Recognition and Respect

Mental Health Carers Report 2012

Mental Health
Council of Australia

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Council of Australia

Acknowledgements

The Mental Health Council of Australia (MHCA) would like to thank the mental health carers who took the time to complete the survey and share their experiences.

The MHCA acknowledges the contributions of Tracey Davenport from Academic Research and Statistical Consulting and Duncan Rintoul from the University of Wollongong, who analysed the data received from survey participants.

The MHCA is grateful to the Aboriginal outreach workers from Carers WA and Aboriginal & Torres Strait Islander Community Health Service (ATSICHS) Brisbane Limited for their assistance in arranging the Aboriginal and Torres Strait Islander mental health carers' consultations. The MHCA also acknowledges Carers Qld and Carers ACT for their assistance in organising the CALD consultations.

The MHCA would like to thank the many groups who promoted the survey on our behalf.

Finally, the MHCA wishes to thank the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) for their generous funding and ongoing support to develop and conduct this research.

All images used in this report were entries in the World Mental Health Day photo competition.

Contents

Abbreviations

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
PHaMS	Personal Helpers and Mentors (program)

Explanatory terms

(mental health) Carer	A person who provides personal care, support and assistance to another person who has a mental illness without being paid to do so
Carer respite	Time away from the caring role, often using care workers to temporarily act in the role of carer
Care worker	Paid worker who provides services to consumers and/or carers
Clinical mental health services	Clinical services, provided by a hospital or mental health clinicians
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, community mental health services	Non-clinical services for the consumer which work towards recovery-based care, usually provided by non government organisations or volunteers
(mental health) Consumer	A person who has a mental illness or who uses mental health services
Comorbidity	The condition of having more than one illness – e.g. schizophrenia and substance abuse disorder
Peer worker/peer support worker	A person who is living with a mental illness who is employed to share their lived experience of mental illness to assist other people with a mental illness
Recovery-based care	Coordinated system of care services provided in the community to assist consumers to maintain wellness in an atmosphere of hope and to progress according to self identified goals
Step-up/step-down facility	A service which provides support for people who are at risk of becoming unwell, and for people leaving hospital who need more intensive support before returning home
Supported accommodation	Safe and secure housing with regular support from mental health clinicians and support workers to improve the lives of people with a mental illness and prevent relapse into serious illness

Foreword

It is a privilege to be asked to write this foreword to a very important report acknowledging the importance of "recognition" and "respect", because these are what have been missing from the lives of mental health carers for a very long time. Recognition is something that can be prescribed by legislation and policy, but is often just rhetoric. The Carers Recognition Acts across Australia are examples of this, but they are a good start towards greater acknowledgement of the involvement and rights of carers.

Respect is more a question of culture and the lack of respect for carers has been prevalent in some services for so long it will take a while to change. In this regard carers want to be listened to because they are experts with a lived experience, but they also want to be respected for that experience. This does not mean they will always have the right answers, but a lot can be achieved by them being involved in all aspects of admission, treatment and recovery.

The Report Card contained in this document highlights what still needs to be done, but I am pleased that there are some positive things occurring to improve the lives of mental health carers and the people they care for. This is not to take away from the problems experienced by carers, which are real and troublesome.

This document should not just be read as a stand-alone report outlining a snapshot of current mental health carer experiences. It should also be used as an advocacy tool to bring about systemic change and improvement in the lives of mental health carers. This can be done by individual carers and the organisations representing their interests. I commend this *Recognition and Respect* report to you, as I am sure that if it is used to best advantage then the lives of both mental health carers and the people they care for will be measurably improved.

Tony Fowke AM

Mental Health Carer

Mental Health Council of Australia – Board Member

Mental Health Carers Arafmi Australia – President

World Federation of Mental Health – Immediate Past President

Executive summary

This report provides an insight into the lives of some of the most dedicated yet vulnerable members of our community: people who regularly care for someone with a mental illness. Carers provide help, understanding, guidance, support and often a financial safety net for mental health consumers. Unfortunately, their role is not always appropriately recognised by service providers, government agencies or the broader community.

Recognition and Respect: Mental Health Carers Report 2012 builds on the ground-breaking work of *Adversity to Advocacy: the lives and hopes of mental health carers* (2009) and the *Mental Health Carers Report 2010.* It is based on a survey of 508 mental health carers and describes their perspectives on the services available to them and to the people they care for.

One of the principal hopes that carers have is for recognition of and respect for the important contribution that they make to the lives of the people they care for. They are best placed to provide advice on appropriate solutions for consumers, but are often not properly consulted or informed. Carers often feel alone and isolated, and their physical and mental health can deteriorate as a result of their caring role.

There are currently a range of support services available to carers, including respite, carer counselling and carer support groups, yet these services are not always accessible for a range of reasons. This might be because a carer believes that a service is not appropriate, or that the person they care for would not cope with a particular service. Sometimes it is a lack of knowledge of what is available in a local area, or even of the existence of any service at all, that prevents carers from accessing beneficial services. A range of strategies are therefore required to assist carers, from simple awareness-raising and outreach to more innovative models of service delivery.

Of course, carers have many views on the services available to mental health consumers and whether these meet the individual needs of the people they care for. This report describes carers' perspectives on the extent to which mental health and other services are accessible, appropriate and sensitive to the needs of consumers.

Being a mental health carer is lonely, frustrating, emotionally exhausting and dehumanising. I am constantly treated by staff and services as irrelevant or even as a problem. The only time I am usually contacted is when they want something from me such as driving the person I care for to an appointment. Of all the roles I've had in my life, this is by far the most challenging, exhausting, stressful, and poorly supported.

> *I have truly struggled being a carer and recently had eight weeks off work suffering from burnout. I was back at work a month and have been struck down again with physical health issues. I do not know how I can continue to work. I am trying, however it is very difficult. If I said to my workplace I needed time off to care for my husband because he had cancer or needed an operation, there would be no problem. To say I need time off to care for my husband because he has post-traumatic stress disorder has been very difficult.*

Not all carers' experiences are adequately captured in this report. Some carers are very difficult for service providers and researchers to identify, yet their needs can be the most pressing of all. Such carers can be 'hidden' for a range of reasons: because they do not regard themselves as carers (but rather family members), because they do not wish to access the service system or contact other carers, or perhaps because the person they care for has not yet been diagnosed with a mental illness.

Hidden carers are more likely to be young, to be from a different cultural background, or to be Indigenous. While this research deliberately targeted each of these population groups, more needs to be done to understand the needs of hidden carers and the barriers to them receiving the support they need for their caring role.

> *I live in hope that independent supported living will be freely available and accessible to all people with mental illness. Appropriate levels of monitoring will occur from within the system to enable early intervention before hospitalisation. Care plans will be individually tailored and carer inclusive, holistic, realistic and adequately supported from within the system and also that carers will have peace of mind that their child will be looked after once they are no longer around to support them.*

Report card

The Report Card below summarises what this research tells us about the experiences of mental health carers across 15 key domains identified by carers across Australia and reported in *Adversity to Advocacy* in 2009. It also describes what policies and programs are in place in each area.

While the experiences of carers are often negative, it should be noted that considerable progress has been made in a range of policy areas since the publication of the *Mental Health Carers Report 2010*. In addition, many of the policies and programs described below were not in existence at that time. Several initiatives currently in development, including the National Disability Insurance Scheme and the Partners in Recovery Program, have the potential to deliver substantial benefits for mental health carers and consumers.

Key Issues for Mental Health Carers	Policies and programs to address the issue	What the survey tells us about the experience of mental health carers
Issue 1		
Listen to and respect carers	*The Carer Recognition Act 2010* acknowledges the significant role of carers and the importance of ensuring that the needs of carers are considered in the development, implementation and evaluation of policies, programs and services that directly affect them or the care recipient(s). The *National Carer Strategy* also formally acknowledges the vital role of carers. The Strategy will build on what the Australian Government already provides for carers and complements reforms across the aged care, disability, mental health, primary health care, and hospital and community care systems. The *National Carer Strategy Implementation Plan* acknowledges the need to link this work to policies and programs in the mental health arena.	Carers want greater recognition for their role and 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. Mental health carers identified as major issues a lack of respect for their caring role and the unwillingness of clinicians and mental health professionals to generally listen and include them in treatment plans. Carers have varying experiences with different types of services and professionals. They reported that GPs are the most willing to listen to their concerns about consumers, along with community workers. They were less likely to say that psychiatrists listened to their concerns, with around a quarter saying that psychiatrists rarely or never listened.

Key Issues for Mental Health Carers	Policies and programs to address the issue	What the survey tells us about the experience of mental health carers
Issue 2		
Integrated recovery-based care for the consumer	The recently developed Partners in Recovery (PIR) initiative aims to promote coordinated support and provide flexible funding for people with severe and persistent mental illness. The Personal Helpers and Mentors Program (PHaMs) program was recently expanded to help people with mental illness on income support to work more closely with employment services. These PHaMS workers will assist people with mental illness to find employment and support them in maintaining employment. The *National Recovery Framework* is currently being developed to promote the adoption of a recovery-oriented culture within mental health and other services. The Framework is intended to ensure that practice is consistent with recovery principles and to expand the role of peer workers in the mental health workforce.	Carers strongly support recovery-based care in the community for the people they care for. Unfortunately, such care is not always readily available or appropriate, and carers want to see an improvement in recovery-based services. In the absence of individualised, coordinated support to help consumers on their journey to recovery, pressure on carers continues to grow, leading to physical, psychological and financial stress.
Issue 3		
More and better trained staff at all levels	Mental Health Professional Online Development (MHPOD) is a learning resource which has been developed for people working in mental health. It is based on the *National Practice Standards For the Mental Health Workforce* and draws on the evidence base for mental health care and contemporary practice wisdom. Clinicians, consumers, carers and educators across the country have contributed to the development of MHPOD. A pilot MHPOD for community-based mental health workers in PHaMS and Day to Day Living Services is currently underway. PHaMS services are required to employ peer support workers; peer workers are also used extensively by Mental Health Respite Care Support Services (see Issues 6 and 12). It is now possible for peer workers to gain professional accreditation through a Certificate IV qualification in Mental Health Peer Work.	Carers cite inadequate staffing and high staff turnover as major impediments to obtaining adequate care and support for the people they care for. Survey results suggest that few consumers and carers are in contact with peer support workers—a key gap in the mental health workforce.

Key Issues for Mental Health Carers	Policies and programs to address the issue	What the survey tells us about the experience of mental health carers
Issue 4		
Knowledge and information for carers	There are many government-funded services at both Commonwealth and state/territory level that support the provision of knowledge and information to mental health carers, often in tandem with other services for carers. These are usually delivered through non-government organisations, such as members of Carers Australia, Mental Health Carers ARAFMI Australia and others. There are many resources available to carers on various topics relevant to their caring role. However, carers may not know how to find this information or how to use it in their day to day lives.	Carers raise concerns over difficulties in accessing information and acquiring the knowledge required to successfully fulfil their caring role. One in three carers report that the information they need to help them care for the consumer is not easily available. A large proportion of respondents also feel the information they need is not offered at the right time.
Issue 5		
Carer and consumer education to all professional groups and agencies	The Mental Health Professionals Network (MHPN) establishes and supports interdisciplinary mental health networks across Australia. These locally driven networks aim to improve consumer outcomes by promoting collaborative practice and peer support amongst clinicians and service providers, and allow participants to gain continuing and professional development accreditation. Carers and consumers often provide online training to professionals through the MHPN.	Carers want to improve professionals' understanding of mental illness and the role of carers, through education programs provided by carers and consumers. Carers are especially critical of the way prison staff, court officials and Centrelink staff understand mental illness.
Issue 6		
Support systems, services and processes established for carers	The Australian Government has recently allocated additional resources to expand mental health respite and carer support services. Expanded and new services will provide mental health carers with a range of supports, including respite, brokerage, educational programs, counselling, peer support, advocacy services, information and referral, and social and recreational activities.	Many carers are unaware of the services available to them or believe that services are unsuitable for their needs or unavailable in their area. Quality staff and flexible services are said to be unavailable or unknown to carers in some areas. Carer support groups were nominated as the most widely available services to carers and were also rated highest for the quality of services available. Carer respite was reported as the least available carer support service.

Key Issues for Mental Health Carers	Policies and programs to address the issue	What the survey tells us about the experience of mental health carers
Issue 7		
Acute care to be therapeutic and accessible	Improving access to care has been a consistent theme of all four National Mental Health Plans. Programs and policies vary widely between each jurisdiction.	Many carers report that acute services had not been beneficial for the person they care for.
Issue 8		
Stigma, discrimination and isolation for carers and consumers	Despite repeated acknowledgement of this issue in national mental health plans and strategies, there is currently no national commitment to a broad mental health anti-stigma campaign. There are many non-government organisations working to overcome the causes and consequences of stigma and discrimination against people with a mental illness. The National Disability Strategy seeks to promote awareness and understanding of the rights of people with a disability, including people with disability related to severe and persistent mental illness.	Mental health carers and consumers are affected by discrimination and stigma in many aspects of life including employment, housing and health services. The negative impacts of discrimination often lead to social isolation and mental health problems for carers. Around half of survey respondents said that discrimination is widespread in the wider Australian community, while a third said that discrimination is widespread in the local community.
Issue 9		
Accommodation options for consumers at all levels of care	Under the *National Partnership Agreement Supporting Mental Health Reform*, the Commonwealth provides funds to states and territories for stable accommodation and support, and presentation, admission and discharge planning in emergency departments. One of the aims of this Agreement is to break the cycle of hospital admission and homelessness by supporting the recovery of mental health consumers in the community. The Australian Government has also made additional investment in social housing through the Social Housing Initiative and the National Partnership Agreement on Social Housing. On-the-ground housing programs available to people with mental illness vary widely between and within jurisdictions.	The availability of affordable and appropriate supported housing for people with a mental illness is a key issue for carers. Lack of secure and stable housing is a major barrier to recovery and places additional pressures on carers and the care relationship. Around three in four carers surveyed said the person they care for lives with them, with the remainder of consumers largely living in accommodation with little or no other support.

Key Issues for Mental Health Carers	Policies and programs to address the issue	What the survey tells us about the experience of mental health carers
Issue 10		
Financial costs to carers	The Australian Government provides a Carer Payment and a Carer Allowance. Carer Payment provides income support to people who, because of the demands of their caring role, are unable to support themselves through substantial paid employment. Carer Allowance is an income supplement available to people who provide daily care and attention to someone with a disability. Carers incur a range of costs associated with care and these often exceed any benefits available through the welfare system.	Many carers experience problems which stem from the processes used by Centrelink in assessing claims for Carer Payment and Carer Allowance. The current tools are biased towards the recognition of physical assistance provided by carers rather than emotional and social support, organising, encouraging and dealing with emergencies. As a result, many mental health carers report that they cannot access carer payments, despite having significant caring responsibilities. Carers' financial circumstances can also be detrimentally affected by inadequate financial support for the people they care for and the episodic nature of mental illness, which can make a carer's employment situation less stable.
Issue 11		
Physical and mental health of carers	The National Carer Counselling Program provides counselling and related emotional and psychological support services to carers. Reforms to the Family Relationship Services Carer Program aim to improve support services that cater specifically to the needs of parents, siblings and other carers.	The experience of caring for a person with a mental illness can have major negative health impact on carers. Seventy percent of carers reported a recent deterioration of their health as a direct result of being a mental health carer. Greater awareness of existing support services for carers is needed if the continuing mental and physical health needs of carers are to be properly addressed.
Issue 12		
Flexible respite options for carers	The Mental Health Respite: Carer Support Program provides a range of support services, including respite. Flexibility is built into program guidelines to allow service providers to respond to the needs of individual carers. The Australian Government has announced an expansion of this program, as described under Issue 6.	Carers report a range of barriers to accessing respite services. Some say that what they need from respite is often not available when required, while others are unaware of what services are available locally or believe that no such services are offered in their area. Just one in five carers say they use respite services.

Key Issues for Mental Health Carers	Policies and programs to address the issue	What the survey tells us about the experience of mental health carers
Issue 13		
Privacy and confidentiality issues	The basis for national policy on privacy and confidentiality in mental health services is covered in the *National Mental Health Standards*. Issues of privacy, confidentiality and information sharing in mental health services are governed by a complex combination of law, policy and professional codes. These rules must strike a balance between ensuring consumers' right to privacy and the needs of carers to be informed and involved. Australia has no national legislation addressing the needs of carers specifically. However, the *National Mental Health Policy 2008* nominates clear goals for greater carer involvement in service provision and development.	Carers report that privacy and confidentiality is often used by mental health professionals as a reason to exclude them from being involved in the decision-making process and accessing relevant information for the person they care for. This can be the case even when carers have permission from the consumer to be involved.
Issue 14		
Early intervention at each episode of care	Early intervention is a key feature of the *Fourth National Mental Health Plan*. The Plan commits to assisting people to seek help for themselves and others to prevent or intervene early in the onset or recurrence of mental illness.	One in five carers are extremely dissatisfied with the early response from mental health services. On a more positive note, most carers report an improvement in access to early intervention care in the past year.
Issue 15		
Employment options for carers	The *National Mental Health and Disability Employment Strategy* mentions the importance of employment for carers, as part of the Government's Social Inclusion agenda. The *National Carers Strategy* indicates that carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.	Being a mental health carer can severely limit employment options. Caring for someone with mental illness can be intermittent and needs can emerge quite suddenly. The caring role places restrictions on the amount and type of paid work that carers are able to undertake.

1. Background

In 2008 and 2009, the Mental Health Council of Australia (MHCA), with funding from the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), carried out 116 full day workshops throughout Australia to listen to the concerns of mental health carers. The feedback from those workshops was subsequently synthesised into a list of 15 major issues, providing a foundation for the major 2009 MHCA landmark report *Adversity to Advocacy: the lives and hopes of mental health carers*.

The 15 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

Following this, in 2010 the MHCA distributed a survey to all carers who attended the workshops and many other consumers and carers in contact with the MHCA's membership. These results were published in the *Mental Health Carers Report 2010*. In late 2011 and early 2012, the MHCA distributed a second survey with similar questions. This report describes the results of that survey.

Various comments by carers who completed the survey have been included throughout the report. These provide additional context for the interpretation of survey findings and some unique insights into the lived experience of mental health carers.

