MENTAL
HEALTH
COUNCIL OF
AUSTRALIA

Adversity to Advocacy

The Lives and Hopes of Mental Health Carers

October 2009

Acknowledgements

MHCA wishes to thank all of the mental health carers who gave their time and expertise at the workshops as it would have been impossible to complete a project of this magnitude as thoroughly and successfully without the help, insights and candour of carers, including those from the Indigenous, CALD and young carer communities.

MHCA acknowledges the crucial planning and administrative work of local workshop coordinators, all of whom were recruited from outside its own ranks; as well as those MHCA and Mental Illness Fellowship staff who filled all of the workshop facilitator positions.

Also providing essential contributions were local guest speakers, including representatives of the police, housing, respite and mental health services; Centrelink; carer organisations; the judiciary; schools; and local government.

MHCA is grateful to the CEP Advisory Group who provided invaluable assistance and enthusiasm for the project: Tony Fowke (Advisory Group Chair), Ruth Carson, Barbara Hocking, Allison Fillery, and Colleen Sheen (until February 2008).

Thanks to URS Australia Pty Limited who were engaged by the MHCA to develop an evaluation plan for the CEP; and specifically to URS Project Director and Principal Social Scientist Gaye Mackenzie as well as to evaluation author and Senior Social Scientist Vicki Williams for their objective insights and key efforts in this regard.

MHCA thanks the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) for generous funding required to conduct the comprehensive Community Engagement Project on which this report is based.

Suggested reference: Adversity to Advocacy: The Lives and Hopes of Mental Health Carers

ISBN: 978-0-9807007-1-8

Design: Levitate Graphic Design

Printing: Blue Star Printing

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Acronyms and Abbreviations

ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
AIHW	Australian Institute of Health and Welfare
ASGC	Australian Standard Geographical Classification
CALD	Culturally and Linguistically Diverse
CEP	Carer Engagement Project
DOCS	NSW Department of Community Services
FaHCSIA	Australian Government Department of Families, Housing, Community Services and Indigenous Affairs
GDP	Gross Domestic Product
GP	General Practitioner
HACC	Home and Community Care
HASI	Housing and Accommodation Support Initiative
HREOC	Human Rights and Equal Opportunity Commission
MHCA	Mental Health Council of Australia
MP	Member of Parliament
NATSEM	National Centre for Social and Economic Modelling
NGO	Non-government Organisation
NSW	New South Wales
NT	Northern Territory
PARC	Prevention and Recovery Care
PHaMs	Personal Helpers and Mentors
QLD	Queensland
SA	South Australia
TAFE	Technical and Further Education
TAS	Tasmania
TIS	Telephone Interpreter Services
VIC	Victoria
WA	Western Australia

Foreword

It is with pleasure that I present to you the first ever national survey of mental health carers in Australia.

This survey reveals the 15 key issues which affect mental health carers and provides a national report card on how Australia is managing these issues.

Unfortunately, this survey also highlights the gulf which continues to exist between policy and practice. While there is now a plethora of government reports, policies and strategies which aim to address the needs of carers, the results of this first national survey show that these policies are yet to impact positively on the experience of care felt by the mental health carers who participated in the survey.

Adversity to Advocacy continues the saga initiated by the 1993 National Inquiry into the Human Rights of People with Mental Illness ['the Burdekin report'] continued by the Not for Service report 2005 and the report of the Senate inquiry in Mental Health of 2006, From Crisis to community. It extends the same national listening ear specifically to mental health carers to enable them to speak openly about their lives and, very sadly, reveals that the stories told were very much the same as in these earlier reports. Little has changed in carers' access to services when things start to deteriorate, their anguish at being excluded from information to help them to provide better care, and in many cases their desolation at the thought:

> **"What will happen to the person I care for when I am gone?"**

For the many carers who participated in the workshops that produced this survey, there was the sense that nothing had changed or will change, and the sad stories will continue to stay the same. Yet, many also reported 'hope' as the best thing to come out of the workshop experience and the hope is that this survey can be a platform of action for change. Responding to its findings is a responsibility shared by funders and decision-makers. Ignoring it is not an option.

Tony Fowke

Tony Fowke AM

Mental Health Carer

World Federation for Mental Health President

Mental Health Council of Australia Board Member

1. Executive Summary and Report Card

Adversity to Advocacy is Australia's first ever national survey of mental health carers. It is a unique insight into the difficulties and concerns of Australians caring for someone with a mental illness.

More than 1,500 mental health carers from across the nation came together in small groups from Broome to Bega, and from Cairns to Carnarvon. The carers attended workshops delivered by the Mental Health Council of Australia (MHCA) in partnership with local organisations where they talked about the issues and concerns they faced as carers of those with a mental illness. The MHCA visited 116 locations throughout Australia with two thirds being rural or remote. Many mental health carers are older people, but the workshops also engaged specifically with young carers, some as young as nine years old.

The MHCA has built a national network of mental health carers and will be striving to ensure that this survey is just the first in an ongoing series designed to ensure the voice of mental health carers is heard loudly and clearly.

This survey reveals the 15 key issues identified by mental health carers, which are all based directly on stories, experiences and ideas from the carers who attended the workshops. These key issues must be addressed if mental health carers needs are met:

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**

These key issues relate to carers and their role alongside priorities that relate directly to the mental health system and the care of the consumer. This reflects the fact that in many situations the needs of carers and those they care for are intrinsically entwined.

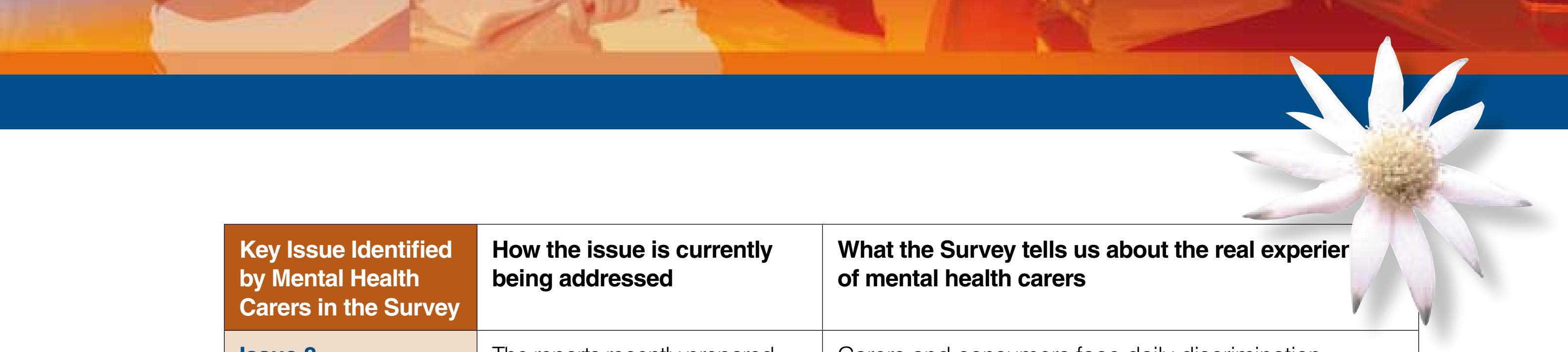
The table below outlines each of the 15 key issue identified by mental health carers in the survey, how these are currently being addressed, and what the survey reveals about the real experience of mental health carers.

The table below highlights the gulf that exists between the existing policy approaches and the reality of the experience of care in each of the 15 key areas identified in this first national survey of Australia's mental health carers.

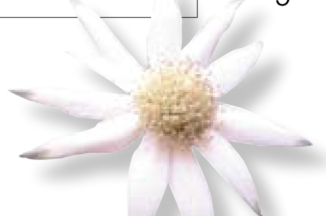
The 15 Key Issues Affecting Australia's Mental Health Carers

Key Issue Identified by Mental Health Carers in the Survey	How the issue is currently being addressed	What the Survey tells us about the real experience of mental health carers
Issue 1 **Listen to and respect carers**	The need to increase respect for carers is part of the new House of Representatives Inquiry announced on 1 May 2009, but has been a consistent theme in both national and state mental health strategies for more than a decade.	The common view among carers is that they are neither listened to nor respected. The rhetoric of including carers as part of the care 'team' for the consumer is not borne out in reality. Often this leaves carers trapped, excluded, feeling unable to provide adequate care, but also unable to find the services needed for the person they are caring for.
Issue 2 **Integrated recovery-based care for the consumer**	The term 'recovery' now features in key government documents in relation to mental health, such as the 4th National Mental Health Plan and the new National Mental Health Service Standards. These documents clearly refer to the need to provide holistic care, involving clinical and non-clinical care, and services beyond health care in order to meet consumer needs towards recovery.	The intolerable stress faced by carers reflects the inadequacy of the care available to consumers. Of particular note here is the common experience faced by carers of lack of integration between different health services, and between health services and other community services such as housing or employment services, and lack of services such as Personal Helpers and Mentors. Recovery is very much an individual matter, assessed in the eye of the beholder. The system is not currently able to provide individualised or tailored approaches to care.
Issue 3 **More and better trained staff at all levels**	This is the central role of the Mental Health Workforce Advisory Committee, which works as part of the Australian Health Ministers' Advisory Council structure. It has been highlighted in key national reports as a major issue for the future of mental health in Australia. The Better Access Program has enabled Medicare-funded access to psychology services for hundreds of thousands of Australians, although this access still relies on GPs providing a mental health care plan.	Carers identify inadequate staffing as a key part of current service failure. Access to psychiatry remains extremely limited. Increased access to registered psychology services was not seen as a significant benefit when inadequate workforce numbers impact on availability. Carers report that access to other forms of care, in particular sub acute care, remains a significant issue, particularly in non-metro areas.

Key Issue Identified by Mental Health Carers in the Survey	How the issue is currently being addressed	What the Survey tells us about the real experience of mental health carers
Issue 4 **Knowledge and information for carers**	The workshops to inform this survey were initiated by FaHCSIA partially out of concern to provide more information to mental health carers about available programs and services. Increasing mental health literacy has been identified as an important target in the National Health and Hospitals Reform Commission recommendations, and is implied in most Australian mental health strategies.	One of the most debilitating aspects of being a mental health carer is the sense of isolation and helplessness. Knowledge of services such as Commonwealth Carelink is minimal at best. Carelink's understanding of mental health also varies greatly from office to office. Knowledge of peer support options also seems very patchy, with many carers meeting for the first time at the local workshops. Carers reported that the knowledge of how to care for someone with a mental illness was rarely available at first onset of illness.
Issue 5 **Carer and consumer education for all professional groups and agencies**	In areas such as policing and medicine, there are a number of jurisdictions now incorporating carer / consumer education and awareness components into required training.	Many carers feel ignored or patronised by professional groups and agencies. Most carers feel professionals appear to have no understanding of the role of carers, in particular their integral role in the ongoing care of the consumer. There is a real need for increased carer / consumer informed professional development for mental health and other service providers.
Issue 6 **Support systems, services and processes established for carers**	This is a recommendation made by the National Health and Hospitals Reform Commission, and echoes the sentiment in previous national mental health plans about engaging more directly with carers.	The need for more carer led support programs for carers was raised in many workshops. The infrastructure to support carers is generally very weak, with some exceptions. Overall, mental health carer organisations are very poorly resourced. Health services have also generally failed to invest in robust systems to enable engagement with the carer sector. Carers often use their own resources and pay their own way in order to participate in policy and service development activities.
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 and was a key matter assessed by the 2007 Survey of Mental Health and Wellbeing. The second progress report on the COAG Action Plan 2006-11 reports on the therapeutic value of mental health care nationally for the first time.	The 2007 Survey of Mental Health and Wellbeing confirmed Australia's inability to lift access to care over the past decade. While the reasons for this are not clear, the impact on carers is very clear. Carers indicate they are commonly faced with providing care to consumers who are acutely unwell, leaving them and the people they care for more vulnerable to the effects of ill health. Carers also considered that acute care (when accessible), was rarely of a therapeutic or recovery oriented nature and often increased the trauma of an acute illness.



Key Issue Identified by Mental Health Carers in the Survey	How the issue is currently being addressed	What the Survey tells us about the real experien of mental health carers
Issue 8 **Stigma, discrimination and isolation for carers and consumers**	The reports recently prepared by both the National Health and Hospitals Reform Commission and the Prevention Taskforce articulated the need for a national campaign to address the issue of community stigma towards mental illness. This follows repeated acknowledgement of the issue in national mental health plans and strategies. There is currently no major national mental health awareness or promotion campaign.	Carers and consumers face daily discrimination and stigma. This manifests itself in the realms of employment, housing, health services, schools, in fact all professional agencies Sometimes even extended family members can look down on people with a mental illness and their carer. This stigma leads to increased isolation with many carers feeling silence is better than reactions from admitting they care for someone with a mental illness.
Issue 9 **Accommodation options for consumers at all levels of care**	An appreciation of the intimate link between mental health and housing is clear both in mental health policies and strategies, and also in the Australian Government's recent housing policy, *The Road Home*. There has been some investment by states in mental health housing through programs such as the Housing and Accommodation Support Initiative (HASI).	Carers report that access to safe, supported housing is a critical problem particularly for consumers with chronic and complex mental health problems. Failure to provide access to housing, or only to unsustainable housing options, leaves consumers very vulnerable to dangers, including worsening health and experiencing violence.
Issue 10 **Financial costs to carers**	The Australian Government has moved to make carer payments a fixture in the welfare system. Annual payments plus other allowances paid by Centrelink recognise the financial impost on carers. Eligibility criteria are still primarily focused on physical care needs – able to shower, toilet or feed themselves.	In the absence of consumer access to regular mental health care, carers often take on complex and time consuming caring roles including meeting increased costs of transportation or private treatment. The carer role often precludes participation in paid employment leading to significant current and future financial disadvantage for both consumer and carer. Mental health carers are often refused entitlements from Centrelink which, in any case, only partially defray costs incurred, and rarely allow for the level of support and monitoring involved in caring for someone with a mental illness.
Issue 11 **Physical and mental health of carers**	A range of government reports have acknowledged that mental health carers have a much higher rate of mental health disorders themselves.	Carers do not feel as though their needs are addressed by anyone. Financially they are not in a strong position leaving them isolated and often facing their own deteriorating health without adequate access to the support they need.
Issue 12 **Flexible respite options for carers**	The Australian Government has attempted to come to grips with the respite needs of mental health carers under the FaHCSIA portfolio. New FaHCSIA programs are operating well below capacity, with some of this activity catering for people with intellectual disability rather than mental illness.	The new respite care program implemented by FaHCSIA has only partially met the needs of mental health carers. Service providers have commonly not understood mental health carers' needs and carers have concerns about respite workers with little or no knowledge of mental illness. As a result, carers do not feel as though respite is a realistic or safe option, and those who try to use the respite services often report problems in finding appropriate options. A possible option suggested by some carers is the co-location of the Personal Helpers and Mentors service for consumers and the respite service for carers within the same organisation (sharing services).



Key Issue Identified by Mental Health Carers in the Survey	How the issue is currently being addressed	What the Survey tells us about the real experience of mental health carers
Issue 13 **Privacy and confidentiality issues**	The Australian Law Reform Commission undertook a review of privacy law in 2008 and recognised that disclosure of information to 'a person responsible for an individual' can occur within privacy law. The need for legislative reform in this area was also recognised by the 2009 House of Representatives Inquiry into Better Support for Carers.	Carers' rights to be part of the care team are frequently trammelled as they are excluded on the erroneous grounds of privacy and confidentiality. Carers who were aware of Advance Directives for consumers endorsed their implementation to help navigate the privacy and confidentiality minefield.
Issue 14 **Early intervention at each episode of care**	Early intervention has been a key feature of successive national mental health plans and also features in the recommendations made by the National Health and Hospitals Reform Commission.	The vast majority of mental health funding remains targeted at acute mental health care. There is only one comprehensive early intervention service for psychosis operating in Australia. Carers are forced to watch consumers wait until their conditions become sufficiently florid to demand the attention of the largely hospital-based acute care system currently in place. This is often despite repeated calls from carers for help and assistance prior to the issues escalating into more dangerous, unhealthy and long lasting situations.
Issue 15 **Employment options for carers**	The recent National Mental Health and Disability Employment Strategy mentions the significance of employment for carers, as part of the Australian Government's Social Inclusion agenda. The needs of carers are to be addressed as part of the commitment to develop a National Disability Strategy.	The poor rates of employment or meaningful occupation for consumers means that many carers are also unable to work or unable to work as many hours as they would like. This leaves many carers vulnerable to the negative effects on physical and mental health associated with financial disadvantage.

2 About the Carers Engagement Project

The Mental Health Council of Australia (MHCA) was contracted in 2007 by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) to deliver a series of workshops across Australia for families and carers of people with a mental illness. Their original aim was to assist families and carers in developing coping and management skills for caring for those with a mental illness. While the workshops achieved this goal, they also provided carers with an important opportunity to share their own views on the key issues and challenges that they face, thus providing a foundation for subsequent annual monitoring.

This initiative, known as the Carer Engagement Project (CEP), has been a resounding success. The initial plan to deliver 40 workshops during 2008 was soon expanded, resulting in 85 being delivered in the first round alone. Efficient fund and resource management in conjunction with further demand for such workshops, enabled the MHCA to provide another 31 such events in early 2009. In total more than 1,500 carers from across Australia attended 116 workshops.

The MHCA-FaHCSIA contract made provision for some of the workshops to focus specifically on priority client groups of Indigenous families; those from culturally and linguistically diverse (CALD) backgrounds; carers in rural and remote areas; and young people. Ultimately, 12 workshops specifically for CALD carers were delivered, with another nine for Indigenous carers, and seven more for young carers. Representatives of all of these particular target groups also attended the ‘general’ workshops, enabling the MHCA to engage intensely with these often underrepresented groups.

MHCA plans to undertake subsequent annual monitoring to fill an existing gap in knowledge about mental health carers in Australia, and provide crucial data on the experiences of mental health carers over time, across states and territories and for different population groups. Issues to be monitored are those that mental health carers themselves have identified as the most important and the process will be designed to let carer voices be heard.

2.1 Rationale

While no data collected currently can identify the total number of mental health carers in Australia, Australian Bureau of Statistics (ABS) figures indicate that there are about 2.6 million carers in Australia[1]. With 45 per cent (7.3 million people) of Australians aged between 16 and 85 having experienced a mental or substance use disorder at some point in their lives, and with 20 per cent (3.2 million individuals) having experienced a mental or substance use disorder during the twelve months prior to the survey[2], it is probable that the number of mental health carers in Australia is extremely large.

Yet since the release of the Burdekin Report and its recommendations 16 years ago,[3] care in the community for mental health consumers has continued to be inadequately funded and chaotically distributed. There have been attempts to identify problems and redress the issues, but a consequence of changes to mental health policy has been the transfer of the majority of care from mental health institutions to the family. The MHCA has, through its *Not for Service* and *Out of Hospital Out of Mind* reports, highlighted the inadequacies in related service provision and the need for change.[4] These and other reports include comprehensive descriptions of the service interactions and life experiences of consumers and carers and have been instrumental in delivering information to all levels of government.

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[1] ABS 2004 *Disability, Ageing and Carers, Australia: Summary of Findings, 2003 (ABS Cat 4430.0),* ABS, Canberra.

[2] ABS 2008a *National Survey of Mental Health and Wellbeing: Summary of Results, Australia 2007 (ABS Cat. No. 4326.0)*, ABS, Canberra.

[3] Burdekin, B., Guilfoyle, M. and Hall, D. 1993 *Human Rights and Mental Illness: Report of the National Inquiry into the Human Rights of People with Mental Illness*, HREOC, Sydney.

[4] Groom, G., Hickie, I. and Davenport, T. 2003 *Out of Hospital Out of Mind, A report detailing mental health services in Australia in 2002 and community priorities for national mental health policy for 2003-2008*, MHCA, Canberra; MHCA 2005 *Not for Service: Experiences of injustice and despair in mental health in Australia,* MHCA, Canberra.

The MHCA, however, continues to hear firsthand from carers about their daily lives, the difficulties that they experience and the lack of accessible service delivery available to them. The CEP workshops were designed as a response to the need for stronger services identified by mental health carers. Highlighting the significance of this project is that mental health carers are often isolated both by continued stigma and discrimination towards mental illness as well as by the lack of information delivered to them or processes to provide it.

2.2 Objectives of the Carers Engagement Project (CEP)

The immediate objectives of the CEP were to:

- provide mental health carers throughout Australia with high-quality workshops of relevance to them;
- hear the experiences of mental health carers;
- facilitate the sharing of ideas on coping strategies;
- hear from local guest speakers and facilitate interactive discussions with carers about local services;
- provide at least 25 per cent of the workshops to the priority client groups (Indigenous carers, CALD carers, young carers, rural and remote carers); and
- engage with carers in determining the most important issues affecting their lives as mental health carers.

The objectives of ongoing monitoring of carer experiences are to:

- build and develop ongoing relationships with mental health carers;
- evaluate those items that carers recognise as affecting their lives the most and, identify common themes relevant to all carers;
- devise an annual survey tool;
- access carers on an annual basis utilising such a survey tool to ascertain changes;
- provide an annual report on mental health carers, based on the information received; and
- engage additional mental health carers to help with ongoing monitoring.

2.3 Workshop Design Methodology

2.3.1 Workshop Design Consultation

The MHCA consulted widely with carers both individually and in groups. Specific groups in the general mental health caring field, including those from the CALD and Indigenous communities, were asked to contribute. An Indigenous mental health consultant was engaged to assist with content and delivery of the Indigenous workshops. Telephone consultations were held with Indigenous and CALD workers and carers throughout Australia. In addition, two focus groups were held.

2.3.2 Focus Groups

Twenty eight mental health carers, both new and experienced, from across Australia participated in an initial focus group held in October 2007. The purpose of that session was to obtain feedback on the possible content and the delivery of the workshops, information that was vital in determining final workshop design. The group included Indigenous, CALD, rural, remote and regional carers as well as those caring for family members.

In December 2007, the MHCA convened a youth focus group, designed and run in collaboration with community experts on matters relating to young carers and young people at risk. Eleven young mental health carers attended, with participants ranging in age from 14 to their mid-20s, apart from one who was over 30 and provided a valuable reflective perspective. While most of the young carers were from the ACT and surrounding areas, representatives also came from urban and rural areas and from two states: South Australia and Queensland.

Those attending were asked to comment on the content of the proposed young carer workshop, and their comments assisted greatly in the drawing up of plans for it.

2.3.3 Workshop Design and Content

Three types of workshops were held as part of the CEP. One was the general workshop designed for presentation to all groups of adult carers throughout Australia whatever their level of experience in the field. This workshop was adapted to meet local and regional needs; for CALD groups; or for special interest groups.

Another variety was the Indigenous carers workshop which was very flexible and adapted entirely to meet the needs of each local Indigenous community.

Yet another type was the young carers workshop, designed to meet the needs of young carers and thus included many more interactive and ‘fun’ activities.

Design and content of all three categories of workshop drew heavily on carer expertise as articulated in feedback, including that provided during small and large group discussion. MHCA staff were generally the workshop facilitators, who, after being flown in specifically for the events, needed to establish the trust of participants right from the outset. Support of local coordinators was instrumental in facilitators expediently achieving a good rapport with participants and becoming familiar with local issues (see section 2.4.1).

Fortunately, once the facilitator had established a safe environment, carers were ready to share openly their experiences and concerns. Because carers can be reluctant to talk about matters such as drug and alcohol issues of those they care for, facilitators sought to encourage open and frank discussion by introducing specific topics and recommending relevant resources for carers, such as those suitable for individuals with comorbid drug or alcohol use and mental illness.

Workshops were composed of five sessions:

1) Carer experiences: designed both to enable carers to speak freely about issues affecting their own lives, rather than affecting those they care for; and to prioritise them.

2) Coping strategies: encouraged carers to share strategies to deal with the issues highlighted in the first session.

3) Local guest speakers: at the adult carer workshop these ideally included local police representatives, Centrelink and an organisation providing services to carers, as several carers have reported difficulties when dealing with Centrelink and the police. This session was designed to give carers access to representatives of these groups, hear their perspectives and have questions answered. In the young carer workshop guest speakers ideally included a school principal – something that young carer focus group participants were adamant about.

4) Identification of key issues: during which participants identified eight to fifteen issues which would be utilised in ongoing mental health carer monitoring.

5) Evaluation: a two part evaluation, one written to fulfil the MHCA reporting requirements to FaHCSIA, and another informal evaluation exercise designed to help with ongoing planning and final project evaluation.

2.3.4 Workshop Preparation

To achieve consistency throughout the workshops, MHCA staff chosen to facilitate workshops were trained in the workshop format. CALD and Indigenous workshop facilitators received extra training in working with non-English or Indigenous- language speaking groups and effective ways to work with translators. An invaluable resource in developing workshops for both Indigenous people and staff learning was *Yarning about mental health*.[5]

Literature considered useful for mental health carers and reflecting the content of workshops was identified and prepared for distribution at these events.

2.4 2008 and 2009 Workshops

A total of 1,514 mental health carers participated in 116 CEP workshops held across Australia throughout 2008 and 2009.

2.4.1 Partnership Between the Local Coordinator and the MHCA

The success of the project depended on the establishment of partnerships between local coordinators and the CEP manager at a very early stage. Much was expected of the local coordinators and it was essential to make this clear at the outset.

With modest funding from the MHCA, local coordinators agreed to provide or find a venue; arrange catering and guest speakers; and confirm a minimum of about fifteen mental health carers would attend each workshop. To help with that task the MHCA provided a coordinator's pack which included a project overview; extensive coordinator's notes; a workshop timetable; a media brief; advertising flyers; as well as invitations and information for the guest speakers. Local coordinators were instrumental in arranging local guest speakers, which was important in developing further links within the local mental health community.

2.4.2 CEP Workshop Organisation

The workshops were promoted as widely as possible and MHCA organisational members and those in the MHCA database of carer groups and individuals received information about the workshops and requests for expressions of interest in being a local coordinator for a workshop. Email recipients were encouraged to forward information to other potentially interested parties, while CEP workshop application information was provided on the MHCA website.

Well over 150 expressions of interest were received during the month in which applications were open and each applicant was immediately contacted with a view to establishing a strong working relationship and addressing issues and queries.

The response exceeded the MHCA baseline expectations that at least 25 per cent of workshops would be delivered to rural, remote, Indigenous, CALD and young carers.

The response from the rural sector was particularly strong. The Australian Institute of Health and Welfare (AIHW) defines rural and remote populations as those outside major cities with populations greater than 250,000 people in terms of the Australian Standard Geographical Classification (ASGC). Based on this, 32 per cent of the Australian population lived in rural and remote areas in 2008.[6] If the above definition is accepted, 68 CEP workshops were conducted in rural and remote locations. The large proportion of workshops delivered in the often underserviced rural and remote areas was an extremely positive development indeed.

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[5] Nagel, T. and Thompson, C. 2007 *Yarning about Mental Health Manual*, Australian Integrated Mental Health Initiative Northern Territory, Darwin.

[6] AIHW 2008 *Australia's Health 2008 (AIHW Cat. No. AUS99)*, AIHW, Canberra; ABS 2003 *ASGC Remoteness Classification: Purpose and Use (Census Paper No. 03/01),* ABS, Canberra.

