



**Inquiry into  
Mental Health  
Services**

July 2007

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## 1. Background

### 1.1 Mental illness, carers and consumers

The number of people in Australia affected by mental illness and disorders is significant and continues to grow. Approximately 20 per cent of the adult population and 14 per cent of young people are affected in any one year (AIHW 2006).

Family and other carers are the lynchpin of mental health care in the community. Reforms to the delivery of mental health care in Australia over the past 14 years have shifted the focus of care for people with a mental illness from stand-alone psychiatric institutions to local community settings. The earlier massive under-resourcing of reforms to mental health services has placed a huge responsibility on families, carers and friends to support the care, safety and recovery of people with a mental illness or disorder (consumers).

This disengagement from specialist care and insufficient provision of quality mental health services to meet community need has resulted in a significant burden on families and carers. Research conducted by the Mental Health Council of Australia (MHCA) and Carers Australia through focus groups with carers, mental health service providers and stakeholders in each state and territory indicated that individual carers on average contribute 104 hours per week caring for a person with a mental illness. For many carers this time includes periods they are 'on call' or alert for early warning signs arising with the person they care for. This indicates that family carers sustain the fabric and operational effectiveness of mental health service systems across Australia (MHCA and Carers Australia 2000).

While the impacts of caring on carers of people with a mental illness are similar to most carers, other factors increase the risks, stress and isolation experienced. These include stigma in the community, the nature of mental illness and likelihood of co-morbid substance misuse, the exclusion of carers by mental health services, and deficiencies in the system. Carers of people with a mental illness can feel traumatised and overwhelmed, and can suffer their own long-term mental health consequences, especially depression, anxiety and stress disorders.

The extent to which carers and other family members successfully negotiate changes in the mental health system and other stresses can be affected by the degree and quality of understanding, information and support received from mental health services and informal sources.

### 1.2 Carers Australia

Carers Australia is the national peak body representing the 2.6 million carers in Australia who provide care for people with a disability, mental illness, chronic condition or who are frail.

Carers Australia has a commitment to promote the specific needs and concerns of carers of people with a mental illness to government and service providers, including their unique circumstances and need for better recognition and support.

Our members, the eight state and territory Carers Associations deliver services to carers of people with mental illness, including carer advice, specific education and training, and carer counselling.

While this submission has specifically focused on carer issues, this should not detract from the need to provide more accessible and effective interventions and community supports for people with mental

illness. Carers indicate that access to appropriate services for the consumer is a major factor in reducing the stress of caring.

Carers Australia acknowledges the significant policy and funding initiatives for people with mental illness, their families and carers through the Council of Australian Governments (COAG) National Action Plan on Mental Health 2006-2011 (the 'national action plan'), which are beginning to be rolled out.

## **2. This submission**

The Terms of Reference for this inquiry are to look at ongoing efforts towards improving mental health services in Australia, with reference to the National Action Plan on Mental Health 2006-2011 (agreed by the Council of Australian Governments (COAG) July 2006). The inquiry will also examine the commitments and contributions of the different levels of government with regard to their respective roles and responsibilities, and identify any possible remaining gaps or shortfalls in funding and in the range of services available for people with a mental illness.

As COAG recognised in the foreword to the action plan, it will take time to strengthen the capacity of our mental health services. Carers Australia has reviewed the national, state and territory individual plans and identified that there are significant initiatives that provide services for consumers, but initiatives for carers are still inconsistent across Australia and insufficient to meet their need for support and services in their own right.

This submission addresses the Terms of Reference by drawing on the final report of Carers of People with a Mental Illness Project finalised by Carers Australia in June 2006, and a 2000 project undertaken in partnership by the MHCA and Carers Australia. These projects drew upon current research findings and consultations with carers, Carers Associations and mental health service providers.

The submission includes issues identified as important to carers of people with mental illness:

- nationally consistent mental health legislation
- carer participation and representation
- services and programs, including income support
- specific mental health carer populations including Indigenous, young and CALD
- carer education and training
- workforce education and training
- information and carer resources.

Note: Reference to carers of people with a mental illness in this submission includes mental disorders as well.

## **3. Issues for carers of people with mental illness**

### **3.1 Nationally consistent mental health legislation**

#### **3.1.1 General**

Most states and territories have reviewed or are reviewing their mental health legislation, and have recently passed or are about to present draft bills to parliament (see Table 1.). For example, the ACT Individual Implementation Plan on Mental Health includes funding for a full review of the ACT Mental Health (Treatment and Care) Act. The review will include "...full consultation with consumers, carers and all other key stakeholders" (COAG 2006).