2. Method

The MHCA utilised its networks of mental health carers throughout Australia to recruit survey participants. The survey was promoted extensively using established carer, consumer and membership databases (which included all major carer organisations), with potential survey respondents encouraged to complete the survey online. In addition, the MHCA posted email and website advertisements through relevant mental health sector groups and other interested individuals and organisations at the national and state/territory levels.

The survey was open to participants for six weeks from late 2011 to early 2012; a total of 508 carers completed a survey. Because of the sensitivity of the subject matter, carers were able to choose whether they provided an answer to each question. For this reason, the number of responses reported below is often less than the total number of respondents in the survey sample.

The MHCA made particular efforts to promote the survey among CALD and Indigenous carers, as well as providing an opportunity for young carers to access the survey through social media.

Young carers

An alternative version of the survey was developed for young carers (13-18 years old). This survey covered many of the same issues using language that was more appropriate for a younger audience.

This survey was promoted via Facebook, through a marketing campaign utilising:

• Social Advertisements (regular, paid advertisements that appear while users interact with friends on Facebook)

• Social Action Advertisements (incentive-based viral promotion appearing in Facebook's News Feed from survey participants who recommend project content on Facebook to their 'friends').

A total of 72 young carers completed the survey.

Indigenous carers

Following advice from Indigenous stakeholders, it was agreed that the survey format was not the most appropriate mechanism to seek input from Aboriginal and Torres Strait Islander mental health carers who may not speak English as a first language. Instead, consultation workshops were held with Indigenous stakeholders in West Australia, the Northern Territory and Queensland.

These workshops were held between September 2011 and May 2012.

Culturally and linguistically diverse carers

The survey was translated into four community languages—Arabic, Chinese, Italian and Greek—and distributed widely to over 200 government and community sector organisations with an interest in multicultural health and wellbeing, seeking their support in reaching potential survey respondents from the four language groups. Despite heavy promotion, a relatively small number of CALD carers (12) completed the survey in their own language. A further 36 CALD carers completed the survey in English.

To collect further information on the specific needs of CALD carers, workshops were held in Victoria, with Somali community members in Swan Hill and Turkish community members in Mildura. In addition, the MHCA held consultations with CALD service providers through Carers Qld and with CALD mental health carers through Carers ACT.

Data analysis

Many of the survey responses in this report are broken down by the 'wellness' status of the consumer. There were often revealing differences between carers looking after a consumer who is relatively well and carers looking after someone who had experienced significant problems in the past 12 months. The following approach was used to define the 'wellness' status of the consumer.

• *Very unwell* includes respondents who said the consumer was extremely unwell during the past 12 months.

• *Somewhat unwell* includes respondents who were not in the *very unwell* category, but nevertheless said that the consumer had accessed acute inpatient hospital services, had exhibited suicidal or self-harming behaviours, or had otherwise been unwell (but not extremely unwell) in the past 12 months.

• *Well* includes all other respondents.

Where appropriate, survey findings have been broken down by other respondent characteristics which revealed interesting differences. These include the carer's relationship with the consumer (parent, child etc), type of mental illness, and CALD status.

3. Recognition and respect for carers

This section reports on survey findings relating to the recognition of and respect for the important contribution that carers make to the lives of people with a mental illness. Topics covered include health professionals listening to and involving carers in decision-making; stigma, discrimination and isolation; and privacy and confidentiality issues.

Health professionals listening to and involving carers

Many mental health carers mentioned a lack of respect for their caring role and the unwillingness of clinicians and mental health professionals to generally listen and include them in treatment plans. Carers want greater recognition for their role and expertise, to be included in treatment planning, and to work in partnership with mental health service providers and the people they care for through open and honest dialogue.

As Figure 1 illustrates, carers believed that GPs were the most willing of all clinicians to listen to their concerns about the person they care for, with 43% of respondents reporting GPs *always* listen.

Over a quarter of carers (28%) stated that psychiatrists *rarely* or *never* listened to their concerns.

When asked to what degree mental health professionals had made them feel part of the caring team, just 36% of mental health carers indicated that they *mostly* or *always* felt included, while 38% of respondents *never* or *rarely* felt part of the caring team. This highlights the inconsistency with which mental health carers are valued by professionals working with mental health consumers.

- *Carers need to be included and not made to feel like they do not exist.*

- *Being a mental health carer is lonely, frustrating, emotionally exhausting and dehumanising. I am constantly treated by staff and services as irrelevant or even as a problem. The only time I am usually contacted is when they want something from me such as driving the person I care for to an appointment. Of all the roles I've had in my life, this is by far the most challenging, exhausting, stressful, and poorly supported.*

Figure 1: Health professionals listening to carer concerns

GP (n=328)	7%	7%	17%	26%	43%
Community worker (n=224)	8%	10%	21%	25%	37%
Psychologist (n=189)	12%	12%	16%	20%	40%
Mental health nurse (n=207)	9%	15%	23%	24%	29%
Psychiatrist (n=296)	13%	15%	20%	27%	25%

▪ Never ▪ Rarely ▪ Sometimes ▪ Mostly ▪ Always
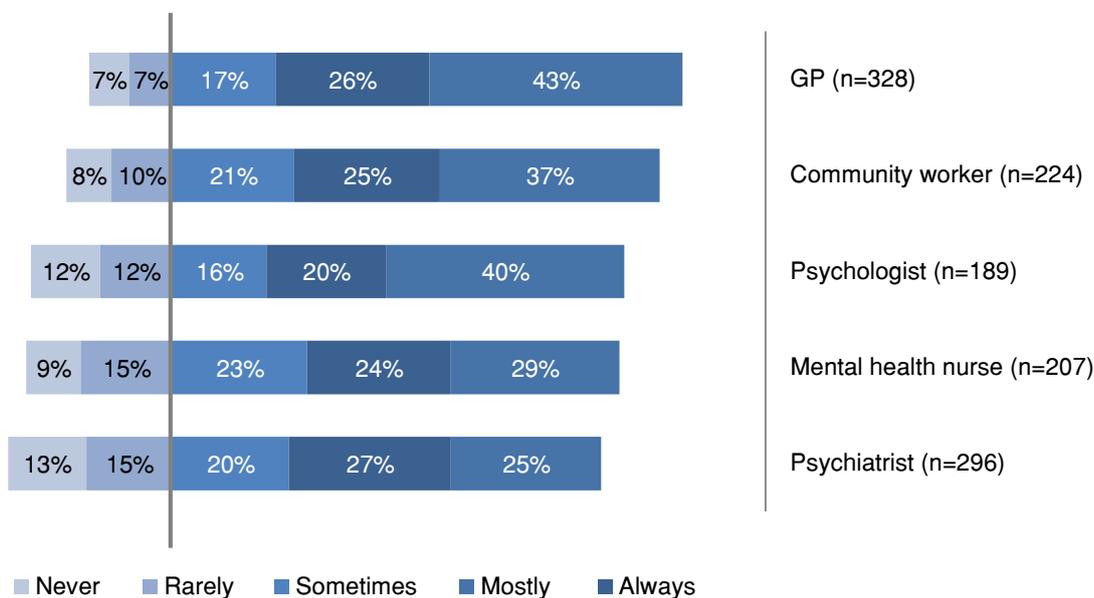
Question wording: "Please indicate how much each of these people listened to your concerns about the consumer during the last 12 months"

Figure 2: Health professionals including carers as part of the 'caring team'

21%	17%	26%	22%	14%	Total (n=434)
25%	13%	18%	27%	17%	Consumer has been well (n=71)
20%	13%	34%	20%	13%	Consumer has been somewhat unwell (n=104)
20%	20%	25%	21%	14%	Consumer has been very unwell (n=259)

■ Never ■ Rarely ■ Sometimes ■ Mostly ■ Always
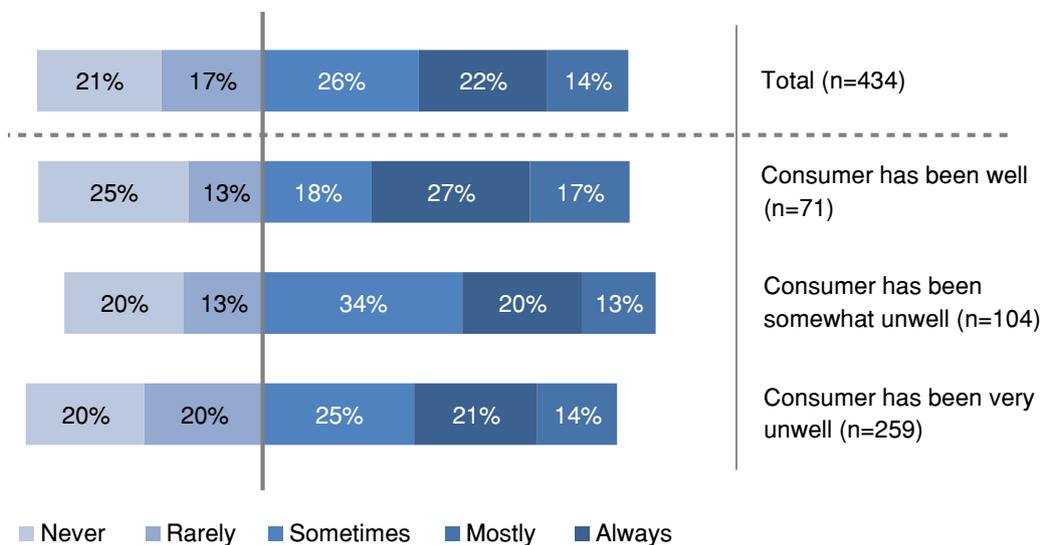
Question wording: "During the last 12 months, have you been made to feel part of the 'caring team' by the mental health professionals involved in the care of the consumer?"

Stigma, discrimination and isolation

Mental health carers and consumers are affected by discrimination and stigma in many aspects of life including employment, housing and health services. The negative impacts of discrimination can also lead to social isolation. This was reflected in the survey results, with 66% of respondents reporting that they *always* or *often* felt alone and only 9% indicating that they *never* or *rarely* felt alone.

Half of respondents (50%) believe that discrimination is widespread in the general Australian community, whilst 33% think that

discrimination is commonplace in their local community. Only a small proportion of respondents (2%) reported that stigma did not exist in the wider Australian community, while only 10% of respondents had not experienced discrimination in their local community.

Survey results show that consumers and carers experience greater levels of discrimination when the consumer has been very unwell during the past 12 months.

Figure 3: Discrimination experienced by carer or consumer in their local community
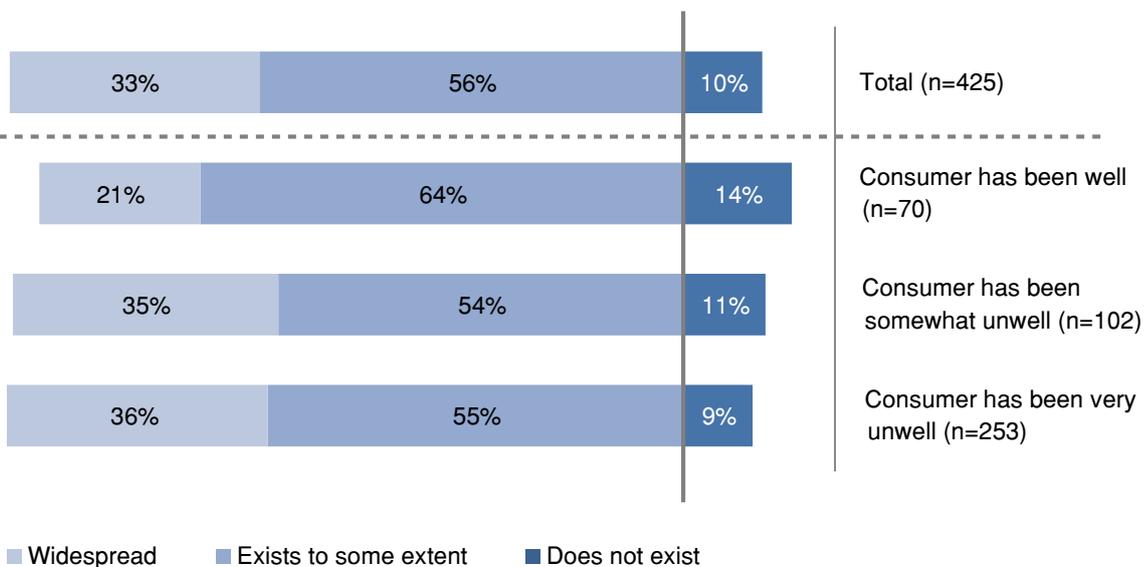
	Widespread	Exists to some extent	Does not exist	
Total (n=425)	33%	56%	10%	
Consumer has been well (n=70)	21%	64%	14%	
Consumer has been somewhat unwell (n=102)	35%	54%	11%	
Consumer has been very unwell (n=253)	36%	55%	9%	

■ Widespread   ■ Exists to some extent   ■ Does not exist

Question wording: "What has been the extent of discrimination you or the consumer has experienced in your local community during the last 12 months because of mental illness?"

- *It has been and remains an unbearable experience of aloneness and helplessness, as we have to fight against the system to be heard.*

- *Social isolation is a major issue for us.*

- *Stigma is still a significant problem. The media could do more to educate the public and inform them about mental health issues.*

In my opinion, the biggest issue facing mental health carers is stigma. Stigma is experienced in the workplace, in the local community and in the wider community. It is shocking; I do not believe things have improved in this area in the past few years.

Figure 4: Discrimination experienced by carer or consumer in the wider community
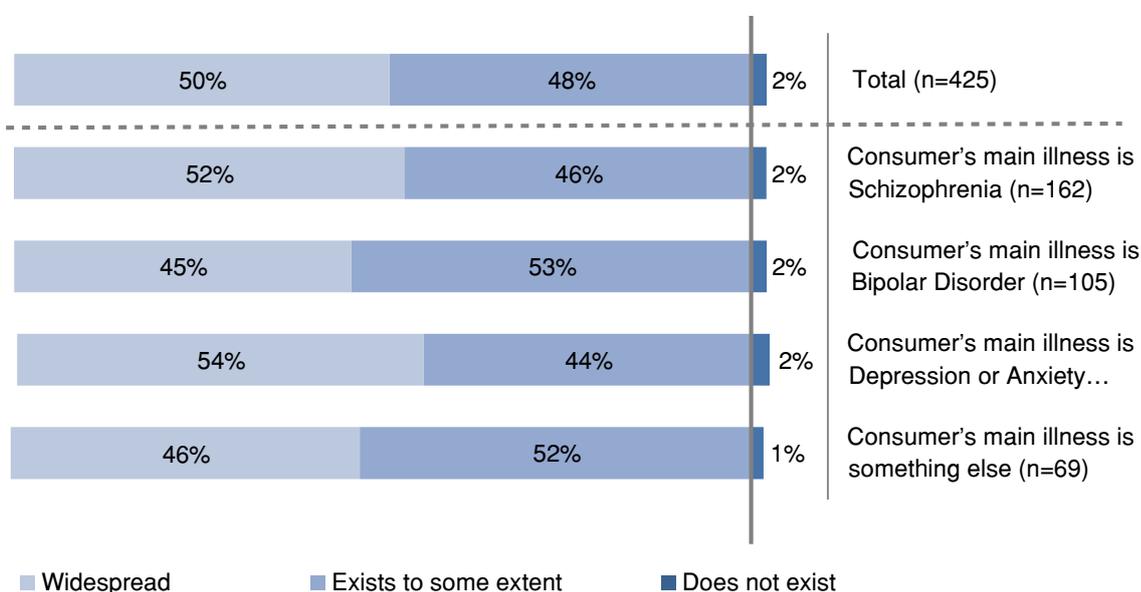
50%	48%	2%	Total (n=425)
52%	46%	2%	Consumer's main illness is Schizophrenia (n=162)
45%	53%	2%	Consumer's main illness is Bipolar Disorder (n=105)
54%	44%	2%	Consumer's main illness is Depression or Anxiety…
46%	52%	1%	Consumer's main illness is something else (n=69)

■ Widespread   ■ Exists to some extent   ■ Does not exist

Question wording: "What has been the extent of stigma around mental illness in the wider Australian community during the last 12 months (e.g. as represented in media coverage and attitude)?"

People do not ask how [the person I care for] is because the answer will take them out of their comfort zone. A lot of people do not even know about her illness or are not prepared to be confronted by such an unsociable disease, unlike breast cancer which brings out the sympathy and is socially acceptable.

Privacy and confidentiality

Carers reported that privacy and confidentiality were used by mental health professionals to exclude them from the decision-making process and accessing relevant information for the person they care for, even when they had permission from the consumer to be involved. This caused significant impediments to providing care and the overall quality of that care.

Carers were asked if privacy and confidentiality issues created a barrier between themselves and mental health professionals when seeking information they required to care for the consumer.

Around one quarter of respondents (23%) said they were *always* or *mostly* excluded from information by professionals.

Thirty-eight per cent of respondents had experienced concern and anxiety about the health of the person they were caring for due to lack of disclosure from mental health professionals. There was a higher degree of concern and anxiety experienced when the consumer was the carer's parent (50%) and where the consumer had been unwell in the past 12 months (45%).

Figure 5: Concern and anxiety due to lack of disclosure by professionals

15%	23%	26%	18%	17%	Total (n=427)
12%	27%	21%	24%	15%	Consumer is the carer's child under 18 (n=33)
14%	27%	27%	18%	15%	Consumer is the carer's adult child (18+) (n=222)
27%	23%	23%	4%	23%	Consumer is the carer's parent (n=26)
13%	16%	24%	22%	25%	Consumer is the carer's partner (n=105)
16%	22%	38%	16%	8%	Consumer had another relationship to the carer
6%	16%	23%	22%	33%	Consumer has been well (n=69)
13%	21%	32%	22%	13%	Consumer has been somewhat unwell (n=102)
18%	27%	25%	16%	15%	Consumer has been very unwell (n=256)

■ An extreme amount of anxiety   ■ A large amount
■ A moderate amount   ■ A small amount

Question wording: "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?"

4. Services and support for carers

This section describes survey findings on mental health carers' views of the services and support that are available to them. Topics covered include interaction with professionals, knowledge and information, quality and availability of carer services, financial costs, physical and mental health of carers, use of respite services and employment options for carers.

Interaction with professionals

When asked how well professionals understood carer issues, the responses varied. A little over half of respondents (53%) rated carer services as having the best comprehension of carer issues, saying they understood carer issues *extremely well* or *very well*. Of all health professionals, psychologists and counsellors were rated most positively. Around a quarter of respondents rated psychologists (28%)

and counsellors (24%) as understanding carer issues extremely well or very well.

