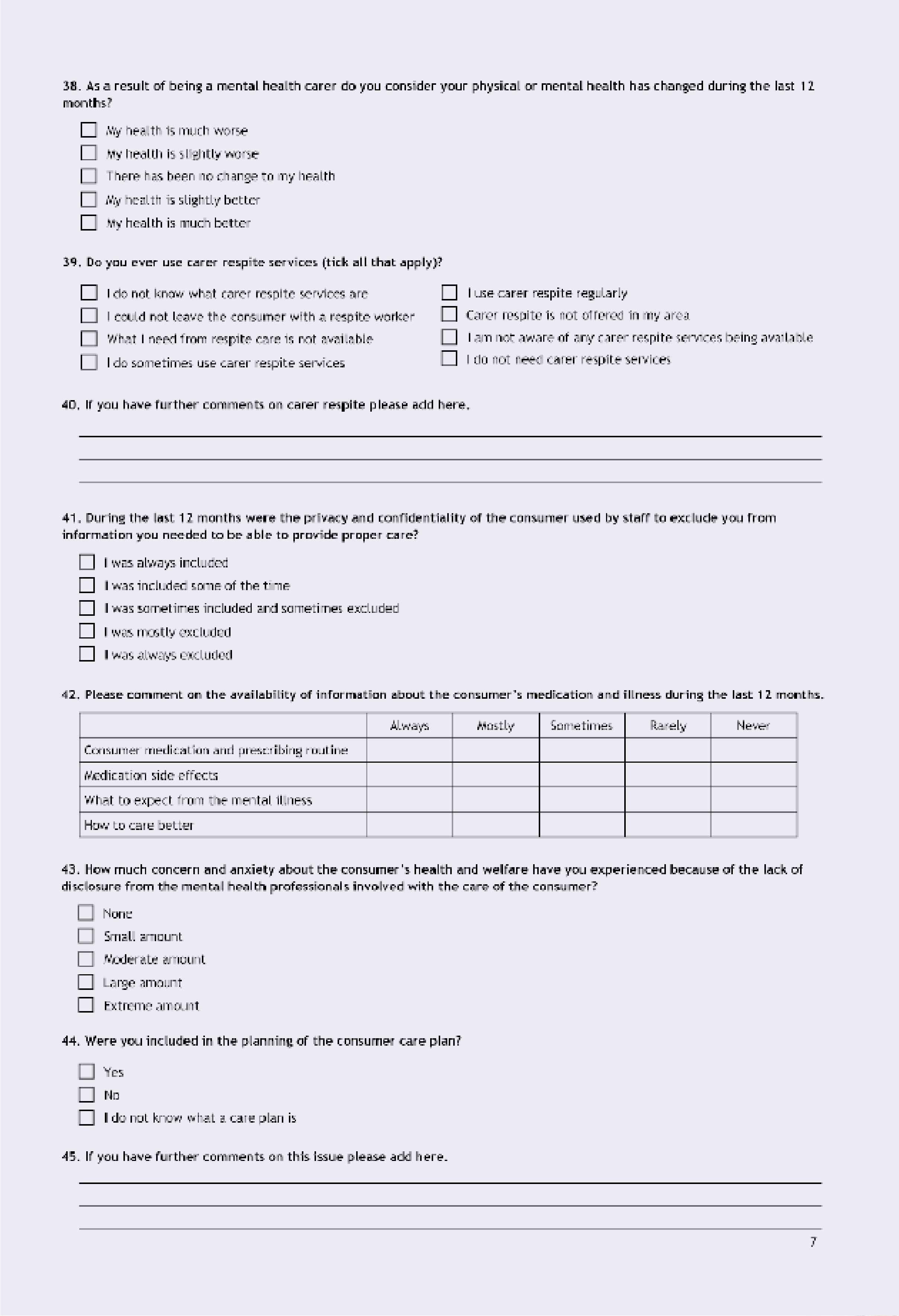
36. We know that many carers support the consumer financially. Please estimate the average amount (in dollars) you provide or spend on the consumer each fortnight (eg costs of transporting consumers to activities and appointments etc.)

$ ____________________

37. Please indicate which of the following coping strategies or services you have used during the last 12 months (include details of any associated costs/subsidies)?

	100% of cost	Subsidised cost	Free carer service	Not used
Sleeping pills				
Anxiety medication				
Anti depressants				
Counselling				
Massage				
Acupuncture				
Gym membership				
Respite / time out				
Holiday				
Other				





38. As a result of being a mental health carer do you consider your physical or mental health has changed during the last 12 months?

☐ My health is much worse
☐ My health is slightly worse
☐ There has been no change to my health
☐ My health is slightly better
☐ My health is much better

39. Do you ever use carer respite services (tick all that apply)?

☐ I do not know what carer respite services are
☐ I could not leave the consumer with a respite worker
☐ What I need from respite care is not available
☐ I do sometimes use carer respite services
☐ I use carer respite regularly
☐ Carer respite is not offered in my area
☐ I am not aware of any carer respite services being available
☐ I do not need carer respite services

40. If you have further comments on carer respite please add here.

41. During the last 12 months were the privacy and confidentiality of the consumer used by staff to exclude you from information you needed to be able to provide proper care?

☐ I was always included
☐ I was included some of the time
☐ I was sometimes included and sometimes excluded
☐ I was mostly excluded
☐ I was always excluded

42. Please comment on the availability of information about the consumer's medication and illness during the last 12 months.