Table 1 Summary of mental health and carer legislative framework in States and Territories			
State/Territory	Mental Health Act		Carer Recognition Act
	Review	Name	
New South Wales	Yes. Mental Health Bill under review 2007	Mental Health Act 1990	Whole of Government Carer Policy in progress
Victoria	No. Ss 120A amendment 1996 acknowledges carers in relation to confidentiality	Mental Health Act 1986	Whole of Human Services Department policy framework 'Recognising and supporting care relationships' released July 2006, together with an action plan for carer involvement in Victorian Public Mental Health Services
Queensland	Completed 2000. Minor amendment 2007 related to forensic patients and victims of crime	Mental Health Act 2000	Carer Recognition Policy 2003 Carer Action Plan 2006-2010
South Australia	Review completed in 2006, draft Bill for consultation expected in August 2007	Mental Health Act 1993	Carer Recognition Act 2005
Western Australia	Yes, draft Bill expected 2007	Mental Health Act 1996	Carer Recognition Act 2004
Tasmania	Amended 2005	Mental Health Act 1996	No
Northern Territory	Yes, Mental Health and Related Services Amendment Bill February 2007	Mental Health and Related Services Act 1998	Carer Recognition Act 2006
Australian Capital Territory	Yes, completed 2005	Mental Health (Treatment and Care) Act 1994	Caring for Carers Policy 2004-07 Carers Recognition Bill proposed

The purpose of the various Mental Health Acts is primarily to protect the patient with the mental illness: to protect their rights, articulate treatment, assessment and care provisions. The purpose of these Acts is not primarily to address the needs and rights of carers, even though they are integral to the care and safety of the consumer. Reviews of the Acts have identified the importance of the recognition of carers and their access to information which allows them to provide quality care to their family member.

Mental Health Acts may or may not define carers specifically. Provisions that allow for information to be shared with other people, or for treatment to be initiated, are drafted in ways that do not adequately define a "carer." For example, these include the concept of an "allied person" (*Queensland Mental Health Act 2000*), or "a person assuming the responsibility" for the care of the patient (*Western Australia Mental Health Act 1996*). These provisions address practical realities but do not articulate carer rights

in relation to information, admission treatment and discharge of the patient, provide carer recognition, or recognise the social and psychological aspects of caring.

For this reason, the Northern Territory's *Mental Health and Related Services Act 1998* is considered model legislation. Included in the Act are provisions for carers' rights in relation to information, admission, treatment and discharge of the patient. The Act made provision to balance the rights of both carer and patient.

Amendments and proposed amendments to mental health legislation in most states and territories indicate there is a recognised need to support carers of people with mental illness in their caring role. Carers also have needs in their own right and this should be stated in legislation

### **3.1.2 Impact of legislation on carers**

Carers of people with a mental illness are impacted by a range of legislation. Many people with a mental illness do not come under the jurisdiction of the various Mental Health Acts. So, it is necessary to provide legislative options to ensure rights for carers (and associated enforceability) in relevant legislation.

There is now a move towards a whole of government approach to recognise, support and meet the needs of carers. Some states and territories have enacted Carer Recognition Acts and carer recognition policies are in place or about to be introduced in others (see Table 1 above). This ensures a whole of government approach to ensuring that policy, program and service development meets the needs of carers. These Carer Recognition Acts provide legislative recognition for carers.

Carer's access to information continues to pose persistent challenges. Carers Australia acknowledges the needs of carers to have access to information about the consumer must be balanced against the needs of the consumer to have their rights to privacy protected. Program and practice policies at national, state and territory levels need to be cognisant of the carers' need to know.

Stakeholders and service providers recognise that legislative provisions are adequate in most jurisdictions but that systemic misunderstanding of the rights, obligations and responsibilities of carers, consumers and service providers exists within all relevant services. This lack of understanding leads to inconsistencies in application and frustrating interactions between carers and mental health service providers.

There is an urgent need for programs to ensure that carers' rights, obligations and responsibilities are understood and that mental health service providers comply. Some states and territories already support carers and provide information to assist them understand their rights to access information within the existing legislative framework.

An unexpected outcome of the complex interaction of the *Privacy Act 1988*, the *Freedom of Information Act 1988* and Mental Health Acts is that carers denied information about a consumer are still "expected" to care for and support the consumer upon discharge.

The 2003 New South Wales Sentinel Events Review Committee (SERC) found that 50 per cent of suicide of people with mental illness occurs within a week after discharge from a hospital (public hospital data only). (A copy of the report is available at [www.health.nsw.gov.au/pubs/t/serc\\_contents.html](http://www.health.nsw.gov.au/pubs/t/serc_contents.html))

Figures for 2005-06 indicate that in New South Wales, Victoria and Queensland at least 314 patients who had been in contact with the public mental health system in the previous seven days had committed suicide.

The SERC report states that a follow-up care plan is critical. It is likely that many family carers would not be involved in, or advised of these care plans although they will become the primary carer when the consumer is discharged. Professor Peter Baume, SERC Chairman, believes that parents and carers have a right to know and that involving them in post-discharge care should override any rights of the consumer. The committee's report recommended that:

15. By April 2004, Area Health Services shall ensure that families and significant others, when recognised as active carers or guardians are given enough information and support to allow them to participate effectively in the assessment process, care provision and supervision of the acutely ill person before admission, during admission and after discharge, despite the current privacy requirements of the Mental Health Act.

Similar recommendations have been made by Coroner Hennessy in Queensland, and include:

... those providing care for persons under treatment should have the right to be informed of information necessary to carry out their carer's role and for the protection of others in the household. Medical staff need to be "advocates for the person's well being, not necessarily their wishes ...