Prison staff, court officials, school staff and Centrelink all scored poorly on their levels of knowledge of carer issues. There were many carer comments in relation to Centrelink and the quality of service it provides, as highlighted in the comments below.

Carer comments on Centrelink

- *I believe Centrelink contributes to mental illness. A person who is not mentally well cannot deal with queues and forms. There are often gaps of time between various Centrelink payments (e.g. moving from sickness benefits to job seeker benefits), leaving people without necessary funds for medication, food and day to day living costs.*
A case management system is needed for people with mental illness, who have to rely on Centrelink periodically due to the cyclical nature of their illness.

- *I cannot express how disgusted I am in Centrelink's approach to carers. After 10 years of drought, no crops and a large debt, I am not eligible for a carer payment as I have too many assets.*

- *Centrelink exhausted me; the process, refusal of payment, the lost paperwork and cancellation of carer payments when [the consumer] turned 16.*

- *The Centrelink form for carer payment and carer allowance does not easily recognise the role of mental health carers and needs to be changed to be inclusive!*

- *It would be good to see financial help out there for mental health carers other than Centrelink. I applied for carers allowance and they said my mum was not sick enough for me to get the carer allowance. (17 year old caring for their mother)*

Figure 6: Understanding of carer issues by professionals

	Not at all well	A little	Quite well	Very well	Extremely well
Carer services (n=351)	9%	12%	25%	26%	28%
Counsellors (n=246)	17%	23%	36%	17%	7%
Psychologists (n=309)	18%	25%	31%	18%	8%
GPs (n=359)	17%	27%	30%	18%	8%
Social workers (n=239)	21%	25%	33%	15%	5%
Mental health nurses (n=325)	23%	24%	30%	16%	8%
Psychiatrists (n=352)	25%	23%	28%	19%	6%
Community workers (n=304)	23%	26%	29%	11%	10%
Pharmacists (n=295)	28%	31%	30%	9%	3%
Triage / helplines (n=234)	32%	29%	23%	12%	6%
Centrelink staff (n=272)	46%	30%	17%	7%	1%
Police (n=262)	37%	37%	18%	5%	3%
Housing staff (n=174)	49%	30%	14%	4%	3%
School staff (n=149)	52%	32%	11%	4%	1%
Court officials (n=112)	52%	33%	11%	1%	3%
Prison staff (n=69)	58%	33%	4%	4%	1%

Question wording: "How well do you think carer issues are understood by the following professionals?"

Knowledge and information for carers

Carers raised concerns over difficulties in accessing information and acquiring knowledge to successfully fulfil their caring role. One in three (33%) carers reported that the information they needed to help them fulfil their role was *rarely* or *never* easily available. A large proportion (44%) of respondents also felt that the information they needed was *rarely* or *never* offered at the right time.

The amount of information carers receive varies considerably. Respondents were more likely to receive specific information about the consumer's medication, with 39% of carers reporting information on medication and prescribing plans were *always* available.

Carers were less likely (10%) to receive information about their own caring role. It is worth noting that carers associations in each state and territory provide carers kits with this kind of information.

When asked where they had sourced information to help in their caring role, over half of respondents (53%) had used the internet, followed by GPs (43%) and carer services (41%). Carers were less likely to use housing services (6%), police (8%) and triage/helplines (8%) as sources of information. It is worth noting that carers associations in each state and territory provide carers kits with this kind of information.

Figure 7: Information available to carers
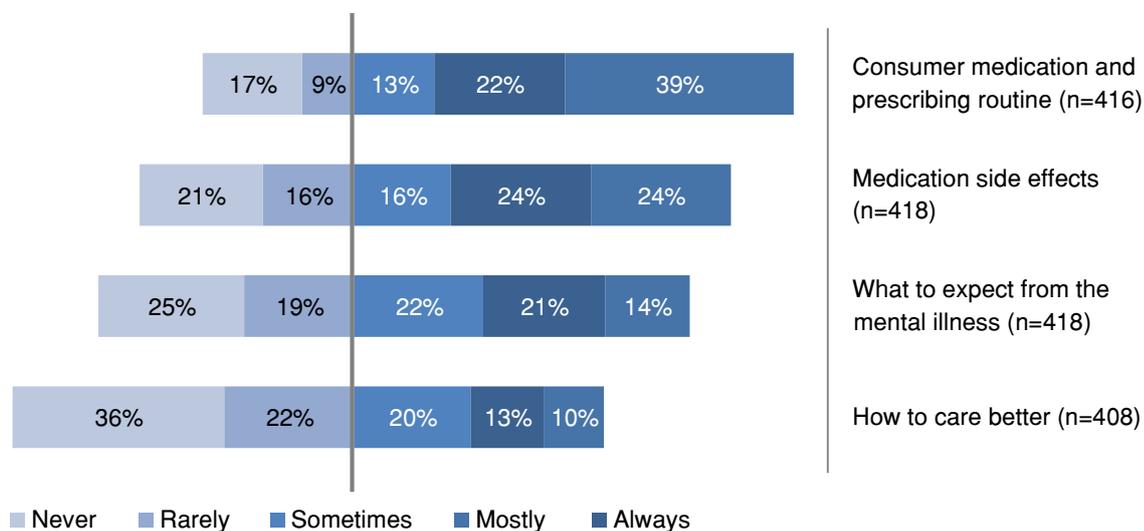
	Never	Rarely	Sometimes	Mostly	Always
Consumer medication and prescribing routine (n=416)	17%	9%	13%	22%	39%
Medication side effects (n=418)	21%	16%	16%	24%	24%
What to expect from the mental illness (n=418)	25%	19%	22%	21%	14%
How to care better (n=408)	36%	22%	20%	13%	10%

■ Never ■ Rarely ■ Sometimes ■ Mostly ■ Always

Question wording: "Please comment on the availability of information about the consumer's medication and illness during the last 12 months."

Quality and availability of carer services

Carer support groups were nominated as the most widely available services to carers and were also rated highest with regard to the quality of the services available.

Carer respite was reported as the least available carer support service and information on how to help the consumer was ranked the lowest for the to quality of services available.

The support services provide all the contact details to the consumer, but who can the carer call when they are worried and afraid? The concern that when your child goes away they may not come back, or nights when you lay awake with worry that they might not be alive the next morning.

Figure 8: Availability of services for carers

	Never/not available	Rarely	Sometimes	Mostly	Always
Carer support groups (n=390)	17%	4%	18%	21%	40%
Internet-based services (n=341)	15%	8%	23%	25%	30%
Pharmaceutical drug information (n=366)	17%	9%	22%	29%	23%
Information on how to help the consumer (n=396)	19%	18%	31%	20%	12%
Career counselling (n=364)	27%	13%	23%	18%	19%
Carer respite (n=320)	39%	11%	23%	13%	13%
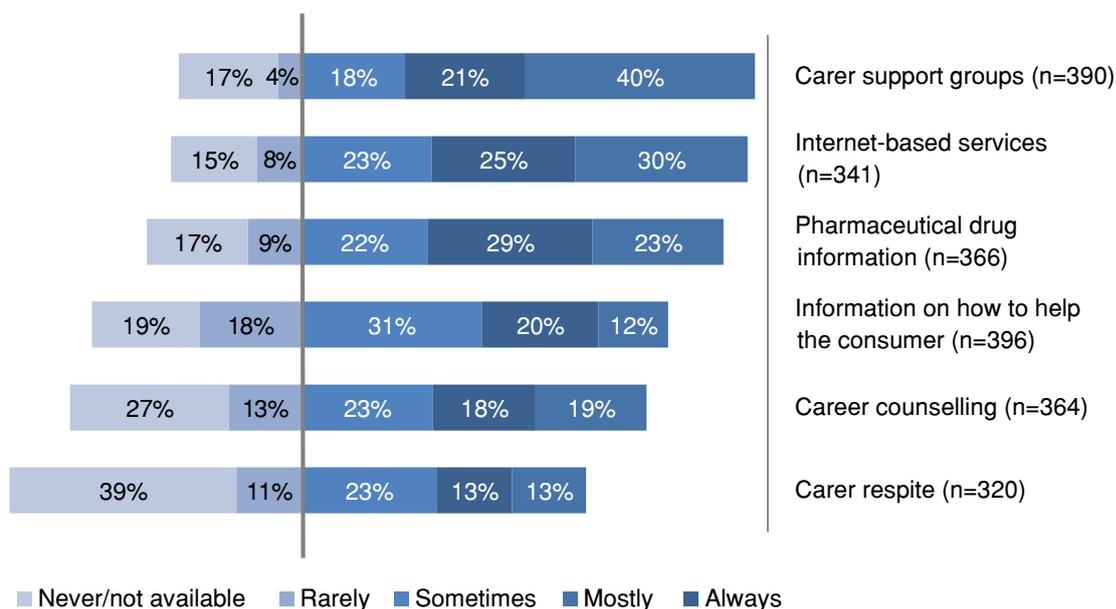
Question wording: "Have the following services been available to you over the last 12 months?"

I have great concern in regard to the financial management of my son when I am no longer here. I have tried to contact the state Guardian Tribunal and several other services. No one seems to be able to assist me with clear information so that I can make an informed decision and I find the process to be very confusing.

Figure 9: Quality of services for carers
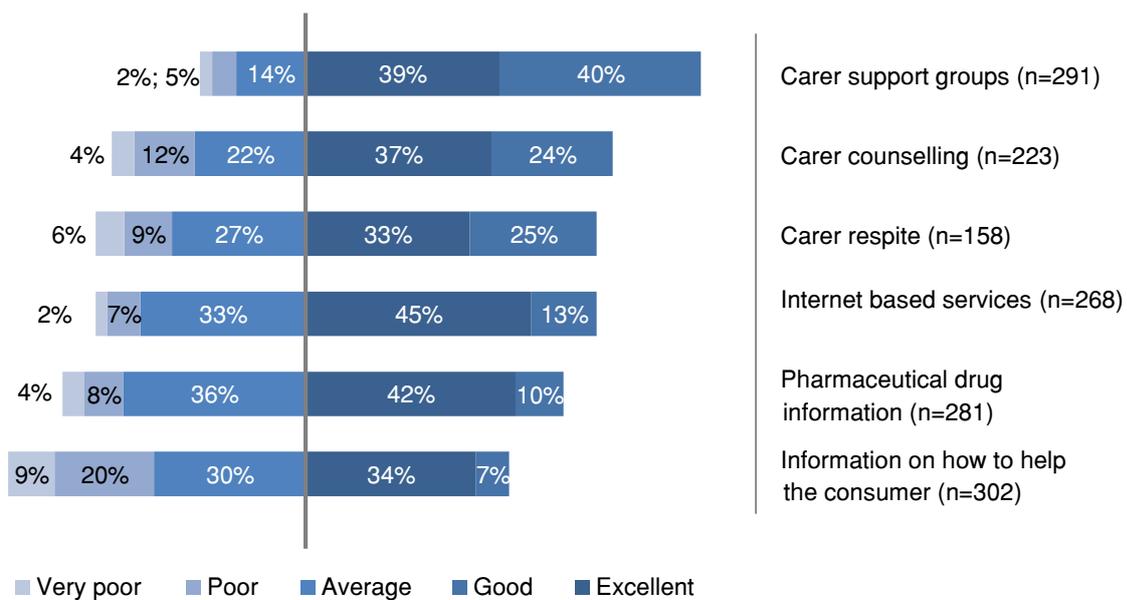
2%; 5%	14%	39%	40%	Carer support groups (n=291)
4% 12%	22%	37%	24%	Carer counselling (n=223)
6% 9%	27%	33%	25%	Carer respite (n=158)
2% 7%	33%	45%	13%	Internet based services (n=268)
4% 8%	36%	42%	10%	Pharmaceutical drug information (n=281)
9% 20%	30%	34%	7%	Information on how to help the consumer (n=302)

■ Very poor   ■ Poor   ■ Average   ■ Good   ■ Excellent

Question wording: "Please comment on the quality of the services available to you over the last 12 months."

Financial costs to carers

Mental health carers incur a range of associated costs as a direct result of their role as carers, including the provision of outside care, medication, accommodation and transportation. Even where consumers do not live with their carer, many carers still take on the cost and responsibility of caring, and often do so for years without financial recompense.

Overall, carers reported spending an average of $144 each fortnight on the person they cared for. Young carers reported spending an average of $45 per fortnight, while for carers from CALD backgrounds this amount was $232.

> *I believe that the government could support mental health carers more financially. We save the government a great amount of money and in most cases our health suffers because of this caring role.*

Figure 10: Financial costs for carers
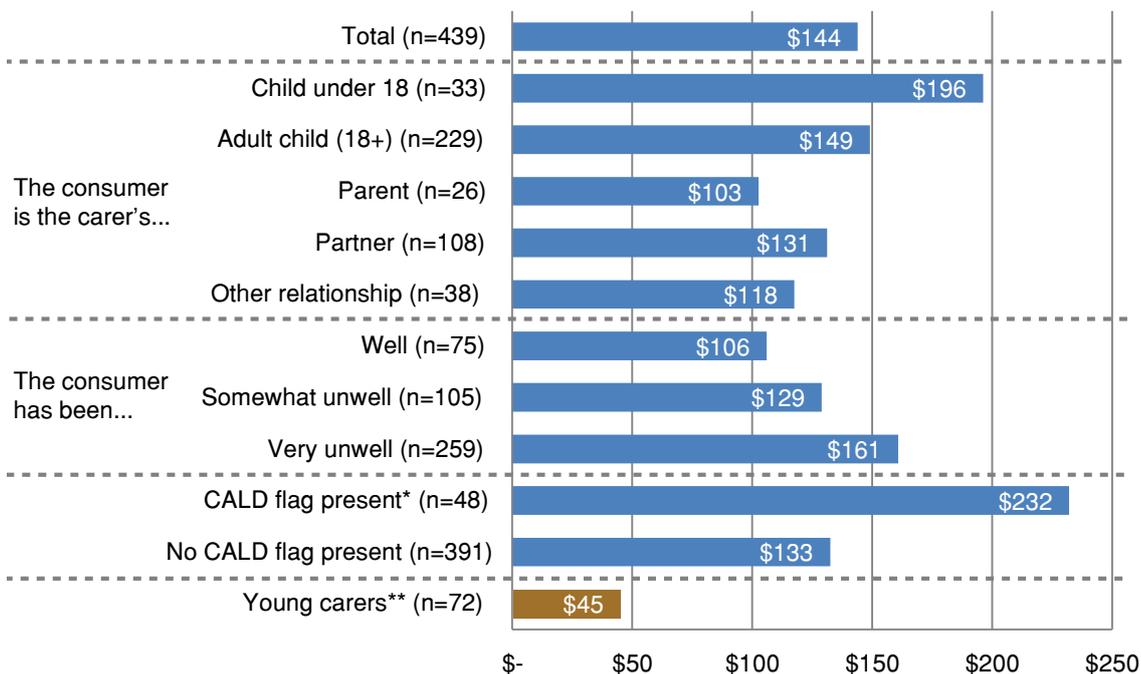
Question wording: "Please estimate the average amount (in dollars) you provide or spend on the consumer each fortnight (eg costs of transporting consumers to activities and appointments etc)?"

* "CALD flag" refers to markers of cultural and linguistic diversity. This includes having completed the survey in another language, speaking a language other than English at home and/or identifying racially as anything other than Caucasian or European (including having an Aboriginal or Torres Strait Islander background).

** Data taken from a separate survey of young carers (the same question was asked in both surveys). Most of the results from the young carers survey are reported in section 7.

While I spend approximately $200 a fortnight in providing support for my son, I have also purchased a home for him to live in. I did this because, financial burden aside, I could see that having a secure home would make a large difference to his stress levels and quality of life. This decision has also greatly assisted my stress levels whilst managing my carer responsibilities, because I can come and go as my son needs me and I can also stay over for short periods when required.

As a result of these expenses I need to remain in the workforce indefinitely. My carer role and associated financial responsibilities now make my retirement plans impossible. I live in hope that independent supported living will be freely available and accessible to all people with mental illness. Appropriate levels of monitoring will occur from within the system to enable early intervention before hospitalisation. Care plans will be individually tailored and carer inclusive, holistic, realistic and adequately supported from within the system and also that carers will have peace of mind that their child will be looked after once they are no longer around to support them.

Living fortnight to fortnight is a constant struggle. Neither society nor the government recognise the significance of the role of the carer. Especially how much money they save by the carer looking after the consumer.

Physical and mental health of carers

The experience of caring for a person with a mental illness can have major negative health impacts on carers, especially as they frequently neglect their own health requirements. The focus of carers and health professionals is often entirely centred on the consumer's health, while carer needs are often not considered.

Carers were asked if their mental or physical health had been affected as a result of being a mental health carer. Over two-thirds (71%) of respondents reported a deterioration of their health in the previous 12 months as being a direct result of caring for someone with a mental illness.

A majority of carers (78%) reported their own physical and mental health had deteriorated more substantially when the consumer had been unwell in the past 12 months. Around half of respondents (53%) stated that their own physical and mental health had been affected even when the consumer had been in good health during the past 12 months.

My physical and mental health have deteriorated over the past 12 months, to the point that my psychologist has strongly suggested I should not be working but I have to work to support my son's ongoing care when his government funding runs out next year.