Because workshop information was distributed widely at the outset, expressions of interest were received from a diverse yet comprehensive group, composed of interests ranging from carer groups with loose organisational structures and no funding; to funded and staffed carer support services run from within mental health services.

MHCA had the difficult task of selecting workshop locations. It was a priority to distribute workshops nationally so MHCA considered research on population density, isolation, definitions of rural and remote and access to other services when making its decisions. Based on earlier research a balance was sought between the:

- type of workshop: general, Indigenous, CALD, young carer;
- locality: rural, remote or urban; and
- state populations and areas of population density.

Areas or populations for which no organisation offered local coordination were canvassed to achieve comprehensive coverage. The national spread of workshop is in Table 1:

Table 1: Total Workshops 2008 and 2009

State	General	CALD	Indigenous	Young Carers	Special Groups	State Total
ACT	2					2
NSW	26	10	1	1	1	39
NT	4					4
QLD	19		1			20
SA	10		3	1		14
TAS	2					2
VIC	15	1	1	3	1	21
WA	8	1	3	2		14
Total	**86**	**12**	**9**	**7**	**2**	**116**

The enthusiastic strong response to the first round of workshops encouraged the MHCA to provide a second round in 2009. This latter round enabled the MHCA to fulfil requirements not completely met in round one and target areas where an imbalance existed.

2.4.3 Workshop Locations

Potential dates for workshops were limited by existing workloads of MHCA staff facilitators; the proximity of one workshop to another; and the need to maintain staff in the MHCA office to continue to organise CEP delivery as well as liaise with carers and local coordinators. Travel expenses were a consideration and kept to a minimum by combining workshops where possible into a series of three or four per week in locations connected by road. Large urban areas were easier to access given the frequency of flights from Canberra (where the MHCA Secretariat is based) and the possibility of a day return trip.

Of the workshops presented in round one, 14 were delivered by the Mental Illness Fellowship in NSW, South Australia, Western Australia, Northern Territory, and Victoria. MHCA partnered with the Mental Illness Fellowship in these states in recognition of the important role established mental health carer groups have in reaching mental health carers. This left MHCA able to focus its efforts on those mental health carers who may not be already engaged with state/ national mental health and/or carer organisations.

Table 2: Workshop Locations by State

State	Workshop Location	Type
ACT	Belconnen	General
	Canberra city	General
NSW	Albury	General
	Albury	Indigenous
	Alstonville	General
	Bankstown	Culturally and Linguistically Diverse
	Bega	General
	Bombala	General
	Broken Hill	General
	Broken Hill	General
	Campbelltown	General
	Canley Vale	Culturally and Linguistically Diverse
	Canley Vale	General
	Chatswood	Special Workshop
	Deniliquin	General
	Dubbo	General
	Gosford	General
	Gunnedah	General
	Lake Macquarie	General
	Lightning Ridge	Culturally and Linguistically Diverse
	Lockhart	General
	Moruya	General
	Muswellbrook	General
	Newcastle	General
	North Ryde	General
	Orange	General
	Port Macquarie	General
	Queanbeyan	General
	Sydney SW	Culturally and Linguistically Diverse
	Sydney SW	Culturally and Linguistically Diverse
	Sydney SW	Culturally and Linguistically Diverse
	Sydney SW	Culturally and Linguistically Diverse
	Tamworth	General
	Temora	General
	Wagga Wagga	General
	Wagga Wagga	Young Carers
	Woollahra	Culturally and Linguistically Diverse
	Woollahra	Culturally and Linguistically Diverse
	Woollahra	Culturally and Linguistically Diverse
	Wyong/Toukley	General
	Young	General

State	Workshop Location	Type
NT	Alice Springs	General
	Darwin	General
	Darwin	General
	Katherine/Batchelor	General
QLD	Biloela	General
	Brisbane	General
	Brisbane	Indigenous
	Brisbane Lutwyche	General
	Brisbane PA Hospital	General
	Brisbane Redlands	General
	Brisbane Woolloongabba	General
	Cairns	General
	Gladstone	General
	Gympie	General
	Hervey Bay	General
	Ipswich	General
	Logan	General
	Maroochydore	General
	Mackay	General
	Robina	General
	Rockhampton	General
	Roma	General
	Toowoomba	General
	Townsville	General
SA	Adelaide	Young Carers
	Adelaide Fullarton	General
	Berri	General
	Coober Pedy	Indigenous
	Copley	Indigenous
	Keswick	General
	Marion	General
	Modbury	General
	Murray Bridge	General
	Naracoorte	General
	Port Augusta	Indigenous
	Port Augusta	General
	Port Lincoln	General
	Victor Harbour	General
TAS	Hobart	General
	Launceston	General

VIC	Bairnsdale	General
	Ballarat	Indigenous
	Camperdown	General
	Coburg	General
	Fairfield	Special Workshop
	Frankston	Young Carers
	Geelong	Culturally and Linguistically Diverse
	Hawthorn/ Richmond	General
	Inverloch	General
	Kilsyth	Young Carers
	Korumburra	General
	Melbourne E	General
	Melbourne SW	General
	Mildura	General
	Parkville/ Moonee Ponds	General
	Preston	General
	Sunshine	General
	Traralgon	General
	Warracknabeal	General
	Warrnambool	General
	Warrnambool	Young Carers
WA	Albany	General
	Broome	Indigenous
	Bunbury	General
	Carnarvon	General
	Geraldton	General
	Geraldton	Indigenous
	Kalgoorlie	General
	Mandurah	General
	Mandurah	Indigenous
	Mirrabooka	Culturally and Linguistically Diverse
	Perth	General
	Perth	General
	Perth E	Young Carers
	Perth SW	Young Carers

An overview of workshop distribution is detailed on a map of Australia in Appendix A.

2.5 Project Evaluation

MHCA built in evaluation processes from the beginning of the project, to ensure that the workshops were refined as they were delivered and provided a positive experience for carers.

The evaluation was undertaken by URS Australia Pty Limited and focussed on the process of organising and delivering the workshops. In broad terms the evaluation approach looked at a detailed understanding of the project, including its objectives, components, strategies, and administration processes. It sought to define monitoring, reporting and evaluation arrangements and methods of assessment, as well as consulting with key stakeholders and primary project managers. In addition, the approach looked at the collection, collation and analysis of information, along with assessment of the extent to which the project was successful in achieving its goals and objectives, and finally it formulated findings and produced a conclusion.

A mix of quantitative and qualitative information was drawn together for analysis and assessment purposes. Major sources were the questionnaires and surveys conducted at the workshops, information supplied by the MHCA about the project administration, delivery and reporting, and additional project reports.

Data was gathered on outputs, processes, feedback from participants, and feedback from staff. Coordinators provided feedback on all workshops conducted. Two issues stood out as consistently occurring for coordinators across all regions. Both were related to recruitment of both guest speakers and participants as it was difficult to secure agreement for attendance from some speaker groups, and the recruitment and attendance of participants varied greatly – from two to 41.

Facilitators also provided feedback and commented that different management was needed for both guest speakers and participants. Guest speakers came with varying degrees of empathy, understanding and knowledge. Some guest speakers required more time management direction than others and some participant groups, more intensive management and facilitation.

Participant feedback produced information on the best aspects of the workshops and those that were not so good. Meeting and sharing stories with other carers tended to be considered the best aspect of the workshop. Participation in the workshops provided a sense of empowerment to many groups who felt that they had been given a voice without judgment. Consistent with coordinators feedback, participants rated the guest speakers in the ‘not so good’ category. Some referred to those guest speakers that did not attend or, when they did, were not compassionate or made inappropriate comments. Another aspect that did not rate well was the low number of carers in attendance.

This feedback enabled the information gathered to be incorporated into the project’s improvement cycle with the possibility of it serving as a useful resource for future similar projects. The data also sought to identify some of the additional benefits of the workshops such as increased networks between participants and the development of shared projects.

2.6 Ongoing Nature of the Project

The workshops composed only the first part of the CEP, while the second part of the project continues. Currently, there is no system of accountability in mental health for consumers or carers and no way of measuring the success or otherwise of either clinical work or community-based services. Without accountability measures there is no way of recording what works well, what is improving and what areas need further attention.

Carers worry that comments made to service providers could be detrimental to the ongoing care of those they care for, and when complaints are made they often find there is no response anyway. The MHCA, through the CEP workshops, held the first national survey of mental health carer issues and will do so on an ongoing annual basis. The process of identifying those issues commenced at the 116 workshops held across Australia in 2008-09.

The carers at each workshop spent time identifying and prioritising major issues of concern to them. This information has been analysed and collated, with the results discussed in the next section. Fifteen major issues of concern emerged and are listed in order of the frequency with which they were raised at the workshops:

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. Therapeutic and accessible acute care
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

Mental health carers who attended the workshops and others who wish to participate will be invited to respond to an annual questionnaire based on these 15 issues. Each year the MHCA will develop a mental health carer report based on carer responses. This will be the first time mental health carers have been accessed directly on an ongoing basis to comment on the impact that mental illness has on their own and their family's lives. Carers have commented that they want their own voices to be heard, rather than have professionals or advocacy organisations identify what their priority issues are and lobby for them on that basis.[7] While MHCA is an advocacy and lobbying group, it is committed to basing its annual survey of carers on issues that carers themselves have identified as important and having the greatest impact on their lives.

A major consideration for this ongoing project is that of access to mental health carers. Of the 1,514 carers who attended the workshops approximately half did not own or use a computer and had no access to the internet, or could only access the latter at work and thus could only utilise it for limited personal use. Of those who did use a computer many were on a dial-up system in rural areas. It is also important to consider the implications both in terms of time and cost when basing contact with carers on telephone contact, the postal system and face to face meetings when continuing annual monitoring of carers.

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[7] See for example Holland, K.E. and Blood, R.W. 2008 *Don't wait: Carers say listen and act now: A report on the Carers Virtual 2020 Summit*, Carers Australia, Canberra.

3. Carers Engagement Project findings

Priority issues identified by carers attending each of the 116 workshops have been collated and those fifteen most commonly mentioned are listed in order of importance. While many of these relate to carers and their role, numerous others pertain directly to the mental health system and consumer care.

This is supported by other research findings. For example, the AIHW submission to a recent House of Representatives Inquiry into Better Support for Carers stated specifically that '…supporting carers involves providing services to address a carer's own needs but also ensuring that the wider service 'system' works for carers in relation to the people they assist'. Indeed, the Inquiry itself also recognised that 'the needs of carers and those they care for are inextricably bound'.[8]

3.1 Priority Issue 1 – Listen to and respect carers

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

3.1.1 Respect for carers in clinical settings

Carers wanted to see a collaborative team approach to consumer care, with carers seen as 'partners in care'. This approach should involve carers in all stages of the process including care planning, treatment, referrals, discharge planning, as well as decisions in such areas as treatment, housing, and money management. Carers said that they possess crucial information as a result of their close relationships and often almost constant contact with consumers. They also felt that they could provide the 'true picture', arguing that some consumers can give a deceptively positive impression of their wellbeing during brief consultations with mental health professionals, hiding the reality of their ill health at home. This is supported by other evidence.

A carer providing a submission to the MHCA *Not for Service* report of 2005 called for 'An inclusive attitude for carers and families – where they are listened to and really heard and consulted more closely.'[9] As McMahon et al argue, 'Carers are partners in the provision of healthcare to those they care for. Supporting them is a sound investment in continuity of care and recovery'.[10]

> **How can my son get decent treatment if they don't hear what I have to say when he doesn't even think he has a mental illness?[11]**

Another submission to the *Not for Service* report raises similar issues:

> Carers are often best placed to notice subtle changes in the person for whom they care, and usually the first to notice the early warning signs of a relapse. However, health professionals usually do not recognise

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[8] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009 *Who Cares…? Report on the Inquiry into Better Support for Carers*, Parliament of the Commonwealth of Australia, Canberra, pp.ix, 191.

[9] MHCA 2005, op. cit., p.133.

[10] McMahon, J., Hardy, J. and Carson, R. 2007 *Identifying the Carer Project: Final Report and Recommendations*, Private Mental Health Consumer Carer Network (for the Commonwealth Department of Health and Ageing), Marden, p.12.

[11] Wherever possible in this report the individual stories of carers at the workshops are utilised and emphasised in bold text as in this particular example.

> the value of this information, and in fact when carers try to pass on this information it is often ignored. This can lead to additional problems for carers and a full blown episode for the consumer often with devastating consequences. Unfortunately it is the carers who usually bear the consequences of a relapse, not the health professionals.[12]

Research by the MHCA and the Carers Association of Australia (now known as Carers Australia) found that mental health carers consistently reported negative experiences after having engaged with mental health professionals. They felt that they are not considered partners in care and are excluded from the treatment process, and that the value of the role is not recognised.[13]

Carers attending the CEP workshops thought it essential that they be included in the treatment process, given that they would have primary responsibility for assisting the consumer once they left hospital or when they were not receiving formal support. They felt that they were expected to provide high-quality care even though requests for information that might help them to do so were considered unreasonable and were not met. This matter was also raised in the *Not for Service* report which states that:

> Some carers report a 'double whammy' wherein the mental health system expects them to assume and accept the responsibility of care but fails to involve them in the development of treatment plans or provide them with the information necessary to fulfil this role.[14]

Other research reinforces the view that it is essential to include carers in treatment discussions and decisions about consumer care. Highet et al, for example, write of the likely adverse outcomes of excluding carers from providing or receiving information, and argue that 'The legitimate roles of carers and families within our healthcare systems require formal recognition and promotion'. This is particularly true because when treatment teams have consulted with the carers, consumers, carers and service providers seem to have benefitted.[15]

Research from Queensland on carer-mental health service provider relationships found that fewer than 50 per cent of carers reported that mental health professionals 'always' or 'often' discuss treatment plans with carers; involve family members in discussions; provide the carer with information about new treatment approaches; or keep the carer informed. A major theme of the open-ended responses of carers was that of poor communication between professionals and carers. Authors of that report added that:

> Carers have a wealth of knowledge of the ill person's condition, which the professional person does not appear to want to share and if told tends to disregard it. Carers felt that this valuable information was wasted and were frustrated that it was not accepted.[16]

As one carer providing information for the *Not for Service* report asked:

> What is acceptable about a clinician making an assessment in a 15 minute appointment whilst ignoring the information of these same carers who are in the position of being far more sensitive to the signs of deterioration in the person for whom they care?[17]

Similarly, McAuliffe et al found that carers reported 'a general disregard and lack of appreciation of the needs and knowledge of carers in relation to the person they care for', and that:

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[12] MHCA 2005, op. cit., p.201.

[13] MHCA and Carers Association of Australia 2000 *Carers of People with Mental Illness Project: Final Report*, MHCA, Canberra.

[14] MHCA 2005, op. cit., p.158.

[15] Highet, N.J., McNair, B.G., Davenport, T.A. and Hickie, I.B. 2004 '"How much more can we lose?": carer and family perspectives on living with a person with depression', *Medical Journal of Australia* 187(7 Suppl.):S6-S9.

[16] Hodgson, O., King, R. and Leggatt, M. 2002 'Carers of mentally ill people in Queensland: Their perceived relationships with professional mental health service providers: Report on a survey', *Australian e-Journal for the Advancement of Mental Health* 1(3), www.auseinet.com/journal/vol1iss3/Hodgson.pdf, accessed 20 July 2009.

[17] MHCA 2005, op. cit., p.165.

> …carers also strongly identified the need to be listened to and included in the treatment process from this initial point of contact with the mental health service.…many felt excluded and alienated from the diagnostic and treatment process. [18]

This was particularly the case with regard to the discharge planning process, even in situations in which the consumer would be living with the carer after discharge. Carers considered that this demonstrated a lack of respect for them given the impact that discharge would have on their lives.[19]At the very least, carers wanted to be kept informed of diagnoses, changes in medication, discharge dates and other key aspects of consumers' treatment, in addition to signs and symptoms of the illness that they need to know about to care effectively. Most carers, however, would prefer a three-way partnership between consumer, carer and clinician, with the voices of all being heard and influencing treatment decisions.

One carer at the workshops had tried unsuccessfully for nine years to get clinicians treating her daughter to reduce her medication because it was causing unwanted side effects. This was made more difficult by the fact that her daughter had had 23 different doctors in a six-year period. After nine years the carer finally decided unilaterally to reduce her daughter's medication. The carer reports her daughter is now healthy as she is benefiting from the absence of side effects.

Carers reported they were particularly ignored at times of mental health crisis even when they have important knowledge about those they care for, especially relating to illness, which could have been useful in identifying the need for more professional involvement. Carers were often left feeling ignored or disbelieved. One, for example, reported that their:

> **…son became unwell earlier this year. The family recognised the signs of illness but the mental health service would not listen to us. It took four months of my son becoming sicker and sicker before they finally agreed he was unwell. By this time he was acutely unwell and admitted to the acute system. By that time the damage was done and it will take months for him to get back to the health he had five months ago.**

One of the more depressing incidents that this carer experienced during the period that she tried to access care for her son was when a mental health nurse told her that she had 'attachment issues' with her son.

Carers felt that they should be actively sought out and supported by professionals, and should not have to fight to be involved in the treatment process. They wanted to see the establishment of mechanisms for automatic feedback and information exchange between carers and treating clinicians. Strategies must be implemented which provide carers with essential information if the consumer has not provided consent for sharing detailed information; this theme is explored further in section 3.13.

Carers viewed GPs as gatekeepers to accessing assistance in the first instance of mental illness. They also considered GPs to be the first in a line of professionals unwilling or unable to work in partnership with both consumers and carers for better outcomes and wellbeing of consumers. Carers also reported not having access to those doctors providing treatment and that information they possessed about the state of health of consumers was not sought after.

A consistent theme in many of the workshops was that medical professionals refuse to disclose information to carers on the grounds that a consumer is an adult. This frustrates carers because of the essential role that they play and the episodic inability of some consumers to care for themselves.

The need for better recognition of carers is supported by ARAFEMI research, which found that:

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[18] McAuliffe, D., Andriske, L., Moller, E., O'Brien, M., Breslin, P. and Hickey, P. 2009 ''Who cares?' An exploratory study of carer needs in adult mental health', *Australian e-Journal for the Advancement of Mental Health* 8(1), www.auseinet.com/journal/vol8iss1/mcauliffe.pdf, accessed 20 July 2009.

[19] Ibid.

> Supportive professionals made a huge impact in carer ability to access the right type of care, have the necessary information to assist them to care, to proactively work with treatment providers to prevent relapse and cope with the ongoing caring role. They highlighted the impact of simply receiving recognition as a vital part of the treatment puzzle.[20]

3.1.2 Challenges for specific population groups

Some groups of carers face particular challenges in receiving adequate recognition and respect from mental health professionals for their role and their expertise. Young carers are disadvantaged by their age and the lack of understanding that they receive from many professionals and other people generally regarding the value of their role in caring for consumers. This theme is explored in more detail in section 4.4. Young carers have indicated that they want to see much greater recognition of the role that they play; and a family-focused approach by service providers, involving respect for young carers.[21]

CALD carers can also face additional barriers, particularly due to language difficulties. Interpreters may need to be employed to ensure that carers can comprehend the often complex information provided by clinicians and other service providers, and can ask for further information.

As one CALD workshop presenter commented:

> **I cannot stress enough the needs of carers with little or no English skills. They really are hanging by a thread. If the government was to spend money on interpreters this alone would improve their situation ten-fold.**

Rural and remote carers also faced barriers because of the great distances involved when accessing treatment for those they care for. Maintaining contact with a treating clinician is made even more difficult when large distances are involved and the carer has never met the clinician.

Carers attending one remote workshop said that acute care services for their area were more than 2,000 kilometres away. Doctors providing treatment maintained little or no contact with the carer, causing carers enormous anguish.

3.2.2 Societal respect for carers

Carers not only sought more respect and acknowledgment from clinicians, they also hoped that carers will receive much broader recognition through clear policies and consistent national legislation to firmly establish carer status and rights. They also called for the implementation of strategies to build broader awareness of the role and the rights of carers. They emphasised that their work and input should be included in official statistics and national data collections, with information collected more frequently on carers and caring. Some of these themes were also explored in Carers Australia's 'Carers Virtual 2020 Summit'. Respect and recognition for carers were major themes at that event.[22]

Carers also wanted to see recognition of the health and financial impacts of the caring role, and appropriate services and benefits. These two areas are explored further in sections 3.6, 3.10 and 3.11 below. Carers considered that better financial benefits and increased support and services, to assist them both in managing their caring role and with their own health, would demonstrate practical recognition of the burdens of the caring role and the needs of carers.

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[20] ARAFEMI 2007 *Research Report 1: ARAFEMI Carer Consultation*, ARAFEMI, Hawthorn.

[21] Carers Australia 2009 *Final Report: Bring It! Young Carers Forum 26-27 November 2008*, Carers Australia, Canberra; Moore, T. 2005 *Reading Between the Lines: Listening to Children and Young People about their Experiences of Young Caring*, Youth Coalition of the ACT, Canberra; Noble-Carr, D. 2002 *Young Carers Research Project: Final Report*, Carers Association of Australia (for Department of Family and Community Services), Canberra.

[22] Holland and Blood 2008, op. cit.

Carers are worthy of greater recognition because of the significant role they play in supporting people with a mental illness; and/or physical disability; and/or severe physical illness. The monetary value placed on informal care in Australia by Access Economics is staggering. The opportunity cost of time spent on informal care, measured in terms of reductions in paid employment due to caring commitments, is estimated to be at least $4.9 billion in 2005 dollars. That figure is equivalent to 0.6 per cent of forecast Gross Domestic Product (GDP) and 9.9 per cent of the value of formal health care in Australia. An alternative measure is the replacement valuation, which indicates the level of resources that would need to be diverted annually from the formal economy to replace the work completed by informal carers if they were unable to provide care. If all informal care was replaced with services provided in the home by formal care providers, the informal care replacement value would be $30.5 billion, or 3.5 per cent of forecast GDP and 62.2 per cent of other formal health care.[23]

Based solely on the economic value of caring, it is abundantly clear that carers make an enormous contribution to Australian society and provide substantial cost savings to the government. Even before the social and humanitarian value of their work is taken into account, their efforts are of such economic value to Australia that they must be given more respect and recognition, and much greater support.

3.2 Priority Issue 2 - Integrated Recovery-Based Care for the Consumer

Carers attending the CEP workshops strongly supported recovery-based care in the community for those they care for. They also considered that such care was currently supported insufficiently, and thus wanted to see improvements across a range of areas related to recovery. In this context, recovery does not necessarily refer to the absence of a mental illness or its symptoms, but rather to engagement with community and living as well as possible. There are various definitions of the concept of recovery, but one commonly cited was developed in 1993 by William Anthony, director of the Boston Centre for Psychiatric Rehabilitation and defines it as:

> a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.[24]

Several MHCA publications have called for stronger community recovery-based services.[25]

3.2.1 Adequate community support

Carers favoured the establishment of much stronger supports to enable those they care for to live in the community and rebuild connections with community members and activities. Although they considered this essential to recovery, carers at many of the workshops said that services were being *reduced* when a significant *expansion* was required. Carers wanted to see services that received sufficient funding to meet consumer needs in their catchment area; and were funded over the long-term rather than on a one-off basis.

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[23] Access Economics 2005 *The Economic Value of Informal Care*, Carers Australia, Canberra.

[24] Cited in Australian Health Ministers 2003 *National Mental Health Plan 2003-2008*, Australian Government, Canberra.

[25] See, for example, MHCA 2006a *Smart Services: Innovative Models of Mental Health Care in Australia and Overseas*, MHCA, Canberra; MHCA 2006b *Time for Service: Solving Australia's mental health crisis*, MHCA, Canberra.

Carers reported that recovery-based services were frequently difficult to find, and that ideally there should be a 'one-stop-shop' that would identify local services required by consumers and carers and connect or refer them to those. Mental health services should be able to provide referrals to other relevant services that support recovery, such as those in charge of housing and employment. Ideally services should be locally-based, with a strong understanding of the community and population which they are serving.

Carers suggested various support models that contributed to recovery. Consumer mentoring programs, including those conducted through the Personal Helpers and Mentors (PHaMs) program were considered valuable. The purpose of that particular Australian Government program is to help people with a mental illness overcome social isolation and establish and achieve goals to reconnect with their community with the assistance of a trained mentor.[26] The Clubhouse model was also seen as a very good example of support that can contribute to recovery. This model aims to provide '…a restorative environment for people who have had their lives drastically disrupted, and need the support of others who believe that recovery from mental illness is possible for all', and includes support in areas including social interaction, employment, housing, education and community engagement.[27]

> **Why can't services like PHaMs and Clubhouse be available to all consumers?**

3.2.2 Clinical practices to support recovery

Carers identified a number of clinical practices that they considered would support recovery. Better coordination of services was seen as important, with easy access to case notes and records, including information on treatment and medication, by all members of the treatment team. Consistency in staff and continuity of care were also viewed as essential. Carers considered that the use of a single permanent care coordinator or alternatively a single care plan – accepted by consumers, carers, and all agencies involved in treatment and support – might eliminate some issues.

Carers identified a simple, yet often overlooked objective that clinical staff should possess the right 'attitude', defined as empathetic, understanding and positive.

Many carers commented on the value of diagnosis in consumer recovery, noting the problems that arise from not having obtained one; having changing diagnoses; or having a late diagnosis. Changes in treatment staff were mentioned as contributing to difficulties in obtaining a diagnosis.

Assertive case management and outreach were also considered vitally important, with support services actively engaging with the consumer; assisting them to identify and achieve goals; and identify if a consumer is becoming unwell and requires more intensive care. These services should also prompt regular reviews of care plans and medication and ideally should be provided in the consumer's own home or local area.

> **What would help is regular phone calls from mental health staff to enquire how my son is doing and ask how the family is coping! So that we don't feel all alone.**

Carers also felt strongly that 'recovery' should be understood as a process and not a result where consumers are cut off from ongoing care and support. Carers wanted flexible service delivery that takes into account the recurring nature of mental illness. They wanted all cases to be considered 'open', and all consumers involved in a service at any point able to re-engage with the service and access care, even if they have not required assistance for some time.

Advance directives were seen as valuable to recovery-based care, as they allow consumers to make an agreement when they are well, which provides details on care they are likely to require if and when they become unwell. More importantly, they allow consumers to identify other aspects of their lives – such as

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[26] FaHCSIA 2009a 'Personal Helpers and Mentors Program', online at www.fahcsia.gov.au/sa/mentalhealth/progserv/PersonalHelpersMentorsProgram/Pages/default.aspx, accessed 20 July 2009.

[27] International Center for Clubhouse Development 2007 'What is a Clubhouse?', online at www.iccd.org/article.asp?articleID=3, accessed 20 July 2009.

employment or education, housing and finances – that might need to be considered when they are receiving treatment.

3.2.3 Involvement of and support for carers

The involvement of carers in ongoing treatment and care planning was also considered essential to recovery. Carers wanted to be involved in all parts of treatment and ongoing planning, including transitions between services and changes in medication. They maintained that they have a right to be part of the care team and to have a say in the decision-making process.