That Queensland Health review and implement changes to the present confidentiality provisions to ensure that confidentiality of the person receiving treatment is balanced with the rights of the public to protection against the risk of harm, including the persons who have responsibility to care for and support the person under treatment and other members of the household. In particular, that there be sufficient provision in the Health Services Act to provide for Mental Health staff sharing information regarding the patient with key people in certain circumstances.

(Source: Coroner Hennessy  
<http://www.justice.qld.gov.au/courts/coroner/findings/perry1105.pdf>)

Carers Australia believes that where a family carer has significant responsibility for the care, support and safety of a person with mental illness they should have the right to discuss relevant care and treatment with mental health service providers to assist them to provide quality and continuous care for the consumer.

### **3.1.3 Consistency between acts and implementation of national standards**

Though states and territories conduct legislative reform within a framework provided by the National Mental Health Strategy, differences exist. These differences mean that the consumer, carer and service provider relationship varies in the different states and territories. For example, Continuing Treatment Orders and Community Treatment Orders are unenforceable across borders. Carer's access to information and involvement with the treatment, care and discharge of the consumer is also inconsistent across jurisdictions.

In submissions to the Senate Select Committee on Mental Health Inquiry in 2005 consumer and carer organisations sought a National Mental Health Act so that legislative consistency would remove barriers to continuity of care between jurisdictions.



The Australian Human Rights and Equal Opportunity Commission (HREOC) proposed the Australian Government enact a Family Responsibilities and Carers' Rights Act in March 2007 (HREOC 2007). The purpose of this proposed legislation is to protect the rights of families and carers and remove disadvantages primarily in the workforce. Carers Australia believes this legislation should be drafted to include rights for carers and families in all care situations, including mental illness.

Carers Australia recommends the Australian Government:

1. develop national mental health legislation that enshrines the rights of carers to formal recognition, information to assist them to care, inclusion and support in the delivery of mental health care
2. develop a national Carer Recognition Act or the Family Responsibilities and Carers' Right Act as proposed by the Australian Human Rights and Equal Opportunity Commission
3. develop national policy and practice guidelines to accompany the enactment of mental health and carer recognition or carers' rights legislation, and provide adequate financial and human resources to promote and ensure adoption of legislative requirements regarding carers in the delivery of mental health care
4. fund, as a priority, the comprehensive training of mental health specialist and primary health care professionals about legislative provisions, associated policy and practice guidelines, carers contribution to consumer wellbeing, and the experiences and needs of families and carers
5. monitor and enforce compliance with legislative requirements through the development of measures and performance indicators, as well as independent security and compliance mechanisms (such as a Mental Health Ombudsman or Carer Ombudsman)

### 3.2 Carer participation and representation

The National Mental Health Strategy comprises a number of policy documents and standards that have driven reform of mental health services in Australia over the last decade. As indicated, families and other carers now play a major role in the community care of people with mental illnesses because of the increasing incidence of mental illness and deinstitutionalisation of mental health care in Australia.

A recognition of carers' rights and needs in this respect, and avenues for carers' involvement as key stakeholders in all levels of mental health care are outlined in various NMHS documents. These include:

- Mental Health Statement of Rights and Responsibilities (MHSRR) (1992)
- National Standards for Mental Health Services (NSMHS) (1996)
- National Practice Standards for the Mental Health Workforce (NPSMHW) (2002)
- National Mental Health Plan (NMHP) 2003-08.

These documents outline the nature of carer involvement at two levels.

1. Carer participation is required at an individual care level in assessment and care management processes to enhance the treatment and consumer health outcomes, generally contingent upon consumer consent or in certain circumstances the clinician's judgement. At this individual level, mental health services are also directed to assist carers manage their caring role and the impacts of mental illness on them and their family.
2. Carer participation is required as a key stakeholder in the planning, development, delivery and evaluation of mental health services at a system-wide and local service level. This

acknowledges carers' perspective on the components of a quality mental health service, and the importance of addressing carers' unique needs in its development.

Feedback from carers indicates that the system has been slow to meaningfully engage carers at either level. However, in Victoria, the Department of Human Services (2006) publication, 'Doing it with us not for us' provides new strategic directions in consumer, carer and community participation across the health services system. The policy has seven guiding objectives illustrating how participation can include health policy, care and treatment and the wellbeing of community members. It outlines priority actions with clear directions and examples of participation.

The MHCA has been funded by the Australian Government Department of Health and Ageing (DOHA) to provide an opportunity for mental health consumers and carers to participate in mentoring and training programs – the *Consumer & Carer Mentoring for the Future* program, and the *National Register of Consumer & Carer Representatives* program. (For more information see <http://www.mhca.org.au/documents/TheMentalHealthCouncilofAustralia.doc>)

The *Consumer & Carer Mentoring for the Future* program will include a range of activities such as training, mentored participation in national policy initiatives, and online opportunities to communicate with other members of the program. The *National Register of Mental Health Consumer and Carer Representatives* program will provide up to 25 places each for mental health consumers and carers and includes a two-day basic representatives skills training workshop. MHCA indicated in its call for applications in June 2007 that membership "will entail a willingness and availability to work at the national level to promote the issues and concerns of consumers and carers."