Figure 11: Physical and mental health of carers

	Much worse	Slightly worse	No different	Slightly better	Much better	
Total (n=431)	30%	41%	20%	5%	3%	
Consumer has been well (n=71)	15%	38%	34%	4%	8%	
Consumer has been somewhat unwell (n=104)	37%	31%	23%	6%	4%	
Consumer has been very unwell (n=256)	32%	46%	14%	5%	2%	

■ Much worse ■ Slightly worse ■ No different ■ Slightly better ■ Much better
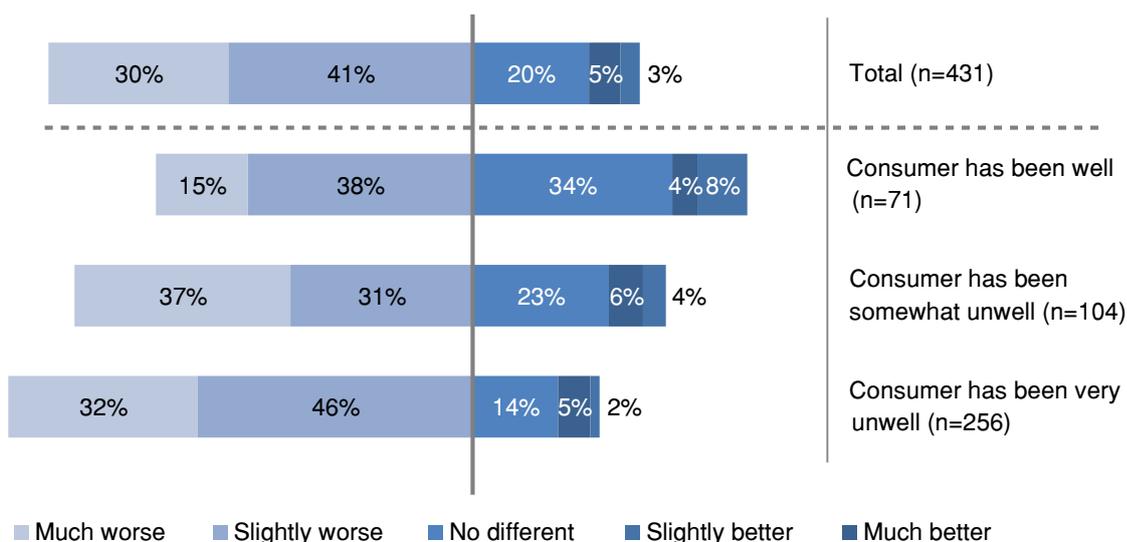
Question wording: "(As a carer) has your physical or mental health changed during the last 12 months?"

Carers reported using a range of coping strategies or services, with counselling (49%) and medication (47%) being used most often.

One in five (22%) had accessed a counselling service free of charge, while 11% had used free respite services.

I became ill last year due to the accumulation of maintaining my caring role both for my husband and my son who moved back home due to his anxiety disorder and becoming unemployed.

Figure 12: Coping strategies or services used by carers

Service	Not used	Used a free carer service	Paid a subsidised cost	Paid 100% of cost
Counselling (n=394)	51%	22%	16%	11%
Stress and anxiety medication…	53%	2%	21%	24%
Holiday (n=387)	53%	1%	3%	42%
Massage (n=383)	66%	5%	4%	25%
Respite / time-out (n=377)	69%	11%	7%	12%
Gym membership (n=364)	79%	1%	2%	17%
Acupuncture (n=353)	91%	1%	2%	6%
Other (n=257)	77%	1%	2%	19%

■ Not used ■ Used a free carer service ■ Paid a subsidised cost ■ Paid 100% of cost
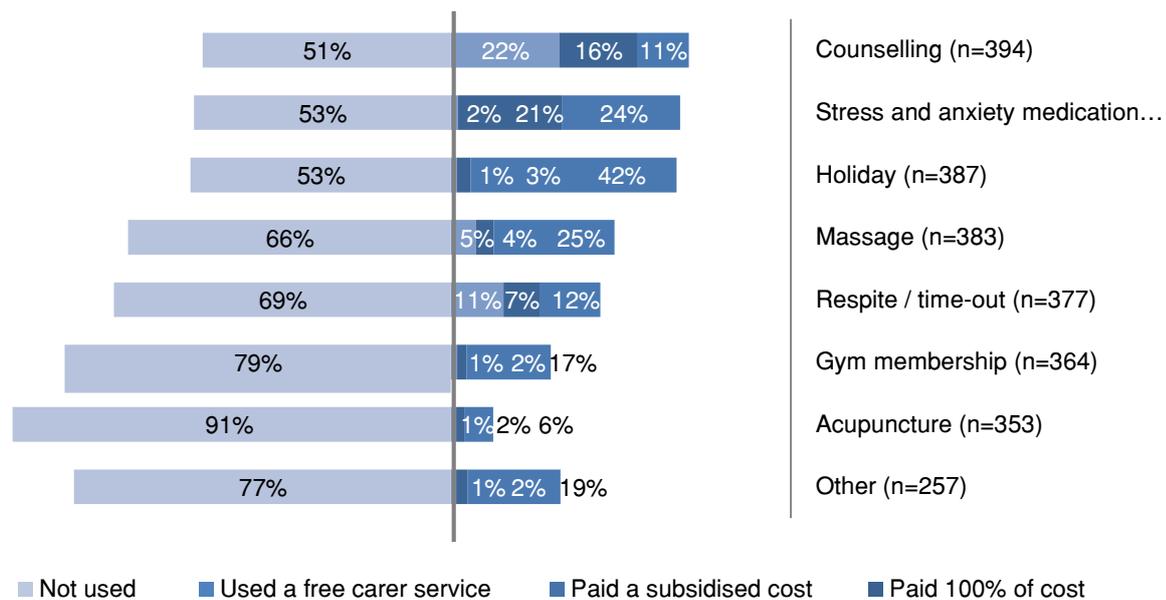
Question wording: "Please indicate which of the following coping strategies or services you have used during the last 12 months (including details of any associated costs/subsidies)?"

Use of respite services by carers

Various forms of respite are essential in assisting carers to continue their caring role, by enabling them to have a break from their caring responsibilities and a chance to take some time for themselves. There are several types of respite, ranging from emergency respite to planned respite for a few hours or several days.

Just one in five survey respondents (18%) reported using respite services. Reasons for not using respite were varied: nearly half of those who did not use respite (42%) said that they did not need it, while 27% said what they need from respite is not available. Another 23% said they could not leave the consumer with a respite worker, while 11% had not even heard of respite. Five per cent reported that carer respite is not offered in their area.

- *I would access carer support services if I knew where to find them.*

- *It is extremely hard to take holidays when caring for someone with a mental illness as usually they like a lot of structure in their life and this is very important to their health.*

Figure 13: Why carers do not use carer respite services

I do not need carer respite services — 42%
What I need from respite care is not available — 27%
I could not leave the consumer with a respite worker — 23%
I am not aware of any carer respite services being available — 13%
I do not know what carer respite services are — 11%
Carer respite is not offered in my area — 5%

(n=342 who do not use carer respite services)
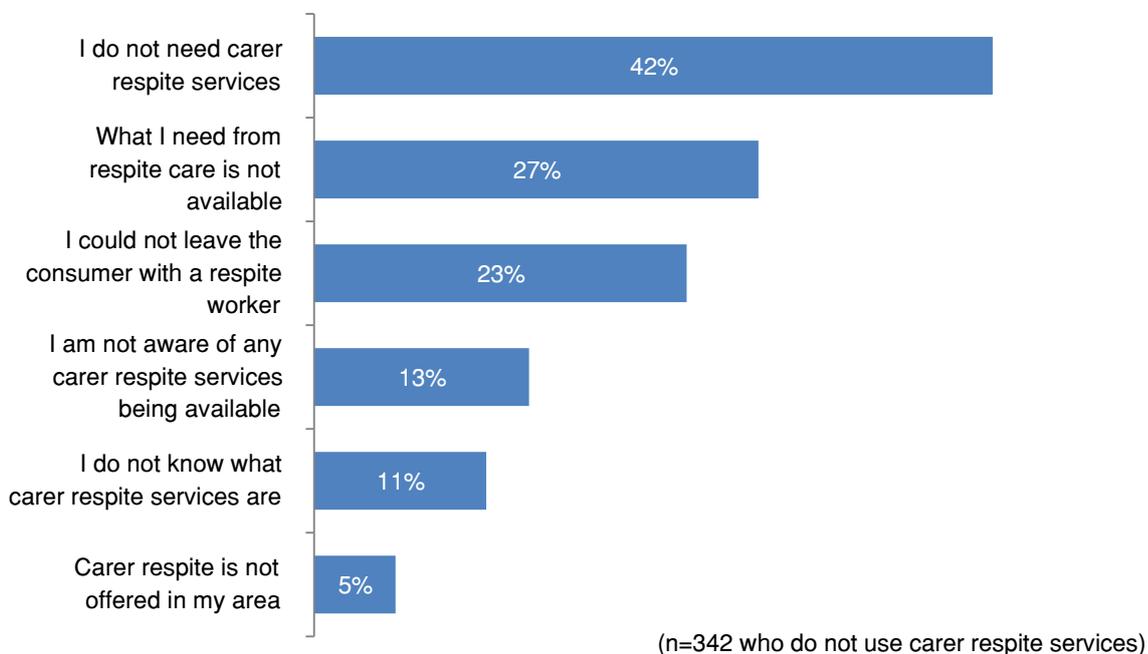
Question wording: "If you do not use carer respite services, why is this?"

- *We cannot access respite services as our daughter is considered too high a risk for workers to deal with, which leaves us very alone.*

- *Respite is inflexible as it only applies for my son and I would have to book another respite worker for my father through a different agency. These kinds of complications make daily life difficult. I would like someone, like a case worker, who could assist with coordinating both members of the family.*

- *I have found in the past that my daughter is unhappy with in-house respite so we do not use it. The government houses are horrible and I would not use them either.*

- *The only reason my workplace has been flexible is because I work as a carer consultant. In previous roles there was no flexibility.*

- *I had to resign from my position as a nurse because I was unable to access either suitable hours or services.*

Employment options for carers

Being a mental health carer can severely limit employment options. Caring duties for someone with a mental illness can be intermittent and emerge quite suddenly. Caring restricts the amount and type of paid work that carers are able to undertake. This may limit available hours for work and restrict how far from home they are prepared to travel, thus affecting job opportunities and career planning.

A large proportion of carers who were employed (62%) felt that their workplace understood their needs as a mental health carer. About one in five of respondents (18%) reported they were not in the workforce due to their caring role.

Respondents were evenly split when asked if they had seen an improvement in workplace flexibility. Approximately 40% of working carers agreed that workplace flexibility to assist them in their caring role had improved over the previous 12 months. Around 40% of working carers said there had been no change in flexibility within the workplace to assist them as a mental health carer.

I work for [the consumer] so am unable to find work in the outside world as I am needed at home. If I am not here things deteriorate.

I have truly struggled being a carer and recently had eight weeks off work suffering from burnout. I was back at work a month and have been struck down again with physical health issues. I do not know how I can continue to work. I am trying however it is very difficult. If I said to my workplace I needed time off to care for my husband because he had cancer or needed an operation, there would be no problem. To say I need time off to care for my husband because he has post traumatic stress disorder has been very difficult.

5. Services and support for consumers

This section describes survey findings relating to carers' perceptions of services and support for consumers. Topics include recovery-based care, interactions with professionals, therapeutic and accessible acute care, accommodation options and early intervention.

Recovery-based care

Carers strongly support recovery-based care in the community. They also commonly believe that such care is not currently supported sufficiently, and want to see improvement across a range of areas related to recovery. In this context, recovery does not necessarily refer to the absence of a mental illness or the symptoms, but rather the engagement of consumers within communities and living as well as possible.

When asked to indicate which recovery-based options were available to the person they cared for during the previous 12 months, carers' knowledge was limited. Between 31% and 49%

of respondents were unsure about the availability of different recovery-based options. Where availability of options were known, services were more frequently not available than readily available.

Survey results show some carers knew about the availability of clubhouse (29%), Personal Helpers and Mentors (PHaMS) (28%), supported employment and training (22%) and living skills (22%).

Figure 14: Availability of recovery based care options
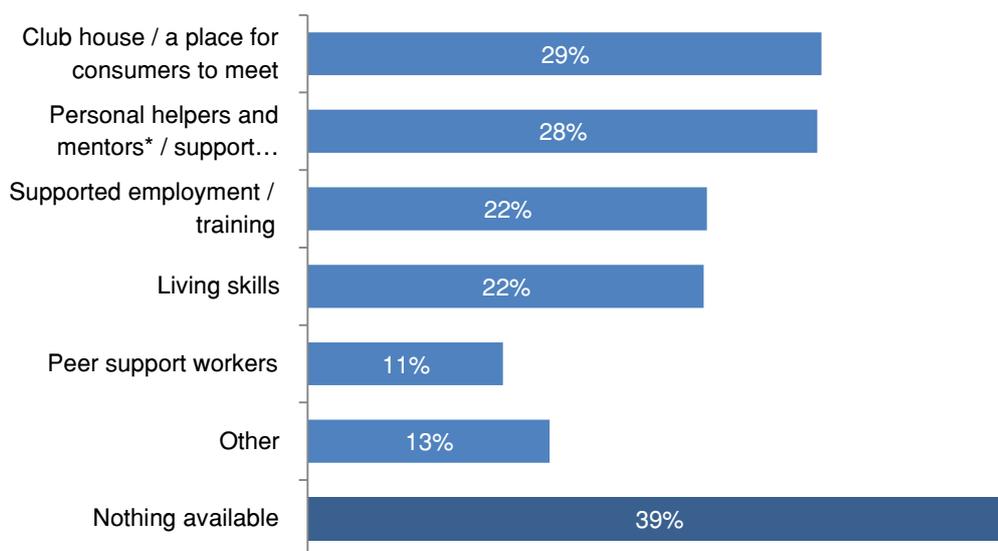
(n=424 who rated the availability of one or more of these recovery based care options)

Question wording: "Were any of the following recovery based care options available to the consumer during the last 12 months?"

* PHaMs workers

A large number of respondents (87%) reported that they, as the carer, or a close family member, organised the majority of non-medical care for the consumer. The community worker organised the majority of care in 11% of cases, with medical workers doing this 9% of the time.

Interactions with professionals

Carers identified high staff turnover of health professionals as a major impediment to obtaining adequate care and support for the people they care for. Due to this turnover, carers had to repeat their story several times, and were sometimes provided with different information or advice by different professionals.

Around half of respondents (51%) rated carer services as the best at understanding consumer issues saying they understood consumer issues *extremely well* or *very well*. They were much less likely to say prison staff, court officials, school staff, Centrelink staff, housing staff and police understood consumer issues. It should, however, be noted that carers may not interact with these professionals as regularly as primary service providers for consumers.

Figure 15: Understanding of consumer issues by professionals

	Not at all well	A little	Quite well	Very well	Extremely well
Carer services (n=372)	6%	15%	28%	32%	19%
Mental health nurses (n=343)	10%	18%	33%	27%	12%
Psychologists (n=362)	8%	20%	30%	28%	13%
Psychiatrists (n=402)	10%	19%	28%	32%	11%
Counsellors (n=275)	11%	24%	32%	25%	8%
GPs (n=428)	11%	25%	36%	20%	8%
Community workers (n=344)	12%	25%	33%	21%	9%
Social workers (n=273)	16%	24%	31%	23%	6%
Pharmacists (n=355)	14%	30%	36%	15%	5%
Triage / helplines (n=267)	23%	22%	28%	20%	6%
Police (n=316)	28%	36%	22%	10%	3%
Housing staff (n=193)	37%	34%	18%	7%	4%
Centrelink staff (n=327)	39%	34%	19%	6%	2%
School staff (n=205)	40%	35%	16%	6%	3%
Court officials (n=126)	43%	33%	17%	5%	2%
Prison staff (n=75)	51%	31%	11%	8%	

Question wording: "How well do you think consumer issues are understood by the following professionals?"

> *I had a fantastic social worker when my son had his first psychotic episode, and she set up some wonderful support systems and care plan. Unfortunately, she was moved on to another role because she was so good and since then I have been struggling to find other supports.*

Therapeutic and accessible acute care

When asked about the benefit of hospital inpatient acute services to the consumer's health during the preceding 12 months, 54% of respondents reported not using these services. Among those respondents who had accessed acute services, around half (48%) indicated that such services were *mostly* or *always* beneficial,

while 29% of respondents believed inpatient acute services were *not beneficial*. Notably, among respondents caring for someone with depression or anxiety, carers were more likely to say that acute services were not beneficial.

Figure 16: Benefits of hospital inpatient acute services for consumers

	Never	Rarely	Sometimes	Mostly	Always	
Total* (n=202)	13%	16%	23%	32%	16%	
Consumer's main illness is Schizophrenia (n=74)		7%	12%	28%	39%	14%
Consumer's main illness is Bipolar Disorder (n=54)		9%	15%	20%	26%	30%
Consumer's main illness is Depression or Anxiety…	28%	18%	15%	26%	13%	
Consumer's main illness is something else (n=33)	15%	24%	27%	27%	6%	

■ Never ■ Rarely ■ Sometimes ■ Mostly ■ Always
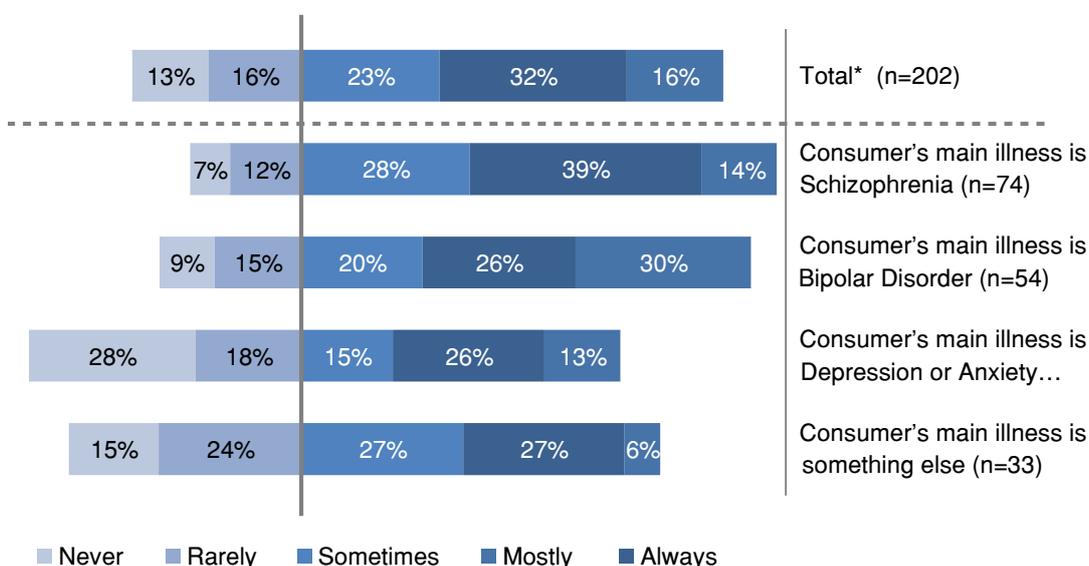
Question wording: "Were the hospital inpatient acute services beneficial to the consumer's health during the last 12 months?"