Two carers at the workshops were very critical of the process when their son was taken off a community treatment order. The carers were not consulted, and their son received a letter saying that he was 'under no legal obligation' to continue taking his medication. His mother's comment was that**:**

> **The letter might as well have said 'Have a happy psychosis'.**

Carers also wanted to see a case management model for carers and families, so that their support requirements were also considered. This was particularly important for young carers. Some carers also said that they wanted free mediation services to be implemented to assist in the management of conflict between consumer, carer and other family members.

3.2.4 Holistic view of treatment and recovery

Many carers favoured an approach to treatment that goes beyond the provision of medication.

> **We need better services that help Mum recover, not just give her medication.**

In addition to mental health treatment and psychosocial rehabilitation services, carers wanted those they care for to have access to a range of integrated health services to help them to achieve recovery, including occupational therapists, counsellors, social workers and general practitioners. They also wanted to see all mental health services incorporated or integrated with drug and alcohol services, so that matters involving dual diagnosis could be addressed adequately. Some carers argued that a choice of services was very important in the recovery of consumers.

Carers also wanted those they care for to have access to advice on diet, exercise, education, hygiene, general health and education as well as on the consequences of stopping medication use. They also saw the provision of assistance in building independent living and social interaction skills as important for some consumers.

Carers maintained that recovery should lead to a reduction in symptoms of mental illness, and also re-engagement with community. Thus, they also felt that a holistic approach to recovery must involve social interaction, employment, and living skills. Support services should include supported work and study opportunities as well as vocational training for consumers.

> **My son wants to work and has amazing skills, but is unable to work normal hours like someone without an illness. He needs a supported employment program or someone to talk to the employer. To help people achieve better mental health they need help to get work and keep it!**

Where children are involved, carers wanted to see liaison between child support services and mental health services, to ensure that children's needs are considered if consumers become unwell. Conversely, parents of young people with mental illness wanted their own role caring role to be recognised as central, and not seen as peripheral in these young people's lives.

3.2.5 A mental health system – what system?

Carers were concerned about the lack of continuity and coordination of mental health service provision in Australia, and the impact that this lack of continuity had on recovery-based care and on all other aspects of the mental health 'system'. Although the paucity of a national Mental Health Act was seen as fundamental to this problem, each state and territory has its own Mental Health Act, which can cover different things in each jurisdiction.

Each state's mental health services are independent with services and providers named and funded differently. Services provided in one state are not known about in others. While the reason for this is mainly historical, it is also highly inefficient, wasting both carer time and money, while arguably influencing the quality and quantity of services that can be offered.

Carers called for consistency and clarity in service provision nationally to benefit both themselves and those they care for. Mental health consumers often relocate to another state where carers are unfamiliar with the provisions of the Act or how it applies to them. Carers attending the CEP workshops thought it illogical that different state Acts exist when mental illness was the same throughout Australia, and called for the establishment of a national Mental Health Act which would flow through to national policies and procedures that might, in turn, rationalise at least one part of the confused and confusing existing system.

Mental illness and drug and alcohol problems often go hand in hand, yet they are defined by separate strategies and services which have not worked well together in Australia since the outset.

> **We were told he had drug problems so we went to the drug service but they said he had a mental illness. In the end he didn't get any help.**

New Zealand takes a different approach to these illnesses. It launched a national strategy, *Te Kōkiri: The Mental Health and Addiction Action Plan 2006-2015*, which deals with both illnesses.[28]

This noted disharmony and lack of coordination of services between Australian states/territories was reflected to some extent in local service provision. Carers attending the CEP workshops discussed programs that did essentially the same thing yet had many different names. This has caused considerable confusion and replication of services. Nevertheless, some regions where workshops were held did have well integrated service providers who knew each other; referred to each other's services; and aimed to provide the area with a coordinated and clear service response to mental illness. At one particular workshop service providers said that the clear and effective referral system between NGOs and Mental Health Services produced the best possible consumer services. Each service knew the guidelines and shortfalls of the other services and worked with what was available to provide a clear service provision path for the consumer.

Examples such as this, however, were rarely discussed at the workshops. It was sad to see local service providers attending some workshops introducing themselves to each other for the first time. A constructive and ongoing working relationship between NGOs and mental health services would provide the continuity of ongoing recovery-based care that carers so desired. At other workshops there was disharmony between service providers and it was reported that information was not forwarded to the carers by some service providers because they had 'ownership' of individual carers and were unwilling to pass on information about other services. This behaviour is to the detriment of all service providers, consumers and carers.

3.2.6 Needs of specific population groups

CALD consumers viewed access to bilingual support services or translators as essential to their recovery. Carers also required access to appropriate services to enable them to support the recovery of those they care for. CALD carers and consumers face significant issues in accessing a range of treatment and support services owing to linguistic and cultural issues.

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[28] Minister of Health 2006 *Te Kōkiri: The Mental Health and Addiction Action Plan 2006-2015,* Ministry of Health, Wellington.

Similar issues are faced by Indigenous carers and consumers. Services for Indigenous carers and consumers need to be based on a thorough and respectful understanding of Indigenous culture, involving concepts such as community grief and intergenerational trauma. One way to do this is to listen in a respectful manner to solutions that carers and consumers see as fundamental to wellbeing rather than imposing ill-considered projects and capital expenditure originating outside the community.

Recovery-based care was a key concept outlined by carers at the workshops. Improving recovery services for consumers would reduce the burden on carers, allowing them to view the future more positively and improve their own quality of life, as well as that of their families and the people they care for.

3.3 Priority Issue 3 - More and Better Trained Staff at all Levels

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

3.3.1 More workers are required

Carers identified a range of professions and services which they considered to have particularly inadequate staffing levels. They wanted to see more trained staff at all levels from care workers to psychiatrists, including GPs, psychologists, crisis staff, counsellors, community workers and case managers. Many reported long waiting periods before consumers could access these service providers, particularly in rural and remote areas where specialists such as psychiatrists might visit only occasionally. Carers argued that insufficient staff levels had resulted in an increased burden for the carer. Low staff numbers severely restricted consumer choices if they did not have a good relationship with a clinician or mental health worker or if a consumer or carer were unhappy with the quality of the service provided. An issue raised in one state capital was the difficulty of finding a psychiatrist who was willing to treat particular consumers. Carers reported that psychiatrists often have very restrictive criteria such as an unwillingness to treat males or young people, and that even when a suitable psychiatrist is found, waiting periods for appointments are very long.

Carers and service providers attending the workshops indicated that staffing was also a problem in the community sector. There were not enough staff with the right qualifications or experience to fill or maintain the positions available and low salaries in the community sector combined with high demand for service was identified as a cause of staff turnover.

High staff turnover was a significant concern for carers. Carers reported that because of this they had had to repeat their stories several times, and that they were often provided with different information or advice by different professionals. They said that they wanted to hear consistent messages about the health and wellbeing of the person they care for.

> **We have had 23 doctors in 6 years; we haven't changed, they have. We have to repeat the same story again and again – doesn't this cause PTSD? They write it all down and come up with different diagnoses. I've written it all down but they don't want to read it.**

These issues were also raised in the MHCA *Not for Service* report, which highlights the problem of poor access to mental health professionals and the resulting burden on families and carers. As one submission noted:

> In general the mental health services are inadequate and stretched, and this often results in ineffective treatment. Ineffective treatment can mean that consumers' wellness is often not maintained to a satisfactory level, and this in turn creates an increased load for carers.[29]

It is not just carers who report that access to mental health professionals is inadequate. The latest ABS statistics on mental health and wellbeing in Australia shows that almost two thirds of people who experienced a mental health problem over the past 12 months did not receive either treatment or support for their illness, and that there is a significant unmet need in mental health services. During the 12 months prior to the collection of this data, 2.1 million adult Australians with a mental health disorder did not receive services for their mental health problems and recognised that they had an unmet need.[30]

There is also significant disparity in access to mental health services depending on where one lives in Australia. MHCA analysis of data on the new mental health Medicare item numbers through the Better Access to Mental Health Care program found that access to psychologists and clinical psychologists in rural and regional areas was far lower than in urban areas. Young people and men are also under-represented in the use of these services.[31]

A 2008 roundtable discussion paper prepared by the Australian Healthcare and Hospitals Association, The Mental Health Services Conference and Pricewaterhouse Coopers identified various problems with the current model of mental health service provision in Australia that limit access to these services for many people. While a huge funding increase is required so that mental health services can adequately meet the needs of all Australians experiencing mental health problems, another key issue is that no single agency sets national standards and monitors the state of mental health services in Australia. This essentially means that there is no common national standard for mental health care. Other issues identified in the paper include:

- the lack of investment in community care;
- current funding methodologies, such as 'fee-for-service' systems, do not encourage collaboration, continuity, integrity and quality;
- mental health spending is out of synch with health requirements of the population-at-large, and varies between locations and states/territories;

  funding methods do not support workforce reform;
- the ability of consumers and carers to exercise choice in services is limited; and
- the separation of Commonwealth and state/territory mental health responsibilities is problematic.32

All of these factors contribute to inadequate levels of high-quality staff.

3.3.2 High-quality workers are required

Apart from wanting to see more staff, carers emphasised the need for those of high-quality, possessing specific characteristics such as:

- compassion and open-mindedness;

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[29] MHCA 2005, op. cit., p.413.

[30] ABS 2008a, op. cit.

[31] Crosbie, D. and Rosenberg, S. 2008 *COAG Mental Health Reform – Mental Health and the New Medicare Services – 2nd Report November 2006-August 2008*, MHCA, Canberra.

[32] Australian Healthcare and Hospitals Association, The Mental Health Services Conference and Pricewaterhouse Coopers 2008 *Mental Health Funding Methodologies: Roundtable Discussion Paper*, Australian Healthcare and Hospitals Association, Canberra.

- good communication skills, which include an excellent grasp of the English language and cultural subtleties;
- excellent knowledge of mental health services, including services available to carers;
- good awareness of mental health issues by those, such as GPs and nurses, not specifically employed as mental health workers;
- a willingness to take the time to explain things, such as medical terms and acronyms, to carers and consumers;
- an understanding of the concept and practice of recovery-based care;
- a willingness to engage and work with the carer; and
- a willingness to collaborate and share information with other services and professionals so carers do not have to repeat their story.

Carers emphasised that staff must be able to work within policy, procedures and guidelines in a humane and empathetic manner, as these are essential in providing good service, although such qualities are often underrated.

Carers in one remote town reported that medical professionals there possess only a basic knowledge of mental health and know even less about lower-prevalence disorders.

Some CALD carers indicated their preference for more bilingual health workers. Where this is impossible, staff working with CALD carers and consumers must work effectively with translators to ensure strong communication and understanding. CALD carers also wanted to see an improved Translating and Interpreting Service (TIS), with translators demonstrating better awareness of mental health and respect for different cultures within a particular language group (see section 4.2).

Indigenous carers are often reluctant to use services due to a lack of cultural understanding of the way these are provided. Staff working with Indigenous communities must demonstrate strong cultural awareness, and possess a good understanding of issues such as intergenerational trauma, community grief, as well as the concept and prevalence of shame.

Carers also wanted to see nationally accredited training for mental health workers, from entry-level care worker positions to senior level positions. Carers noted a lack of care workers who were knowledgeable about or able to care for those with a mental illness, particularly in the area of respite. This shortage highlights a problem within the sector: although mental health clinicians have clear qualifications and career paths, pathways in the community mental health sector are not nearly so clear.

No specific qualification or different levels of qualifications exist for this work and no clear career structure applies to workers in the community mental health sector, hence low paid workers are often employed over the short-term. Mental health is a growing industry and a series of qualifications for respite support workers through to senior management level are required to train and retain high-quality staff. Education pertaining to mental health consumers and carers should be given serious weight. The Certificate IV in mental health (non-clinical) provided by TAFE is a starting point in the development of a relevant qualification. However, shorter courses are also required, progressing to distinct community mental health qualifications at postgraduate level.

Carers wanted to see staff workers outside of the mental health services, especially those with the police and housing services as well as Centrelink, possess sufficient training to provide them with an excellent understanding of mental illness. Carers also identified the potential value of pharmacists as a source of mental health information and advice, and said they favoured the establishment of a national system that supported pharmacists in explaining to carers and consumers the use and effects of mental illness medication.

3.3.3 Strategies to attract and retain workers

Carers saw subsidised training and retraining for mental health staff as a means to attract quality staff to the mental health workforce and to encourage them to upgrade their skills and to remain in the sector. Carers added that ongoing capacity building for staff and organisations would reduce staff burnout.

In rural and remote areas in particular, carers were very vocal about the need for effective strategies to attract and retain high-quality mental health professionals and workers. They wanted to see permanent staff based locally, rather than professionals flying in and out as infrequently as once a month. Carers suggested the use of more appealing financial or professional incentives, to attract mental health clinicians to rural and remote areas.

In one remote town, carers reported that their visiting psychiatrist is supposed to be receiving patients there once a month, but sometimes it is less than that and thus it is very difficult to get an appointment.

This lack of health and community care services in rural and remote areas was also recognised in the *Who Cares…? Report on the Inquiry into Better Support for Carers*, which recommended that these shortages should be addressed.[33]

In addition, carers also proposed strategies for staff accountability and assessment for ensuring that mental health professionals and workers met identified standards. They called for formal complaints procedures, which were easily accessible and understandable, and for outcomes to be published and released for public consumption. They also wanted to see external and nationally consistent monitoring of key competencies. Some carers argued that funding for a particular organisation should be cut if its staff did not meet agreed standards.

High-quality and compassionate staff have a considerable impact on the experience of mental health treatment and support for both consumer and carer. Workshop attendees articulated clearly the need for improvements in the quality and quantity of staff.

3.4 Priority Issue 4 – Knowledge and Information for Carers

A theme raised by carers at almost every workshop was the difficulty that they experienced in accessing information and acquiring knowledge required to successfully fulfil their caring role. This included information about ‘how to’ care as well as information on what services are available for carers and those they care for. This issue was also one of the broad themes identified in evidence to the House of Representatives Inquiry into Better Support for Carers, and in the Carers Virtual 2020 Summit organised by Carers Australia.[34]

3.4.1 Knowledge and information about caring

Carers indicated that they wanted access to much more information on ‘how to’ care for a person with a mental illness. This was particularly important for new carers, who often find themselves unexpectedly in a caring role and feel ill-prepared for it. Carers argued that information on ‘how to’ care should include facts on a broad range of areas relating to mental illness and caring, such as:

- detailed information on specific illnesses – including treatment, what the diagnosis means, and the likelihood of recovery;

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[33] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit.

[34] Holland and Blood 2008, op. cit.; House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit.

- medications – including side effects and effects of withdrawal, as well as advice on how to manage non-compliance by the person they care for;
- comorbid drug and alcohol use – including likely effects, possible interactions with medications and how to discourage substance use;
- coping skills and strategies for carers – including the importance of looking after oneself and how to cope with the practical and emotional challenges of caring;
- assertiveness and communication skills – including advice on how to interact with clinicians and service providers;
- rights and responsibilities of carers;
- how the mental health system 'works' – including at a national, state/territory and local level; and
- where to go for help – including where to access help for the carer and for the consumer.[35]

Carers also said that they wanted to be kept informed of the latest research about mental illness and its treatment, as well as research about carers and caring.

At one regional workshop, a carer with many years experience asked the facilitator:

> **Can you tell me what schizophrenia is? My daughter has been diagnosed for several years, but no-one has ever explained the diagnosis to me. When people ask what is wrong with my daughter I tell them it is depression, because I understand what that is.**

3.4.2 Knowledge and information about services and supports

Carers spoke almost universally of the difficulties of finding out what services were available to them and how they could access them. Carers reported difficulties in finding out about a range of services and supports, including:

- Centrelink carer benefits;
- carer support services and groups;
- planned and emergency respite;
- consumer services;
- legal advice for such matters as what to do if a consumer became involved with the criminal justice system while unwell, or if the carer wanted more information about advance directives or powers of attorney; and
- financial advice and assistance.

Many carers reported that for extended periods after they started caring they were unaware of these services and benefits, or their eligibility for them. In fact, some carers heard about services for the first time when they attended the CEP workshops.

At one workshop, two carers of their adult son praised the services that were now available, but said:

> **We needed to know about these 10 years ago when our son was first diagnosed.**

At one remote workshop, carers indicated that they were unaware of their entitlements and had not been provided with such information as what they should do when a consumer is on a Community Treatment Order (CTO) and the carer is expected to transport them to the service provider. Although in such an instance carers are entitled to a refund on petrol costs, none of the carers attending the workshop knew this.

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[35] McAuliffe et al 2009, op. cit.

Carers said that the complexities of service delivery for both consumers and carers arising from multiple tiers of national, state/territory and local funding and service provision created a maze that often seemed impossible to navigate. As one carer providing evidence to the Inquiry into Better Support for Carers wrote:

> …within my home file I have information on the following agencies – Commonwealth Carers Respite Centres; Commonwealth Carelink Centres; Carers SA; Carer Support and Respite Centre Inc; Commonwealth Carer Resource Centre; HACC; local government; plus a number of NGOs offering respite. Where do I start?[36]

The report on the Inquiry found that:

> …carers may have to identify community care services for themselves or their care receiver from different government departments and agencies, across different levels of government and delivered through a range of community or private sector organisations. These fragmented and complex service systems have resulted in a 'service maze', which is a source of frustration to carers.'[37]

3.4.3 How to disseminate knowledge and information to carers

Carers had firm views about how information should be provided to them. They were adamant that information should be provided from the consumer's first episode or contact with the mental health system. Carers wanted to see this readily available as part of contact with the mental health system, including having information provided in hospitals and by treating clinicians, including GPs.[38] As one carer providing evidence to the *Not for Service* report notes:

> When the first diagnosis comes, we'd like to see families/carers given information about the illness they're suddenly dealing with, and all the resources available to help them and the person they care for. When we were suddenly given the diagnosis "chronic paranoid schizophrenia", which was such a surprise, we were left with the diagnosis as if it was the flu.[39]

Research by the MHCA and the Carers Association of Australia indicates that mental health carers had great difficulty in accessing mental health education and information both at the onset of the mental illness of those they care for, and during ongoing treatment and care processes.[40]

Carers attending the workshops argued that carers should be provided automatically with information, and should not have to go searching for it themselves. One concern frequently reported by carers was that they did not know what questions to ask clinicians providing treatment.[41]

Attendees at one workshop said that they had found out about carer resources and services entirely through good luck. They added, however, that when those they care for are in crisis, carers may be too distressed to process all the information presented to them at the first point of contact with the mental health services and written information and follow-up discussions would allow them to absorb it at their own pace, a position supported by other research.[42]

Carers wanted to see information provided in a range of media sources. There is a considerable amount provided online, but it is of little use to those without access to the Internet. Of significance to future planning

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[36] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit., p.81.

[37] Ibid., p.157.

[38] ARAFEMI 2007, op. cit.; Nankervis, J., Waxman, P, O'Hara, D. and Burbidge, M. 2002 'Caring for family carers in general practice', *Medical Journal of Australia* 177:405-407.

[39] MHCA 2005, op. cit. p.359.

[40] MHCA and Carers Association of Australia 2000, op. cit.

[41] Reid, J., Lloyd, C. and de Groot, L. 2005 'The psychoeducation needs of parents who have an adult son or daughter with a mental illness', *Australian e-Journal for the Advancement of Mental Health* 4(2), www.auseinet.com/journal/vol4iss2/reid.pdf, accessed 20 July 2009.

[42] McAuliffe et al 2009, op. cit.; Reid et al. 2005, op. cit.

is that 50 per cent of workshop attendees lacked access to a computer or the Internet. Carers wanted alternatives to be available through printed material, telephone information services as well as television and radio advertising. One suggestion was to provide both consumers and carers with a list of local services printed annually.

CALD carers maintained that information should be available in several languages to provide greater accessibility to members of their community. Language barriers, including the lack of accessible translated information, have been described elsewhere as 'one of the key impediments to accessing support'.[43] CALD carers faced various language and cultural barriers to accessing services.[44] As one CALD workshop facilitator noted in relation to service knowledge and access:

> **At the moment the majority of the group has nothing and knows nothing.**

The problems experienced by CALD carers are also noted in the report of the Inquiry into Better Support for Carers:

> The fact that many carers, particularly CALD carers, knocked at the wrong doors, did not know or use the 'right' language, and/or disclosed needs to the wrong person resulted in frustration and led to many participants taking on an excessive burden of care.[45]

Difficulty accessing information about services was also a common theme for Indigenous carers at the workshops.[46]

Young carers also reported problems finding information. They felt that if it were disseminated at school, particularly through school counsellors, it would be an effective mechanism, in addition to treating clinicians engaging with young carers when those they care for come into contact with the mental health service. As one young carer attending Carers Australia's 'Bring It' forum commented:

> It is navigating through the maze. It would be a lot easier if people who were giving services to my Mum would say, who's looking after you? Is there anyone at home looking after you?…Centrelink, Centacare, Carelink. If I was 10 years old looking for services I would be wondering what do these words mean? What services do they provide? It's a really tough thing to find out.[47]

Information for young carers should be culturally and age appropriate, but simultaneously reflect the level of responsibility taken on by many young carers in an effort to keep their family together.

In relation to telephone services, carers emphasised that their preference was for a local phone number, rather than a national, centralised number. They wanted to draw on the knowledge of someone taking their call who was from the local area rather than hundreds of kilometres away and answering their questions based on services listed for their postcode or region in a computerised database. Carers also complained that some telephone services provided an answering machine and asked carers to leave a number on which they could be contacted. This is often not a convenient option for carers, who might not want other family members to know that they have called for assistance, or who might simply be unavailable to answer the phone later on.

Carers wanted to see the establishment of a 'one-stop-shop' for service information that is easily accessible, such as over the phone or in a shopfront. Information provided should cover services delivered and funded at the national, state/territory and local level, with a focus on carer requirements rather than particular funding

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[43] St George Migrant Resource Centre 2002 "Nobody cared about me before…." *Report: Consultation for "Carers" of Culturally and Linguistically Diverse Backgrounds*, St George Migrant Resource Centre, Bexley.

[44] Ibid.; and Cardona, B., Chalmers, S. and Neilson, B. 2006 *Diverse Strategies for Diverse Carers: The Cultural Context of Family Carers in NSW*, NSW Department of Ageing, Disability and Home Care, Sydney.

[45] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit., p.159.

[46] Hepburn, R. 2005 *Be with us, Feel with us, Act with us: Counselling and support for Indigenous carers*, Carers Victoria, Footscray.

[47] Carers Australia 2009, op. cit., p.v.

arrangements of services. In the absence of such a system, carers in a number of locations reported that a person in their local area was recognised as a fountain of knowledge about the available services. Although carers spoke favourably about being able to call someone they knew for information and advice, they said they would prefer to see formalised arrangements for information to be delivered by a key person locally.

As is noted in the report of the Inquiry into Better Support for Carers:

> The evidence suggests that carers expend energy, time and resources which they often do not have, exploring various options to find information and services that they require for themselves or for the care receiver. Carers report that they feel that the onus is on them to ask the right questions to the right agency to elicit relevant information.[48]

Carers also made it clear that they believed that information and training should be available at low or no cost. They wanted to see distinct funding allocated for carer training, and free courses on 'how to' care. Few carers attending the workshops reported having had access to such training, and the Inquiry into Better Support for Carers found that existing formal training for carers is largely ad hoc and is limited in scope and duration.[49] Other research, however, estimates that the provision of education and training to carers is a cost-effective way of reducing psychotic symptoms, episodes and relapses for people with mental illness, as well as reducing stress and poor health outcomes for carers.[50] Other benefits include increased coping skills, adaptive capacities and satisfaction with the caring role.[51]

There are groups of mental health carers, who are 'hidden carers', who are little known to service providers and would find it hard to come to workshops. Group members may be unaware they themselves are mental health carers and of the services and programs to help them or find it too difficult to be identified as mental health carers. Carers of someone with forensic issues or comorbidity of mental illness and drug and alcohol use often find it too difficult to disclose the circumstances of their lives. Same sex partner carers may also avoid accessing services for fear of rebuff. The life circumstances of young mental health carers, and the fact that they are not identified by any existing process, can also result in them being placed into the 'hidden carers' category as well. They may be within families at risk known to government departments (e.g. DOCS) or they may be struggling alone. In short, there are substantial numbers of hidden mental health carers, but they are hard to access, leaving them with few services and little support. Effective strategies to access these groups are required.

3.5 Priority Issue 5 - Carer and Consumer Education for all Professional Groups and Agencies

Carers attending the CEP workshops recommended consumer and carer education for a broad range of clinicians and professional groups to address their lack of understanding of mental illness and the role of carers. Carer enthusiasm for education about, and led by, mental health consumers and carers is supported by other research. For example, following a survey of Queensland mental health carers on their relationships with health professionals, Hodgson et al called for more active involvement of consumers and carers in the training of professionals; the inclusion of carers and consumers in performance appraisal, as well as in staff selection and promotion processes; and targeted brief training interventions

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[48] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit., p.75.

[49] Ibid.

[50] Cited in Cameron, P. and Flanagan, J. 2004 *Thin ice: Living with serious mental illness and poverty in Tasmania*, Anglicare Tasmania, Hobart.

[51] Reid et al, op. cit.

for mental health professionals addressing their communication with carers.[52] As explored below, however, carers who attended workshops were in favour of a number of professional groups receiving information about carers.

Stigma and discrimination associated with mental illness and caring are explored in section 3.8 while the lack of understanding of the caring role is addressed in section 3.1.

3.5.1 Professional groups require education

Carers identified various professional groups that they believed required a better understanding of mental illness, consumers and the caring role. These included:

- General Practitioners and other clinicians:

  Carers felt that GPs and other clinical service providers were often unwilling to include carers in the treatment process. Some carers also reported that GPs lacked an understanding of mental illness; the role of carers; and carer relationships with consumers.

  Carers emphasised the need for intensive engagement between consumers and mental health professionals on a respectful and individual basis.

- Nurses, especially in emergency department triage:

  Carers wanted to see carer expertise recognised by nurses, particularly in crisis situations. Some carers also indicated that various nurses, especially emergency department triage nurses, demonstrate a lack of understanding of mental illness and compassion. One carer reported that an emergency department nurse had told the person they care for:

  You haven't got a mental illness, you just need an audience.

- Social workers and other non-clinical service providers:

  Carers said that some people in these positions have a poor understanding of mental illness. As for clinical professionals, there is also often a reluctance to include carers in discussions about care.

- Centrelink staff:

  Carers reported that Centrelink staff lacked understanding of mental illness and the role of carers.[53] For them access to Centrelink was seen as a traumatic experience, particularly when an office visit was required.

- Housing officials:

  Given the importance of safe, secure and appropriate housing to mental health and wellbeing, carers felt that those processing applications for priority housing and those who handle complaints about housing that is unsuitable for those with mental illness should have a much better understanding of such illness.

- Interpreters:

  CALD carers reported stigma and discrimination from interpreters, and recommended that interpreters working with those with a mental illness and their carers have a much better understanding of such illness.

- Police:

  As the police are often the only service that carers can call on in a crisis, carers were especially eager that police understand mental illness and have a several strategies to manage a crisis situation without exacerbating it. Police training pertaining to mental illness varies from state to state and the level of their knowledge is illustrated by the contrasting examples below.

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[52] Hodgson et al 2002, op. cit.

[53] Training of all Centrelink staff in carer awareness began in June 2009.