This is a welcome initiative but it needs ongoing commitment and funding by the Australian Government if there is to be a sustainable contribution by consumer or carer representation at a national level.

The National Mental Health Consumer and Carer Forum has developed a booklet – *Consumer and Carer Participation Policy: A Framework for the Mental Health Sector* – for use as a guide by participants involved in mental health within the public, private and non-government sectors for the development and implementation of consumer and carer participation policies.

In the private sector, the Private Mental Health Consumer Carer Network (PMHCCN) (formerly the National Network for Private Sector Consumers and Carers) has produced a useful resource package of policies and guidelines to assist private hospital mental health services implement carer participation opportunities at an organisational level. However, carers of people with a mental illness who receives treatment in the private mental health sector still face barriers to meaningful engagement in the above areas. (See 3.3.1 below; especially in relation to care engagement by mental health services to assist carers manage their care of consumers as outlined in 1. above.)

The growing number of requests for carers to sit on national, state and territory wide and local mental health service committees, participate in professional training and education, act as clinical reviewers, speak at forums or represent carers in other activities indicates that government and other organisations are now responding to the carer representation and participation statements above.

This has placed considerable strain on peak carer organisations. These bodies have traditionally sourced carers from experienced members, but as more public and private sector mental health

service seek carer representatives, they now need to expand and formalise their process to sustain quality carer representation.

Carers Australia recommends the Australian Government:

6. provide leadership to foster in Australian, state and territory governments the systematic planning for meaningful carer participation at all levels of mental health care, the capacity to implement participation as planned, and ensure meaningful accountability for outcomes
7. encourage professional and industry bodies in the private mental health sector to increase their commitment and resources for carer participation, and to implement at national, state and territory levels inclusive and responsive carer practice in systemic, organisational and individual care activities
8. commit resources to strategies that will enhance the sector's capacity to meet national carer participation goals, including relevant workforce education, carer education and staff to support implementation
9. increase its commitment to develop infrastructure to recruit, train and support effective national carer representation; and to encourage a similar commitment by state and territory governments

### **3.3 Services and programs**

#### **3.3.1 Introduction**

People with mental illness and their family and carers have prioritised a number of aspects of mental health care and related services. These include:

- access to professional care, particularly in emergency and other acute care settings
- treatment with dignity and concern for the consumer and carer irrespective of location of care
- prioritisation of safe and high quality services
- an emphasis on clinical care, rather than 'containment' of those with mental disorders
- earliest possible access to professional care in acute and non-acute circumstances, including step up and step down services
- response to a consumer's needs, including recognition of the complexity of comorbid substance abuse, personality dysfunction or socioeconomic deprivation
- coordination of health, welfare and related community support services
- access for consumers to programs and support to live independently and work
- respect for the legitimate interests of family and carers in accessing care and participating in ongoing treatment decisions
- support for those who provide direct clinical services
- provision of appropriate community housing options
- access to appropriate medical services especially physical health and mental health services.

While much of the work of the national mental health reform process in Australia has focused on moving care from institutions to care in community-settings, little work has focused on whether the experiences of care by those who use services have been enhanced by this process. Work that has occurred has tended to draw mostly from critical incident reviews rather than everyday experiences of care.

In 2004 the MHCA recorded ongoing experiences of care by those who had used mental health services during the previous twelve months. It extended a framework initially developed in other areas

of health care to measure the quality of services provided. It relied on actual experiences of care and was not limited to critical incident reporting or ad hoc surveys of consumer participation or satisfaction with services.

Of 228 completed surveys in November 2004, 127 (56 per cent) were from consumers, 58 from carers (25 per cent) and 43 (19 per cent) from family members or close friends. Forty-one per cent had contact with public health services, 30 per cent with private health services, and the remaining 29 per cent a mixture of the two.

The survey revealed:

- only 57 per cent of respondents said that they were treated with respect and dignity always, or nearly always
- 69 per cent felt that they did not have adequate access to services
- 20 per cent said that they were not able to find a health professional to talk to about their concerns
- 41 per cent felt they were given insufficient, or no information about the condition or treatment
- nearly 60 per cent of respondents who wanted information given to family and friends felt that not enough information was given
- overall 19 per cent had not had the diagnosis discussed with them, this included 17 per cent of consumers, 10 per cent of carers and 37 per cent of family members or close friends
- only 6 per cent had received a care plan (MHCA 2005).

These findings indicate the inconsistency and gaps in the quality of services and experiences of people with a mental illness and their carers.

Housing and housing support has been flagged as a priority issue by some Carers Associations. In July 2007, Carers SA wrote to the South Australian Minister for Housing on behalf of carers about the need for appropriate accommodation for adult children with a mental illness:

Families struggle to find suitable accommodation for their family members and live in fear that their adult child will become homeless and chronically unwell without suitable supported accommodation ... The National Summit called by Mr Rudd is an ideal opportunity to address not only the housing needs of everyday Australians but also those of carers, who have the right to affordable housing choices for themselves and their families. Carers contribute \$30.5 billion worth of care (if it were to be replaced by formal services) in the community per annum in Australia and community care is based on the premise that families and those cared for have access to 'a home' (Carers SA 2007).