Accommodation options

The term *supported accommodation* refers to safe and secure housing with regular support from mental health clinicians and support workers to improve the lives of people with a mental illness and prevent relapse into serious illness. Supported accommodation enables people with a mental illness to choose where and how they live and ensures they live as independently as possible. Many carers raised the matter of adequate and appropriate accommodation for the person they care for as a major concern.

The majority of respondents (72%) reported that the person they care for lived with them during the previous 12 months. This is not always the ideal solution for either the carer or consumer, but the lack of other options means that accommodation and support provided by the carer was the only thing preventing the consumer from becoming homeless.

Figure 17: Accommodation options for consumers

■ Consumer has been somewhat unwell (n=104)   ■ Consumer has been well (n=72)
■ Consumer has been very unwell (n=258)
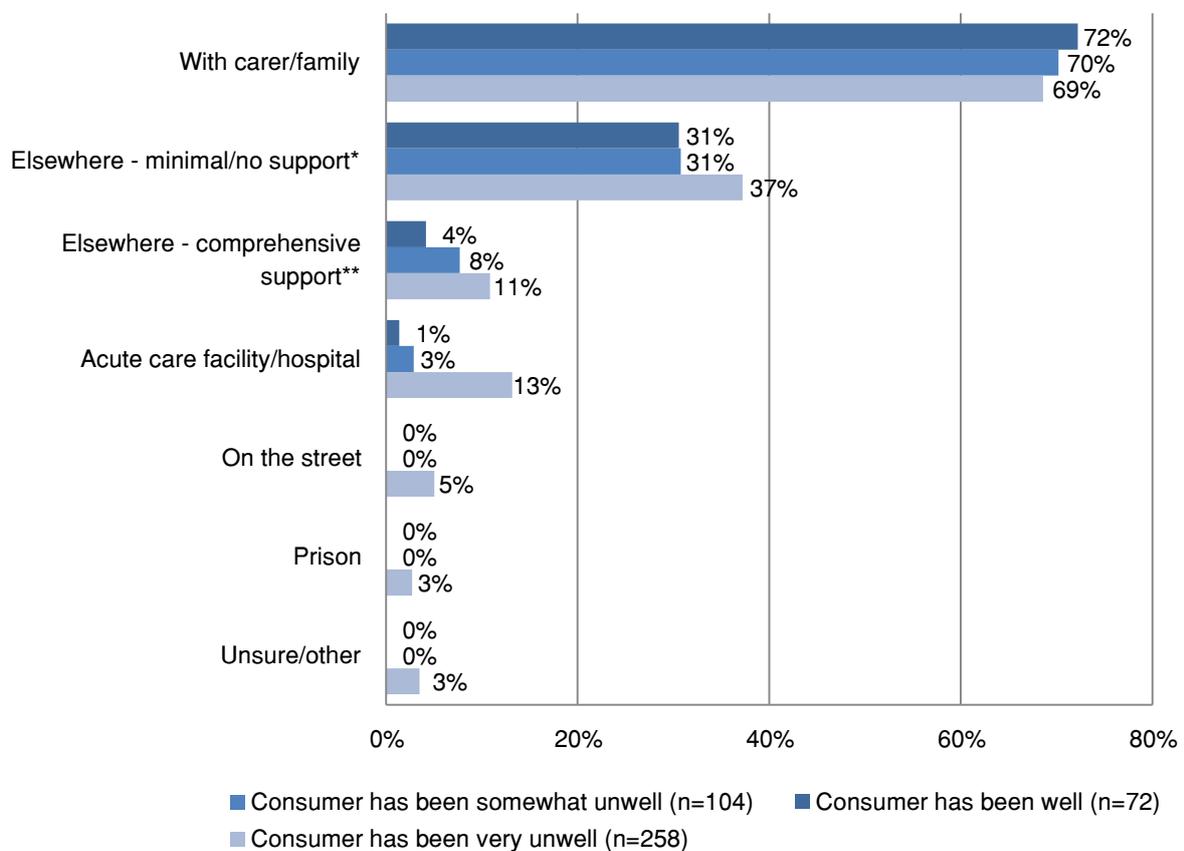
Question wording: "Where has the consumer lived during the last 12 months (tick all that apply)?"

* Includes supported independent living, residential rehabilitation and step up/step down facilities

** Includes public or private unsupported accommodation, independent living and hostels and group homes

> *Our family member is in rehabilitation in a government facility and has enjoyed the best level of improved health he has had for years. However, we are still awaiting the decision from mental health services as to what his future plans are. There have been indescribable mistakes during the pursuit of permanent supported housing through the system ... we still live in hope our son will be adequately housed in the near future.*

Early intervention

Carers place a high priority on promotion, prevention and early intervention and reported that it was often difficult to access early intervention services for the people they care for. One in five (21%) respondents who had accessed early intervention services were 'extremely dissatisfied' with the early response from the mental health service.

On a more positive note, approximately 60% of carers reported that there had been an improvement in access to early intervention care during the previous year. Carers identified GPs (23%), psychiatrists (23%) and psychologists (19%) as being responsible for that improvement.

Figure 18: Mental health professional responsible for improvement in early intervention care

(n=226 who reported some improvement)
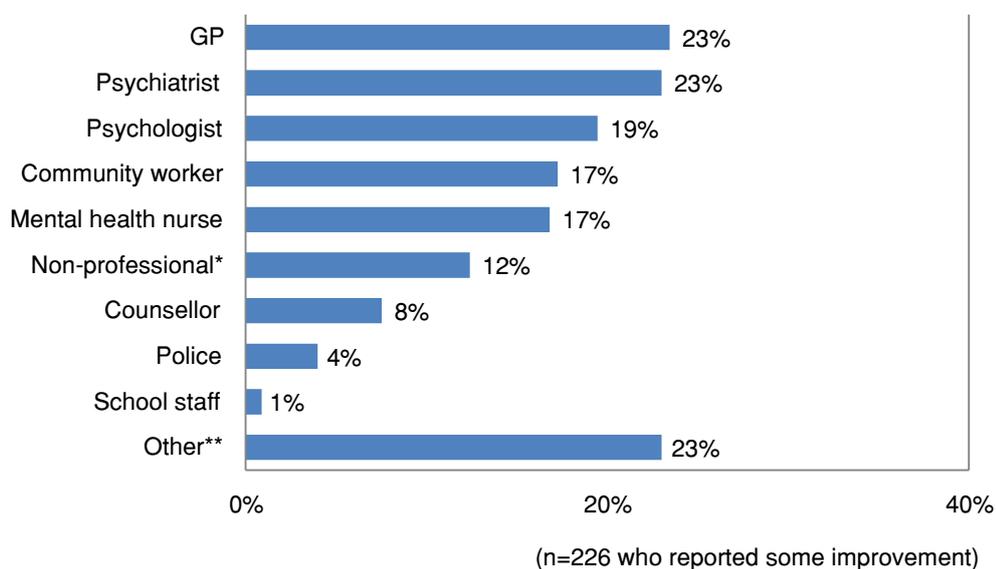
Question wording: "If there has been an improvement during the last 12 months in access to early intervention care for the consumer, who was responsible for that improvement?" (multiple response)

* Where specified, this was mostly family and friends (11% of the n=226) and specific organisations (9% of the n=226).

6. Young carers

Young mental health carers experience significant disadvantages. Caring responsibilities are often detrimental to schooling, work and socialising. Over the long-term, this can result in lower rates of employment and education, poorer physical and mental health and social isolation.

A separate survey questionnaire was developed for young carers of people with a mental illness. This survey collected information from young carers about their caring role, what sort of caring activities they undertake, how caring impacts on their day to day lives, what supports are available in their area and the appropriateness of these supports. Seventy-two young carers completed the survey; their responses are reported below.

About young carers

Nearly half of respondents (47%) cared for a parent and approximately 40% cared for a sibling. Around one-in-three (35%) had been caring all of their life. Over half of respondents (60%) lived with the person they cared for. 19% of young carers said it was their role to help the person they care for organise their day to day life. A third (36%) reported that another relative undertook this role and 22% reported the consumer was responsible.

In relation to how young carers are involved directly in the care of the consumer, a majority reported being responsible for home and living tasks (69%) and listening and offering emotional support (65%). Young carers were less likely to be involved in organising medical care (11%) or providing financial and administration support (12%).

The role of young carers and its impact on their lives

One of the main themes to emerge from the survey was that young carers feel they are not treated with respect or listened to because they were seen as children and not capable of understanding or fully contributing to the care of the consumer.

Young carers were asked if their physical or mental health had changed as a direct result of their caring role. Nearly half (42%) indicated that it had become worse. Only 8% said their physical or mental health had improved, and for half of respondents (50%) there had been no change.

Around half of respondents (54%) believed that being a young carer had meant that they have missed out on things that they would have liked to do as a result of the time they had to spend in their caring role.

When asked about the impact of their caring role, 77% of respondents reported that their caring role had affected their studies to some extent and 68% of those in work said it had affected their job.

- *The biggest problem is that I find I am viewed as a child, and not informed of anything.*

- *My life was difficult as a child, I started caring aged 7. My dad is suicidal and was not compliant with medication. Professionals do not take you seriously when you are a kid in this situation. They do not tell you what is happening and they do not offer support. They will only talk to other adults.*

- *The psychiatrist and GP talked to my mum even though she worked during the night and I cared for my dad every day from after school until the next morning. Their main concern is the patient, not the kid who cannot sleep through the night because their parent is threatening suicide. I was only offered help at 16 and by then it was too late, I had already had to leave school. Kids need to be included in discussions; they need to be told what is going on.*

Figure 19: Impact of caring role for young carers

| 20% | 26% | 20% | 17% | 17% |

Had an impact on your studies? (n=70 who are studying at high school, TAFE or university)

| 13% | 23% | 16% | 16% | 32% |

Had an impact on your job? (n=32 who are employed)

■ Yes, a lot ■ Yes, quite a bit ■ Yes, sometimes ■ Yes, but only rarely ■ No impact
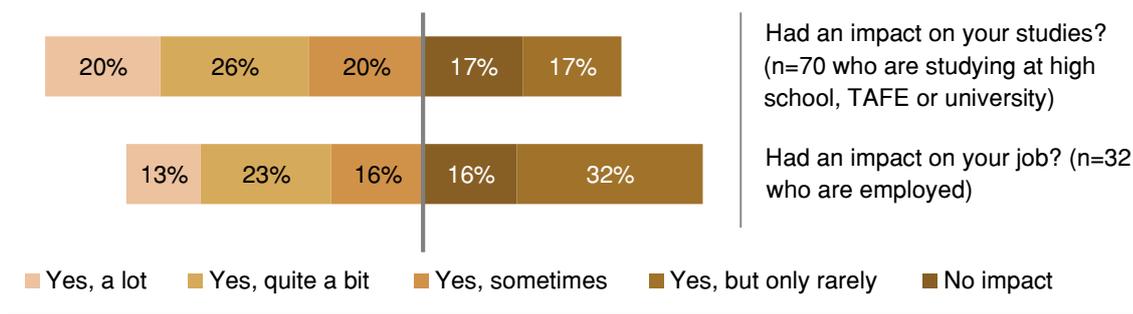
Young carers often feel worried and anxious about the wellbeing of the person they care for, and they feel alone and stressed as a result. Survey results showed 70% of respondents feel alone in their role, 76% experienced anxiety about the person they cared for and 81% feel stressed as a result of being a young carer.

Figure 20: Isolation, anxiety and stress for young carers

| 13% | 17% | 29% | 32% | 9% |

Have you felt alone in your role as a young mental health carer in the last 12 months? (n=69)*

| 8% | 15% | 33% | 26% | 17% |

Are you worried, or do you feel anxiety, about the wellbeing of the person you care for? (n=72)

| 13% | 7% | 44% | 24% | 13% |

Do you feel stressed as a result of being a young mental health carer? (n=72)

■ Never ■ Rarely ■ Sometimes ■ Mostly ■ Always
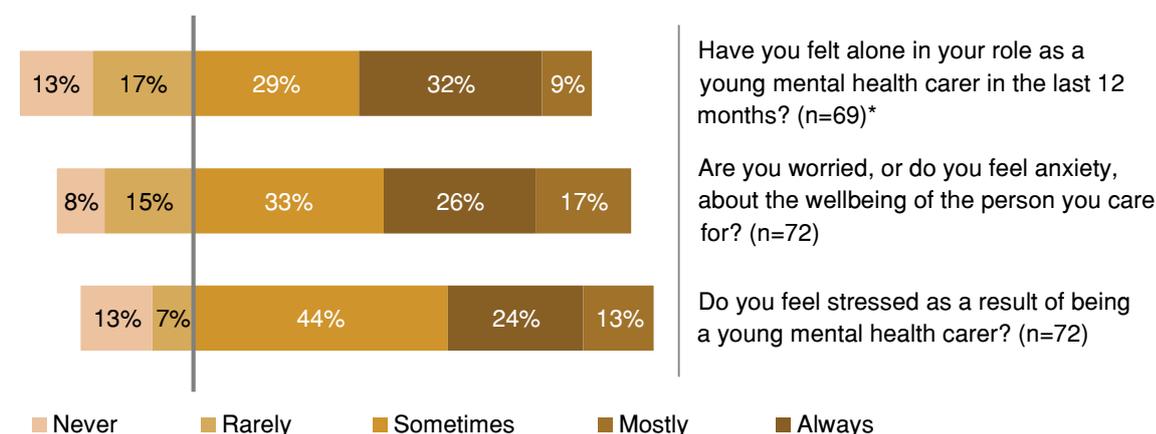
* Excludes n=3 'not sure'.

Interactions with service providers

When asked which professionals understood what the consumer needed, young carers rated psychologists (40%) and GPs (33%) as the most understanding. Young carers reported housing staff (1%), Centrelink staff (4%) and police (4%) were less understanding of what the consumer needed. They found counsellors (35%) and GPs (22%) to be the professionals that really understood what young carers needed and were the most helpful. Nearly one in five (18%) believed that no young carers professional really understood or helped them.

A third of respondents (35%) did not feel that professionals included them when making plans for the person they cared for, while a quarter (28%) reported they were included. The remaining 37% were unsure if they were included.

Forty-two per cent of respondents believed that professionals listened to their concerns about the person they cared for, while only a small proportion (8%) reported they did not feel they were heard. However, a further 43% reported they had not shared their concerns about the person they cared for with professionals. Around a quarter of young carers (27%) believed professionals used concepts or words like 'privacy' and 'confidentiality' as a reason for not providing information to help them in their caring role.

Support for young carers

Survey results show that young carers receive the most support from informal networks such as family (73%) and friends (62%). Meanwhile, nursing staff (5%) and Centrelink (11%) provided the least support.

Figure 21: Sources of support for young carers
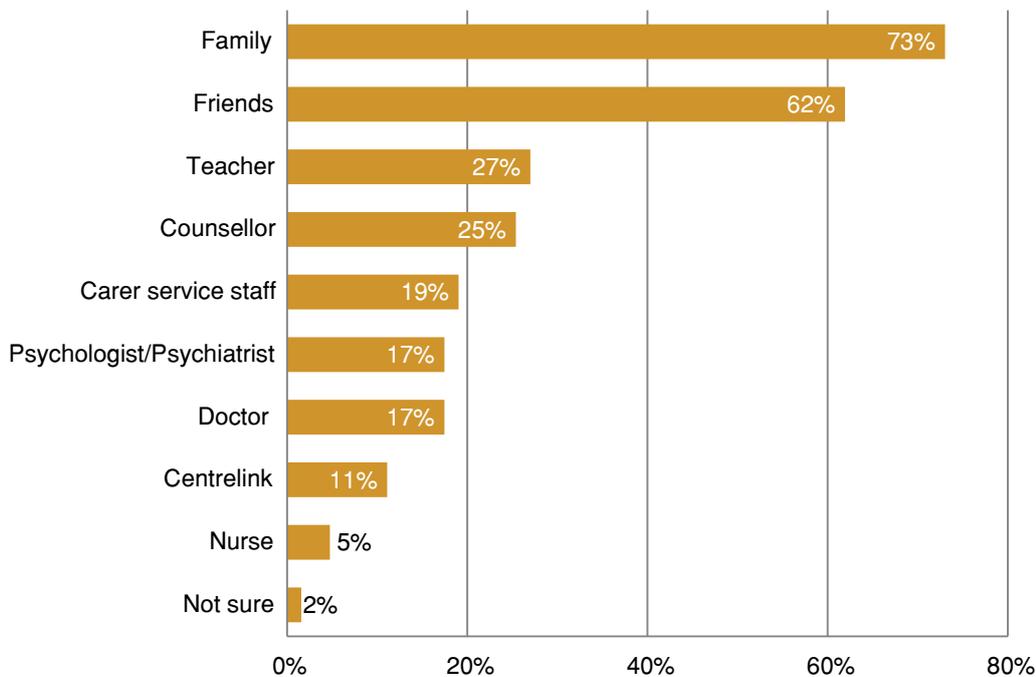
Question wording: "In the last 12 months, have you received support as a young mental health carer from any of the following?"

* This chart is based on the responses of 63 young carers who have received support; it excludes 9 young carers who said they had not received support.

I have helped my mum care for my father, who has depression, for the last 4 years. It saddens me that there is not much help available for a person that cares for someone with a mental issue. My mum cares for my dad with no help other than me. Schools are not very supportive and do not talk enough about it to students.

Similarly, family and friends were seen as the most helpful to young carers, with 59% of respondents finding family and friends *extremely* or *very* helpful in their caring role. Young carers were less likely to find professionals helpful, with only 28% finding professionals *extremely* or *very* helpful in their caring role.

Nearly half (41%) of young carers had not told their school, TAFE, uni or workplace that they were a mental health carer.

Figure 22: Sources of help for young carers
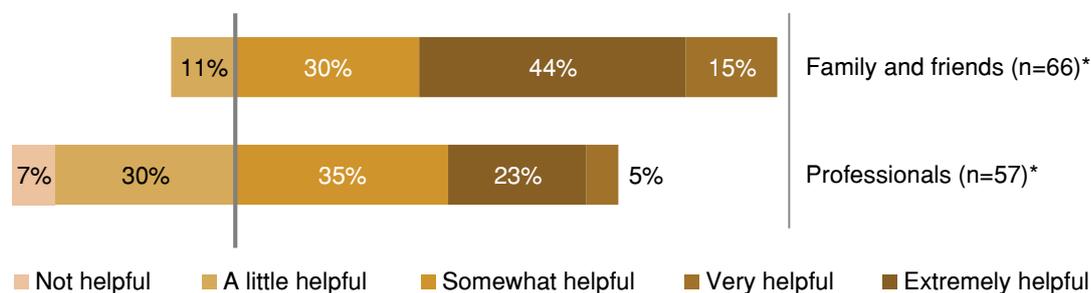
Question wording: "How helpful have the following people been to you in your role as a young carer?"
* Excludes young carers who did not seek help from these people (n=6 for family and friends, n=15 for professionals).