One police officer who attended a workshop was, in the words of the workshop presenter: ‘completely unaware of his ignorance in mental health, yet confident enough to believe he had the answers with a tazer in his hand. All this and he was a nice bloke! He came over as more than willing to protect the carers and to do the right thing, but did not understand carers wanted him to use negotiating skills rather than making the priority the protection of them or their property’.

In another state a police inspector attended a workshop on his day off because he felt that the concerns of mental health carers were so important. His officers were trained in mental illness and he had monthly meetings with the ambulance and mental health services to review issues of concern and procedural changes if required.

- For magistrates, lawyers and barristers:

  As many people with a mental illness can come into contact with the criminal justice system, carers wanted to see those who they might deal with in that context possess a better understanding of mental illness.

- Prison officers:

  A high proportion of people in the prison system have a mental illness and carers felt prison officers should be very knowledgeable about mental illness to cope effectively with situations that will arise at work.

- School principals, teachers and counsellors:

  Some young carers reported that teachers bullied them because of their caring role and/or their mental illness. Carers of young people with mental illness also reported that they had difficulties within the school setting and wanted to receive more support and understanding from teachers, particularly from principals who are key in shaping school culture.

- Supervisors in the workplace generally:

  As the workplace is very often a setting for stigma and discrimination, Carers wanted there to be a much better understanding and acceptance of mental health issues and of caring responsibilities within that setting with supervisors leading the way. Issues of carer access to suitable employment owing to a lack of employer understanding and flexible workplace practices are explored in section 3.15.

3.5.2 Education by carers and consumers

Carers were adamant that the emphasis of such education should be on understanding mental illness through the perspectives of consumers and carers lives. They were eager that service providers understand how certain service practices make life more difficult for consumers and carers, and to promote alternatives that will improve outcomes for all stakeholders. Lack of understanding of carer and consumer issues and their attempts to access treatment and navigate the mental health system is severely lacking in education for professional groups and agencies.

Carers maintained that training be based partly on the provision of an understanding of the integral and complex nature of the consumer-carer relationship. A generally accepted carer definition is when the consumer is well the carer steps back and both the consumer and carer lead active independent lives; when the consumer is unwell the carer steps in with understanding, compassion and support, while assisting the consumer to access necessary services.

The goal of such education should be to increase understanding of the consumer-carer relationship, mental illness and reduce stigma. For this reason, carers wanted such training to cover several key areas, including:

- an understanding of the complex and integral nature of the consumer-carer relationship;
- the importance of family and friends to the ongoing wellbeing of consumers;

- the need for professionals to engage actively in an ongoing if intermittent relationship with consumers and carers;
- the appropriate treatment of acutely ill consumers – ‘they are not criminals and should not be treated as such’;
- the cyclical and episodic nature of mental illness;
- the effects and side effects of medication;
- the need for integrated care when mental illness as well as drug and alcohol issues are present;
- the effects on the consumer and the carer of having no diagnosis or a delayed diagnosis;
- why stigma is so damaging to consumers and carers; and
- ‘myth-busting’ of common beliefs about mental illness.

Such education should also focus on providing a better understanding of the caring role. Carers envisioned professionals and service providers leaving such training with a greater understanding of why it is so important to engage with consumers if the latter are to be treated successfully and recover.

There should be additional aspects to the training for specific population groups. For example, training about and by young carers should address their specific requirements and the challenges that they face. Like attendees at MHCA workshops, young carers at the 2008 ‘Bring It’ forum indicated that it was important to include young carers in the development of such training.[54] Instruction about and by CALD and Indigenous carers would include information about the importance of culturally appropriate services.

Carers also indicated that relevant training by consumers and carers should be based on national guidelines. While the delivery of the educational activities would vary depending on the experiences of consumers and carers involved, carers considered it important that key messages were consistent on a national level.

Carers, as well as those they care for, face a myriad of mental health and other professionals’ lack of understanding of the experience of caring as well as the difficulty of negotiating the mental health system. Education for professional groups and agencies, delivered by carers and consumers, may go some way to increasing professionals’ awareness of these experiences.

3.6 Priority Issue 6 - Support Systems, Services and Processes Established for Carers

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

3.6.1 Types of support and service provision required by carers

Carers identified a number of areas in which they wanted to see new or improved services that would support them in their caring role. Earlier research conducted by the MHCA in conjunction with the Carers Association of Australia found similarly that there is a substantial gap between carer support requirements and available relevant services and supports.[55]

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[54] Carers Australia 2009, op. cit.

[55] MHCA and Carers Association of Australia 2000, op. cit.

Assistance to navigate the service system

As noted in section 3.4, carers found it extremely difficult to identifying suitable services and navigate the service system. They wanted to see better services that assist carers to navigate the service system and find essential information. Carers felt that these should be locally-based, rather than national and able to access national, state/territory and local information on all levels of service provision simultaneously from a single service point.

Carers also suggested that a mentoring or case management approach would assist them in navigating the service system. They would then have a single source of information and advice that would provide the necessary support required to help them through crises as well as transition points such as the commencement of care or changes in caring arrangements. This option was also suggested by a carer of two daughters with mental illness who provided evidence to the Inquiry into Better Support for Carers:

> As soon as a family member is thought to have a mental illness, the prospective carer should be able to discuss the situation with a Social Worker (free of charge) to help the carer start off on the path to accessing help – medical, counselling, financial. If a caseworker were assigned from the start, the carer would be more competent and over time require less help from government. It would prevent subsequent problems, and facilitate people rejoining society.[56]

Respite

Respite, including home assistance, was a significant area in which carers wanted to see improved services. For them, respite included time away from the caring role, but could also involve assistance with household tasks. This was particularly important for young carers. Respite requirements of carers, including those areas that workshop attendees identified as needing improvement, are discussed in more detail in section 3.12.

Centrelink

Carers at the workshops wanted to see a number of improvements in Centrelink services and access to benefits. Difficulties faced by carers of those with a mental illness in qualifying for Carer Payment and Carer Allowance are discussed in section 3.10. Carers identified several service issues at Centrelink, including that staff there seemed ill-informed and provided incorrect information about their entitlements and options. Another common concern was the difficulty they faced in obtaining information, sometimes experiencing long queues at Centrelink branches and delays when telephoning. Carers also had difficulty filling out forms and understanding requirements for Carer Payment and Carer Allowance. They wanted Centrelink staff to have a greater awareness of carer benefits and other relevant information and called for easier access to information and assistance, from Centrelink Social Workers or Carer Liaison Officers for example, in filling out forms.

At one workshop, a Centrelink Carer Liaison Officer provided information on carer benefits, but also announced that his position had become redundant and he would be working in another area beginning the following week. When the group became quite upset about this and asked who else at Centrelink they could speak with, the response was ‘No-one, no-one is taking over this role’. In short, carers had gone from having a nominated contact with personal rapport to being left without any clear information source at their local Centrelink office.

One carer in her mid-70s who had been caring for her seriously ill daughter for many years reported that a Centrelink worker, when rejecting her claim for Carer Allowance, said to her:

> **Well, isn’t that what mothers are for?**

Similar problems with Centrelink were also raised in the Report of the Inquiry into Better Support for Carers. It also revealed the provision of inconsistent or incorrect advice; the existence of poorly trained staff; and long queues. The Carers Support Network of South Australia submission noted that:

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[56] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit., p.96.

> The Centrelink system is a nightmare for many carers. Most resent the condescending and suspicious attitude they receive from Centrelink staff. The entire system of allowances, reviews and eligibility requirements is often referred to by carers as 'insulting'…. Many report that many Centrelink staff do not know how their own system works and carers are then financially disadvantaged because they have not received the correct information.[57]

Carer support groups

Essential support mechanisms for many carers are carer support groups and networks. When carers were asked at one workshop session to identify the strategies and tools that helped them to cope with their caring role, many mentioned carer support groups and talking to other carers. They stressed the importance of sharing their experiences and frustrations with others who understood their situation, and drawing on the knowledge and advice of others with similar issues.[58] Carers attending the CEP workshops, particularly those in rural and remote areas who already had access to support groups of this kind, were adamant that these should continue to be funded and supported.

A workshop facilitator noted that attendees at one rural workshop identified the need for an ongoing support group, but worried about funding because the carers came from two different areas. Fortunately, a local councillor was present and assured the group that she would sort it out with both councils.

> **When one listens closely to the experiences and problems of carers as well their relatively limited requests, who could refuse them?**

Carers without access to support groups said that this was an area in which they wanted to see improved services. At one workshop, only half of the carers in attendance were aware of the mental health carer support group in the local area. By the end of the workshop, however, all of the carers planned to become involved.

Other areas

Carers also identified a number of other areas in which they hoped to see more or improved service delivery. As noted in section 3.4, carers were keen to be able to access education and training on 'how to' care and about mental illness and its impact. Some carers wishing to re-enter the workforce sought access to employment assistance that recognised their responsibilities as carers and their need for flexible employment (see section 3.15). Carers also wanted free or low-cost legal services to be made available to mental health carers, to assist them in understanding and implementing arrangements such as advance directives, guardianship and powers of attorney and provide assistance if the person they care for became involved with the criminal justice system. Many carers called for free or low-cost financial planning and advice to help them manage the additional financial burdens associated with caring and to plan for their own future and that of the person they care for(see section 3.10). In addition, they said they required access to health and wellbeing services that recognised the additional health burdens faced by carers (see section 3.11).

Specific population groups

Specific population groups considered other services as particularly important. CALD carers, for example, emphasised the importance of culturally appropriate services, and the need for greater access to translators, particularly those with a strong understanding of mental illness.[59] CALD carers also indicated that it was crucial to strengthen existing community ties through the use of a non-mental health specific community development workers as a stronger community offers more non- directed support to carers. A Vietnamese group, for example, valued the efforts of such a community development worker, but when the project ended that job position became redundant.

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[57] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit. pp.129-31, 137.

[58] Cameron and Flanagan 2004, op. cit.; Highet et al 2004, op. cit.

[59] Cardona et al, op. cit. 2006.

Indigenous carers also favoured the expansion of culturally appropriate services, ideally staffed, at least partially, by Indigenous workers. An alternative suggested by Carers Victoria is for partnerships to be established between mainstream services and Aboriginal community organisations.[60]

Young carers emphasised that existing services should demonstrate greater awareness of young carers and their requirements. Specific services should be developed to meet the additional needs of young carers, including assistance to enable them to complete their education and enter the workforce. They called for peer support programs for young carers, and improved services, such as counselling, at schools. They also emphasised the importance of identifying young carers early and referring them to service providers. One possible way of doing this discussed at the Carers Australia's 'Bring It' forum, is the provision of family-focused initial services for those requiring support, thus automatically identifying young carers and linking them to services.[61]

Carers from rural and remote areas suggested the establishment of additional services, involving transportation to and from distant medical appointments and respite services. They also pointed out how difficult it was for many carers to access services as this entailed substantial travel. Very few workshop attendees were aware of patient assistance transport/travel schemes available in most states and those who were did not know if this applied to carers.

3.6.2 Service and support delivery to carers

Carers emphasised that they wanted to see streamlined service delivery. As one carer said:

> **You should only have to tell your story once, and then the services should follow.**

Yet carers reported they had to provide details of their situation to multiple agencies. Thus they favoured the establishment of a centralised referral service to which they could provide their details and thus be easily connected with relevant services. Alternatively, they wanted better information-sharing between organisations to eliminate any need to provide the same details repeatedly.

Carers also called for services to be available, and for carers to be connected with them, from the first episode of illness experienced by those they care for. This was also discussed in relation to the provision of information to carers (see section 3.4)

Flexibility was another important aspect of service delivery identified by carers. They called for services based on carer needs, rather than narrow funding guidelines and rules. Carers thought that these should recognise the changing requirements of carers throughout their caring journey, while remaining flexible enough to meet these changing needs. At some workshops, carers spoke favourably of services that were willing to bend the rules so that they could access them, even if they did not technically meet eligibility requirements.

At one remote workshop, several attendees who were caring for those with autism spectrum disorders rather than mental illness, pointed out that they had been provided with services by an organisation that usually assisted carers of people with mental illness, as no services in the region were available for carers of people with such disorders. These carers expressed their gratitude that a worker from this service had been willing to stretch the eligibility requirements and provide them with some support.

Carers also reported that they required effective services provided with ongoing, rather than time-limited, funding. They felt that services that had proved beneficial to carers were often wound up and not replaced owing to funding limitations.

As noted above, carers identified a need for services targeted at specific population groups, including young, CALD and Indigenous carers. These services should take into account factors such as age, language and cultural appropriateness of service delivery.

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[60] Hepburn, op. cit. 2005.

[61] Carers Australia 2009, op. cit.

Better services for carers across a range of areas, including respite, are one step to ensure better support for and recognition of the difficulties many mental health carers face on a daily basis.

3.7 Priority Issue 7 - Acute Care Should be Therapeutic and Accessible

Ideally, acute or crisis situations can be avoided through early intervention when symptoms first become apparent. As discussed in section 3.14, however, carers reported great difficulty in accessing early intervention, increasing the likelihood that acute situations will occur. Carers attending the CEP workshops said that there should be significant improvements in the quality and accessibility of acute care during crises for those they care for.

3.7.1 Access to acute care services, admission and assessment

Acute care and treatment services should be available 24 hours a day, including on weekends, and response times to crisis calls must be reduced. Although 24 hour crisis phone services are available in many major cities, this is not the case in rural and remote communities. The only 24 hour service that carers reported to be available there was the police.

> **We always seem to have a crisis at 5.30pm on a Friday.**

Some carers reported having their calls answered by an answering machine, which is unacceptable particularly in a crisis situation. Carers also wanted telephone services to be staffed locally, rather than through a centralised state or national service.

CALD carers need 24-hour access to respectful translation services to ensure that they can get help expediently during a crisis. Carers also required 24-hour services to support them when those they care for have a crisis, as that is an extremely stressful time for carers.

In addition, carers attending the workshops called for greater consistency and more respect for carer viewpoints from Crisis Assessment and Treatment teams, as many had had significant difficulties in obtaining assistance for those they care for even during a crisis. As one submission to the *Not for Service* report said, ‘We are fortunate that she becomes a danger to herself and others when acutely unwell otherwise she would probably receive no treatment at all’.[62]

When crisis services are unavailable, the only alternative is for carers to involve the police. While carers at some workshops spoke highly of their interaction with the police, others were more critical due to stressful or unpleasant experiences. Regardless of the quality of the police response, many carers find it difficult to decide to involve the police in the first place as this can cause ongoing consumer-carer tensions.

Hospital emergency departments must be better equipped to deal with acutely ill consumers. Carers attending many of the CEP workshops criticised the untherapeutic features of most emergency departments and believed that in many cases these exacerbated a crisis. Long waiting times were also a major concern. One carer submission to the *Not for Service* report provided an example in which a consumer was:

> …admitted to hospital, after having to see five different people for a decision to be made that he needed to be hospitalised, instead of taking notice of his mother, and eight hours after arriving at emergency he was admitted to the psychiatric ward.[63]

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[62] MHCA 2005, op. cit., p.417.

[63] Ibid., p.502.

Carers attending some workshops praised the establishment of 'mental health rooms' in some emergency departments as these provided a less stressful environment for consumers waiting for admission.

Many carers argued that admission procedures must be more carer-friendly, with recognition of the value of carer input and respect for their opinions.

3.7.2 Acute care settings and treatment

Carers were in favour of acute treatment facilities, but felt that the establishment of services such as step-up/step-down services[64] in their own local area would reduce the need for acute services. This was a critical issue in rural and remote settings, where acute care settings could be many hundreds of kilometres away. It was also a crucial matter for some carers in metropolitan areas who may have to spend long periods on public transport to visit those they care for who are in acute care.

At one remote workshop, carers reported that the Royal Flying Doctor Service was the only way those they cared for could access acute care as the closest appropriate facilities were more than 2,000km away.

During a workshop in a state border-town, carers reported that although the nearest acute care service was just across the border, the police, if they were involved, were required to transport people much further away to the nearest hospital within the state in which they resided.

Carers in general reported that the environment and care in acute care settings was not therapeutic or conducive to the recovery of those they care for.

> **My aim in life is to keep my son out of the acute ward – it's no place for someone with mental illness.**
>
> **At [our local] hospital the staff and I witnessed [a person] being physically attacked by the only other patient in the so-called Secure Unit in front of the Nurses' Station. When he was moved in to the open ward, there was a general lack of supervision and occupation of the patients, resulting in a culture of intimidation and cigarette smoking being the main activity.**

Carers called for more treatment and therapeutic activities in the acute care setting. Disturbingly, some carers stressed the need for recognition of basic human rights in acute care settings.

> **Consumers in crisis should not be treated like criminals.**

Acute care should be appropriate for particular population groups. For example, it is inappropriate for young consumers to be hospitalised in an adult psychiatric ward. Acute care settings also need to demonstrate respect and cultural competence in their treatment of CALD and Indigenous consumers.

Some carers criticised the quality of staff in acute care settings, as well as staffing levels (see also section 3.3).[65] Carers also wanted experienced staff deployed in acute care settings who are permanently attached to a service.

> **There are a lack of services and psychiatric support. For example: [our local] mental health unit doesn't have an onsite psychiatrist. Visiting psychiatrists are overworked.**

As discussed in section 3.1, carers wanted to be kept involved and informed throughout the treatment of the person they care for. This is particularly true in periods of crisis, when carers are understandably extremely concerned about those they care for and want to contribute to their care in any way possible. Carers need to be kept informed of transitions between services and changes in medication or other treatments, and be seen as part of the treatment team, with information-sharing at all stages of acute care.

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[64] Step-up services, called PARC (Prevention and Recovery Care) services in some parts of Australia, provide inpatient care and residential support when a person is experiencing an episode of mental illness but does not require admission to an acute psychiatric unit. The intention is that the crisis stage of an episode and the need for hospitalisation will be avoided.

[65] Reid et al 2005, op. cit.

In situations where an advance directive is in place, these need to be respected by treatment services. Some carers attending the CEP workshops argued that these should be binding.

3.7.3 Discharge from acute care

This was another area in which carers called for improved services. They wanted to know that those they care for had received sufficient care and treatment and had recovered adequately before being discharged from acute care services, yet in many instances carers reported that this was not the case. Some carers wanted greater emphasis to be placed on the opinions of mental health nurses in acute care settings, rather than those of the psychiatrists providing treatment, as they felt that nurses had probably observed the consumer more and thus had greater insights into their health status. Other carers wanted opinions of more than one doctor to be taken into account before a decision is made to discharge consumers. Many carers also believed that those they care for had been discharged too early because there were insufficient acute care beds, not because they were well enough to be discharged.

Carers wanted to be told when those they care for are discharged, but this often does not occur. They also felt that they should be provided with discharge summaries and care plans, and be able to seek advice from treating psychiatrists, but again, this occurred only rarely. While some carers noted the value of discharge plans, others said that these were only valuable if they were acted upon, and this happened infrequently in their experience. Consistent national guidelines and policies for discharge were one suggestion to improve these processes.

Carers at one workshop pointed out that when consumers are hospitalised, no transition plans are developed for discharge and felt very strongly that such lack of planning increased greatly the likelihood of relapse.

The discharge plan should include the scheduling of follow-up appointments, involving both carers and consumers, to assess the situation and determine how the latter are coping with the return to the community. Ideally discharge should be to a step up/ step-down facility, to allow the consumer to readapt to community life in a supported environment.

One aspect of discharge planning is that of access to transport at discharge, particularly in rural and remote areas where hospitals can be many hundreds of kilometres from the consumer's or carer's home.

Carers at some remote workshops reported that after discharge those they care for were put on a bus to be returned home – in some cases a journey of ten or more hours. Yet in many cases if carers had been notified that discharge was imminent then they would have made alternative and more therapeutic transport arrangements for those they care for.

Stories of acute care told by mental health carers at the workshops illustrate the need for greatly improved services for those attempting to access it; and those being discharged from it. Involving carers in treatment and discharge planning ensures better outcomes for both carers and consumers.

3.8 Priority Issue 8 - Stigma, Discrimination and Isolation for Carers and Consumers

Carers identified the extremely negative effects of stigma and discrimination that resulted from caring for a person with mental illness. They spoke of discrimination not only against those they care for, but also against themselves, owing to their relationship to a person with mental illness, which is often highly stigmatised. Some also argued that the caring role was generally misunderstood and had stigma associated with it.

Certain groups within the mental health carer fraternity reported that stigma was excessive. Carers of consumers with forensic or drug and alcohol issues found it difficult to go to the workshops. The issue of concurrent mental illness and drug and alcohol addiction was addressed during each workshop and carers who identified with these issues talked of excessive isolation; withdrawal both from friends and society; and a reluctance to disclose the issues affecting them due to real or perceived discrimination against such families. Public shunning and a lack of human compassion were identified as added burdens for these groups.

3.8.1 Mental illness stigma

Stigma arises from a lack of understanding of the nature of mental illness. Common myths and misunderstandings brought up at the workshops are that:

- mental illnesses are all the same;
- mental illnesses are not ‘real’ illnesses;
- people with mental illness should be kept isolated from the community;
- mental illness is rare;
- mental illness is the same as intellectual disability;
- recovery from mental illness is impossible;
- people with mental illness are unpredictable, violent and dangerous;
- people with mental illness are unable to hold down a job;
- people with mental illness are ‘weak’ and could ‘snap out of it’ if they wanted to; and
- a person’s parents (especially the mother) are to blame for their mental illness.

As McMahon et al write:

> Few families are familiar with specific diagnoses and what they really mean. This is particularly so with mental illness diagnoses as it taps into the stigma that continues to permeate our society and also to our personal prejudices determined by our past experiences with any people we might have known with a mental illness, or worse still what the media has told us about such people.[66]

Carers attending the workshops reported that such myths had resulted in significant difficulties for themselves and those they care for in various settings, including within the family; in employment; in education and during treatment. Carers called for campaigns and strategies to dispel myths associated with both mental illness and caring.

3.8.2 Locations of stigma

Stigma was present in all dimensions of carers’ lives, and contributed significantly to their social isolation. A perceived lack of community support and acceptance resulted in carers and consumers feeling disengaged from society, and in some cases unable to connect with their communities. Research indicates that some carers are reluctant to identify as carers of people with mental illness owing to the stigma associated with mental illness.[67] A 2006 survey of carers found that 88 per cent of Australian carers agreed that stigma and discrimination against people with mental illness make it harder for those they care for to be well.[68]

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[66] McMahon et al 2007, op. cit.

[67] Ibid; and House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit.

[68] World Federation for Mental Health and Eli Lilly and Company 2006 *Keeping Care Complete: Summary of key findings*, Eli Lilly Australia, West Ryde.

Stigma was often reported within the carers' immediate and extended families, and was seen as a cause of breakdown in relationships. Many carers spoke of the deterioration of family relationships due to negative perceptions and a lack of understanding of mental illness.

> **A member of our extended family said to [the consumer]: 'Get off your bum and get a job'.**

Some also said that they lost contact with long-term friends, again due to stigma and lack of understanding, combined with social isolation due to the limitations arising from the caring role. They also felt limited in who they could talk to about the issues they were experiencing, due to common misunderstanding of mental illness.[69]

> **You learn who your real friends are.**

Stigma was also blamed for difficulties in building new relationships:

> **I found it very difficult to meet someone special due to the stigma around mental illness and my brother's need for frequent care. (This carer says she found someone eventually and he is very supportive.)**

Consumers and carers identified the workplace as another significant place where stigma exists. Carers reported that those they care for often had significant difficulty finding a supportive workplace, if they could find employment at all, because employers lacked understanding of mental illness. This reflects data in the MHCA *Let's Get to Work* report, which indicates that the workforce participation rate for people with a mental illness in Australia was only 29 per cent in 2003.[70] This is particularly frustrating for carers because of the positive mental health effects that consumers often experience while in employment. It can also be difficult for carers to find suitable employment because of stigma associated with the caring role and the mental illness of those they care for. This is explored further in section 3.15.

Educational institutions are another setting where stigma and discrimination can be an issue. This is particularly the case for young carers, whose caring role is frequently not identified or acknowledged and can be misunderstood by teachers and other students, sometimes resulting in bullying. When a consumer is involved in education, lack of understanding of mental illness can result in inadequate consideration of their particular support and special consideration requirements if they are unwell. This can result in disadvantage in assessments, and some consumers might leave school early. As 75 per cent of people with an adult-type psychiatric disorder will experience its onset by the age of 24,[71] many young people with mental illness are likely to be in either secondary or tertiary education at the onset of the illness. Support must be in place to increase understanding, reduce discriminatory practices and assist them to complete their education.

Particularly regrettable is that treatment settings are another location in which stigma and discrimination are faced by carers and consumers. Some carers reported discrimination against those they care for by health workers, emergency department staff and other clinical staff. Carers themselves also say that they face discrimination from treating staff.

Several mothers who attended the CEP workshops said they felt that they were 'blamed' by psychiatrists and psychologists treating those they care for, and in some cases this perception was due to explicit statements. In other cases, discrimination resulted in carer views not even being considered.

This was also raised in submissions to the *Not for Service* report, in which carers refer to the 'patronising put down' attitude from some people working in mental health.[72]

Interactions with the police were, in some cases, another area in which carers reported discrimination. Nevertheless, some carers could not praise the police highly enough, and stressed how understanding

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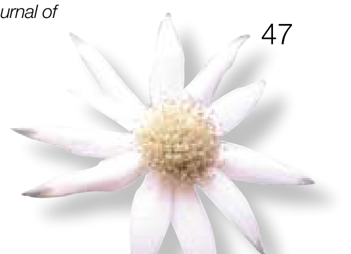
[69] Highet et al 2004, op. cit.; McAuliffe et al 2009, op. cit.

[70] MHCA 2007 *Let's Get to Work: A National Mental Health Employment Strategy in Australia*, MHCA, Canberra.

[71] McGorry, P.D., Purcell, R., Hickie, I.B. and Jorm, A.F. 2007 'Editorial: Investing in youth mental health is a best buy', *Medical Journal of Australia* 187 (7 Suppl.):S5-S7.

[72] MHCA 2005, op. cit. p.133.



and supportive they had been in their dealings with the person they care for. When this was not the case, however, problems were sometimes extreme.

The opening remarks of a senior police officer of a remote town who had been invited to a workshop to discuss what the police can do for carers of people with a mental illness were that police often had to deal with people who are ‘A few sausages short of a barbecue’. He went on to tell the carers that mental health training for the police was not required because ‘You only think mental health is an issue because you’re dealing with it’. When he was informed that certain carers in the group had had negative experiences with the local police in situations arising from the consumer’s mental illness, his response was simply, ‘Bullshit’.

Most examples of stigma and discrimination from the police were not this extreme or this public. Many carers, however, said that they would like to see the police have a greater understanding of mental illness.

Some carers argued that Centrelink forms for carer benefits discriminated against carers of people with mental illness, due to their emphasis on physical disability. This is explored in more detail in section 3.10.

Certain population groups can face additional discrimination. CALD carers, for example, reported stigma associated with mental illness from interpreters. They also said that they faced a dual burden of stigma and discrimination because of mental illness and race. Cultural factors can also increase mental illness stigma, reducing the willingness of carers to identify with a member of the family with a mental illness, and to seek appropriate treatment and support.[73]

Indigenous carers similarly faced discrimination, particularly in employment, because of mental illness and race. Adding to the burden of this stigma and discrimination was the Aboriginal concept of shame. Self-shame associated with the perceived embarrassment of mental Illness and caring, and the shame of having to ask for extra help, is a serious and added burden for many Indigenous carers.