The Mental Illness Fellowship of Australia advised Carers WA that housing and housing support was one of five top issues identified through a survey they conducted recently. Others were employment and employment support, consumer and carer education, mental health research and Social Security.

### **3.3.2 Continuum of care**

Carers Australia completed a pilot project on improving carer health in June 2007, which was funded by DoHA through the Sharing Health Care Initiative. An overarching finding is that a continuum of care approach that takes into account the life course of carers is essential to effective carer health and wellbeing interventions. That is, an approach that recognises that different groups of carers have different needs and, more particularly, that carers have different needs at different stages of their caring

experience. All carers are in a different place and need different things, driven more by where they are in their caring journey and life stage than who or what type of carer they are (Carers Australia 2007a).

The cost effectiveness of interventions at the various transition points of a carer's life course is an important consideration for future carer support program funding. The continuum of care approach particularly for carers of people with mental illness is well illustrated by research undertaken by Deanna Pagnini for Carers NSW, which emphasises that the continuum of the caring experience is not linear (Pagnini 2005).

Pagnini also identifies that there are six phases within a carer's caring journey:

- suspicion that something is wrong
- confirmation of mental illness
- adjustment
- management
- purposeful coping
- end of active caring role.

<b>Table 2 Support needs</b>	<b>Phase(s)</b>	<b>Potential sources</b>
<i>Structured education, support and psychotherapeutic group programs</i>		
<ul style="list-style-type: none"> <li>• General mental illness educational programs focusing on information and beginning coping strategies (eg 14 Principles, Well Ways)</li> <li>• Illness-specific education and coping programs</li> <li>• General carer support courses (eg Talk-Link)</li> </ul>	2	<ul style="list-style-type: none"> <li>• Mental Health Services</li> <li>• Carer Respite Centres</li> <li>• Carers NSW</li> <li>• Schizophrenia Fellowship and other illness-specific organisations</li> </ul>
<ul style="list-style-type: none"> <li>• In-depth grief and loss courses (eg Seasons for Growth)</li> <li>• Psychotherapeutic courses (eg 8 Stages)</li> </ul>	4	
<i>Support groups</i>		
<ul style="list-style-type: none"> <li>• General carer support groups</li> <li>• Mental illness-related support groups (eg ARAFMI)</li> <li>• Illness-specific support groups (eg bipolar or schizophrenia)</li> </ul>	2-4 depending on carer	<ul style="list-style-type: none"> <li>• Mental Health/Community Health Services</li> <li>• Schizophrenia Fellowship</li> <li>• ARAFMI</li> <li>• Carers NSW</li> </ul>
<i>Counselling</i>		
<ul style="list-style-type: none"> <li>• Individual face-to-face counselling</li> <li>• Family counselling</li> <li>• Telephone counselling</li> </ul>	2	<ul style="list-style-type: none"> <li>• Mental Health Service</li> <li>• Private psychiatrists, psychologists, counsellors</li> <li>• Counselling Agencies (eg Centacare)</li> </ul>
<i>Formal support</i>		
<ul style="list-style-type: none"> <li>• Access to a carer-specific support worker who can provide tailored information, emotional support, and advocacy assistance</li> </ul>	2	<ul style="list-style-type: none"> <li>• Some area health services</li> <li>• Carers Support Unit, Schizophrenia Fellowship</li> </ul>
<i>Informal support</i>		
<ul style="list-style-type: none"> <li>• To be listened to, acknowledged, and reassured</li> <li>• Emotional and practical support from other family members and friends</li> <li>• To be included in social and family activities</li> </ul>	1	<ul style="list-style-type: none"> <li>• Family and friends</li> <li>• Other carers</li> <li>• GPs</li> <li>• All service providers</li> <li>• Community and religious groups</li> <li>• Internet</li> </ul>
<i>Respite</i>		
<ul style="list-style-type: none"> <li>• Daily (through consumer activities and rehabilitation)</li> <li>• Longer periods</li> <li>• Camps (for young carers)</li> </ul>	3	<ul style="list-style-type: none"> <li>• Mental Health Service</li> <li>• Carer Respite Centres</li> <li>• Young carer program, Carers NSW</li> <li>• COPMI</li> </ul>

(Permission to reproduce this table was provided by Carers NSW. Original source is from Pagnini (2005), pp 64-65.)

Her research also indicated six support needs for carers, and their relevance to the six different caring phases (see Table 2 above). The table includes potential sources carers can access for this support.

### 3.3.3 Barriers to carer support

Caring for a person with mental illness can adversely affect a carer's own physical and mental health and psychological wellbeing. (See 3.5.5 The need for carer education and training below.)

Specialised carer support can help carers, and other family members, maintain their own health and wellbeing. Support for carers also has a demonstrable positive impact on consumer wellness and, as a consequence, is a cost effective approach to mental health care. Carer feedback from a father participating in a Carers NSW education program for carers of people with mental illness indicated:

"My daughter had mental health episodes all the time. Since my wife and I have done the courses on coping ... my daughter hasn't been hospitalised for six months.

I want to do the course again and bring my other daughter because we all share the care."