Information for young carers

A large number of respondents (68%) understood the mental illness or disorder affecting the person they cared for *very well* or *quite well*. Only a small proportion (1%) did not understand the mental illness or disorder at all.

Respondents were more likely to receive information about the mental illness to help them care for the consumer, with 38% having access to lots of information. They were less likely to receive information about medication.

The most common source of information for young carers is the internet, with nearly half (49%) saying they had found information online. Other common sources of information were counsellors (29%), social workers (18%) and mental health nurses (18%).

Figure 23: Access to information for young carers

Do you feel like you have access to the right information ...
(n=72 young carers survey)

Don't want to know	Not sure				
3%	10%	17%	33%	38%	...about the mental illness, to help you care for this person?
4%	22%	19%	43%	11%	...about the medications taken by the person you care for?

■ I don't have access to information ■ I have access to some information ■ I have access to lots of information
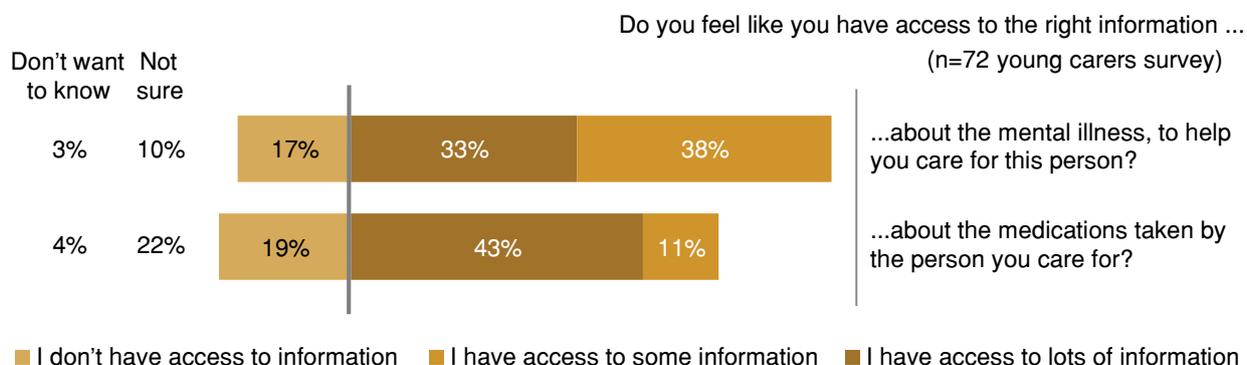
Question wording: "Do you feel like you have access to the right information about the mental illness or disorder to help you care for this person?"

Figure 24: Sources of information for young carers

Source	%
Internet	49%
Counsellor	29%
Social worker	18%
Mental health nurse	18%
Carer service staff	17%
Pharmacist	14%
GP	14%
Psychologist	13%
Community worker	11%
Triage or telephone helpline staff	8%
Psychiatrist	8%
Centrelink staff	6%
Other	24%
NA - haven't tried to get information	22%
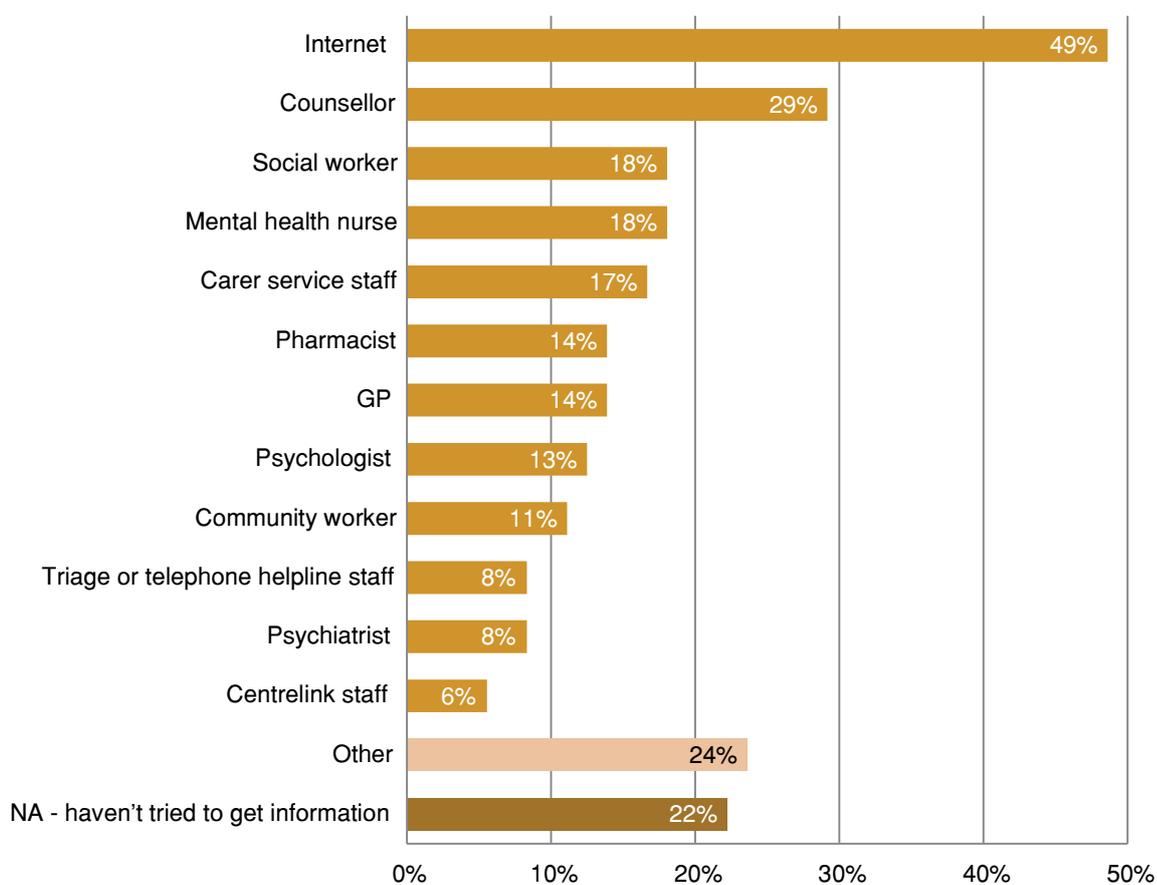
Question wording: "Where or who do you go to for information that helps you care for the person?" Tick any that apply.

7. Culturally and linguistically diverse carers

To encourage survey responses from CALD mental health carers, the MHCA provided translations of the survey in Arabic, Chinese, Greek and Italian through MHCA membership networks. Only a small number of CALD carers competed the survey in their own language; numbers were boosted by respondents who completed the survey in English, with a total of 48 CALD carers completing the survey overall. Where responses from CALD carers differed noticeably from those of non-CALD carers, these findings are reported in this section. Feedback gathered through these consultations is reported below.

Stigma, discrimination and understanding of mental illness

Stigma and discrimination were major issues raised by many CALD carers, with CALD communities viewing mental illness in different ways compared to the mainstream population. Attitudes were said to differ from one cultural group to another and even within particular communities, meaning it is difficult to make generalisations across the CALD population. However, some broad observations can be made.

Many cultures believe that mental health is a weakness and that it should not be discussed outside the family. This can lead to social isolation as the whole family is looked upon as having mental illness or an affliction.

CALD carers said it is common to feel shame about mental illness and not acknowledge or discuss it; in some cultures, a family member with mental illness will be locked in their room when visitors come.

Around half of CALD survey respondents (54%) believed that stigma is widespread in the wider Australian community, whilst 41% thought discrimination was widespread in their local community. Only a small proportion (4%) reported that stigma did not exist in the wider Australian community, while 9% had not experienced discrimination in their local community.

Figure 25: Discrimination experienced by carer or consumer in their local community and the wider Australian community
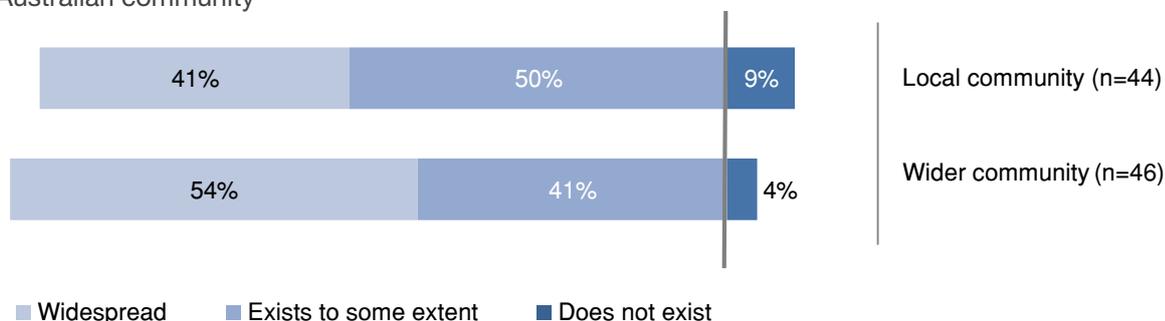
Local community (n=44): Widespread 41%, Exists to some extent 50%, Does not exist 9%

Wider community (n=46): Widespread 54%, Exists to some extent 41%, Does not exist 4%

■ Widespread   ■ Exists to some extent   ■ Does not exist

Question wording: "What has been the extent of discrimination you or the consumer has experienced in your local community during the last 12 months because of mental illness?"; "What has been the extent of stigma around mental illness in the wider Australian community during the last 12 months (e.g. as represented in media coverage and attitude)?"

CALD carers and service providers referred to a widespread lack of basic knowledge about mental illness in their communities. One carer spoke of watching her son transform into a violent person with no warning signs and being unable to comprehend what was happening because of her lack of experience with mental illness. There is fear among some people from other cultural backgrounds that a diagnosis of mental illness can lead to people being taken from their families, especially children with mental illness.

CALD carers and service providers were adamant that much more needs to be done to educate and inform CALD communities about mental illness.

Culturally-specific needs

CALD carers are less likely to identify themselves as 'carers', since it is part of the family role to look after family members when they are ill. This can mean that carers do not apply to Centrelink for carer payments, although reluctance to seek financial assistance can be overcome by explaining the eligibility criteria and the purpose of the payments.

The use of interpreters was also considered problematic by some carers. There were concerns that an interpreter may be known within the community and therefore information may 'leak out'. Additionally, carers had experiences where information being translated was inconsistent and inaccurate. One carer with a medical background was shocked, when accompanying the person they care for to an appointment, to discover the interpreter was translating the medical information incorrectly. Gender issues can also be a barrier, because in some cultures men will not discuss mental health issues with a woman.

Multicultural groups are much smaller outside larger cities and CALD-specific services are not always available. In Sydney and Melbourne, by contrast, Greek and Italian communities can see health professionals who are fluent in their language and understand their cultural beliefs and values. The needs of carers who are not part of an extended local community can be particularly pressing because they do not have access to services in their own language.

Carers believed that the length of time people had lived in Australia and made community connections influence how well cultural barriers can be overcome. Many carers said that mainstream Australian culture is more accepting of mental illness compared to their own cultures of origin and appreciated the support they had received from service providers.

Seeking help

There is often resistance among CALD communities to obtaining an initial diagnosis of mental illness. It is quite common for situations to lead to a crisis, such as police becoming involved. Once a diagnosis has been made, people in some cultures will still not accept a mental health condition and continue to be unwilling to seek further help.

Carers from CALD backgrounds were reluctant to access respite services for a variety of reasons, including difficulties in finding culturally appropriate respite services. Because negative experiences spread quickly by word of mouth, carers can be quickly deterred from using respite. Additionally, cultural norms can influence whether a CALD carer will access services; in Asian cultures, for example, if a person is unable to care for their family member at home at all times, other members of the family and community view this very unfavourably.

Carers were more likely to use respite services if they were introduced and appropriately orientated to these facilities. In cases where a worker took the time to show CALD carers what respite services were available, outcomes were positive and carers were more likely to use the service.

Respondents who did not use carer respite services were asked why this was the case. A third of CALD respondents (34%) said they could not leave the consumer with a respite worker, while 28% said what they needed from respite is not available. One in three CALD respondents (34%) did not know what respite services were.

Figure 26: Why CALD carers do not use carer respite services

Category	Percentage
I do not need carer respite services	25%
What I need from respite care is not available	28%
I could not leave the consumer with a respite worker	34%
I am not aware of any carer respite services being available	19%
I do not know what carer respite services are	34%
Carer respite is not offered in my area	6%
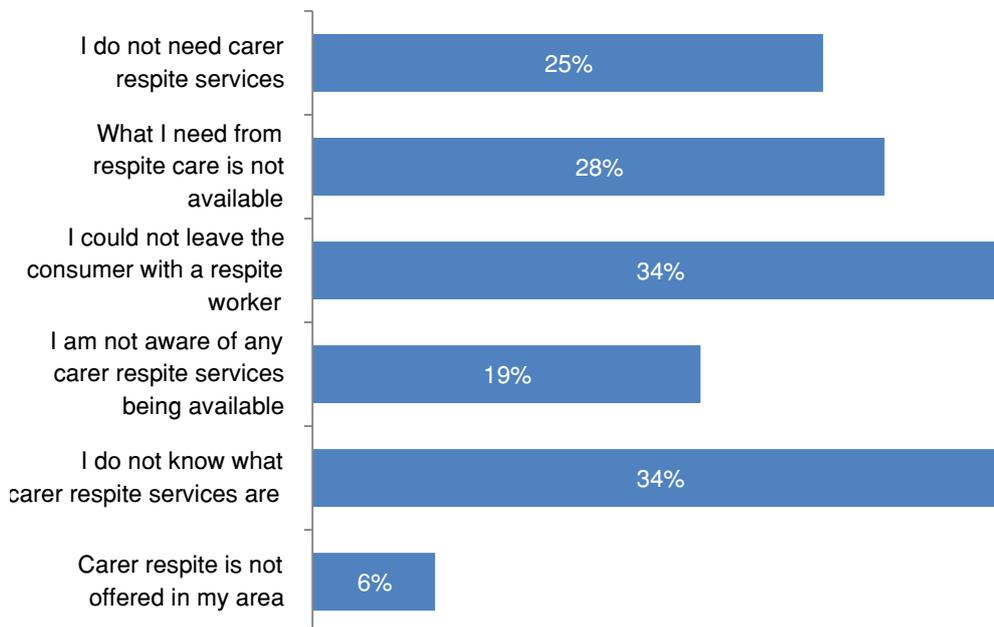
Question wording: "If you do not use carer respite services, why is this?"

A substantial number of people from CALD backgrounds do not seek help, or are reluctant to do so. Often, they miss support services because information is not available in certain languages, or there is no culturally appropriate service available. As a result, many may be confused about how services operate, or simply unaware of the range of services and supports that are available. Cultural sensitivities and differences and communication problems are also barriers to CALD carers accessing services that might benefit them.

Figure 27: Understanding of carer issues by professionals
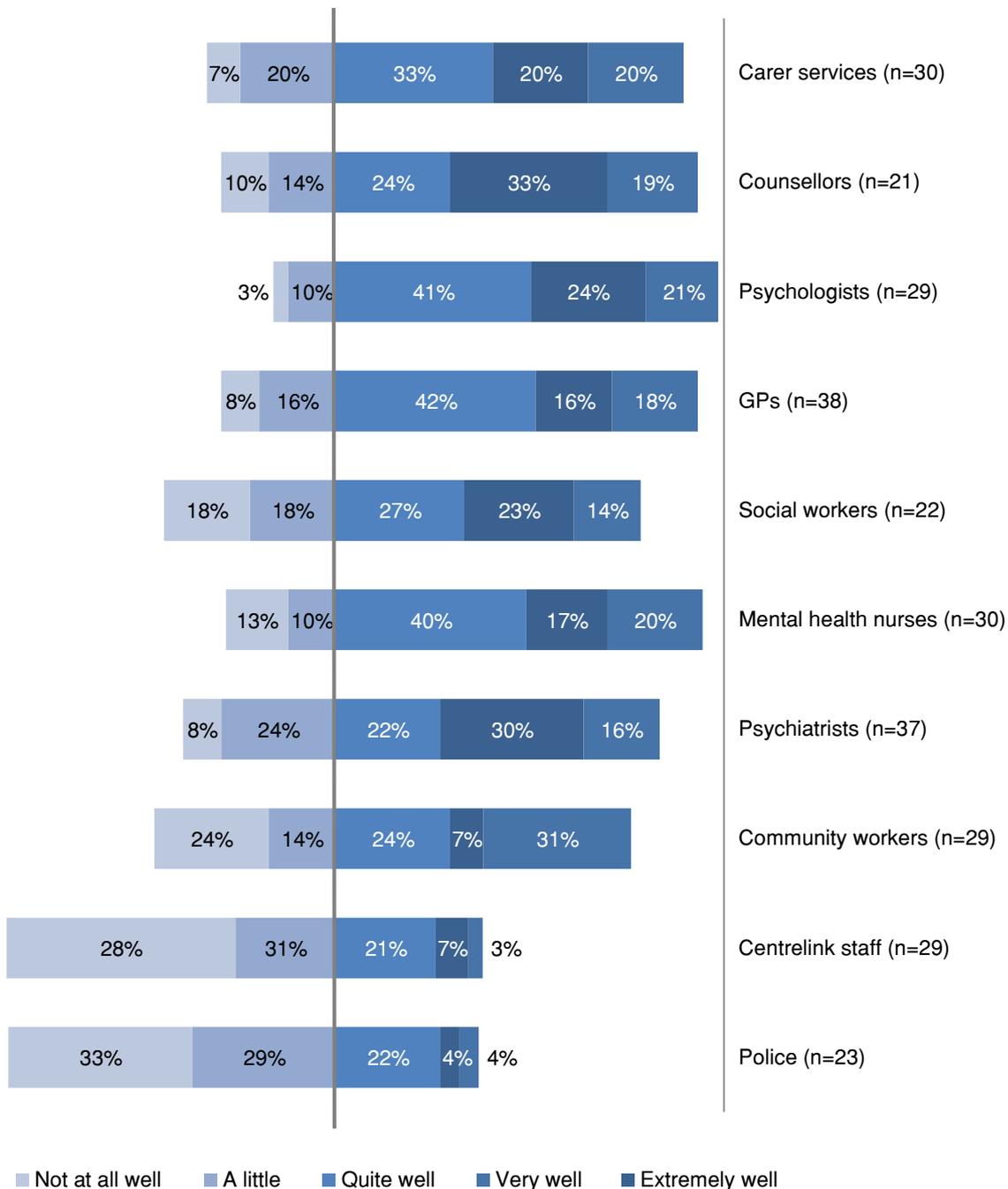
	Not at all well	A little	Quite well	Very well	Extremely well
Carer services (n=30)	7%	20%	33%	20%	20%
Counsellors (n=21)	10%	14%	24%	33%	19%
Psychologists (n=29)	3%	10%	41%	24%	21%
GPs (n=38)	8%	16%	42%	16%	18%
Social workers (n=22)	18%	18%	27%	23%	14%
Mental health nurses (n=30)	13%	10%	40%	17%	20%
Psychiatrists (n=37)	8%	24%	22%	30%	16%
Community workers (n=29)	24%	14%	24%	7%	31%
Centrelink staff (n=29)	28%	31%	21%	7%	3%
Police (n=23)	33%	29%	22%	4%	4%

Question wording: "How well do you think carer issues are understood by the following professionals?"