Rural carers indicated that they faced additional stigma and discrimination because of a lack of anonymity in small towns and communities. One workshop held in rural NSW had extremely low attendance, in spite of the local coordinator’s best efforts. One of the two carers who attended said that he was well aware of other carers of people with mental illness within the town and the surrounding area, but that stigma was so strong in the community that they were unwilling to attend a workshop that would identify them publicly in this particular role.

As noted above, young carers also reported stigma and discrimination as a result of their caring role and the mental illness of the person they care for, often resulting in bullying by their peers and in some cases by teachers. The House of Representatives Report on the Inquiry into Carers gives the example of young carers being teased about ‘disability germs’.[74]

3.8.3 Carer solutions to stigma

Carers attending the workshops proposed a variety of solutions to reduce or remove stigma and discriminatory behaviour in society. They called for the introduction of public and community education campaigns on mental illness, designed to dispel myths and encourage social inclusion of people with a mental illness and their carers. While carers recognised the value of the work of organisations such as *beyondblue: the national depression initiative*,[75] they wanted to see campaigns that addressed mental illnesses other than depression. Carers also considered that there should be specially targeted programs for particular population groups. However, carers also wanted existing anti-stigma programs to be assessed for their effectiveness, and tailored as required. They argued that successful pilot programs should receive ongoing funding, rather than one-off support.

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[73] Cardona et al 2006, op. cit.; St George Migrant Resource Centre 2002, op. cit.

[74] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit., p.23; Moore 2005, op. cit.

[75] See for example: *beyondblue: the national depression initiative* 2006 ‘*beyondblue* National Advertising campaign’, online at www.beyondblue.org.au/index.aspx?link_id=105.903, accessed 21 July 2009.

Better education about mental illness in schools was also considered essential. Carers saw great inconsistency in the messages that were provided in schools and believed that individual schools made their own decisions about what students are taught about mental illness and available support services. The question of those teachers with little understanding of mental illness teaching classes about mental illness as part of the curriculum was raised at a number of workshops. The work of the multi award-winning programs of Mental Illness Education ACT (MIEACT), where consumers and carers are the educators, was highlighted as a proven successful alternative or adjunct.

The negative portrayal of mental illness in the media was a major concern for some carers who called for stronger guidelines relating to the presentation of stories about mental illness, with the application of penalties if such guidelines are not followed. Some carers praised the work of SANE Australia's StigmaWatch program in tackling negative portrayals of mental illness,[76] but wanted to see stronger measures on a national level, backed up by legislation specifically addressing this issue.

Carers also favoured the implementation of uniform mental health and anti-stigma legislation across Australia. They indicated that such legislation should include specific recognition of the rights of carers, including their right to live free from discrimination. Carers argued that there is a currently a lack of protection for carers from stigma and discrimination, and considered that new legislation would go some way in reducing the discrimination that they face. In 2007, the Human Rights and Equal Opportunity Commission (HREOC) acknowledged that 'Current federal anti-discrimination law provides insufficient protection for men and women workers with family and carer responsibilities'.[77] Carers called for improvements in legislation so that their rights as carers are acknowledged and protected.

Mental health carers consider stigma and discrimination to be significant barriers to the recovery of those they care for, and their ability to connect with the community and live productive lives. Reduction of stigma is a major priority for many mental health carers.

3.9 Priority Issue 9 - Accommodation Options for Consumers at all Levels of Care

3.9.1 Carers providing and supporting accommodation

Carers at many of the workshops raised the matter of accommodation for the person they care for as a major concern. This reflects the significance of housing as an issue for people with mental illness. Rates of mental illness in the homeless population are high, and people with mental illness may face a range of additional barriers in maintaining stable housing as explored in detail in the MHCA *Home Truths* report.[78]

Many carers who attended the workshops had those they care for living with them. In some cases this was not an ideal situation for either carer or consumer, but the lack of other accommodation options meant that accommodation and support provided by the carer was the only thing keeping the consumer from homelessness.

> **I care for my brother, who lives independently some of the time and at others times lives with my family and I. Sometimes I worry about having my brother in the same house as my young children when he is unwell. While he has not been violent before, his behaviour is unpredictable and erratic at times.**

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[76] SANE Australia undated 'StigmaWatch', online at www.sane.org/stigmawatch/stigmawatch/stigmawatch.html, accessed1 July 2009.

[77] HREOC 2007 *It's About Time: Women, men, work and family*, HREOC, Sydney, p.57.

[78] MHCA 2009, op. cit.

In other cases both carer and consumer were happy with the arrangement, but the carer, often an ageing parent in these circumstances, had serious concerns about what would happen when they themselves were no longer able to live at home or provide care, or died.

> **He just has me and I'm 82 – what will happen to him when I'm gone?**
>
> **Sometimes I wish my daughter would die first.**

Two carers who provided evidence for the MHCA *Not for Service* report expressed similar concerns:

> I feel that I can no longer cope with him living at home due to this illness. But there is nowhere for him to live. It's all unavailable. I would not want him locked away in an institution. But where can people with a mental illness live?[79]
>
> I have a son in his early 20s. He has schizophrenia and lives with me. He is unmedicated…he is impossible to live with, and only lives with me because he has nowhere else to go. There is no mental health vacancy anywhere in the ACT and he is incapable of living independently. There is just nowhere for him.[80]

In other cases, carers funded alternative accommodation arrangements for those they care for by funding the purchase or rental of another property; providing significant financial support including money for bonds (in some cases repeatedly when bond money has been kept by previous landlords); contributing to rental or mortgage costs; and funding maintenance, repairs or modifications. Some carers argued for schemes, such as low interest loans, tax offsets or deposit assistance, to support them to purchase or fund housing for those they care for. Funding for accommodation is just one area in which carers can face additional financial burdens as a result of their caring role. See section 3.10 for detailed consideration of the financial issues faced by carers.

Even when financial support is not provided and the consumer does not live with the carer, carers often provide significant emotional and practical support that assists consumers to continue to live in the dwelling. For example assistance with cleaning and household tasks; grocery shopping and transport; as well as support in managing symptoms and treatment. The provision of support or accommodation can require significant disruption to the carer's own living arrangements.

A carer in her 80s has moved to a city 300 kilometres away from where she had lived previously and rents a bedsit to provide significant daily care for her son. He lives independently, but visits her daily at 4.30am for a cup of tea, and she then visits him later in the morning. He has difficulties keeping on top of household tasks such as laundry, and his mother assists him with this. She receives no carer benefit or pension.

One young carer's biggest problem was finding suitable accommodation for himself and his father. His father had a one bedroom flat, while the young man rented in another area. Because they lived in different areas it was extremely hard for the young man to convince the housing department to provide a two bedroom flat for the two of them to share. At the time of the workshop the young man was renting in one place and sleeping on his father's floor at night because he felt that it was unsafe to leave him alone. The same young man was unable to access Centrelink payments.

One carer who provided evidence to the House of Representatives Inquiry into Better Support for Carers argued that:

> …the current expectation that carers will care until they die or until they become incapacitated themselves should be replaced with an expectation, supported by policies and services, that people with a disability will be able to live separately from their families once they reach adulthood.[81]

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[79] MHCA 2005, op. cit., p.443.

[80] Ibid., p.709.

[81] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit.., p.194.

This reflected a view commonly expressed by carers in the workshops that there must be alternatives to accommodation provided, funded or supported by the carer. One carer unable to attend the CEP workshops sent an email stating that:

> **My son has paranoid schizophrenia, which at present is reasonably well controlled. He does require care in his daily life as he finds it difficult to motivate himself to do the usual daily chores such as cleaning, cooking and shopping. Things are fine when I am at home and he joins in (most of the time) and does his share. I wonder what would happen if I was not around? At the moment I am relying on friends to help out as I am only away for four months, but what would happen if I was no longer around? How do others in a similar situation actually cope? What assistance is available on a long-term basis?**

Similar views were expressed by a carer who provided evidence to the *Not for Service* report:

> He lives downstairs, and we live up…But we are getting older, and won't be able to do this forever….it would be nice for us to have a little freedom before we are too old to enjoy it. My husband has just retired, but we will be virtually stuck at home, full time.[82]

3.9.2 More options for consumer housing are required

Carers indicated that consumer accommodation should be:

- quiet and safe/secure;
- therapeutic;
- affordable;
- long-term or permanent;
- age-appropriate;
- in good condition;
- well-located;
- culturally appropriate; and
- involve a choice of independent, or group house/clusters.

The importance of housing characteristics to mental health is reinforced by research outlined in the MHCA *Home Truths* report, which finds that housing features including low affordability, insecurity of tenure, housing conditions and quality, safety and security, and location and environment can all jeopardise mental health.[83]

Support provided by quality staff should be delivered in conjunction with accommodation to assist the consumer to live independently, and so that such lodging is suitable for those who are not supported by carers. Research indicates that carers with family or friends in supported accommodation or residential care have higher levels of wellbeing than those who have family or friends living with them, or alone or in another household.[84] Those carers attending the workshops whose family or friends were in supported accommodation or residential care were generally satisfied with these arrangements.

Carers also stressed the importance of having various accommodation options, to meet consumer needs and support requirements; as well as provide consumers a choice in their accommodation. Options raised by carers included step-up/step-down facilities for support before or after admission to a psychiatric unit;

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[82] MHCA 2005, op. cit., p.515.

[83] Ibid.

[84] Cummins, R., Hughes, J., Tomyn, A., Gibson, A., Woerner, J. and Lai, L. 2007 *The Wellbeing of Australians – Carer Health and Wellbeing: Australian Unity Wellbeing Index Survey 17.1*, Deakin University, Australian Unity and Carers Australia, Geelong.

transitional accommodation to provide consumers with the skills for independent living; and supported independent living models such as the NSW Housing and Accommodation Support Initiative (HASI).

Carers also emphasised that housing should be available as soon as a person is discharged from psychiatric care. This issue was recognised in the Australian Government's 2008 White Paper on Homelessness, which argued for a new strategy of 'No Exits into Homelessness' in recognition of the increased risk of homelessness that can result when someone is discharged from psychiatric or other care without stable housing arranged beforehand.[85]

Carers identified that in some cases existing policies and structural issues jeopardise housing. For example, the suspension of Centrelink payments for up to eight weeks, due to failure to meet activity requirements when on Newstart or a similar payments scheme, might result in the consumer being unable to pay their rent. Carers also maintained that processes should exist to ensure that rent is paid when a consumer is in hospital. This is particularly so for consumers who are employed and who may receive no income during their period of hospitalisation. In addition, carers considered that levels of rental assistance were inadequate, particularly in the context of housing affordability issues and the lack of availability of appropriate properties for consumers. They also said that even when accommodation costs are supported or subsidised, the cost and availability of suitable furniture and whitegoods creates additional burdens, the latter being especially acute in rural and remote areas where second hand items are more difficult to acquire.

3.9.3 Increased assistance for carers

Some carers indicated that they would be happy to continue providing care in the home or supporting the accommodation elsewhere of the person they care for if they could access appropriate support and respite services to assist them in providing this care. The types of support and respite that they would value are discussed in more detail in sections 3.6 and 3.12. A greater focus on recovery-oriented care in the community for those they care for would also reduce the burdens associated with supporting or providing accommodation. This matter is discussed further in section 3.2.

Carers also wanted help in planning for the future, especially those heavily involved in funding or supporting those they care for. They were extremely keen to obtain planning advice and assistance to assuage their concerns about the future health and comfort of those they have been caring for when they themselves are no longer to care.

Many mental health carers actively support accommodation options for mental health consumers and it is often only the carer's intervention that keeps a consumer from being homeless. Better housing solutions, many already identified in a range of reports, need to be implemented as a priority.

3.10 Priority Issue 10 - Financial Costs to Carers

Carers of people with a mental illness may face a range of associated financial burdens, some of which may be expenses related directly to provision of care itself, such as those for medication, medical appointments and transportation. Other costs might pertain to the behaviour of those in their care when that person is unwell and cover such things as damage to property, fines, and financial commitments. The financial burden on many carers is considerably greater because they have to give up or reduce paid employment as a result of their caring responsibilities. Research indicates that one-third of those providing primary care for elderly or

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[85] Commonwealth of Australia 2008 *The Road Home: A National Approach to Reducing Homelessness*, Commonwealth of Australia, Canberra.

disabled people live in households with incomes falling into the poorest one fifth of households in Australia.[86] A 2006 survey found that 44 per cent of carers of those with mental illness reported that their financial situation worsened when those they care for experience a relapse.[87] While carer support payments and allowances are available from Centrelink, carers often report that these are difficult to access and insufficient.

3.10.1 The costs of care

Carers of people with a mental illness often find that they are financially responsible for varying consumer needs, including accommodation, medication, treatment and transport costs. While some consumers can support themselves financially or contribute to their living costs, others face significant financial difficulties, which can in part be explained by disrupted education, social isolation, and the low workforce participation rate of people with a mental illness, which was a mere 29 per cent in 2003.[88] Those who are unable to work, or who are capable of holding down a job, but cannot find a supportive workplace, may find that the Disability Support Pension or another Centrelink benefit is their only source of income. Recent research by SANE Australia found that a third of people with a mental illness have incomes below $20,000 per annum, with the majority of those surveyed reporting that there were times when they had to choose between paying for medication or buying food.[89] In some cases, consumer poverty may be exacerbated by poor and often binding financial decisions made when they are unwell.

Accommodation for those they care for can be a significant cost for carers, and participants at CEP workshops identified this as one the most important elements which required monitoring (see section 3.9). Many carers fund or support the accommodation of those they care for because of the paucity of appropriate and affordable housing for those with a mental illness. This was discussed in detail in the MHCA *Home Truths: Mental Health, Housing and Homelessness in Australia* report which stresses that in many cases the provision of accommodation and support by families and carers may be the only reason that some people with a mental illness do not become homeless.[90]

While some carers look after consumers in a shared home, often this is not an ideal arrangement for individuals from either group, and in that case carers may rent or purchase alternative accommodation for the person they care for. With high housing and rental costs throughout Australia, carers are likely to find it enormously challenging to support two households, and may spend substantial parts of their savings to do so.

In addition to bond, rental or mortgage costs that carers may have to pay on behalf of those they care for, many carers reported that they also paid for other household expenses, including utility bills, home maintenance and groceries. One carer reported that:

> **I do her shopping. It's just too hard to ask her for the money – so I don't.**

Carers are also often required to pay for medication and treatment costs. While medication costs are subsidised under the Pharmaceutical Benefits Scheme (PBS), carers reported that related costs to them are still significant and because of the long-term nature of many mental illnesses are likely to be recurring and permanent. In many cases consumers also have comorbid physical conditions for which additional medication costs may also be covered by carers.

Carers also often pay substantial bills amassed by consumers for medical or other treatment appointments with GPs, psychologists, psychiatrists, counsellors or other specialists or mental health professionals. Bills are increasing in size as few health professionals, including GPs, now bulk bill, and payment of full fees, even with the expectation of subsequent reimbursement, can be a real challenge. A result is that carers may neglect their own health due to competing financial demands (see section 3.11).

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[86] AMP.NATSEM 2006 *The cost of caring in Australia 2002 to 2005 – Who Cares?*, AMP, Sydney.

[87] World Federation for Mental Health and Eli Lilly and Company 2006, op. cit.

[88] MHCA 2007, op. cit.

[89] SANE Australia 2009 *SANE Research Bulletin 9: Money and Mental Illness*, SANE Australia, Melbourne.

[90] MHCA 2009, op. cit.

Transportation costs are another important issue for carers, particularly for those in rural and remote areas. Even in metropolitan areas, treatment facilities might be some distance away, necessitating expenditure on public transport, taxis or parking fees for both carer and consumer. The situation is much more difficult for those in rural and remote areas, however. In many of the locations visited for the CEP workshops, carers reported that there were no local treatment services, and long journeys were often required to access a range of service providers. Often there is no public transport available, and the journey must be made by road. Extremely long road trips are made even more difficult because of rising fuel costs, or expensive air travel. Consumer and carer overnight accommodation, sometimes for several nights, will then be required, adding further to the cost of treatment.

One carer who attended the CEP workshops lived in a capital city due to a lack of employment opportunities in her home town, but regularly made the 11 hour drive or caught irregular flights to return to her home town to assist her son with cleaning and other aspects of his care. Her husband still lives in the town, but has a physical disability. The costs associated with this regular travel are significant.

Young carers face burdensome transport costs, as they are often too young to drive or unable to afford a vehicle. They are often responsible for making their own travel arrangements if their parent or a family member is hospitalised; or accessing respite or support services.

Young carers also experience additional difficulties because of their youth. Like other carers, they are often adversely affected by the low income of those they care for, but in many cases they are too young to work, or cannot leave school to do so. Young carers who attended the workshops said that their access to educational activities was impeded by financial barriers. This included problems accessing school excursions, uniforms and after school activities. Young carers also reported being unable to play sport or learn music because of conflicting financial demands, such as the need to pay for medication; and because they did not qualify for income support. An issue not raised in the workshops, but discussed in other research, is that of young carers turning to crime due to family poverty with the result that 'a number of these young carers saw their criminality as one of their caring responsibilities'.[91]

All carers may find that they face additional burdens due to the activities or poor financial decisions of the person they care for when they are unwell. In some cases, people who are experiencing mania or other acute mental illness symptoms may make major purchases, take out loans or enter into payment contracts that they cannot afford. Carers in many workshops were particularly concerned about people taking advantage of those they care for and leaving these consumers without all or a large part of their savings. When this happens the consumer no longer has enough money to pay rent, utility costs and other expenses, and thus the carer usually picks up the cost instead. Carers reported that they often have no choice but to pay bills or fines incurred by those they care for; and/or support the payments of contracts entered into; and/or pay financial penalties so that these contracts can be ended. Many carers commented on how easy it was for those they care for to obtain credit, get loans or make interest-free purchases even with low or no income, and how difficult it can be to break these loans.

In making such payments, many carers reported that they faced further problems due to the assumption that they would have a credit card. For some service providers, payment by credit card was the only option, or the least complicated one, but some carers, particularly those on low incomes, are unable to use this payment method.

The costs of care were recognised by the House of Representatives Standing Committee on Family, Community, Housing and Youth in its *Who Cares…? Report on the Inquiry into Better Support for Carers*. It notes that:

> Carers make a significant contribution to society, often at significant costs to their own financial, physical and emotional wellbeing. Many carers have indicated that they are under serious financial stress due

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[91] Moore 2005, op. cit., p.38.

> to their reduced capacity to participate in paid employment and inadequate government financial assistance. Many of these carers who report that they struggle to meet the everyday costs of living including the costs of food and housing, are also faced with the increased costs associated with disability and the provision of care.[92]

3.10.2 Financial support for carers: Centrelink benefits

Some carers have access to benefits from Centrelink. Carer Payment is an income support payment that may be available to carers if, because of the demands of their caring role, they are unable to support themselves through 'substantial workforce participation'. Carers, including those with access to Carer Payment, may also qualify for Carer Allowance, which is a supplementary payment available to those providing daily care and attention for someone who has a severe disability or medical condition or is frail and aged. Unlike the Carer Payment, Carer Allowance may be paid in addition to wages or other Centrelink payments.[93]

Throughout the CEP workshops, two comments were made consistently about Centrelink payments. The first was that the level of the payments is inadequate, and does not reflect the workload involved in the caring role or the financial burdens experienced by carers. The second was that it is extremely difficult for carers of people with mental illness to qualify for Carer Payment or Carer Allowance, as questions on the application forms are not pertinent to that type of caring.

At the time of writing, Carer Allowance amounts to $105.10 per fortnight, and the maximum Carer Payment is $569.80 per fortnight for a single person, or $475.90 each for a couple.[94] Carers at the workshops considered that these amounts are very inadequate, particularly given the significant financial burdens that they experience. A carer providing evidence to the MHCA *Not for Service* report argues that:

> They pay us an inadequate amount a fortnight to do a job they know we are unqualified and ill-equipped for, when they are the ones who should be providing us with the people and services to care for our families properly.[95]

Carers providing evidence to the Inquiry into Better Support for Carers shared this perception of the rates of carer payments, leading the Committee to report that:

> Many submissions from carers have stated that government financial assistance does not adequately compensate carers for the indirect cost of care (i.e. opportunity costs) or the additional direct costs associated with being a carer such as medical expenses, costs of accessing support services, provision of equipment, aids and appliances, and transport.[96]

The Committee added that '…current restrictions [in income and asset testing] force carers to reduce to a state of near poverty before they can receive support, which when received, is insufficient to lift them out of poverty again'.[97]

These issues were also raised by many participants in the St James Ethics Centre's 'national conversation' on the ethics of caring.[98]

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[92] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit., p.115; Cameron and Flanagan 2004, op. cit.

[93] Centrelink 2008 *Caring for someone? A guide to your options and our services*, Australian Government, Canberra.

[94] Centrelink 2009a 'How much Carer Allowance (adult) do I get?', online at www.centrelink.gov.au/internet/internet.nsf/payments/pay_how_caadult.htm, accessed 17 June 2009; Centrelink 2009b 'How much Carer Payment do I get?', online at www.centrelink.gov.au/internet/internet.nsf/payments/pay_how_carer.htm, accessed 17 June 2009.

[95] MHCA 2005, op. cit., p.181.

[96] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit., p.118.

[97] Ibid., pp.127-28.

[98] St James Ethics Centre 2009 *The Ethics of Caring in a Good Society: a national conversation*, Carers NSW, Sydney.

Though carers who receive the Carer Allowance or Carer Payment considered that the sums involved should be greater, many carers who attended the workshops reported that they were unable to access these payments, or had had great difficulty in doing so. They argued that the claim form is designed far more for physical disability than for mental illness, and does not reflect the significant level of care that is required for a person with a mental illness.

The initial instructions on the claim form for the completion of the Adult Disability Assessment Tool state that:

> Where the person's disability or condition is episodic or is only apparent at certain times, the question should be answered for when the person is not experiencing an episode or flare-up of the disability/condition (a 'good day' not a 'bad day').[99]

Carers of people with mental illness consider that this places them at a significant disadvantage. The very nature of mental illness is that it is episodic. For many people with a mental illness, little care will be required when they are not experiencing an episode. However, episodes can be long-lasting, and extremely disabling, and a very high level of care will be required during those periods. Some carers have received oral advice to fill out the form based on a 'bad day', but this is in direct conflict with the instructions on the form. However, the instructions on the Child Disability Assessment Tool state conversely that 'If the child has a condition that changes from day to day, please base your answers on the child's behaviour when the child's condition is at its **worst**'.[100] Clearly, far greater consistency is needed.

Carers believed that the questions themselves exhibit a bias towards physical disability, and do not reflect the nature of care for a person with a mental illness. Although instructions for the claim form do state that 'Help' with an activity does include 'prompting the person to undertake daily activities', which is often likely to be the form of care required by those with a mental illness, carers still have concerns. These result from questions which ask, for example, whether the person cared for:

- can move around the house (with/without assistance);
- falls over indoors or outdoors;
- can move to and from bed, chair, wheelchair and walking aids;
- has difficulty hearing others (with hearing aids);
- has difficulty seeing clearly (even with glasses);
- is incontinent; and
- uses continence aids.[101]

Other questions are more relevant to care of a person with mental illness, for example whether they:

- need help or attention during the night;
- eat their food;
- shower or bathes him/herself;
- can dress him/herself;
- look after his/her grooming; and
- take care of his/her own medication.102

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[99] Centrelink 2009c *Claim for Carer Payment and/or Carer Allowance: Caring for a person 16 years or over*, Australian Government, Canberra, p.12.

[100] Centrelink 2009d *Carer Payment Care Needs Assessment (For a child under 16 years)*, Australian Government, Canberra, p.3 (emphasis in original).

[101] Centrelink 2009c *Claim for Carer Payment and/or Carer Allowance: Caring for a person 16 years or over*, Australian Government, Canberra, p.12.

[102] Ibid.

There are also questions relating specifically to behaviour, which are much more relevant to the care of those with mental illness. Carers reported that overall the form is much more targeted at physical disability, however, the Child Disability Assessment Tool provides much more scope for describing the caring burden associated with mental illness.

Those questions on the medical report form which must be completed by a doctor or specialist, reinforce this view. These relate to the 'day to day needs' of those cared for and the instructions state that:

> If the person needs to be supervised or prompted to perform certain tasks because of their disability and/or medical condition(s) they are considered to be 'dependent' depending on the level of assistance that they require for the task.[103]

The questions themselves, however, are clearly targeted at physical disability. A person with mental illness, for example, may require prompting to prepare food and/or eat. Yet the question relating to 'Feeding' refers to 'Able to eat any normal food (not only soft food). Food cooked and served by others, but not cut up. Help = food cut up, person feeds self'. The options to answer this question are 'Unable', 'Needs help in cutting, spreading butter etc', 'Independent (food provided within reach)'.[104] This does not reflect the prompting, coaxing and wheedling that carers said may be required before a person with mental illness will eat.

The difficulties with the Centrelink application process, and the applicability of the forms for carers of people with mental illness, are also raised in the House of Representatives Standing Committee on Family, Community, Housing and Youth *Who Cares…? Report on the Inquiry into Better Support for Carers*. Recommendation 20 of this report is that assessment for Carer Payment and Carer Allowance should be reviewed and suggested the development of:

> …a new assessment process that acknowledges the level of support provided by carers of people with intellectual disability, mental illness or with challenging behaviours. The assessment should also have regard to the episodic nature of some conditions.[105]

One carer, on having her claim for Carer Allowance rejected, wrote an impassioned description of the care provided to her daughter which gives insight into other financial challenges faced by carers of people with a mental illness, particularly ageing carers.

This distressing case study is reproduced here after having been provided to the MHCA with permission for it to be included in this report.

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[103] Centrelink 2007 *Medical Report Carer Allowance and/or Carer Payment Special Disability Trust Beneficiary Status For a Person – 16 Years or Over*, Australian Government, Canberra, p.3.

[104] Ibid., p.4.

[105] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit., pp.xxiv-xxv.

One Carer’s Story

Acting on advice received from several sources I applied to Centrelink and filled in the forms needed to apply for a Carer’s Allowance in relation to our daughter.

Our application was rejected this week, I did not spend enough time actually in her flat feeding, bathing, cooking, supervising etc.

I read the letter with disgust and the following case study is my reply to them.

Our Daughter aged 46 has been in the Mental Health System for the past 4 ½ years. She has had four previous admissions to the [local] Clinic and is currently in the Hospital. Each time, given medication, monitored for up to three weeks, then discharged back into the community. Some sheltered living was provided for a short time after discharge, and a Case Worker allocated. Her medication was ordered by the Hospital Psychiatrist, provided and monitored by the Case Worker.

Three years ago because of our ages (71 and 70) we mortgaged our home and purchased a unit for her, so she could be independent, and wouldn’t be out on the streets, as she was at liberty to find her own accommodation and manage on her own. She is in receipt of a total disability pension, and has no other means of support. She is divorced and has a six year old daughter, who is in the custody of her Father.