The National Mental Health Plan (2003-2008) had a strong policy focus on improving access to support for families and carers, underpinned by earlier national mental health strategy documents. This policy focus needs to be aligned to the current COAG national action plan, and future policy direction.

Feedback by carers to Carers Australia, however, suggests that access to services and support that they and other family members need is not always possible. Carers Australia's research into mental health services and carers' needs has identified five major barriers to services:

**Systemic barriers** that arise from a lack of resources in the mental health sector so that carers cannot access timely or ongoing support for their relative or themselves, and where the focus is maintained on consumer needs rather than their own. Delays in assessment and diagnosis, and poor integration between general practitioners, specialist professionals and services providing mental health care, as well as across various health systems and sectors, further contribute to a lack of recognition of carers' needs and limit access to support.

A major systemic barrier for carers is the lack of acknowledgement and inclusion of carers in consumer assessment, discharge and ongoing care processes carried out by some health providers. As a consequence they are not appropriately provided with, or linked with supports by the treating clinician.

Inadequate funding for dedicated work with carers within the clinical setting and by mutual support organisations limits the amount of support that can be provided to carers. For carers in rural and remote areas, resources are even more thinly spread and may be difficult to access due to distance and associated costs. Access and affordability to services provided by allied and alternative health professionals, such as counselling and wellbeing programs, is beginning to be addressed under mental health Medical Benefits Scheme initiatives announced in the past two Federal Budgets and the COAG national action plan. However, there is a need to develop policy and practice guidelines that can contribute to service providers' maintenance of appropriate standards and services quality.

**Programmatic barriers** are presented by eligibility criteria, program priorities and related assessment measures that discriminate against people with mental illness, their families and carers. Carers encounter difficulties in accessing in-home and outreach support programs, such as Home and

Community Care and disability services funded under the Commonwealth State and Territory Disability Agreement, and Centrelink benefits.

A lack of staff skills and appropriateness of design and flexibility in delivery of generic programs can also reduce their relevance or usefulness to carers of people with mental illness. Some respite services have insufficient processes for ensuring carer participation in the development and delivery of respite services, and respite care provision frequently does not match the needs or preferences of the carer or consumer. Although the respite for carers of people with mental health funded through the COAG national action plan (developed in consultation with carers and carer organisations) may start to address these difficulties.

The roll out of the program requires the support of program and policy direction resources at state and territory level to ensure the development of nationally consistent, meaningful and innovative respite programs and the sharing of best practice.

Other programs such as counselling help lines, carer support groups or in-home services often fail to accommodate and meet the specific needs of carers of people with a mental illness.

Carers' access to relevant programs can also be restricted because of their particular life stage, relationship to the consumer, or the consumer's diagnostic category. Most available support programs are not tailored to the unique needs of young carers, partners and siblings of a person with mental illness, or to carers where the consumer has a dual diagnosis (especially substance misuse) or a non-psychotic condition (such as depressive, anxiety, eating and personality disorders).

***Mental illness related barriers*** can be complex. Foremost is the stigma and shame attached to mental illness. This deters many carers from seeking help for the consumer and formal support for themselves in managing caring and its impacts. Shame also prevents carers seeking support from extended family members, friends or work colleagues. Stigma in the community can also mean that families and carers are cut off by their informal networks and become increasingly isolated. For some families in Indigenous and culturally and linguistically diverse (CALD) communities, stigma can be an especially strong barrier to accessing both formal and informal support.

Other factors associated with mental illness also create barriers to support – its often episodic nature (in contrast to the constancy of care of somebody with a chronic condition or disability), and possibly the consumer's lack of insight and reactions when unwell to carers receiving services. Carers can feel that seeking help is not worth the trouble when the consumer is insensitive to the carer's needs or if they are resistant to or become distressed by engaging with services.

***Carer factors*** that reduce access to support relate to the carer's and family's own values of privacy and self-reliance and their limited knowledge of mental illness. This may result in failure to identify symptoms or seek help as they feel they are to blame and must face the situation alone.

Many carers who want support do not know where to start to get help. Most families are not familiar with support services, some workers do not discuss such services or the information provided may not be useful or relevant to their needs.

Promoting targeted support for carers can also fail to register with carers and families in the mental health sector. Carers of people with a mental health problem often do not identify with the term "carer" because of the less hands-on nature of caring, long diagnosis processes, sensitivity to consumer

feelings and independence or they are also consumers. For Indigenous and CALD families, the term has little cultural relevance as caring responsibilities are a usual part of family and community obligations.

The PMHCCN has been funded by the Australian Government to undertake a project primarily on carer identification. It includes:

- international literature search with the focus on the United Kingdom, USA, Canada, New Zealand, Germany, Sweden and the Netherlands to determine current practices regarding identification of the carer
- examination of national policies and state and territory mental health legislation to identify specific references to identification of carers
- examination of current policy and practice in the private and public hospital sector regarding identification of carers
- consultation to ensure the necessary input of both the private and public sector, support of key peak carer organisations and consumer input. Issues to be examined in consultations would include:
  - processes for identification
  - processes for review of engagement; and
  - identification of issues of concern for consumers and possible solutions.