8. Aboriginal and Torres Strait Islander carers

This section is based on feedback collected through a series of workshops and consultations with Indigenous mental health workers, remote respite workers, clinicians, policy workers, and Aboriginal mental health carers in Western Australia, the Northern Territory and Queensland. It documents many of the issues identified by these communities as well as some potential solutions.

- *Each remote community is different from any other remote community. They cannot be looked at or treated as a whole. They each have different backgrounds, language, needs and current issues.*

- *It's impossible to lump all remote NT Aboriginal people together. It's just like Europe - each country in Europe has its own language, traditions and culture. It's just the same up here.*

Cultural issues

The quotes above from mental health workers in remote Aboriginal communities reflect the need for a deeper and more comprehensive understanding of the problems faced by Aboriginal carers and consumers in remote Australia along with their ongoing and often unfulfilled needs. The history and background of each community must be understood and inform policy and program development. Some communities have evolved from missions, some from original habitations and others created by bringing together a number of unrelated clans and family groups. Many communities have their own language(s) and culture. All this has

an impact on the problems and issues of each separate community, and what works in one community may or may not work in another.

In addition, communities have experienced ongoing pain and trauma for generations. Many people interviewed for this report referred to intergenerational trauma: the ongoing trauma experienced by Aboriginal people as a result of the stolen generations, the loss of community, loss of parenting skills and family experience, loss of individuals through alcohol, drugs and mental illness and more recently the volume of youth suicides experienced in communities.

Like many non-Aboriginal carers, many Aboriginal carers experience problems in communicating with medical staff about the consumer's health, medication and care. Medical staff utilise the Translating and Information Service extensively when assisting consumers and carers from non-English speaking backgrounds.
However, this service is not available to assist Aboriginal carers whose first language is not English. In these situations, medical professionals often use family members or Aboriginal mental health workers to act as translators. When a professional interpreter is not available, there is no scrutiny of the accuracy of the medical translation, potentially compromising the quality of service available.

The use of non-professional translators can also compromise the position of the translator within the community. For example, it may not be culturally appropriate for a female Aboriginal worker to translate for an older male; similarly, it may not be appropriate for a younger brother to assist in translations for an older brother. Such cultural barriers may not be obvious to the treating medical professional.

To solve these translation problems, workers and Aboriginal people stressed the importance of adequate English language education for community members. Medical workers' competence in Indigenous languages was considered important but not to the detriment of local people learning English. Without this proficiency, carers and consumers are excluded from wider education and employment opportunities.

Carers made reference to a lack of cultural awareness by clinical staff appointed to assist consumers as case managers or clinicians. Many carers and consumers discussed the need for their cultural beliefs regarding mental illness to be acknowledged, understood and addressed by the treating professionals. Aboriginal people commonly believe that by breaking Aboriginal lore or not complying with cultural duties a person can be afflicted with behaviours consistent with mental illness. Examples of transgressing Aboriginal lore included breaking bloodlines or marrying the wrong person, though it is possible to break the lore and not be aware of it. The widely held belief is that the health of the consumer will only be restored once correct cultural practices provided by the appropriate person are observed. Mainstream medicine may help relieve the symptoms of mental illness but true healing will not be achieved until the cultural transgression is fixed. Aboriginal people in remote, rural and city locations were said to hold such beliefs.

Services and support for Aboriginal carers

Aboriginal carers expressed a desire to be better informed about mental illness and available training to help consumers. Information about basic medication, its side effects and how that medication should be administered was lacking.

When support was provided, carers reported an ad hoc and inconsistent system. The most successful services were said to employ Aboriginal workers with good knowledge of Aboriginal culture and family obligations.

The inability to drive can be a major problem for carers in remote communities. It was therefore suggested that driving lessons and on site testing would be a useful carer-based initiative. In some remote communities there is little or no access to driving tuition, very few cars in which to practice and the cost of travel to take the test and acquire a license is prohibitive.

Problems can arise when a consumer is admitted to a distant hospital. In some jurisdictions, some assistance to travel is available through government-funded schemes. However, remote carers are not familiar with buses, trains, timetables and large shopping centres. Information about public transport systems and on how to find local shops would be a valuable service for carers who have to travel long distances.

We are not getting the right information from the doctors. They [consumers] just get the pills.

Financial burdens

Financial costs were a persistent theme throughout the workshops. In many situations, carers bore a substantial financial burden associated with their role, from looking after the consumer in their own homes, holding the responsibility for raising the children of the consumer, or visiting the consumer regularly at a distant hospital. In a number of such cases carer payments were not available. For many, the ability to obtain or supplement their incomes is inhibited by a caring role.

There are limited employment options on communities and in remote towns with the added constraints of caring interfering with the ability to work outside the home. These caring duties can be intermittent and emerge quite suddenly. Moreover, if a carer takes on the responsibility of raising a relative's children the increased and complex family needs and home duties further limit work opportunities.

Respite services

Alongside financial difficulties are the physical and mental strains on carers. Many carers in remote communities and towns felt they had little or no relief from around-the-clock caring. Carers expressed their fears about living with someone who behaved in an unpredictable way, about leaving their home in case it is damaged, and about the safety of the person they care for in the broader community.

On a positive note, an example of a successful respite scheme is the Troopy Respite initiative in the NT. This program provides opportunities for Aboriginal people to camp in the bush and participate in traditional crafts and other pursuits. These trips were much sought after by carers, who found them reinvigorating and appropriate for their needs. The respite was flexible to the needs of carers and highly effective in giving them time out and a sense of community support.

Housing

For many remote workers there is a shortage of housing and a lack of adequate accommodation. One example of this was a worker housed for a number of years in something 'little more than a cupboard'. Compounding the problem of a housing shortage for professionals is the lack of suitable housing for people with mental illness. One carer reported that her brother with schizophrenia was about to lose his accommodation through the 'three strikes and you are out' rule and would have to return to the already overcrowded home of his mother, his siblings and their young children. Another man with mental illness who was being evicted from his home after three infringements of the housing rules had no option but to return to his mother's already overcrowded house. Some family members feared losing their home if the man became unwell and behaved in a destructive manner after moving to the family home.

Stigma and discrimination

Complicating recovery for Aboriginal people with mental illness is stigma and discrimination, which was reported consistently by the communities. Carers called for mental health education of children, parents and clinic staff and felt the employment of Aboriginal mental health workers would help change such attitudes. Carers referred to the intolerance of neighbours towards a person with mental illness and expressed a desire for assistance in providing community-wide education about mental illness, the behavioural effects of mental illness and ways family and neighbours could help rather than hinder the consumer and their carer.

The shame of mental illness was felt even in close-knit families. One carer who looked after her sister said the family did not know their sister had serious mental illness until the death of her mother. The mother had been so ashamed she had kept the extent of the sister's illness, and the care she provided, a secret.

One community has started to address the problem of children's lack of understanding of mental illness by creating the idea of sleepovers at a community member's house for girls and then boys on separate evenings that would provide age appropriate fun activities including a film. The film was to have a mental health theme, which would be discussed during the evening.

The same community is organising bush camps for women, again offering relevant activities aimed at changing attitudes towards mental illness in the community.

Examples of intolerance emerged during discussions about experiences in prison. Prison officers were said to behave differently towards Aboriginal consumers than towards non-Aboriginal consumers, showing little understanding of mental illness or Aboriginal culture. Aboriginal consumers in prison feel intense shame because of their treatment, being considered a behaviour risk and often being separated from the prison community as a result. There were calls for anti-stigma and anti-discrimination training for all prison officers along with the provision of basic mental health education.

Contributing to issues of stigma and discrimination was privacy and confidentiality in remote areas. In these communities and towns, carers were concerned about both their own privacy and the consumer's circumstances. The concept of shame was raised as a reason for the need for discretion. The use of outreach workers was seen as very positive. People who visited the community can listen to carers, relieve their anxiety and at the same time 'take away the secrets' without fear of their lives becoming public knowledge in the community.

Services and support for Aboriginal consumers

A lack of support and services for consumers was also apparent and widespread. Very little or any integrated recovery-based care for consumers in remote communities was reported. There was little or no follow-up treatment available on discharge from hospital and no rehabilitation services provided. Carers expressed their concern that consumers were not well before they returned to their communities and stressed the need for step-down facilities to assist in the re-integration into community life.

Carers believed integrated recovery for Aboriginal people should based within family and community, relying on strong family and inclusive community support to assist and maintain wellness. This is why many carers felt it important for consumers to be discharged back into their own communities. One group of Aboriginal people spoke highly of an Aboriginal Healing Centre. Operating with a recovery-based framework, the centre is small and the staff few but it was said to be of critical importance to the wellbeing of consumers and carers and the larger local Aboriginal community.

For some consumers being discharged back to their own communities is not an option. Carers and workers reported that consumers left city hospitals with no way of returning to their remote community. There is a fear by remote carers that if the consumer is taken away to the city they will never return home. A policy of automatic and assisted return to communities on discharge would help relieve carer anxiety and fear on this issue.

Another major concern raised by carers was the lack of support for consumers – and consequently their carers – on release from prison, especially for female Aboriginal consumers.

It was commonly reported that an integrated approach to service provision is lacking. Many organisations work in isolation to one another and there is no knowledge of schedules and timetables. Sharing even this basic level of information would provide a more consistent quality of care for both consumers and carers. Further, moving towards a more holistic approach to designing complementary services could help

provide a more comprehensive and streamlined system, cutting duplication and inefficiency.

Another essential ingredient to providing optimum care was said to be the employment of Aboriginal staff. It was reported that many service positions remained unfilled, rendering these programs ineffective due to the lack of Aboriginal staff.

However, one community-based service in a town of 3,000 people had overcome all obstacles to achieve their goal of establishing a culturally appropriate rehabilitation service in a location well out of town. It had taken one Aboriginal man 20 years to establish and address the needs of this community. The station will provide an opportunity to reconnect to county at the same time as building individual self-esteem. Opportunities to learn and establish an employable skill base will be offered to consumers during their stay. Of the two employees, one is a qualified mental health worker. This achievement is due to the dedication of the Aboriginal people involved to

the concept of recovery-based care, and their volunteer hours and fundraising efforts over many years.

Access to acute care was reported as not available in remote communities or in remote towns, and many carers saw this as a major problem. They talked of a lack of action in an acute situation by police or, when the situation became less acute, by mental health services, and believed that these agencies would often 'pass the buck' between themselves. Members of one community that is visited by a clinician once every two weeks commented that a seriously unwell person is left alone until the clinician arrives rather than taken to a hospital by the police in the intervening time, leaving the carer and community with complete responsibility for the health of the consumer.

Workforce issues

While more services for mental health consumers are needed in Aboriginal communities, a crucial component to their success is access to more specialist mental health staff. A lack of staff was widely reported, with some communities able to fly in a psychiatrist just once every 10-12 weeks, if at all. Some people reported that often nurses in community do not actually have a mental health specialty and lack an understanding of mental health issues.

A large turnover of staff was also reported, resulting in regular employment of short-term agency nurses that was considered less beneficial to consumers and as undermining community trust. The remoteness of many of these Aboriginal communities caused isolation, stress and overwork for the Remote Area Nurses (RANs), who often work unassisted and without any support. They are often forced to deal with difficult issues by shutting down their clinics.

Training of RANs for remote work was considered inadequate by carers. In one circumstance, workers were given a three-week introduction to remote work before being sent out. This was particularly prevalent among agency staff employed on short-term contracts.

Problems can arise where an Aboriginal person is employed as a health or mental health worker in traditional communities. It was reported that family obligations can conflict with an employee's ability to fulfil their role. For example, if one member of a family has a job, that person is obliged to offer their own family members benefits from that employment, such as access to a vehicle provided by the employer.

Aboriginal outreach workers who are employed to support carers were valued by carers and provide a link to the outside world. They were considered 'safe' partly because they live outside the community. This provides a degree of separation from community issues and can reduce the stress and consequent burnout of the professional. They can also provide transport for consumers and carers to other towns that are often hundreds of kilometres away.

If things got out of hand [with a person in psychosis] we lock the clinic doors until things quieten down.

9. Conclusion

The survey findings described in this report provide many valuable insights into the lives of mental health carers. They reinforce the need to regularly collect information on how carers perceive the services available (or unavailable) to them and to the people they care for. This in turn will allow policy-makers, service providers and clinicians to improve their approach to supporting carers, using on-the-ground experience as the most critical test of success.

One of the principal hopes that carers have is for recognition of and respect for the important contribution that they make to the lives of people with mental illness. Carers are best placed to provide advice on appropriate solutions for consumers, but are often not properly consulted or informed. Carers often feel alone and isolated, and their physical and mental health can suffer as a result of their caring role.

There are currently a range of support services available to carers, including respite, carer counselling and carer support groups. Yet these services are not always accessible for a range of reasons. This might be because a carer believes that a service is not appropriate, or that the person they care for would not cope with a particular service. Sometimes it is a lack of knowledge of what is available in a local area, or even of the existence of any service at all, that prevents carers from accessing beneficial services. A range of strategies are therefore required to assist carers, from simple awareness-raising and outreach to more innovative models of service delivery.

Of course, carers have many views on the services available to mental health consumers and whether these meet the individual needs of the people they care for. Carers continue to hope for integrated recovery-based care which is accessible, appropriate and sensitive to the needs of consumers.

Not all carers' experiences are adequately captured in this report. Some carers are very difficult for service providers and researchers to identify, yet their needs often remain unaddressed. Such carers can be 'hidden' for a range of reasons: because they do not regard themselves as carers (but rather family members), because they do not wish to access the service system or contact other carers, or perhaps because the person they care for has not yet been diagnosed with a mental illness. Hidden carers are more likely to be young, to be from a different cultural background, or to be Indigenous. While this research deliberately targeted each of these population groups, more needs to be done to understand the needs of hidden carers and the barriers to them receiving the support they need in their caring role.

For all the stories of unmet need and tragic circumstances, it must be noted that carers also related positive stories where both they and the people they care for have benefitted from one or another service or intervention. These positive examples are due in large part to the dedication and expertise of individual professionals and organisations, and their contribution to the lives of carers should be emphasised.

Mental Health Carers Survey 2011-2012

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 conducted by the Mental Health Council of Australia. This survey forms part of an ongoing project to find out about the lives of mental health carers during the previous 12 months. Your responses will form part of the Mental Health Carers Report 2011/12. This survey is important. The findings will provide recent and relevant information that will assist in directing future funding into mental health services.

The survey is based on the top 15 issues identified by over 1,500 mental health carers detailed in our 2010 publication 'Adversity to Advocacy', the lives and hopes of mental health carers'. Please include as many contact details as possible - our experience shows that email contact is not enough to maintain annual contact. Your responses will be treated in confidence, meaning that no individual will be identified in any reported findings. Feel confident to complete the survey as fully as possible and be part of the Mental Health Carers Survey 2011-12.

Thank you for participating!

This page is about you, 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 _____

Gender ☐ Male ☐ Female

Year of birth _____

What is the main language you speak at home? English ☐ Other (which language) _____

What race or ethnic group/s do you identify with (please indicate all that apply)?

☐ African-American
☐ Asian
☐ Caucasian
☐ European
☐ Hispanic
☐ Indian
☐ Indigenous Australian
☐ Maori
☐ Middle-Eastern
☐ Torres Strait Islander
☐ Other (please specify) _____

Are you currently employed (please select all that apply)?

☐ I am employed full-time
☐ I am employed part-time or casually
☐ I am not currently employed
☐ I am in receipt of a pension
☐ I am currently employed but on leave due to a health condition
☐ I am unable to work due to a health condition (please specify)

☐ I am retired
☐ I cannot work due to my role as a carer
☐ I am a voluntary worker
☐ Other (please provide details) _____

What is your current living situation?

☐ Living alone in a house or apartment
☐ Living with parents/other family members
☐ Living with friends/acquaintances
☐ Semi-independent living in supervised home/apartment
☐ Currently under hospital care
☐ No current residence
☐ Other (please provide details): _____

What is the highest level of education that you have achieved to date?

☐ Primary school
☐ High school
☐ TAFE/CIT course
☐ Professional course
☐ Undergraduate degree
☐ Postgraduate degree
☐ Other _____

What was your approximate gross (before tax) household income for the 2010/2011 financial year (please enter as a whole number e.g. 30,000)? _____

1

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 either complete one survey for each consumer or answer this survey in relation to only one person.