During this time, she has mentally deteriorated from a person with an IQ of 149, to 60, which is about the ability of a 10 year old. It was only this year that we were able to get a correct diagnosis from the attending Psychiatrist. It is schizophrenia, and the outcome is not good. A report form filled in by her Psychiatrist was requested by Centrelink. This was submitted with our application.

Some behavioural changes which meant that we were spending much more time travelling and helping her quality of life, was what prompted us to seek a carer’s allowance. Unfortunately, as the attached form states, we are not eligible… Who decides what one should do to get help? We are on call 24/7 and have often drive the 100 kms to let her in after she has lost her keys or clogged up the toilet!!!! DAY OR NIGHT. We have replaced many sets of keys. The locksmiths are not cheap.

Does not take prescribed medication at the correct times… if at all.

When awake will sit and smoke to excess and drink coffee to excess, day or night. Uses every mug, plate, pot and pan and eating utensil in the kitchen and then does NOT wash up. Burns most of the food she attempts to cook. Food left uneaten in the pans or plates left out on the bench to dry up or go bad. Milk left out to go sour (I poured three part empty bottles out last week).

Appears to have lost ability to use anything electrical properly, except the jug, toaster and radio. Uses all the wrong settings on refrigerator, washing machine, ovens, clock, microwave, vacuum cleaner, telephone etc.

She is constantly losing her cards, e.g. Debit, Medicare, & Centrelink.

Does not collect or OPEN mail.

Does not take garbage scraps down to garbage bin or put bin out for collection.

Does not flush the toilet during night…blocks it up often. Has been known to pile up used paper in the corner.

Rarely answers the phone or utilises the 101 calling. Does phone people at times and us, but it may be any time of the day or night. Will phone to find out what day or time it is. Calls her brothers for money, $25,000 last time.

Leaves money in her pockets, last collection by myself was $75.

Rarely using the washing machine, and when she does, the clothes are left to dry in the machine. Washing which I do at home and take up to her, is left in the baskets or bags until I go next time. Only changes the bedclothes when she has spilt coffee or milo on them, or burnt another hole. One bottom sheet and the doona had to be thrown out last week. They were too burned to be used, I was able to patch the underblanket.

Does not clean the unit. Carpets were professionally cleaned twice last year. Coffee spills and cigarette ash.

Smoking, eating and drinking in the bedroom is strictly forbidden by us but unfortunately this is ignored. We are forever in fear of her burning herself or the unit. There is a smoke alarm there and we have another to install.

Personal hygiene is at an all time low and on occasions she has worn the same clothing for days and nights on end.

Because she was not taking her medication correctly, and was hiding some tablets, we were offered two weeks of respite care for her, to see if a strict medication regime and more supervision would help. We accepted this care and she was willing to do as she was asked. We were offered another two weeks care and again accepted, but after three weeks she had to go back into the Clinic as she was not responding to the care she was being given. We used this break, not for our own sanity, but to have the unit sprayed for cockroach infestation, and have also driven 400 kms, and spent 37 hours between us, in one week cleaning, and doing necessary repairs. Since then she has had another 6 weeks in the Clinic...an involuntary admission this time

Our daughter is one of the lucky ones in the mental health merry-go-round. She has Parents and two older Brothers who love her and do all they can to make her life bearable. She has a roof over her head which will be her home until she can no longer cope and has to move on.

She has the support of a caring Case Worker, Home Help Worker and visitor volunteer program. BUT where does she go when her health deteriorates to the extent where she cannot function at all? And we are not able to continue the support we now give? What facilities are open to her and the many others who are in the same predicament?

I have added to the original report today. Our Daughter is going to lose the voluntary support in 2 months time as they feel there is absolutely NOTHING they can do to help her. They, three of them have been visiting now for over 6 months. This will leave her with only a Case Worker and we two.

The Case Worker is trying to find some permanent supervised accommodation for her. The openings are few and far between. One as far away as Newcastle and two in Queensland. If we accept any of these our travelling time will increase dramatically and our visits will be very far apart. Just what is happening to mental health in our area?

We remain,

Yours faithfully,

Two very concerned parents

The CEP workshops targeted at young carers indicated clearly that there is currently great confusion about young carers' entitlements to Carer Allowance and Carer Payment. Young carers whose parents are unable to work due to a mental illness or other disability may face significant financial hardship, particularly if they are still at school and/or are too young to obtain paid employment. Issues for young carers are often hidden, and there must be increased recognition of these as well as greater transparency on eligibility for social security benefits that reflect the complexity of their role. None of the young carers who attended the workshops received Carer Payment or Carer Allowance, and other research has confirmed that other groups of young carers do not receive such payments either, even when eligible.[106]

Carers who attended the CEP workshops reported frequently that completing Centrelink forms requires too much effort, particularly if their application has already been rejected. One carer commented:

> **It just makes life more difficult, if it wasn't difficult enough already.**

Another said:

> **I'm too tired and too old and we have been there before and got no help.**

This is even more of an issue for carers from CALD backgrounds, many of whom have poor written and spoken English. Some CALD carers are even unaware that they might be entitled to benefits from Centrelink.[107]

Again, this is an issue recognised in the *Who Cares…? Report on the Inquiry into Better Support for Carers* with a recommendation that application processes should be streamlined and forms simplified. The report notes that:

> The sheer volume of paperwork required by Centrelink, coupled with the time and logistical effort required to complete the paperwork, attend and undergo the required medical and professional assessments were also major causes of frustration for carers.[108]

Other issues with Centrelink, including difficulty accessing information and a lack of understanding from staff, are discussed in other sections of the report.

Mental health carers save the community vast amounts of money per year through their caring role (see section 3.2), but this can be at the expense of their own financial future and retirement through direct costs related to caring.

3.11 Priority Issue 11 - Physical and Mental Health of Carers

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

3.11.1 Health impacts of caring

Stress and anxiety resulting from being a carer were a major health concern for carers and involved:

- anxiety about consumer health;

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[106] Moore 2005, op. cit.

[107] St George Migrant Resource Centre 2002, op. cit.

[108] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit., p.131.

- anxiety about caring responsibilities such as administering medication and persuading the consumer to take medication;
- having to be a continual advocate for the consumer;
- dealing with the consumer's lack of insight or denial of the illness;
- managing the consumer's social life and appointments, including those relating to health care;
- dealing with mental health workers and case managers;
- an ongoing sense of uncertainty;
- the lack of choice in taking on the caring role;
- disruption and breakdown of the family;
- concern about who will take on the caring role when the carer is no longer able to care;
- feeling trapped in the caring situation; and
- desolation and despair.

Obviously the combined weight of these anxieties creates a significant burden on carers, with inevitable repercussions for their mental health. Carers at the workshops used descriptions such as:

> **Caring is the unrelenting weight of responsibility.**
>
> **An utter sense of powerlessness.**
>
> **We're worn down by having to do everything.**
>
> **We are always walking on eggshells so we won't say the wrong thing.**
>
> **Your life becomes owned by the person you care for.**
>
> **You feel sucked into the black hole of someone else's life.**
>
> **It's just a matter of limping through.**
>
> **It becomes our life, our purpose in life, we don't get a life for ourselves.**
>
> **The only way out of this is to kill myself and take my wife with me.**

A carer of a person with mental illness who provided evidence to the Inquiry into Better Support for Carers described the caring experience as:

> Terrifying, traumatic, overwhelming, confusing, stressful, isolating, lonely, undervalued, under-resourced, not understood, unsupported, unheard, invisible, frustrating, depressing, emotionally draining, physically exhausting.[109]

Carers also mentioned fears for their own safety because of the behaviour of those they care for. For some carers these fears were based on the erratic behaviour of the consumer, but others gave examples of extreme violence, threats and abuse, often arising from cessation of medication or treatment. In some of these cases the violence was so severe that the police were called and charges were laid. Feeling safe in one's own home is essential to mental health, but this is something which is denied to some carers.

The constant pressure and anxiety has significant impact on carers' physical and mental health. At least one carer attending the workshops raised the issue of carers turning to substance use in an attempt to manage the 'relentless stress' associated with their caring role.

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[109] Ibid., p.44.

One story shared at the CEP workshops was that of a woman's experiences caring for her husband that had driven her to attempt suicide. The children experienced emotional distress as a result of their father's illness and their mother's suicide attempt.

Carers argued that their health is not currently addressed and considered, even when mental health workers and clinical services staff recognise their essential role in supporting consumers. Several carers reported having neglected their own health care because the health of those they care for was their priority and time and financial factors prevented them simultaneously managing both.

A carer who experienced depression provided evidence to the Inquiry into Better Support for Carers wrote that:

> I am sure you would agree, dealing with depression is difficult for any individual, but it is amplified for those in a caring role. As a Carer, you can't afford to get sick or unable to cope. If you can't be the 'Carer', then who is there to take over for you?[110]

The mental health needs of carers and families were identified in the Inquiry into Better Support for Carers, which had recommendations for expanded counselling services for carers, as well as increased awareness among GPs of the high incidence of mental health problems among carers and their families.

Anxieties experienced by all carers were often felt more intensely by CALD carers due to language barriers, which increased isolation and left them feeling very alone. Cultural taboos relating to mental health and seeking help presented further problems for CALD carers.[111]

Indigenous carers reported similar issues, but these were also often exacerbated by the distance that they lived from health services. The significant gaps in health status between Indigenous and other Australians obviously also apply to Indigenous carers. The lack of Indigenous workers in counselling services presented an additional barrier to accessing health services.[112]

Young carers were another group that faced additional physical and mental health concerns resulting from significant stresses associated with their role, which involved taking on levels of responsibility that many adults never do.[113] In addition to caring, usually for a parent, young carers were often largely responsible for running the household and for the emotional and practical care of younger siblings. Young carers also wonder what will happen if they leave home, or if they will even be able to leave home. A facilitator of one young carer workshop said that:

> **These kids were clearly seriously affected by the toxic environments that they live in. It highlighted the urgent need to address the needs of young people living with someone with a mental illness or they too will become service users and the cycle will continue, but with increasing severity with each generation.**

Some young carers at the workshops were quite open about their own mental health issues, and some reported self-harm.

3.11.2 Research on carer health and wellbeing

Reports on carer health and wellbeing are extremely negative. Data from the ABS 2003 Survey of Disability, Ageing and Carers showed that women primary carers are more likely to rate their health as fair or poor than women without primary caring responsibilities.[114] The impact of caring on carer health increases with age, and woman primary carers can expect to have fewer years of healthy life than women who are not carers.[115] Other research into the health of women carers found that middle aged women carers in particular reported

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[110] Ibid., p.243.

[111] Cardona et al 2006, op. cit.

[112] Hepburn 2005, op. cit.

[113] Moore 2005, op. cit.; Noble-Carr 2002, op. cit.

[114] Cited in NATSEM 2008 *Commonwealth Financial Planning Women Carers in Financial Stress Report*, Carers Australia, Canberra.

[115] NATSEM 2008, op. cit.

poorer physical and psychological health, higher stress levels and more use of healthcare services than non-carers. Older women carers were more likely to report low levels of emotional wellbeing and feeling stressed and pressured than non-carers. [116]

Research from the Australian Unity Wellbeing Index found that carers have the lowest collective wellbeing of any group studied, with an average rating on the depression scale that classifies as moderate depression. Women carers have lower wellbeing than men carers. Carers are more vulnerable to physical pain than non-carers, and are more likely to be experiencing chronic pain. Many carers were not seeking treatment for themselves, mainly because they have no time or cannot afford the treatment.[117]

Research by Edwards et al found that compared with the general population carers had significantly worse mental health and vitality. The mental health of carers was worse than people with a range of serious health conditions including hypertension, congestive heart failure and type 2 diabetes. In line with Australian Unity data, women carers had worse mental health than men carers, but women and men carers both had worse mental health than the rest of the population. Large proportions of carers said that they had experienced clinical levels of depression for six months or more since they started caring. The 12 month incidence of depression in carers for both women and men was seven times higher than the prevalence rate in the general population for the same time period. Risk of depression was also higher for partners and families of carers.[118]

Edwards et al's research indicates that physical health of carers is similarly poor in comparison to the general population. A higher percentage of carers than people in the general population indicated that they had poor or fair health. Carers were less likely to be engaging in preventive health activities, such as having regular health checkups or engaging in regular exercise.[119]

3.11.3 Better management of carer health

Carers who attended the CEP workshops proposed a number of strategies that would result in better management of their health. One proposal was that carers receive free annual health checks, and that these should also be available to others in the family, including siblings and children of the person with a mental illness. Another option suggested was the provision of a specific Medicare item number to cover GP consultations with carers, in recognition of their complex and multifaceted health needs. Another idea was to establish a 'healthy life' program designed specifically for carers. Such suggestions are reflected in the report on the Inquiry into Better Support for Carers, which contains a recommendation that there should be a preventive health care program targeted at carers.[120]

Specific strategies were proposed to combat the stress and anxiety faced by carers. Increased availability and accessibility of respite were seen as essential (this is explored in more detail in section 3.12). Emotional and psychological support services specifically for carers were seen as necessary, even outside business hours. It was deemed essential that services reach rural and remote carers. Although some rural and remote carers were satisfied with telephone or internet-based support, others preferred speaking with someone in person. Other proposals included the provision of alternative therapies for stress management, such as massage, and teaching relaxation techniques to carers. Support groups were viewed as enormously valuable in assisting carers to cope with their role. It was suggested that all of these strategies should be available at little or no cost. For CALD groups, counselling and other stress reduction services must be made available in languages other than English.

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[116] Lucke, J. 2007 'How can we help carers to care? An update from the Australian Longitudinal Study on Women's Health', presentation to *Partnerships for Better Health Outcomes Conference: Carers and professionals working together*, 8-9 March 2007, Sydney.

[117] Cummins et al 2007, op. cit.

[118] Edwards, B., Higgins, D.J., Gray, M., Zmijewski, N. and Kingston, M. 2008 *The Nature and Impact of Caring for Family Members with a Disability in Australia*, Australian Institute of Family Studies, Melbourne.

[119] Ibid.

[120] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit.

To assist in the maintenance of family relationships, which when broken can cause additional stress and health issues, carers suggested a system of case management for families of people with mental illness, and even for secondary carers including siblings, spouse or children.

A key point made by many mental health carers was that greater respect for their role would reduce their stresses and thus have positive health impacts. Increased recognition of the challenges that carers face would probably lead people to place greater value on carers, their work, and their health and wellbeing. Carers also argued that the provision of better services for those they care for would reduce their caring burden which in turn would have positive impacts on their own health.

3.12 Priority Issue 12 - Flexible Respite Options for Carers

Various forms of respite are essential in assisting carers continue their caring role, by giving them a break from responsibilities and a chance to take some time for themselves. The are several types ranging from emergency respite if carers are unable to care because they themselves are unwell or they need to assist another family member, to planned respite from a few hours to several days in length. Respite can also involve assistance with housework or other tasks. Some providers are flexible and innovative in their provision of creative respite options, such as massages and other ‘treats’ for the carer, while others operate under very strict guidelines with respect to eligibility and available services. In some cases the carer and consumer can take respite together. Research indicates that carers consider respite care to be very important.[121]

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

3.12.1 Accessing appropriate respite

Carers called for respite that met their needs, rather than that which simply met the rules and criteria of service providers. They argued that a mix of emergency and planned respite should be available. Planned respite should have the flexibility to provide options such as a one-off block of time, a regular block of a few hours a week (for example, to allow a carer to attend a course or activity), or a block of several days to allow a carer to have a holiday away from home and their caring responsibilities. Respite should be available on weekends and evenings as well as during business hours. Carers also indicated that they would sometimes like to have respite that allowed them to stay in their own homes, while the person they care for participated in activities outside the home. In some cases carers wanted to take the opportunity to catch up on housework, while in others they just wanted to relax in their own home.[122]

Many carers attending the workshops said that respite providers were unable to meet their particular needs and emphasised that service providers should have the flexibility to provide what carers considered valuable. Carers favoured greater availability of and fewer restrictions on respite and argued that it should be available regardless of the state of carer-consumer relations. If respite was not offered for free or at minimal cost, then carers should be provided with an allowance to fund respite services. This would recognise the essential role that carers play and the additional financial burdens that they have.

Carers attending one workshop complained about a particular ‘emergency’ respite service that only operated between 9.00am and 5.00pm. Only one carer present had received service from this provider, while several had been denied service.

Carers recognised the need for them to be able to access respite before crises developed, a position reinforced by a speech to Parliament by Julie Collins MP following the launch of the report into the Inquiry into Better Support for Carers.

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[121] Cummins et al 2007, op. cit.

[122] Holland and Blood 2008, op. cit.

Collins said that:

> The really big issue…was the lack of respite care and certainly the ability in many cases for people only to be able to access respite care if they are in a dire emergency – if they have been coping and coping and coping until it gets to the point where they cannot cope any longer. For many of them this was the only time they actually got access to respite care.[123]

This message was supported in the report itself, which found that although respite is essential to carers, supply is not keeping pace with demand, and there are issues with affordability and flexibility.[124] The report argues that:

> The unmet need for respite services results in increased levels of stress for carers, their families and those being cared for, reduced economic and social participation and reduced levels of health and wellbeing.[125]

Some carers were simply unaware of available respite services and at least some of those who were, had only just heard about them from respite service providers at the CEP workshops. This matter is explored further in sections 3.4 and 3.6.

3.12.2 Quality care in respite

Even when respite services were available, carers had concerns about the quality of the care provided by respite workers, and wanted them to be trained, skilled, knowledgeable and trustworthy so that they could feel comfortable and relaxed when leaving those they care for. The provision of nationally accredited training for respite workers was one way carers felt that this might be accomplished. Carers reported that availability of high-quality staff was particularly important for the mental illness sector as it can take some time for consumers and carers to trust and feel comfortable with the respite worker. If this is not achieved than it is unlikely that respite will be effective for either.

An example of a carer not feeling comfortable with a respite worker is provided in research on Indigenous carers from Carers Victoria:

> A worker would come to my home and take care of my child. When the worker would come they would tell me to leave my child and go do some shopping or something! I had never left her alone before. I felt really uncomfortable about leaving her, so I would leave the house and go and sit on a corner near home and wait there feeling lost, trapped and guilty about abandoning her. I would worry constantly about her. I felt I was letting her down.[126]

An illustration of the importance of employing high-quality staff in respite care who understand the possible consequences of mental illness was a story related at a CEP workshop:

> **He has a son in his 20's with schizophrenia. The parents who had little English were encouraged to take a long overdue holiday and leave the son with a resident respite worker. The parents took a week and travelled 100 kilometres from home. On their return they found their son had bought a Harley Davison motor bike and entered into a payment agreement which he could not afford. The bike cost $14,000. To rescind the contract their son had entered into was going to cost $20,000. At the time of writing the situation has not been resolved. The respite worker had left the young man 'looking' at motor bikes while she went to get shopping. Needless to say the parents no longer trusted respite workers to care for their son.**

3.12.3 Needs of specific population groups

It was particularly difficult for young carers to access respite because of identification issues (discussed in section 4.4) and practical reasons. In many cases the type of respite that young carers desired was assistance with housework, but this is often not available. When respite involves activities for young carers, they may have difficulties participating because there is no suitable transport available to take them to and from it; or because of the situation at home. Other research indicates that young carers have difficulty accessing services that meet their requirements and that they should be able to choose from a

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[123] Commonwealth of Australia 2009 *Parliamentary Debates: Official Hansard*, House of Representatives, 27 May 2009, p.4596.

[124] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit.

[125] Ibid., p.175.

[126] Hepburn 2005, op. cit.

range of respite options, some of which should be family-focused activities. Respite workers must be trained specifically to work with young carers and their families.[127]

To meet the needs of CALD carers and consumers, respite services must be culturally aware and possess proficiency in languages used by them. CALD carers report that there are a lack of respite services and workers who are appropriate in these respects. CALD carers in particular may wish to spend their respite time with the person they care for, through shared supported activities for example, but this is often not permitted.[128]

CALD carers at one workshop identified that they wanted respite care and carers who understood their religious, ethnic and social customs and background. When these were unavailable they were more likely to seek help from within their community.

While the matter was not raised at CEP workshops, other research on CALD carers indicates that they have occasionally been refused services because of language barriers and the assumption that these could compromise duty of care. It also found that CALD carers with language barriers were disadvantaged because services assessing levels of needs tend to favour those who can articulate their requirements more clearly.[129]

Indigenous carers also reported difficulty in accessing respite care that met their requirements and was culturally appropriate.[130] In some places the only chance of them to obtain respite would be to move from their land, but of course this would not be an appropriate option.[131]

At two workshops on opposite sides of Australia, Indigenous carers identified the need for a ‘respite house’, built in a place in the bush specified by Indigenous people, where carers and consumers could go, individually or together, for healing.

Access to respite services is especially important to mental health carers in rural and remote areas where very few services are usually available. Carers may have to drive consumers long distances to reach respite services, using up much of their precious respite time en route. Some carers from rural and remote areas who attended the CEP workshops had concluded that it was just ‘too much effort’ to try to access respite services.

3.13 Priority Issue 13 - Privacy and Confidentiality Issues

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

3.13.1 Exclusion of carers

Numerous carers attending the CEP workshops provided examples of when they had been excluded from the care of those they care for due to privacy considerations. Clinicians providing treatment often refused to share information or involve the carer in treatment planning, even when carers were integral to consumer ability to live in the community. McAuliffe et al also note that: “Confidentiality’ was largely experienced as a

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[127] Carers Australia 2009, op. cit.; Noble-Carr 2002, op. cit.

[128] St George Migrant Resource Centre 2002, op. cit.

[129] Cardona et al 2006, op. cit.

[130] Hepburn 2005, op. cit.

[131] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit.

mechanism which excluded carers and their role in the treatment process'.[132] Privacy and confidentiality were described by one carer as a 'smokescreen' that was used to exclude carers from treatment discussions and care planning, while preventing access to essential information on such matters as when a person is discharged, or the possible side effects of medication.

Two carers told those attending one workshop similar stories about those care for being discharged from acute care in the very early morning, 2.00am in one case and 3.00am in another, without them (the carers) first being informed.

Two other carers told of an incident relating to when the person they care for suffered an adverse reaction to a drug. Although a letter was subsequently sent to the consumer advising them to discontinue using the medication they did not read it for a week. Meanwhile a copy had not been sent to the carers and the consumer continued to be administered the drug and to have the adverse reaction. The carers, who lived with the consumer at that time, added that because of behaviour arising from the adverse reaction 'It's a wonder we didn't kill him'.

3.13.2 Issues when the consumer is unwell

Even if consumers are happy for the carer to be involved in their treatment when they are well, sometimes they will refuse to have their carers involved in their treatment when they are unwell because of the symptoms of mental illness. As one carer providing evidence to the Inquiry into Better Support for Carers said:

> Too frequently a seriously ill, often deluded family member will be placed in hospital, and will be asked, in that state, if he, she wishes to have carers informed of treatment plans etc. If the consumer does not want the carer involved, the carer is out of the picture.[133]

Advance directives, developed by consumers when they are well, can eliminate such problems if they specify in documents that they want carers involved in their treatment. Yet because of variations in relevant legislation, advance directives are not legally binding in all states and territories.[134]

Carers raised the issue that when those they care for are unwell, they might be unable to process the information that is presented to them, or pass it on to the carer. Carers emphasised that this was why it is so important that carers are provided with treatment information. This matter was also addressed in research by Reid et al, who noted that it would be in the best interest of consumers for carers to be provided with the information when consumers are 'too sick to get the information'.[135]

3.13.3 Professionals ignoring carer knowledge

Workshop attendees reported that clinical staff often did not take carer knowledge of consumers and other evidence into account during diagnosis, and when considering medication and treatment options owing, again, to privacy concerns. The matter of carer expertise being ignored and rejected is discussed in more detail in section 3.1.

Carers felt that medical professionals do not consult with carers enough to find out what is going on at home in order to establish a holistic view.

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[132] McAuliffe et al 2009, op. cit.; McMahon et al 2007, op. cit.

[133] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit., p.107.

[134] McMahon, et al 2007, op. cit.

[135] Reid et al 2005, op. cit.

This sentiment emerges repeatedly in the MHCA *Not for Service* report. At one point for example it says that:

> …carers reported that clinicians were often not prepared to even 'listen' to their notifications regarding signs of relapse or fears for the personal safety of consumers or themselves under the pretext of 'privacy and confidentiality'.[136]

It adds that:

> …the role of family members as carers was ignored: they would not listen to our input and apparently valued privacy requirements above everything else, including [X]'s welfare and even his life.[137]

A further related issue is that of the lack of privacy that consumers and carers may experience in a mental health service. Carers, particularly in rural and remote areas where it is difficult to be anonymous, were concerned about the level of privacy they and the consumer received from service providers. In areas which lack understanding of mental illness and where discrimination and stigma flourish, carers said that the service provider must protect the consumer. They expressed concern about attitudes in emergency departments, in cities and in rural and remote areas, as there is little privacy when dealing with triage or when consumers are very evidently unwell in this public space.

One carer reported having experienced poor service from an emergency department triage and felt it necessary to contact mental health services from the public telephone in the emergency department waiting area to discuss the situation of her adult child who had a dual diagnosis. At that point, she was unaware that a teacher from the college that her other child attended was sitting directly underneath the telephone. Her other child subsequently entered the emergency department and was greeted by the teacher who had heard the telephone discussion.

Privacy and confidentiality were particularly obstructive for young carers. Young carers are also disadvantaged because of their age and the fact that they are usually caring for an adult results in them being excluded routinely from treatment planning, despite the essential role they play.

Carers also argued that privacy and confidentiality prevent service providers from working together effectively. Agencies, service providers and professionals say that they are not permitted to share information due to privacy and confidentiality requirements. Thus, carers have to repeat their stories often, while one agency may be unable to access information held by another, even if it is essential to understanding a consumer's condition and may be of great value in providing care and support. Carers identified this as a problem when moving between states or territories as it negatively affects continuity of available care.

3.13.4 Flexibility in information-sharing

Carers were adamant that legislation should allow for information-sharing between different service providers, so that consumers and carers could avoid having to endlessly repeat their story, and so that service providers could draw on each others' knowledge. Carers also maintained that privacy legislation should be uniform on a national level and be much clearer about carer rights. Changes such as these would provide significant benefits to people with mental illness, and particularly to their carers.

> **First respect the person, then respect their privacy.**

McMahon et al argue that:

> Professional codes as they stand neither explore nor develop the moral ground that lies between carers' needs for information to enable them to care and the consumer's need for privacy. Policy guidance is both inconsistent and scattered in a range of documentation. Professionals are uncertain about what they may share and carers are often unaware of their rights. Yet the need to balance rights with responsibilities is an imperative for constructing an ethical basis to enable carers to be identified and to share appropriate information for the benefit of consumers.[138]

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[136] MHCA 2005, op. cit, p.158; Highet et al 2004, op. cit.

[137] MHCA 2005, op. cit., p.160.

[138] McMahon et al 2007, op. cit.