The PMHCCN anticipates the implementation of recommendations from this project will facilitate more extensive carer identification and participation in the delivery of mental health services in both public and private sectors. Focus groups have been held in several locations across Australia, and are still to be completed.

Preliminary findings from these focus groups indicate similar findings to research by the MHCA and Carers Australia, which are discussed above in 2.1:

- Identification is hampered by lack of:
  - legislative requirements
  - a specific Carer Standard
  - policies and protocols to guide practice
  - poor understanding of the Privacy legislation (PMHCCN 2007).

**Financial factors** for carers of people with mental health have been poorly recognised and addressed. Carers often experience income inequality because of their reduced levels of paid employment. ABS (2004) data indicated that carers and their families are under-represented in the higher income quintiles, and over-represented in the two lower quintiles. At the same time carers must manage the extra financial costs related to caring such as medication, equipment, transport and communication, electricity and alternative care.

Access to Centrelink carer entitlements is a major issue for many carers of people with a mental illness. This may be because the Adult Disability Assessment Tool is inadequate to assess the caring responsibilities of carers of a person with a mental illness where constant prompting and encouragement may be required for the tasks of daily living, or constant reassurance with regard to anxieties and fears may be needed.

Many carers of people with mental illness are excluded from workforce participation because of their caring responsibilities, or leave the workforce earlier than they may wish. Initial application for the Carer Payment or Carer Allowance may be unsuccessful and require an appeal.



## Case studies

1. Carers QLD's advisory service received a call this morning from a 78 year old man who, along with his wife, cares for their son who has Schizophrenia. In the course of caring for him they perform many duties including financial management, shopping, dealing with challenging behaviours, etc. Their son has been living with them for over 17 years. For the previous 12 months they have been receiving the Carer Allowance. Recently their Carer Allowance was reviewed and they were deemed as no longer eligible. This has caused them a great deal of distress as they feel they are entitled to this money and, even more so, to be recognised for the care they are providing.

The father conveyed to Carers QLD his concerns about:

- a. Lack of understanding from the GP in their assessment of the person as to what the carer actually does. He mentioned that the GP spent only 10 minutes with their son in his assessment. We often hear of similar scenarios. Obviously this assessment is instrumental in determining if the carer receives the Carer Allowance.
- b. The points system does not adequately take into account the care activities preformed by carers especially people caring for a person with a mental illness. The assessment items are very much geared to assessing people with a physical disability or illness and are often not applicable to people with a mental illness.

2. Mandy cares for her 23 year old son who has been diagnosed with Schizophrenia. Mandy reports that her son is unreliable in taking his anti-psychotic medication, drinks excessively, and gambles away a lot of his Disability Support Pension. Mandy works full time, and she was informed that she would be unlikely to get the Carer Payment because of her income and assets. She applied for the Carer Allowance, and was advised that she was not eligible for this payment.

Mandy estimates that she provides 20 hours of care to her son a week. This care does not qualify as "personal care" (ie she cooks for him, cleans, washes his clothes, drives him to appointments – activities required at a level above that required for an independent adult), but does not provide the kind of personal care that would make her eligible for the payment (eg personal hygiene and mobility).

Mandy works full time, comes home to find her son agitated, and is worried about her financial situation. She is exhausted (physically and emotionally), stressed, not sleeping well and is 'worn out'.

3. Russ is a father of four children under 4 years of age. His wife became unwell with serious post natal depression and psychosis, which required hospitalisation for months. An order was placed on the family that she is to have no contact with the baby or the other children without the father's presence.

Russ was forced to leave work, and had to sell their home because of financial burden and unmet mortgage repayments. He was not able to receive the Carer Payment as his wife was (a) hospitalised, and (b) after discharge from hospital she was placed in a women's supportive housing organisation for psychosocial rehabilitation and intensive parenting counselling. Therefore, he was ineligible for the Carer Payment as the care recipient was not living with him, although he was travelling back and forth from Altona to North Melbourne, where his wife was placed, with the four children so they could be part of the therapy to reconnect their mother with the family.

Russ finally became eligible for the Carer Payment on his third application. At this time one of his children had been diagnosed with a learning disability, which may have made the difference.

*(Case studies were provided by Carers Queensland and Carers Victoria.)*

Strategies need to be implemented to reduce the financial hardship and disadvantage many carers of people with mental illness experience. This includes a review of the eligibility and assessment procession for the Carer Payment (Adult) and Carer Allowance (Adult) similar to the current review of the Carer Payment (Child).

Shorter-term measures to enhance access to the Carer Payment and Carer Allowance could involve education of Centrelink staff, and allow support workers in carer and support organisations to provide information and support to carers to help them complete their application.

Creation of a discretionary carer brokerage fund similar to that in Victoria, which provides financial assistance for items or activities that make it easier for carers of people with a mental illness to continue their caring role, should be implemented across each state and territory. In Victoria the fund has state-wide guidelines covering how it can be spent, decision-making processes and local accountability requirements.