1. How many people with a mental illness do you care for? _____

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

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

3. How long have you been caring for the consumer (please enter approximate years eg 3.5 years) _____

4. What is the primary mental illness / disorder of the person you care for?

☐ Schizophrenia
☐ Bipolar
☐ Depression / anxiety
☐ Obsessive compulsive disorder
☐ Borderline personality disorder
☐ Eating disorder
☐ Post traumatic stress disorder
☐ Substance use disorder (drug and alcohol)
☐ Alzheimer's disease or dementia
☐ Aspergers or autism

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

☐ Yes   ☐ No (please got to question 7)

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

☐ Substance use disorder (drug and alcohol)
☐ Intellectual disability
☐ Acquired brain injury
☐ Physical disability
☐ Eating Disorder
☐ Diabetes
☐ Aspergers or autism
☐ Alzheimer's disease or dementia
☐ Other, please give details _____

This question may be distressing for some people. If you are feeling upset or distressed and need to speak to someone, call Lifeline on 13 11 14 - 24 hours a day.

7. Has the consumer intentionally self-harmed or exhibited any other suicidal behaviours during the last 12 months?

☐ No, not that I am aware of
☐ Yes (please provide any details here that you would like to)

_____
_____
_____

2

8. 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
Community worker						
Mental health nurse						
Psychiatrist						
Psychologist						
GP						

9. 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

10. 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 / a place for consumers to meet			
Living skills			
Supported employment / training			
Personal helpers and mentors (PHaM's workers) / support worker			
Peer support workers			
Other			

11. 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 _____

12. 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
☐ Mostly
☐ Sometimes
☐ Rarely
☐ Never

13. 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

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

☐ Community worker
☐ Pharmacist
☐ Internet
☐ Mental health nurse
☐ Carer services
☐ Police
☐ Psychologist
☐ Centrelink
☐ Psychiatrist
☐ Housing
☐ Triage / helplines
☐ GP
☐ Social worker
☐ Counsellor
☐ Other (please give details) _____

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

	Extremely well	Very well	Quite well	A little	Not at all well	Don't know
Community worker						
Pharmacist						
Mental health nurse						
Carer services						
Police						
Psychologist						
Centrelink staff						
Psychiatrist						
Housing staff						
Triage / helplines						
GP						
Social workers						
Counsellors						
School staff						
Prison staff						
Court officials						

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

	Extremely well	Very well	Quite well	A little	Not at all well	Don't know
Community worker						
Pharmacist						
Mental health nurse						
Carer services						
Police						
Psychologist						
Centrelink staff						
Psychiatrist						
Housing staff						
Triage / helplines						
GP						
Social workers						
Counsellors						
School staff						
Prison staff						
Court officials						

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

	Always	Mostly	Sometimes	Rarely	Never	Not available	Not required
Carer support groups							
Pharmaceutical drug information							
Information on how to help the consumer							
Carer counselling							
Carer respite							
Internet based services							

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

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

19. 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 20.)

	Always	Mostly	Sometimes	Rarely	Never	Not known
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						

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

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

21. How far do you travel to access inpatient hospital mental health services for the consumer (please answer in kilometres)

_____

22. What has been the extent of discrimination you or the consumer have experienced in your local community during the last 12 months because of mental illness?

☐ Discrimination is widespread
☐ Discrimination exists to some extent
☐ Discrimination does not exist

23. What was been the extent of stigma around mental illness in the wider Australian community during the last 12 months? (for example as represented in media coverage and attitude).

☐ Stigma is widespread
☐ Stigma exists to some extent
☐ Stigma does not exist

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

☐ Always
☐ Often
☐ Sometimes
☐ Rarely
☐ Never

25. 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 available
Family						
Close friends						
Carer support groups						
Carer organisations						
Internet forums						
Spiritual or religious beliefs						

26. 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 _____

27. 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 payments				
Carer allowance				
Travel costs to remote hospital				
Carer accommodation costs to access remote hospital				

28. 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.)

$ _____

29. 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
Stress / anxiety medication				
Counselling				
Massage				
Acupuncture				
Gym membership				
Respite / time out				
Holiday				
Other				

30. Has 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

31. 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

32. 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

33. 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					

7

8

34. 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

35. Were you included in the planning of the consumer's care plan?

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

36. 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

37. 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
☐ Mental health nurse
☐ Police
☐ Psychologist
☐ Psychiatrist
☐ GP
☐ School staff
☐ Counsellor
☐ Other (please give details) _____

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

☐ Strongly agree
☐ Agree
☐ No change
☐ Disagree
☐ Strongly disagree
☐ I am not in the workforce because of my caring role
☐ I am retired / not working

39. 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 because of my caring role
☐ I am retired / not working

40. After answering the above questions you may feel there was something else that you really wanted to say but haven't yet been able to. Please write here about any other matter that you wish to raise as a carer of a person with a mental illness.

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

Thank you for being part of the Mental Health Carer Survey 2011-2012

Appendix B – Young carer survey questionnaire

Section 1: About You

1.1: What year were you born?

- 1998
- 1997
- 1996
- 1995
- 1994
- 1993
- Other

Participants who selected "other" were ineligible for the young carers survey.

1.2: What state/territory do you live in?

- ACT
- NSW
- QLD
- VIC
- SA
- NT
- TAS
- WA

Section 2: About the person you care for

In this section, we will ask you some questions about the person with a mental illness or disorder that you care for. If you care for more than one person with a mental illness or disorder, please answer this survey in relation to one person only.

For example, if you care for a father and a sister with a mental illness, you could choose to respond to the questions in relation to your father only, or your sister only, but not both.

2.1: Who is the person with a mental illness that you care for?

- Father
- Mother
- Son
- Daughter
- Guardian or Carer
- Brother
- Sister
- Grandmother
- Grandfather
- Other relative
- Friend
- Other

2.2: Is this the only person with a mental illness or disorder that you care for?

- Yes
- No

2.3: If you care for more than one person, how many people do you care for?

- 1
- 2
- 3
- 4 or more

2.4: How long have you been caring for this person?

- 1 year
- 2 years
- 3 years
- 4 or more years
- All my life

2.5: How long have you been a carer for (this could include this person or any other people you have cared or in the past)?

- 1 year
- 2 years
- 3 years
- 4 or more years
- All my life

2.6: In the last 12 months, where has the person you care for lived? Tick any that apply.

- With me at home
- With other family members
- Group Home
- Hostel
- Hospital
- Prison
- Rehabilitation facility
- On the street
- Don't know
- Other

2.7: In the last 12 months, who helped this person organize their day to day life?

- Me
- The person with the mental illness or disorder
- Another relative
- Close friend
- Medical Worker
- Community Worker
- Other

2.8: Which mental illness or disorder does the person you care for have? (Tick any that you know of).

- Depression
- Anxiety
- Bipolar
- Schizophrenia
- Substance abuse
- Eating disorder
- Borderline personality disorder
- Other

2.9: How are you involved in the care of this person? Tick all that apply.

- Home and living assistance (cleaning, cooking, shopping, looking after siblings and relatives...);
- Transport (for example, helping the consumer get to appointments);
- Listening & offering emotional support;
- Financial and Administrative support (helping to pay for groceries, rent or bills; filling in Centrelink forms...);
- Organising medical care (for example, from a psychologist or nurse);
- Other.

2.10: How far does this person have to travel to access inpatient hospital mental health care ? (A guess or estimate is ok).

_____ KM

2.11: How well do you think you understand the mental illness or disorder affecting the person you care for?

- Very well
- Quite well
- Somewhat
- Not very well
- I don't understand it
- I'm not sure.

2.12: Do you feel like you have access to the right information about the mental illness or disorder to help you care for this person?

- I have access to lots of information
- I have access to some information
- I don't have access to information
- I'm not sure
- I don't want to access information about the mental illness or disorder.

2.13: Do you feel like you have access to the right information about the medications taken by the person with a mental illness or disorder that you care for?

- I have access to lots of information
- I have access to some information
- I don't have access to information
- I'm not sure
- I don't want to know about medications.

2.14: Where or who do you go to for information that helps you care for the consumer? Tick all that apply.

- I haven't tried to get information
- GP
- Psychologist
- Psychiatrist
- Social worker
- Nurse
- Occupational therapist
- Counsellor
- Mental Health Nurse
- Teacher
- Relative
- Friend
- Internet
- Community Worker
- Police
- Centrelink
- Religious or spiritual leader
- Other

2.15: Do you think the person you care for experiences discrimination because of their mental illness or disorder?

- Yes
- No
- I'm not sure.

Section 3: Interactions with Professionals and Services over the last 12 months

In this section, we want to ask you about any professionals and services that have been involved in the care of the person with a mental illness or disorder in the last 12 months.

For example, 'professionals' could mean a doctor or psychologist, nurses or community workers. 'Services' could mean community transport services, cleaning services or living support services, for example.

3.1: Which professionals really understood what the consumer needed? Tick any that apply.

- Community worker
- Pharmacist
- Mental health nurse
- Police
- Psychologist
- Centrelink staff
- Psychiatrist
- Housing staff
- GP
- Counsellors
- School staff
- Court officials
- None.

3.2: Which professionals really understood and helped you? Tick any that apply.

- Community worker
- Pharmacist
- Mental health nurse
- Police
- Psychologist
- Centrelink staff
- Psychiatrist
- Housing staff
- GP
- Counsellors
- School staff
- Court officials

3.1: Are you included when professionals make plans for the care of the person with a mental illness or disorder?

- Yes
- No
- I'm not sure.

3.2: Did these professionals make you feel like you were part of the 'care team' for the person with the mental illness or disorder?

- Yes
- No
- I'm not sure.

3.3: Do you feel like these professionals listened to your concerns about the person with a mental illness or disorder?

- Yes
- No
- I'm not sure
- I haven't shared my concerns with professionals.

3.4: Did professionals ever use concepts like "privacy" and "confidentiality" to not give you information that helps you care for the person with a mental illness or disorder?

- Yes
- No
- I'm not sure.

3.5: How much do you feel these professionals and services help the person with a mental illness or disorder?

- They always help
- They mostly help
- They sometimes help
- They rarely help
- They never help
- I'm not sure.

3.6: When the person with a mental illness or disorder has been very unwell, which of the following services were available? Tick any that apply.

- 24 Hour Mental Health Outreach Team
- 24 Hour Emergency Telephone Support
- Drug & Alcohol Services
- Ambulance Services
- Centrelink
- Other
- I'm not sure
- The person was not extremely unwell.

Section 4: You, the young mental health carer

In this section we want to learn more about your thoughts on being a young mental health carer, and what sort of support you are able to access to help you with the responsibilities that being a young mental health carer brings.

4.1: Have you felt alone in your role as a young mental health carer in the last 12 months?

- Always
- Often
- Sometimes
- Rarely
- Never
- I'm not sure.

4.2: Are you worried, or do you feel anxiety, about the well being of the person with a mental illness or disorder that you care for?

- Never
- Rarely
- Sometimes
- Mostly
- Always.

4.3: Do you feel stressed as a result of being a young mental health carer?

- Never
- Rarely
- Sometimes
- Mostly
- Always.

4.4: In the last 12 months, do you think that your physical or mental health has changed because you are a young mental health carer?

- 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 much better.

4.5: In the last 12 months, have you received support as a young mental health carer from any of the following? Tick any that apply.

- Family
- Friends
- Teacher
- Doctor
- Nurse
- Psychologist/Psychiatrist
- Counsellor
- Carer Support Group
- Carer Organisations
- Other
- I'm Not Sure
- I haven't accessed any professional support.

4.6: How helpful have family and friends been to you in your role as a young mental health carer?

- Extremely helpful
- Very helpful
- Somewhat helpful
- A little helpful
- Not helpful
- I haven't asked for help.

4.7: How helpful have professionals been to you in your role as a young mental health carer?

- Extremely helpful
- Very helpful
- Somewhat helpful
- A little helpful
- Not helpful
- I haven't asked for help.

4.8: If you are at high school, TAFE or university, has being a young mental health carer had an impact on your studies?

- Yes, a lot
- Yes, quite a bit;
- Yes, sometimes;
- Yes, but only rarely.
- No, it hasn't;
- I am not studying.

4.9: Have you ever felt discriminated against because you are a mental health carer? This could mean being bullied or teased.

- Yes
- No
- I'm not sure.

4.10: If you are employed, has being a young mental health carer had an impact on your job?

- Yes, a lot;
- Yes, quite a bit;
- Yes, sometimes;
- Yes, but only rarely.
- No, it hasn't;
- I am not working.

4.11: Has your school,/TAFE/university or workplace been flexilbe and supportive of your needs as a young mental health carer?

- Yes, a lot;
- Yes, quite a bit;
- Yes, sometimes;
- Yes, but only rarely.
- No, it hasn't;
- My place of study/work doesn't know I'm a mental health carer,
- I am not studying or employed.

4.12: How much money does it cost you to be a young mental health carer per month? For example, paying for transport, helping with bills or rent?

$

(in dollars per month – a guess or estimate is ok)

4.13: In the last 12 months, have you applied to Centrelink for any of the following? Tick any that apply.

- Carer payment
- Carer allowance
- Travel costs to remote hospital
- Carer accommodation costs to access remote hospital
- I'm not sure.

4.14: Do you ever use carer respite services?

- I don't know what carer respite services are;
- I could not leave the person I care for with a respite worker;
- What I need from respite care is not available;
- I do sometimes use carer respite services;
- Carer respite services are not available in my area;
- I am not aware of any respite carer services;
- No, I do not use carer respite services.

4.15: Do you think that your role as a young carer has meant that you have missed out on things that you have liked to do because of the time you have to spend looking after someone?

- Yes
- No

Section 5: Demographics

5.1: What is your postcode?

5.2: What is your gender?

- Male
- Female
- Trans

5.3: Are you enrolled at a high school/college, TAFE or university?

- Yes – High School
- Yes – TAFE
- Yes – University
- No ,I am not studying

5.4: Are you currently employed (please select all that apply?

- I am employed full-time;
- I am employed part-time or casually;
- I am not currently employed;
- I am a student;
- I am in receipt of an allowance;
- I am currently employed or studying but on leave due to a health condition;
- I am unable to work or study due to a health condition;
- I cannot work due to my role as a carer;
- I am a voluntary worker.

5.5: Do you identify as Aboriginal or Torres Strait Islander?

- Yes
- No

5.6: What is the main language you speak at home?

- English
- Chinese
- Italian
- Vietnamese
- Greek
- Cantonese
- Arabic
- Mandarin
- Serbian
- French
- Spanish
- German
- Other (please specify)

....

Section 6: Final Thoughts

6.1: After answering all the questions, is there anything else that you want to tell us about yourself, the person with a mental illness or disorder that you care for, or the professionals and services that you interact with?

Appendix C – Focus group discussion guides

For CALD carer service providers

1. **Can you give us an overview of your work with carers?**

2. **What proportion of your client base is from CALD backgrounds? What proportion is carers of people with a mental illness?**

3. **What distinctive issues do CALD carers face compared with carers from a mainstream background?**
   - Identifying as carers (rather than family)?
   - Acknowledging mental illness?
   - Specific aspects of culture?
   - Nature of stigma relating to mental illness within different cultures?

4. **Are there cultural barriers to people identifying themselves as 'carers' (rather than family)?**
   4.1 How do these differ from one cultural group to another?
   4.2 How do you try to overcome these barriers?

5. **Are there cultural strengths which CALD carers and consumers can draw on in dealing with the challenges associated with mental illness?**
   5.1 Can you provide some examples?
   5.2 How do you try to use these strengths in your work?

6. **What are the major barriers to CALD carers accessing the services they need? How do these differ between cultural groups?**
   6.1 Local availability?
   6.2 Nature of service organisations? (eg focus on mainstream population)
   6.3 Knowledge?
   6.4 Willingness to seek help?
   6.5 Keeping the caring role within families?
   6.6 Language/vocab (eg 'respite')?
   6.7 Involvement of CALD carers in designing and delivering services?

7. **What strategies are available to service providers looking to find 'hidden' carers from CALD backgrounds and offer them support?**
   - Can you provide some individual examples of carers that you work with who were previously 'hidden' from the system?

8. **What kinds of (positive and negative) experiences do carers and consumers from CALD backgrounds tend to have with the mental health service system?**
   - Are there aspects of the service system that CALD carers regularly identify as a problem?
   - Can you provide some examples of positive experiences?
   - Which mental health professions tend to do better with CALD consumers and carers?

9. **What experiences do CALD carers have getting information from health professionals about the people they care for?**
   - Privacy restrictions
   - Understanding the information they are given
   - Finding trustworthy sources of information
   - Information about:
     ▶ *Treatment and medication*
     ▶ *Services for consumers*
     ▶ *Services for carers*

10. **Compared with carers from mainstream backgrounds, what kinds of experiences do CALD carers and consumers have in dealing with the welfare system?**
    - Centrelink
    - Employment services
    - Participation requirements
    - Housing

For CALD carers

1. **Can you tell me about your experiences caring for someone with a mental illness?**

2. **What distinctive issues do CALD carers face compared with carers from a mainstream background?**

   2.1 Identifying as carers (rather than family)?

   2.2 Acknowledging mental illness?

   2.3 Specific aspects of culture?

   2.4 Nature of stigma relating to mental illness within different cultures?

3. **Are there cultural barriers in your community to people identifying themselves as 'carers' (rather than family)?**

   3.1 How do these differ from one cultural group to another?

   3.2 How do you try to overcome these barriers?

4. **Are there cultural strengths which CALD carers and consumers can draw on in dealing with the challenges associated with mental illness?**

   4.1 Can you provide some examples?

   4.2 How do you try to use these strengths in your work?

6. **What are the major barriers you accessing the services you need to help you in your caring role?**

   6.1 Local availability?

   6.2 Nature of service organisations? (eg focus on mainstream population)

   6.3 Knowledge?

   6.4 Willingness to seek help?

   6.5 Keeping the caring role within families?

   6.6 Language/vocab (eg 'respite')?

   6.7 Involvement of CALD carers in designing and delivering services?

9. **How do you think service providers could find 'hidden' carers from CALD backgrounds and offer them support?**

10. **What kinds of (positive and negative) experiences have you had with the mental health service system?**

    10.1 Are there aspects of the service system that CALD carers regularly identify as a problem?

    10.2 Can you provide some examples of positive experiences?

    10.3 Which mental health professions tend to do better with CALD consumers and carers?

11. **What experiences have you had in getting information from health professionals about the person you care for?**

    11.1 Privacy restrictions

    11.2 Understanding the information they are given

    11.3 Finding trustworthy sources of information

    11.4 Information about:

    • Treatment and medication

    • Services for consumers

    • Services for carers

12. **What kinds of experiences have you had in dealing with the welfare system?**

    12.1 Centrelink

    12.2 Employment services

    12.3 Participation requirements

    12.4 Housing