The need for legislative reform in privacy and confidentiality was recognised by the House of Representatives Inquiry into Better Support for Carers. Recommendation 14 of the report called for investigation of whether privacy and mental health legislation ‘adequately allow carers to be involved in the treatment of the individuals for whom they care’. This, in addition to the need to promote to health and community care providers the importance of involving carers in treatment and services.[139]

3.14 Priority Issue 14 - Early Intervention at each Episode of Care

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

3.14.1 Early intervention defined

Early intervention is multi-faceted, and can involve:

- supporting people early when they first exhibit symptoms;
- responding quickly to requests for assistance;
- planning advance directives with the consumer when they are well to enable them to make decisions regarding their own care;
- facilitating connections with peer support, networks and advocates to prevent isolation by building links with other people who understand the system;
- listening to family members and carers;
- planning together and developing strategies to avoid acute symptoms and episodes;
- being able to access sub-acute care quickly when required; and
- having clear pathways to a full range of supports.[140]

Carers wanted to see intervention and treatment for every episode of mental illness experienced by those they care for before it reached a crisis stage and required hospitalisation. As one carer providing evidence to the *Not for Service* report wrote:

> I know of no other illness where we wait until the person needs the intensive care ward and their family is in chaos before we address it.

Other stories in that report state that carers are unable to initiate a response from mental health services until a crisis stage was reached.[141] Other work by the MHCA has argued similarly that ‘Current investment is too focused on services for people once they are already acutely unwell’.[142]

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[139] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit., p.xxiv.

[140] MHCA 2006a, op. cit.

[141] MHCA 2005, op. cit., p.198.

[142] MHCA 2006a, op. cit., p.7.

3.14.2 Difficulties in accessing early intervention

Carers at the workshops visualised a significant role for themselves in early intervention, noting that carers are often best placed to observe the triggers and early signs that precede a severe episode of mental illness. As noted in section 3.1 and 3.13, however, carers often find it extremely difficult to have their views heard and their expertise recognised. Carers argued that it was particularly important that clinicians and mental health services listened to them and act on the information that they provide in the early stages of a mental illness episode, as no one benefits if it escalates and becomes acute. Young carers in particular thought that they should be consulted when episodes occur. Carers also thought that people should listen to those they care for in such situations, particularly when an advance directive about their treatment is in place.

> **[The person I care for] tried to get early intervention for a mental illness episode from a mental health service, and they were told to go to the hospital emergency department.**

Some carers said that they would value knowing more about and having a greater awareness of the early signs of mental illness; where to go to obtain help in the early part of an episode; and about strategies to avert a crisis. They called for education and training to assist them in attaining this knowledge (see also section 3.4). They also wanted to access support more easily when it appears that a crisis is imminent, such as a single telephone number, for example, that can be rung for referral and advice in this situation.

Participants at the CEP workshops also discussed the mental health service response to the early stages of mental illness. Carers were adamant that early intervention services and telephone numbers should be available around the clock, as in some workshops carers reported that were available only during business hours. They also indicated that a key problem in accessing early intervention is that services tend to be focused on crises associated with episodes of mental illness, and that there are insufficient resources and staff in many areas to address the early stages of these events. Carers called for better resourcing of services so that early intervention services would be able to avert crises. Yet carers also wanted the mental health services to provide a supportive response in the early stages of an episode by ‘acting but not over-reacting’. In this context, step-up/ step-down services were considered an ideal model for early intervention.

3.14.3 Early identification of mental illness

Early intervention also encompasses early identification and diagnosis of mental illness, and carers were determined that this aspect of early intervention should be better managed in Australia. They saw this as a particular issue for young people, and favoured earlier diagnosis and treatment for this population group so that significant disruptions to education and entry to the workforce could be avoided as much as possible. Statistics support the importance of early intervention for young people, with 75 per cent of individuals with an adult-type psychiatric disorder experiencing its onset by the age of 24.[143]

Carers felt that teachers have a key role to play in early intervention, and wanted teachers to be trained to look for signs of early-onset mental illness. They were also in favour of public education on early intervention, to encourage broader recognition of the early signs and symptoms of mental illness and knowledge of where to go for treatment. Carers of young people with mental illness were particularly vocal about the need for early intervention and diagnosis. One reported that her suicidal child was told to ‘just get on with it’.

It is not only carers who call for early intervention. Evidence supports the effectiveness of early intervention, with reductions in treatment delay, improved clinical outcomes, reduced relapse rates and better social relationships and vocational recovery.[144] Research also indicates that early

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[143] McGorry et al 2007, op. cit.

[144] McGorry, P. 2009 ‘Is early intervention in the major psychiatric disorders justified? Yes’, *British Medical Journal* 337:a695.

intervention has cost benefits when compared to standard treatment, with estimated savings to society of $9,000 per patient per year, or $39,934 per patient over five years.[145] The MHCA has previously called for greater investment in early intervention, particularly for young people,[146] and this is still a critical issue.

3.15 Priority Issue 15 - Employment Options for Carers

3.15.1 Employment status of carers

The proportion of people aged 15 to 64 with caring responsibilities who are employed is lower than the proportion in the general population (63 per cent compared to 73 per cent). For primary carers, this rate is even lower: only 48 per cent of primary carers are involved in the labour force, and they were more likely to be working part-time.[147] Among women carers aged 30 to 64 years, over half are not in the paid labour force, compared with less than a third of women non-carers in that age group. Almost two fifths of all women aged between 30 and 64 are in paid employment, compared with one fifth of women primary carers aged 30 to 64.[148]

3.15.2 Difficulties for carers in accessing employment

Many carers at the workshops reported that they would like to be employed in paid work, or in full-time rather than part-time work, but that this would simply be impossible in conjunction with their caring responsibilities. This is supported by other research. In one study, unemployed carers reported a range of barriers to employment, the most common of which were ‘difficulty arranging working hours’, and ‘no alternative disability care arrangements available’.[149] The majority of employed carers reported having changed jobs or working arrangements because of their caring responsibilities.[150] ABS data on carers indicates that of primary carers who were not employed, almost one third had left work immediately before taking on the caring role.[151] Research also indicates that carers who are employed are often not working at their full skill level, with the Taskforce on Care Costs finding that 67 per cent of carers would refuse a job or promotion if it meant they could not fulfil their caring responsibilities, and that 44 per cent were already working in a role below their skill level because it allowed them to balance work and caring responsibilities.[152]

Some carers at the workshops also said that they felt disadvantaged in their search for work or in their existing workplaces due to their caring responsibilities. This is supported by research such as that of the Taskforce on Care Costs which found that 34 per cent of carers surveyed believed that their own careers had suffered because of the competing demands of their caring responsibilities.[153]

Carers said that they should have both the ‘right’ to work and lives of their own that extended beyond the caring role. They felt that more support from employers, the government and support services should be available to enable them to participate in paid or voluntary employment.

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[145] Access Economics 2008 *Cost effectiveness of early intervention for psychosis*, Orygen Research Centre, Melbourne.

[146] MHCA 2006a, op. cit.; MHCA 2006b, op. cit.

[147] ABS 2008b *A Profile of Carers in Australia (ABS Cat. No. 4448.0)*, ABS, Canberra.

[148] NATSEM 2008, op. cit.

[149] Edwards et al, op. cit. 2008.

[150] Ibid.

[151] ABS 2008b, op. cit.

[152] Taskforce on Care Costs 2007 *The hidden face of care: Combining work and caring responsibilities for the aged and people with a disability*, Taskforce on Care Costs, Sydney.

[153] Ibid.

Many carers required more adaptable or flexible workplaces to sustain employment because of the cyclical nature of mental illness. An ABS survey of all carers found that 32 per cent of employed primary carers required time off work because of their caring role.[154] Some of the carers attending CEP workshops who did work were highly complimentary of their employers who had allowed them leave, when necessary, to focus on their caring responsibilities. Others, however, reported a considerable lack of understanding from employers. Thus, carers were adamant that employers should receive education about mental illness, including about its cyclical nature, and the demands faced by carers of people with mental illness (see section 3.5). They believed that education and increased awareness could lead to increased employment options for both carers and consumers. Carers also suggested that incentives could be offered to employers to encourage them to hire carers. They also felt that employers should receive education designed to assist them to recognise the diverse skills associated with the caring role.

A submission by Valerie Simpson, a carer, to the House of Representatives Inquiry into Better Support for Carers outlined the challenges she faced in finding employment and concluded that:

> …employers see me as being:
>
> a) a Carer first – that is my role and position in life.
>
> b) too old – given that I have years of experience is of little value it would seem; and
>
> c) the perception, from the people I have seen thus far, I believe, see my caring role as one of inconvenience in relation to any work I may obtain.[155]

Similar views were also expressed by carers at the CEP workshops.

The Human Rights and Equal Opportunity Commission (HREOC) report, entitled *It's About Time*, on balancing work and family includes a recommendation that a new 'Family Responsibilities and Carers' Rights Act' be developed, involving the proscription of discrimination, based on caring responsibilities, in employment; and provision of the right for workers to request flexible work arrangements due to caring responsibilities and 'to have the request reasonably considered by their employer'.[156] Similarly, a recommendation of the Inquiry into Better Support for Carers was that the *Fair Work Act 2009* should be amended to extend to workers, with recognised carer responsibilities, the right to request flexible working arrangements.[157] Legislative changes of this kind would go a considerable way in addressing some of the issues identified by carers during the workshops.

An issue that several carers raised was the difficulty that they had had in attempting to balance any form of employment or study with caring responsibilities when receiving Carer Payment from Centrelink. To be eligible for Carer Payment, the total hours that a recipient works, studies or trains cannot exceed 25 hours per week. This includes voluntary work, and travel time to and from the place of employment or study.[158] Carers found that this was extremely restrictive, and that it acted as a disincentive to seeking employment, a position supported by other research.[159] For example, the report from the Inquiry into Better Support for Carers argued that:

> …the 25 hours rule appears to be arbitrary and unnecessarily restrictive … the 25 hours rule is significantly counterproductive in terms of encouraging carers to combine caring with employment and/or education.[160]

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[154] ABS 2008b, op. cit.

[155] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit., p.200.

[156] HREOC 2007, op. cit, p.xiii.

[157] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit.

[158] Centrelink 2008, op. cit.

[159] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit.

[160] Ibid., p.226.

The HREOC position on the complex interactions between Centrelink benefits and paid employment is that:

> Ideally the welfare system should encourage all types of carers to participate in paid work where possible. Appropriate support is essential to enable carers to engage in paid work without neglecting their caring responsibilities.[161]

Carers with paid employment have reported major benefits for their mental wellbeing and coping skills, as it provided them with social contact and interaction outside their caring role. Those attending the CEP workshops often identified ‘going to work’ as a coping strategy. A similar view voiced by another carer, who provided a submission to the Inquiry into Better Support for Carers, was that ‘Going to work is terribly important. It is my respite.’[162]

Carers in rural and remote areas reported that their employment options were particularly limited because of the general lack of employment opportunities in some regions. One carer said that:

> **Being a mental health carer and living 30 kilometres from town hasn’t allowed me the opportunity to work.**

For carers in rural and remote areas, Centrelink’s 25 hour rule about employment participation is particularly restrictive, as duration of travel to and from employment must currently be included in that timeframe, and many of these carers would only be able to find employment far from home.

Young carers also face challenges in gaining employment. Many of them are still too young to work or are still at school and are limited to part-time employment. Young carers who leave school early can face particular barriers in finding employment although they often feel they have no choice but to work, due to a lack of household income from other sources. These conflicting demands relating to employment are reflected in other research.[163]

With respect to future employment prospects, some young carers viewed getting a job as a potential ‘escape’ from their stressful home situation, while others thought that they would be unable to balance their ongoing caring responsibilities with employment. Young carers’ experiences with employment and education are discussed in more detail in section 4.4.

3.15.3 Consequences of unemployment and underemployment

Lower employment levels have a significant impact on carers of people with mental illness. One third of all primary carers are in households whose incomes place them into the lowest income quintile of households nationally. In 2003, 32 per cent of all carers and 44 per cent of primary carers were living in low income households, compared to 17 per cent of non-carers. The median personal gross weekly income for carers during that year was almost 25 per cent lower than for people without caring responsibilities. According to figures published that same year, each year carers on average receive approximately $5,600 less income than those without caring responsibilities.[164]

Over fifty per cent of people without caring responsibilities have income from salaries and wages as their main source of income, but this is only true for 40 per cent of carers and 26 per cent of primary carers. Almost 40 per cent of carers, and 55 per cent of primary carers rely on government pensions for their main source of income, compared with 24 per cent of non-carers.[165]

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[161] HREOC 2007, op. cit., p.136.

[162] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit., p.198.

[163] Moore 2005, op. cit.

[164] AMP.NATSEM 2006 *The cost of caring in Australia 2002 to 2005 – Who Cares?*, AMP, Sydney.

[165] Ibid.

Low income had left some carers under considerable financial stress. In the 12 months before an ABS survey was conducted, 22 per cent had drawn on savings or borrowed funds; 19 per cent had experienced cash flow problems and another 15 per cent had had problems paying bills.[166]

Low income has flow-on effects to retirement savings and superannuation. As was noted in a National Centre for Social and Economic Modelling (NATSEM) study for Commonwealth Financial Planning:

> Spending all or a significant proportion of one's working years out of the workforce also means that there is no opportunity to invest towards retirement income. Given a significant proportion of household expenditure is displaced to meet the high needs of the dependent person […] there is little opportunity for savings. Without superannuation, carers become dependent on the aged pension provided by the government to support their needs in their retirement years.[167]

A submission to the HREOC inquiry on balancing work and family made this point very clearly:

> Under the existing Australian superannuation system, anyone who spends extensive period(s) of their working life caring for young, disabled or frail family members within the family ends up as an economic dependent in retirement because the unpaid nature of most caring duties prevents them accumulating adequate superannuation. The message loud and clear is "Australia does not value its carers, they're bludgers".[168]

Carers in the workshops reported drawing on their superannuation and savings to help meet the needs of those they care for (see section 3.10). Others said that they worried about their inability to accumulate the means to support themselves when they were older. Some sort of provision must be made for the retirement years of carers who are unable to participate in the workforce because of their caring responsibilities.

Flexible employment options and workplaces are vital to ensure mental health carers have the opportunity to participate in the paid workforce in addition to their caring role.

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[166] ABS 2008b, op. cit.

[167] NATSEM 2008, op. cit., p2.

[168] Submission from Metaira Pty Ltd, in HREOC 2007, op. cit.

4. Additional Issues for Specific Population Groups

This section covers issues that emerged during the CEP workshops for specific population groups. Burdens and challenges faced by carers generally across Australia are magnified for CALD, Indigenous, young as well as rural and remote carers who cope with cultural, linguistic, age, and distance barriers.

4.1 Rural and Remote Carers

Approximately two thirds of the CEP workshops were held in rural and remote areas where 32 per cent of Australia's population lives. While the issues detailed below also relate to urban centres, they are much more of a problem in rural and remote areas. It should also be noted that many Indigenous communities are located rurally or remotely, so while there is a section concerning issues relevant to Indigenous communities all the issues in this section also apply.

4.1.1 Access to acute services

There is very little immediate access to local acute mental health services in rural and remote areas. Broome is a prime example, and while this town is located in a particularly remote place, the same issues prevail in locations much closer to major urban centres. Those attending the CEP workshop at Broome reported there are no acute beds for mental illness in that town, although a small subacute unit is planned for the future. Thus consumers requiring access to services are usually transported to Perth, 2,000 kilometres away. This has major implications both for the health and recovery of consumers as well as carer and family access to them. In fact, when consumers are transported in an emergency there is no process by which carers are informed of where they have been taken; their health condition; or their recovery. The status quo is not in the best interest of the health of either the consumer or carer.

4.1.2 24 hour acute service and transportation

The method of transportation to acute services many kilometres from home was an issue of concern for workshop attendees. The police and commercial services can be involved in transportation of people with a mental illness. In large urban areas this is far from ideal, but in rural areas the transportation of consumers can take many hours, in vehicles unsuitable for those who are seriously ill. Some police officers who attended the workshops expressed concern about leaving rural stations understaffed to drive to an acute unit. One example given involved a six-hour drive each way with a two hour minimum wait while the consumer was assessed. Twenty-four hour emergency services are unknown in many rural areas. While some carers reported access to a 24 hour call number for acute metal health services, they would reach an answering machine if calling after 5.00pm.

One carer responsible for a seriously unwell consumer in an area with no acute service accessed her local GP service after hours for assistance in an acute situation. The telephone conversation/consultation cost the carer $180, but they were only eligible to file a claim for up to $60 of that amount.

Carers also reported that consumers were sometimes discharged from acute services hundreds of kilometres from home and although still seriously unwell and without the carer being informed, put on a bus to take them home.

A note on NSW Police and transportation

At the time of the workshops, one police officer in NSW reported that the police force in that state is no longer responsible for transporting mental health consumers as this role has been taken over by the ambulance service. This raises several concerns. As mentioned above, many carers reported that consumers are not diagnosed with a mental illness or refuse to accept such a diagnosis. It is unlikely that mental health consumers in such instances will be on any database which recognises their particular health condition. Thus inevitably the police do transport mental health consumers, whether they are aware of it or not. Yet with the official abandonment of this transportation responsibility is the concern that police will not be given adequate training in the methods of assisting people with a mental illness.

Police training in mental illness was a major issue raised by carers at some workshops. In August 2009, there was an announcement that mental health training will occur across NSW through the Mental Health Intervention Team as a permanent police unit.

4.1.3 Mental health professionals

Access to metal health professionals is limited in rural and remote areas. Recent data indicates that remote areas have less than half the supply of medical professionals found in major cities.[169]

Carers at one workshop in a rural town reported a cut in services resulting in the number of full-time nursing staff being cut from two to one, who would not only work at reduced hours, but was also located more than an hour's drive away.

The major comment by carers on mental health professionals related to continuity of care. Many areas have a 'fly-in fly-out' psychiatrist who visits as infrequently as once per month. Yet, the most serious problem highlighted by carers was the frequent change in the psychiatrists who provide this service, resulting in little consistency of care.

> **Every time we have a new psychiatrist, we have to tell the whole story all over again – and who knows if [the consumer] does tell the story because we aren't included in the consultation – we're just the transport.**

Carers said that visiting psychiatrists have large case loads and often do not have time to read case notes. Carers reported that a frequent change of professionals often resulted in frequent changes of medication, and associated side effects, as well as changes in diagnoses. As many carers in other situations confirm, carers are not informed of any changes or possible side effects, thus being denied information crucial to their caring role.

Another comment about mental health professionals relates to cultural norms. While the carers are desperate to have access to any mental health professionals, some commented on the lack of cultural and linguistic understanding of professionals whose first language is not English. Given the nature of mental illness and the importance of language in describing the nature of that illness during diagnosis, this is a real and often understated issue.

4.1.4 Travel to services

While carers in urban areas said that they need assistance for travel to services, requirements of those in rural and remote areas in this regard are even greater, especially as public transport options are often limited or unavailable. Consumer costs associated with such travel are often paid for directly by the carer. Nevertheless, some carers reported that a rebate system (such as patient transport/ travel assistance schemes) paid some of their costs associated with visiting consumers in a mental health facility located more than 300km from home. Even under that regime, however, the assumption was that all carers have credit cards to make

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[169] AIHW 2008, op. cit.

initial payments. This was a major obstacle for many carers, who are often on a low income and still require subsidies that are provided up front to facilitate such travel. (see section 3.10)

Carers also indicated that they needed help in securing accommodation when visiting consumers in a centralised residential service or acute facility far from home. While some states offer such accommodation carers do not always know this and it is not always available and even when it is, advance payment is required.

4.1.5 Access to information

Many carers, especially those in rural areas, do not have access to the Internet. Approximately 50 per cent of carers who attended the CEP workshops did not have access to the Internet and many who did could only do so from work. When carers do have access to Internet this is often limited to dial-up facilities. In fact, carers in rural areas often still rely on mail, flyers, the radio and the newspaper to find out about services. Yet in 2009, city-based service providers and funding bodies assume that carers have ready access to information and research via the Internet.

Carers attending the workshops said that the type of information they usually sought from telephone information services for mental health carers usually concerned local services for the consumer. Telephone information lines that are not based locally and only offer, at best, other telephone numbers, often result in carers making a series of circuitous telephone calls. Often information provided was described as too general to be of use. Carers emphasised that while a telephone helpline would be of use it must be locally-based and staffed with those willing and able to answer questions about illness, medication and local services.

4.1.6 Respite access

While respite services for mental health carers in Australia are still relatively new it is worrying that so many rural mental health carers were unaware of them. In many cases, this was because such services in a particular area were based in another town some distance away. Respite service providers who attended rural workshops as guest speakers were very popular speakers. During subsequent conversations with carers, it emerged that quality of care of respite services was paramount. It was recognised that while there was a need for sufficiently knowledgeable and skilled respite workers in both the large urban areas and rural areas, the chances of achieving this objective in the latter areas were lower because of the much lower population base and levels of skilled workers in that field. As a result there was fierce competition for employees between care-based professions and growth industries such as mining in some rural and remote areas.

> **When I worked as a care worker (not mental health) I earned $17 an hour. I can earn $25 driving in the mining industry.**

4.1.7 Unfunded groups

Workshops were provided to a number of unfunded groups in rural locations. These were typically informal associations of mental health carers who came together for support and information in each others' homes or a neutral location. One thing that characterised these workshops was that consumers attended as well.

> **I wasn't going to leave him at home, that wouldn't have been safe and I thought he would enjoy the day out.**

The lack of social connectivity and events for consumers in rural and remote areas is demonstrated by the fact that attendance at a carers' workshop is considered to be a 'good day out' for them (although the evaluation process indicated that he did indeed enjoy the workshop).

These unfunded local groups of mental health carers have many stories to tell about difficulties they have in obtaining support. For example, one such group met regularly both as a support group and a social group for consumers and carers. Barbeques were popular and held frequently. The group identified the need for a room to establish a drop in centre and had many plans to expand the use of that room for such things as

life skills courses and other consumer activities. They approached the local hospital without success. Then to further their cause they enlisted the local member (just before the 2008 federal election) to host a public town meeting involving mental health professionals and public leaders. The local group paid for the services of a city-based psychiatrist to attend and provide professional input on the advantages of consumer activities such as recovery-based care.

Although the meeting went ahead carers reported it was of no value to them as they were not heard and their modest request was dismissed. The mental health professionals assumed that the carers would be unable to run the centre on their own and decided that while a professional – such as a mental health nurse, social worker or occupational therapist – was required to do the job there was no funding available. The result was that that group of local well experienced and knowledgeable mental health carers were greatly discouraged by that meeting, held at their expense.

Nevertheless, a few months later these carers contacted MHCA to say they had found a room, available Monday to Friday from a local NGO. The carer group has subsequently taken up residence and is starting its ‘service’ slowly with support meetings for carers; a drop in centre; and an activity base for consumer and carers. It plans to expand so that it can provide badly needed recovery-based activities for consumers in the area.

There are other similar stories of rural groups, which out of sheer necessity have utilised their own resources to provide activities and services aimed at keeping consumers well and engaged, and support mental health carers. The lack of acceptance exhibited by mental health professionals for the existing work and ability of mental health carers to undertake such work demonstrates poor understanding of their needs and their capabilities.

4.2 CALD Carers

A number of language-specific workshops were held that involved interpreters or bilingual workers, while other CALD workshops also took place where the level of English was sufficient enough that there was no need for bilingual workers. A significant number of CALD carers also attended the general workshops. Issues identified by that group of carers generally, particularly those from non-English speaking backgrounds, centred around language and culture.

4.2.1 Access to culturally competent mental health services

The level of need reported by CALD carer groups was enormous. They all emphasised that workers and professions, particularly in the area of mental illness, should become more culturally aware. Research by Cardona et al indicates that that while it is often assumed that Western health and community care models are objective and value-free, they actually operate within complex cultural frameworks that do not always match those of the communities they service. The result is that ‘health and community care workers often believe that it is incumbent upon the client to fit in or assimilate into the mainstream Australian health and community services culture’.[170] A feeling that they are outside mainstream Anglo-Australian culture can discourage some carers from seeking access to services.[171] Some CALD groups that are well established in the community tended to look inwards to their own community for professional assistance, although in acute situations this was impossible.

CALD carers attending the CEP workshops were often completely unaware of support services available to them as carers. Research by Cardona et al has found that length of residency in Australia was not indicative of the level of knowledge of services, as even carers in their study who had lived in Australia for more than 30 years were still unaware of services available to them.[172] Mental health services must be promoted in various languages, through existing cultural social or support groups.[173]

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[170] Cardona et al 2006, op. cit., p.21.

[171] Ibid.

[172] Ibid.

[173] St George Migrant Resource Centre 2002, op. cit.

4.2.2 Non-mental health local support networks

CALD carers attending CEP workshops considered local groups unrelated to mental health crucial in developing confidence in dealing with all English speaking agencies and in gaining support from within the community when caring for a person with mental illness. They believed that secure funding, provided to local support networks to enable these key community support structures to grow and flourish, was also essential. One group of carers was upset that funding for effective functioning networks had been suspended, thus causing them to disband. Outings and social opportunities were rare, at best, and carers relied on opportunities provided by the non-mental health cultural support groups to maintain and grow social support networks.

4.2.3 Language and Interpreters

The Telephone Interpreter Service (TIS) was considered of great importance to carers with little written or spoken English. Some of those attending the workshops, however, said that they required greater access to the service, which should also be improved. Representatives of CALD groups maintained that the TIS was not well known within their communities and that greater knowledge of the service in all CALD communities would be valuable. Sometimes the service was not always appropriate, and even within the TIS cultural misunderstandings were possible, which in turn affected the quality of service received by consumers and carers. Often TIS workers lacked knowledge and understanding of mental illness, and as a consequence misunderstandings could occur during translation, of which the carer was unaware. Some carers reported that TIS workers had been disrespectful to them, because of what they believed to be their lack of understanding of mental illness and its associated behaviours.

4.2.4 Language and services

Workshop attendees also called for changes to the translation rules to enable services to assist carers and consumers more fully. Carers reported that health workers had told them that they are not allowed to discuss cases with carers regardless of circumstances. The situation is made worse when a third party speaks on behalf of a carer who has little or no English because very little information can be exchanged, thus leaving the carer no better informed.

Respite care services discussed at the workshops were of great interest to carers, but few carers knew about them and even fewer accessed that service. Carers were very concerned about leaving those they care for with a worker who lacked understanding of their religious, ethnic or social customs and norms. At the very least respite workers must be able to speak the language of those they care for. Although mental health respite services were available to carers, they felt that those from the CALD community would find them very difficult to access. They also maintained that CALD communities should be able to access the Mental Health First Aid program.[174]

4.2.5 Bilingual workers

The inability of individuals to articulate clearly their level of need can result in them failing to gain access to a crisis service.[175] Greater use of bilingual workers would reduce barriers but there is a serious shortage of bilingual health and community workers. For example, workshop attendees reported that the Liverpool

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[174] Vietnamese, Italian and Croatian language versions of the Mental Health First Aid course have been developed, although currently there is only one instructor for the Croatian course and none have been appointed for the Italian course. There are eight Vietnamese instructors in NSW and ACT. See: Mental Health First Aid undated 'CALD (Culturally and Linguistically Diverse) Courses Information', online at www.mhfa.com.au/cald_mhfa.shtml, accessed 21 July 2009.