	Always	Mostly	Sometimes	Rarely	Never
Consumer medication and prescribing routine					
Medication side effects					
What to expect from the mental illness					
How to care better					

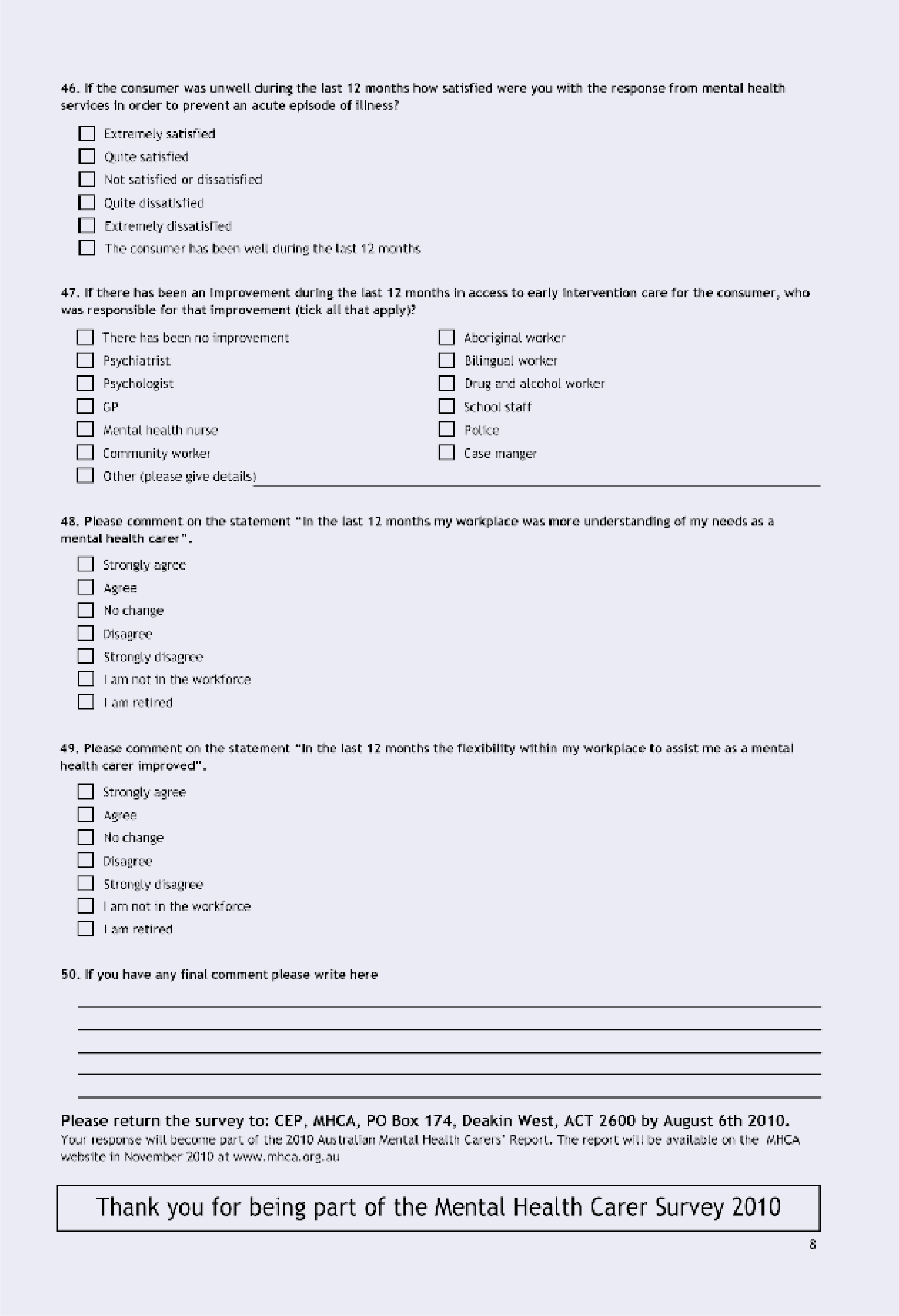
43. How much concern and anxiety about the consumer's health and welfare have you experienced because of the lack of disclosure from the mental health professionals involved with the care of the consumer?

☐ None
☐ Small amount
☐ Moderate amount
☐ Large amount
☐ Extreme amount

44. Were you included in the planning of the consumer care plan?

☐ Yes
☐ No
☐ I do not know what a care plan is

45. If you have further comments on this issue please add here.



46. If the consumer was unwell during the last 12 months how satisfied were you with the response from mental health services in order to prevent an acute episode of illness?

☐ Extremely satisfied
☐ Quite satisfied
☐ Not satisfied or dissatisfied
☐ Quite dissatisfied
☐ Extremely dissatisfied
☐ The consumer has been well during the last 12 months

47. If there has been an improvement during the last 12 months in access to early intervention care for the consumer, who was responsible for that improvement (tick all that apply)?

☐ There has been no improvement
☐ Psychiatrist
☐ Psychologist
☐ GP
☐ Mental health nurse
☐ Community worker
☐ Other (please give details)
☐ Aboriginal worker
☐ Bilingual worker
☐ Drug and alcohol worker
☐ School staff
☐ Police
☐ Case manger

48. Please comment on the statement "In the last 12 months my workplace was more understanding of my needs as a mental health carer".

☐ Strongly agree
☐ Agree
☐ No change
☐ Disagree
☐ Strongly disagree
☐ I am not in the workforce
☐ I am retired

49. Please comment on the statement "In the last 12 months the flexibility within my workplace to assist me as a mental health carer improved".

☐ Strongly agree
☐ Agree
☐ No change
☐ Disagree
☐ Strongly disagree
☐ I am not in the workforce
☐ I am retired

50. If you have any final comment please write here

Please return the survey to: CEP, MHCA, PO Box 174, Deakin West, ACT 2600 by August 6th 2010.

Your response will become part of the 2010 Australian Mental Health Carers' Report. The report will be available on the MHCA website in November 2010 at www.mhca.org.au

Thank you for being part of the Mental Health Carer Survey 2010

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