[175] Cardona et al 2006, op. cit.

area had only one part-time officer.[176] Carers are aware of such shortages and the consequences and have recommended that more empathetic bilingual health and community workers be employed. Bilingual workers could be very useful in helping to provide information about services as many carers at the workshops were unaware of them. Research has indicated that carers with limited English skills often rely on friends and relatives to provide them with knowledge about services, but this often results in inaccurate or incomplete information.[177] Other work has pointed out that, even with a translator at their disposal, '…clients cannot ask for respite if they don't have knowledge of the concept'.[178] Bilingual workers who are connected with support services would be able to provide complete and correct information on available services to CALD carers.

Bilingual workers usually have the added advantage of possessing useful cultural knowledge and being able to learn about family situations. The CALD carers believed that bilingual workers offered them effective translation and communication skills to assist with their exchanges with service providers. The CALD communities are also keen for the bilingual workforce to be expanded.

4.2.6 Within culture support

Many CALD carers who possessed good English skills, along with those who did not, said that would actively seek out services where the provider had the same cultural background as they did. While few services advertise the cultural origins of providers, word of mouth is useful in this regard. The provision of workers for local non-mental health support networks could also help fulfil this need.

> **We need services that cater to our needs. They have Jewish nursing homes and schools, so they need to see mental health care in the same light.**

4.3 Indigenous Communities

The Indigenous community of Australia is often referred to as one entity. CEP workshops accessed a variety of Indigenous communities which shared culture and tradition, but had varying attitudes to and experiences of mental health caring. In terms of this community, the project should be seen more as a snapshot, with eleven Indigenous workshops scheduled and two of these cancelled on the day (see section 4.3.1). Nevertheless, many hours were spent talking informally to the carers and the local coordinators in these two places.

Research indicates a lack of self-identification from Indigenous carers, meaning that their carer requirements are less likely to be met. Little is known of their needs, and more research is required. As the Carers Australia submission to the House of Representatives Inquiry into Better Support for Carers argued, 'In the light of what is known, it is possible to conclude that Indigenous carers and the people they support are significantly worse off than the majority of caring families'.[179] As Hepburn outlines, Indigenous carers experience:

- depression;
- loss and grief;
- isolation, grief and anger;
- anxiety, worry and panic attacks;
- difficulty coping;
- discrimination (due to both Indigenous status and carer status);

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[176] St George Migrant Resource Centre 2002, op. cit.

[177] Cardona et al 2006, op. cit.

[178] St George Migrant Resource Centre 2002, op. cit.

[179] House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit., pp.165-66.

- significant financial hardship, including due to lack of access to carer support payments;
- poor health and wellbeing;
- interrupted education and employment;
- poor access to transport; and
- lack of information about carer support services including respite and counselling.[180]

4.3.1 Trauma in Indigenous communities

While the number of workshops and extent of access and involvement with Indigenous communities was limited, they presented a forum for individuals to speak of the trauma and other issues that community members cope with daily. At one workshop a mother spoke for the first time about the trauma associated with the murder of her daughter. Another workshop focused on an overnight crisis situation involving a carer and a consumer and the lack of services available when they needed them most. Another workshop was delayed for two weeks because of 'sorry time' when three unforeseen and premature deaths occurred in that community. One workshop was cancelled because of the unexpected overnight death of a young Indigenous boy.

Intergenerational trauma was mentioned at many of the workshops, though this terminology was not often utilised. Post traumatic stress disorder was, on several occasions, identified as part of many people's lives, exacerbated or activated by each regular unexpected death or trauma within the community. More than one group indicated that intergenerational trauma had not been addressed throughout communities or even on individual basis, and that only when adequate and appropriate services are provided will the communities and their individual members begin to heal. One Elder identified the need for additional mental health support for the community or the extended family at each instance of 'sorry time'. If support is available it is currently limited to the immediate family.

In one instance, a group of Indigenous women travelled from out of town to attend a rural general workshop and while the local coordinator had not expected them, the whole workshop was delighted by their presence. When discussion turned to what the carers did in an acute mental health situation it was saddening to hear one Indigenous woman, who appeared to be approaching 60 years of age and in poor health, say, with a smile, what she did in a crisis:

> **I run.**

In short, there was no help available for this woman or others like her when faced with an acutely ill mental health consumer. It is indeed a heart breaking reflection of the level of mental health services accessible to this community.

These examples are provided here not to demonstrate the difficulty of accessing Indigenous communities, but to illustrate the ongoing trauma experienced daily by Indigenous people and workers in the field. In planning all of the general workshops, no similar instances of trauma occurred, and this disparity speaks for itself.

4.3.2 Community and shame

While some Indigenous carers accepted conventional medical terminology for mental illness, the basic understanding of all the Indigenous groups accessed was that mental health is part of a more holistic approach to health in which all areas of life and health are included. This understanding of life and health is described as 'social and emotional wellbeing', and can readily be identified with the concept of 'recovery-based care'.

The importance of extended family and family connections cannot be emphasised enough. At meetings where carers did not know each other personally, time was spent finding those connections through family

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[180] Hepburn 2005, op. cit.

ties and establishing a commonality. The community is considered as an extended family and of great importance. Each member of a community is affected by actions, illness or death within their community.

Some groups regularly introduced shame into the conversation. Mental illness and caring were seen as embarrassing for many Indigenous carers and they admitted that they would feel a sense of shame for having to ask for extra help. Self-shame is an added burden over and above the stigma and discrimination experienced by many mental health carers.

4.3.3 Listen to the solutions

A group of Indigenous Elders attended one workshop to speak solely about mental health, drug and alcohol issues in their community, including the reasons for it and the solutions they proposed. In this case the workshop plan was abandoned. At the Elders' invitation the new 'workshop' included a trip a few kilometres out of Coober Pedy to an existing community-owned facility that the Elders themselves had designed. Because the workshop was conducted in an Indigenous language, an interpreter was essential. The Elders were eager to secure a very modest amount of ongoing finance to energise and make the existing facility into a centre of cultural regeneration. After the meeting, local community workers confirmed that if this project went ahead as envisioned the facility would be available not only to the Elders, but also to others working in the field of Indigenous health and prevention.

An urban group of carers on the other side of Australia similarly mentioned the need for a cultural regeneration place in the bush. While this was actually raised in the context of respite, the carers insisted that it should be accessible to both consumers and carers.

> **It's to make us all well and strengthen our spirit.**

4.3.4 Cultural awareness

Each workshop was conducted over the course of one day, which was not long enough to engage fully with the communities. MHCA exceeded its expectations of the number of Indigenous workshops that would be held and level of engagement with participants, developments which can only be attributed to the willingness of the Indigenous people to accept, participate and willingly share insights into their own lives and experiences. If workshops are to be repeated and/or expanded, consideration should be given to the real and practical needs of the application of cultural awareness.

While mental health professionals are aware of the need for cultural awareness this may not extend to their professional practice. A well respected Indigenous community member tried unsuccessfully to explain to a treating psychiatrist that although a mental health consumer may be exhibiting signs of mental illness, in some cases the cause is cultural rather than a diagnosable illness. In this particular case the community member assisted the consumer back to their normal good health and out of the acute ward and without prescription medication by application of appropriate cultural practices. This incident was recorded not in a remote community, but in a large urban centre. While it is only one case, described as 'incidental learning', there was much agreement within the group about the need for treating professionals to understand the power of culture and its effects.

Possibly valuable insights can be learned from studying the work of Police Liaison Officers (PLOs). The Queensland Police Service is one police service where PLOs are employed as part of the Force. Their role is to establish and maintain a positive rapport between the Force and culturally-specific communities. Specifically they seek to promote trust and understanding by liaising with the community and police to assist in the:

- reduction and prevention of crime;
- diversion of people from the criminal justice system;

- education of police officers on culture and cultural issues; and
- improvement of community knowledge of law and order as well as the policing services.[181]

Three PLOs spoke at one Indigenous workshop in Queensland. Although from different cultures, they worked together and understood the needs of each others' cultures. They were well respected by the group and appeared to assist greatly in the understanding of the police force in dealing with cultures other than that of white Australia.

4.3.5 Training for Indigenous mental health workers

Those attending the CEP workshops said that more Indigenous workers should be employed in the field of metal health. While financial aid is provided to individuals wishing to study, workshop participants felt that more frequent travel assistance would help students cope with having to move away from home for advanced education. Mature women with families who had left school early or whose education had been disrupted felt that maturity and experience should be given greater weight when applying for jobs in the mental health field. Attendees also suggested ongoing on-the-job training, using a traditional apprenticeship model, rather than the more usual college-based training. They also mentioned the provision of assistance with training in the field through part-time work and study and more easily available child care.

In addition, carers indicated that they would be more willing to use mainstream services if these employed Indigenous workers, a position reflected in other research.[182]

4.3.6 Ongoing monitoring of Indigenous carers

Several carers attending Indigenous workshops spoke little or no English, and in some cases English was their third or fourth language. A significant number of attendees were uncomfortable writing in English. Some carers who attended were transient and moved location often, thus highlighting the problem of maintaining ongoing contact. Both Indigenous workers and the local coordinators who assisted in the workshops agreed that the only way to access the rural Indigenous community experiences was to revisit the communities annually. It is probably easier to contact Indigenous carers living in larger urban centres by email and post, but their recorded views will be an incomplete picture of Indigenous carers' experiences.

4.4 Young Carers

Although young carers are often identified as those aged between 12 and 25, MHCA young carer workshops included participants as young as nine. MHCA worked closely with existing youth services to ensure appropriate processes around participation and consent were followed, while also ensuring these young carers did have the opportunity to have their experiences heard.

When asked how long they had been in a caring role, many replied 'As long as I can remember'. Research indicates that the average age of young carers in Australia is 12 or 13, and just under half are under 18 years old.[183]

Young carers might be the only person in their family or household capable of providing care.[184] Alternatively, they might supplement the care provided by an adult or an older sibling. Regardless of the intensity of their caring role, young carers take on responsibilities that far exceed those typical for other people their age, and face many additional challenges as a result.

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[181] Queensland Police Service 2008 'Police Liaison Officers', online at www.police.qld.gov.au/join/plo/, accessed 30 June 2009.

[182] Hepburn 2005, op. cit.

[183] Noble-Carr 2002, op. cit.

[184] Research indicates that many young carers are in sole-parent families (see: Ibid.).

4.4.1 Enormous responsibilities of young carers

Young carers often take on all the responsibilities of adult carers. The caring role can be a major burden even for adults, but for young carers it is quite exceptional. According to young carers at the workshops, their roles can include:

- Providing reminders or prompts about medication use;
- Making appointments for the consumer;
- Accompanying the consumer to appointments (often on public transport);
- Providing emotional support to the consumer;
- Ensuring the consumer and other family members are safe;
- Undertaking housework, cooking and cleaning responsibilities far in excess of those typical of a young person;
- Shopping for groceries or supporting the consumer during shopping;
- Organising payment of bills;
- Caring for younger siblings; and
- Caring for pets.

Participants in the young carer workshops were asked to provide an example of a ‘typical day’ in the life of a young carer. At one workshop the following example was provided, from a young carer aged about 13:

6.00am – Get up and shower

7.00am – Remind mum to take medication

7.15am – Make everyone’s breakfast

7.45am – Get stuff ready for school

8.00am – Clean up kitchen, make all the beds

8.10am – Leave for school

3.00pm – Return from school and see how mum is

3.15pm – Begin cleaning

4.00pm – Chill out and do homework

5.00pm – Prepare dinner

6.00pm – Clean up dinner and look after younger kids

7.00pm – Tell mum to take tablets

8.00pm – My time…

The stress and burden of responsibility faced by many young carers creates significant worry for young carers. In addition to concerns such as ‘Will Mum be ok when I get home from school?’, young carers wonder if they will ever be able to leave the caring role; about financial issues arising from being in low-income households; and about balancing their schoolwork and caring responsibilities. Many also worried if they have a genetic predisposition towards being more susceptible to developing a mental illness. Some had even more serious concerns as at one workshop where a young carer, aged about 11, indicated as one of his ‘top issues’ that ‘People with a mental illness shouldn’t have to go to jail’. It emerged that his mother had come into contact with the criminal justice system while unwell, and he was now constantly worried that she would go to jail.

In some cases the substantial burdens and stresses faced by young carers led to their own mental health issues, and even to self-harm.

4.4.2 Reduced education and opportunity

The significant responsibilities and stresses described above left young carers with reduced educational opportunities because of the need to miss school to care, or to leave school at a young age to support the family financially and emotionally. As Cass writes about young carers:

> …care is labour which occupies the time which would otherwise be available for participation in education, training, employment and social/friendship activities…caring incurs costs, of interrupted education and labour force entry which may have long-term implications for future employment and income.[185]

ABS data indicates that carers aged 18 to 24 were less likely to have completed year 12 than non-carers (66 per cent compared to 73 per cent).[186] Other research has found that only four per cent of primary carers aged between 15 and 24 were still in education, in contrast with 23 per cent of other young people.[187]

One young adult had recently given up his studies to care for his father who experienced comorbid mental illness and alcoholism. The young man did not believe that he had a choice about taking on a caring role because there was no one else to care for his father so it was his responsibility.

Young carers at all of the workshops spoke of the difficulties that they faced in balancing their schoolwork with their caring responsibilities. Often they were too tired to complete their homework, had to be absent from school, or fell asleep in class. Young carers reported that some teachers were understanding and provided support, but others denied that they could be taking on such large responsibilities. Disturbingly some young carers reported being bullied by teachers because they had not completed schoolwork.[188]

Difficulties at school are compounded by the rule that carers cannot receive Carer Payment if they participate in more than 25 hours of employment or education per week, including travel time. Full-time secondary education usually involves at least six hours per day, which equals 30 hours per week not including travel time. Young carers who are still at school are faced with the impossible choice of completing their education or dropping out of school to secure financial support for themselves and their families.

Disruption to education also has a flow-on effect on future employment opportunities. Young carers attending CEP workshops expressed concerns about whether they would be able to obtain good jobs as adults because of their low marks; that they had not finished year 12; or that they had been unable to go to university. The continuation of caring responsibilities also had an impact on the ability of young carers to work due to a lack of understanding and flexible working arrangements offered by employers. Sixty per cent of young primary carers aged 15 to 25 are unemployed or out of the labour force, compared to 38 per cent for the general population aged 15 to 25.[189]

In one workshop for young carers, two participants gave conflicting examples of their employment experiences. One had recently had to give up part-time employment, which she was undertaking in addition to attending school, due to her caring responsibilities at home. Another participant had recently commenced employment so she could contribute to the family budget, although this resulted in her having to give up other activities such as soccer.

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[185] Cass, B. 2007 'Caring lives: Employment, health and wellbeing issues for young carers, mid-age carers and grandparent carers: implications for good policy and practice', presentation to *Partnerships for Better Health Outcomes Conference: Carers and professionals working together*, 8-9 March 2007, Sydney.

[186] Cited in: House of Representatives Standing Committee on Family, Community, Housing and Youth 2009, op. cit.

[187] Noble-Carr. 2002, op. cit.

[188] Moore 2005, op. cit.

[189] Cited in: Noble-Carr 2002, op. cit.

The HREOC *It's About Time* report identified a number of young carer requirements that must be addressed if they are to balance paid work, study and caring responsibilities, including:

- the provision of information about their rights and services;
- schools that are more understanding and provide more options to allow young carers to reach their full potential, including linkages with support services;
- more supportive school environments;
- homework assistance;
- career counselling that recognises their unique situation;
- the provision of out-of-school learning and assessment;
- the provision of 'leave' or time away from school without penalty;
- more flexible timetabling;
- flexible work environments, including transition to work and return to work programs;
- regular, flexible and coordinated respite; and
- services for young carers from CALD and Indigenous backgrounds.[190]

Young carers also miss out on social and recreational activities to which most other young people would have access. This is because of a combination of time factors; a reluctance to leave consumers unsupervised or unsupported; and financial issues.

> **If medication was subsidised or kids living in our situation could receive money, we might be able to do things like playing sport and music that other kids get to do.**

4.4.3 Access to support

Young carers attending the CEP workshops reported experiencing great difficulties accessing information and services. Most of the young carers who attended were linked in with young carer service providers and had access to information and support, but prior to their engagement with these services all had experienced difficulties in obtaining assistance. Many young carers have not been identified and therefore do not have access to services.

Young carers for those with mental illness are one of the most vulnerable groups of carers. Unless they are directly accessed by a knowledgeable worker they can remain hidden until possibly high school or later. There are numerous barriers to young carers receiving assistance, including stigma and discrimination relating to mental illness. Young carers have voiced concerns that requests for assistance could result in families being split up with children taken into care. This is a very real concern. If drug and alcohol issues are involved then the reluctance to access family support is intensified. This creates difficulties in identifying young carers, and they are the ones who suffer most. They fill in the gaps left by parental incapacity and do not seek help because that is the only life they know or they are fearful of the consequences to the family, however unreal those fears might be.

> **This is what we have always done.**
>
> **It's just part of family life.**

Young carers require support at the earliest opportunity. If they are left to disclose their carer status then the wait will be too long and significant damage may well have occurred to the young person's future prospects. There is a societal duty of care to protect the young person and their access to education and provide them with the same opportunities as all of their peers. Because families and young carers find it difficult to disclose their situation, other channels must be created for them to receive the support necessary.

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[190] HREOC 2007, op. cit.

Support could start from birth through parental support for vulnerable families. Programs that provide this type of support are already available in some areas, but it is ad hoc and this support is not always ongoing. Its continuity for young carers is a significant issue. Initial family support reduces as the family begins to cope, but that 'coping' often comes at a cost to the young carer. It would indeed be beneficial to coordinate support provided to vulnerable families from birth and ongoing support to the young children in such families, recognising them as young carers. Currently those channels of communication, integration of service delivery, procedures and processes do not exist and young carers are left to fend for themselves. A recent FaHCSIA discussion paper on family support promotes the integration of services for families which could be extremely valuable for young carers if it results in the coordination of services for themselves and their family members.[191] The need for family-focused services was also identified at The Carers Australia 'Bring It' forum for young carers.[192]

4.4.4 Hearing the views of young carers

Young carers attending the workshops, even those who were primary carers, regularly reported that they were not included in discussions about the care and treatment of those they care for. Not only were their views not sought, and they were rarely kept informed of diagnoses. Section 3.1 discusses the difficulty that carers of all ages have in being accepted as part of the treatment team, but for young carers such problems are compounded by their youth. Submissions to the MHCA *Not for Service* report provided an example of a parent being hospitalised and their children, who were also their carers, not being informed about this and coming home to an empty house.[193] Clinicians, mental health service providers and support workers must recognise the crucial role that young carers play in the care of some consumers and include them in discussions about treatment, diagnosis and care.

For two young carers, their biggest concern when their mother was hospitalised was that they were not kept informed by their grandmother and others involved. These carers did not learn of her diagnosis until she told them herself, close to the time that she was discharged. Clinical staff had not involved the children at any stage or attempted to find out what support they needed.

Young carers also experience difficulties in obtaining recognition from other service providers, including Centrelink.[194] For example, at one young carer workshop, a speaker from Centrelink arrived early and asked the young people in attendance if they were the care recipients. She was astonished to learn of the vital role that these young people, aged between nine and 15, played in the care of their families.

Young carers also indicated that they wanted services that meet their own requirements. For example, respite for young carers might include assistance with housework. Issues such as transportation must also be considered when services are provided to young carers. Young carers wanted to be consulted about what they might need and how services should operate to meet these requirements. In this context, the 'Bring It' forum for young carers called for a funding model that '…works from the premise of identifying the needs of young carers and finding solutions to meet those needs – 'thinking outside the square'.[195]

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[191] FaHCSIA 2009b *Developing a Family Support Program: A Departmental Discussion Paper*, Commonwealth of Australia, Canberra.

[192] Carers Australia 2009, op. cit.

[193] MHCA 2005, op. cit.

[194] Carers Australia 2009, op. cit.

[195] Ibid.

Negative experiences of service use, including having experienced a lack of respect because of their youth, can leave young carers reluctant to continue seeking support from services.[196] Many of them do not use formal services. For example, 98 per cent of young carers in one study indicated that they had never accessed respite services despite needing this form of assistance.[197]

4.4.5 Young carers grow up

The effect of being a young carer does not stop when the carer turns 18, and nor does their caring. A major concern of young carers is when, or if, they can leave home. Some never feel able to leave home or suffer great anxiety and guilt when they leave, doing what other young people see as a natural progression in life.

One adult carer attending a CEP workshop thought that she ‘might’ have been a young carer:

> **But I never really thought about it. As long as I can remember mum has been getting ill on and off and my younger sister started to get ill too when she became a teenager.**

This young woman has spent her whole life caring. She is in her mid-30s and continues to feel the isolation of being a carer. At school she felt that she had little in common with her classmates as they would go home to dinner and homework whereas she did not know what she would need to do after classes. On a good day it was just the daily grind of dishes, food, clothes washing, cleaning. On a bad one it was much worse:

> **I didn’t really have much in common with the other kids at school. I didn’t really have the time for friends so I didn’t miss them, but I miss them now. I’d love to have a group to go out with just for coffee or the cinema.**

This young woman still cares for her mother and sister and that care fills most of her weekends. She has a job in the caring industry. More positively, through her attendance at the workshop she learned about social activities for carers, which she planned to try.

Former young carers who are now adults need to be recognised as having been disadvantaged during their youth, and provided with ongoing support services to assist them to complete education, build careers and connect with their communities. This is important for those who are no longer in caring roles, and essential for those who continue on as carers.

4.5 Hidden Carers

While more than 1,500 mental health carers attended the CEP workshops, many carers did not. Some of those who did not attend could be considered ‘hidden’ carers. These people are often unaware they are carers and struggle on alone without support or services. They are family members and friends who help out a consumer when they are unwell and cannot be identified as a member of a specific group. One workshop facilitator identified residents of a long-term sheltered accommodation for elderly men as being particularly in need of additional service. In this particular instance an elderly man with his own health problems helped his friend with a comorbidity of mental illness and drug and alcohol use on a regular basis. He required occasional respite from this ongoing role, but no avenues were available to provide this service.

Other hidden carers are not easily identifiable as carers because of the nature of their care. Carers of people with forensic issues or a comorbidity of mental illness and drug and alcohol use often hide away, fearing stigma and discrimination from the population-at-large and other mental health carers.

Other groups who are ostracised to some extent because of the nature of their lifestyle and are frequently discriminated against would often choose not to identify themselves as mental health carers to service

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[196] Ibid.

[197] Cass 2007, op. cit.; Noble-Carr 2002, op. cit.

providers out of fear of further discrimination. Same sex partner carers of someone with a mental illness often find it difficult to access mainstream services and thus remain hidden with little or no support from either the carer community or within their own gay/ lesbian/ transgender community.

5 Conclusion

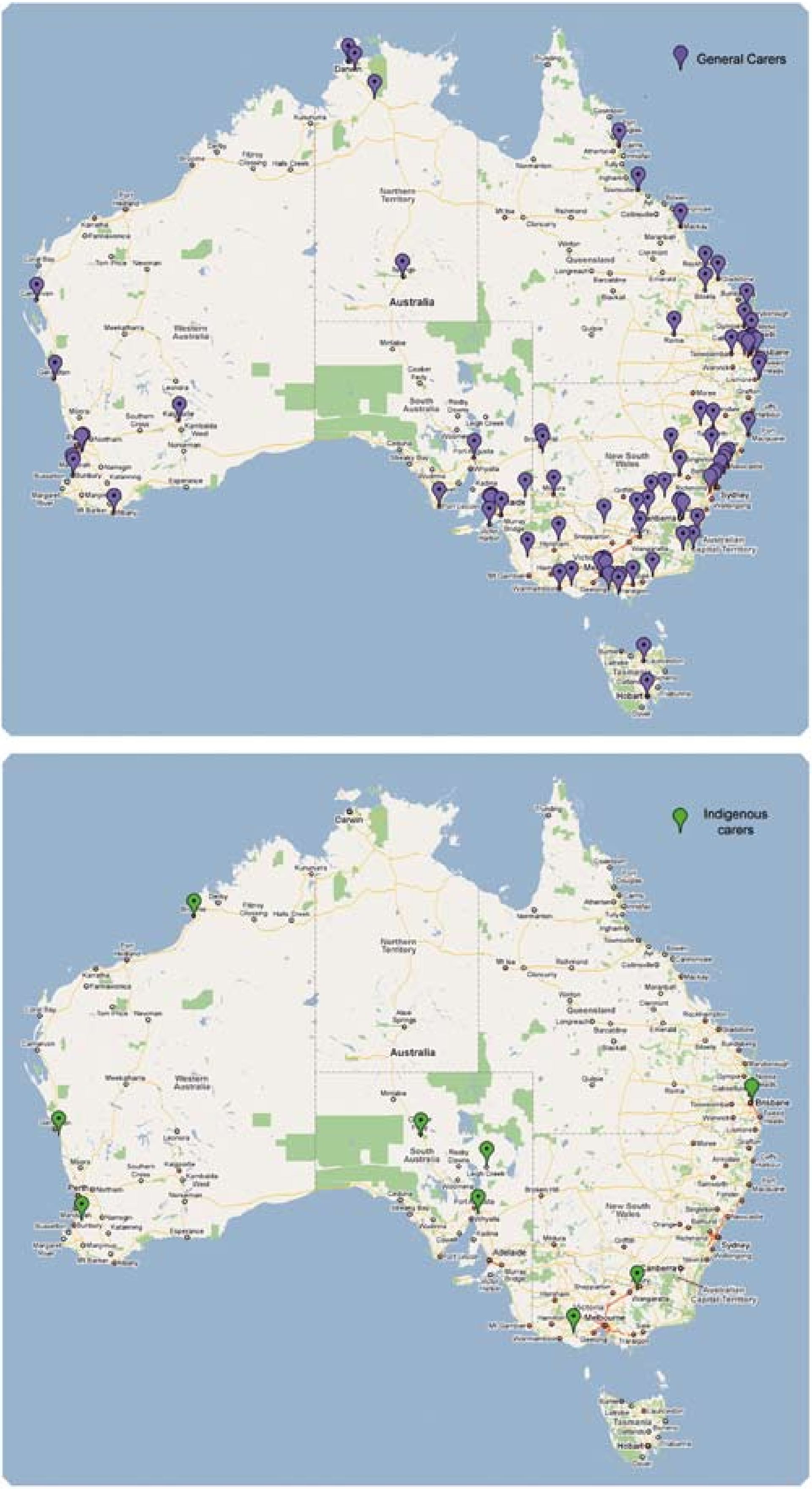
This report takes into account the voices and experiences of over 1,500 mental health carers, identifies common themes, and provides a consolidated account of their lives and the challenges they face. The report card relates to what mental health carers themselves say they need and what initiatives are in place to supposedly address these issues.

The ongoing annual monitoring and reporting that are planned will provide valuable insights into whether things have changed for mental health carers, and whether the burdens experienced by mental health carers have been reduced. It is the voices of carers that will be sought through ongoing monitoring, and the issues that they themselves will identify which will be reported.

Carers play an invaluable role in mental health care in Australia, and their requirements must be addressed and their voices heard.

Appendix A

Locations of Carer Engagement Workshops



• dot within the pointer indicates rural, remote and regional locations

Locations of Carer Engagement Workshops

- dot within the pointer indicates rural, remote and regional locations

Locations of Carer Engagement Workshops