Carers Australia recommends the Australian Government:

10. continue its commitment, and encourage state and territory governments to continue their commitment to significant increases in funding for mental health care commensurate with the national disease burden of mental illness. Accessible and appropriate consumer services, oriented to prevention, early intervention, recovery and a broader family focus, are required to significantly reduce carer burden and facilitate timely carer support
11. commit to improved planning, resourcing, coordination and equitable provision of a comprehensive range of mental health carer and family supports provided through mental health and carer services that meet carers needs at all stages of their caring experiences
12. target mental health carer support resources to strengthen and expand successful programs; provide greater flexibility and meet the needs of carers of people with a mental illness, including groups with particular needs such as Indigenous, young and CALD
13. encourage COAG members to extend their Individual Implementation Plans to include funding to implement carer identification strategies to assist carers, general practitioners and mental health service providers
14. urgently review eligibility for and access to the Carer Payment (Adult) and Carer Allowance (Adult) for carers of people with mental illness, similar to the current review of the Carer Payment (Child)
15. encourage COAG members to extend their Individual Implementation Plans to include discretionary carer brokerage funding to provide financial assistance to carers of people with a mental illness
16. increase and apportion funding for people with psychiatric disabilities and relevant support services in the 2008 Commonwealth-State Housing Agreement

### **3.4 Support for specific needs carers**

#### **3.4.1 Introduction**

Carers Australia recognises that support should be appropriate to the diverse needs of the mental health carer population, but identifies three particularly disadvantaged groups – Indigenous, CALD and young carers.

### 3.4.2 Indigenous carers

Indigenous communities in Australia reflect diverse geographical contexts including rural, remote, provincial, urban, inland, and coastal or island environments. Each community has its own unique pattern of affiliations, cultural values and traditions.

Research conducted by Carers Australia, and in partnership with the MHCA, has identified specific needs and service support requirements for carers in Indigenous communities. These include:

- Carer support is enhanced when Indigenous mental health workers are based in local Indigenous communities. This helps the worker to establish trust and proper accountability with community members including those experiencing mental illness and their carers.
- A culturally sensitive orientation can help facilitate either traditional or Western approaches being used for the support of people with mental illness and their carers.
- Within Indigenous communities care for a person with mental illness is often provided by an extended group of carers rather than by a sole or dominant primary carer.
- Cultural awareness training is needed for staff in mental health and other services to foster respect, understanding and empowering approaches to engaging and working with families and communities.
- Development of collaborative relationships with Indigenous organisations and community elders requires time and flexibility to establish trust and dialogue about appropriate interventions and support.
- Training and employment of Indigenous workers within mental health services or in local non-government organisations is essential. Indigenous mental health workers are able to approach their work with an orientation and expertise which can interpret mental illness in a cultural context.
- Resources are required for developing tailored support programs or, where relevant, introducing existing models to new areas in collaboration with local communities. For example, the “Troopy” outreach respite program in the Northern Territory, Koori Yarning counselling approach in New South Wales, an indigenous support coordinator at Carers ACT, or untied funding for Koori carer support in area mental health and other key services in Victoria.

### 3.4.3 CALD carers

Approximately 40 per cent of Australians were born in countries where English isn’t the first language, or who have at least one parent with a non-English speaking background. 2006 Census data indicates an increase in Australian households that don’t speak English at home. It also indicated that almost 400 different languages were spoken in homes across Australia (ABS 2007).

The prevalence of mental illness among immigrants varies considerably according to country of birth, but the overall rate is not significantly different to that among people who are born in Australia. Despite this similar overall prevalence, mental health services (community-based and in-patient) are significantly under-utilised by non-English speaking background communities. This is due to a complex range of factors, which include:

- high levels of stigma associated with mental illness and psychiatric treatment among non-English speaking background communities
- lack of information about services and how to gain access to them
- the general lack of culturally appropriate services
- great shortages in the availability of interpreters and of bilingual and bicultural mental health professionals in the service system.

This under-utilisation has important implications for families and particularly for carers, and suggests a significant proportion of people from CALD backgrounds with a mental illness are receiving either no treatment or inadequate treatment (MHCA and Carers Australia 2000).

It is also important to recognise that parent carers with a non-English speaking background may have a very different interpretation of mental illness and the role of intervention strategies to those of their son or daughter with a mental illness or the professionals who treat them.

Given the high incidence of families experiencing both mental illness and ethno-cultural diversity, mental health and generalist services must value skills and knowledge in ethno-cultural matters as core practice expertise if they are to effectively address the needs of this large group of consumers and carers.

Targeted action is needed at systemic and program levels to foster support that better meets CALD carers' and families' needs. This includes:

- Cultural sensitivity training regarding mental health and caring issues in migrant communities, targeted at general practitioners and mental health professionals to increase knowledge and skills in communicating and working with CALD consumers and their families.
- Planned liaison with ethno-specific and other organisations with expertise in working with particular community groups prominent in the service's catchment area. Such organisations can provide in-service training or consultation as required.
- Training and employment of bilingual-bicultural workers within the service or broader region, with a preference for workers with personal experience of caring and, or mental illness in their families.
- Flexible support programs to establish relationships with families and community organisations that are developed according to their preferences and needs. Carers express a need for practical assistance and a range of social support options including carer support groups and family activities, ethno-specific help lines, community visitors, transport and respite care relevant to their circumstances.

Funding for CALD information and resources needs to reflect the additional costs required for their development and distribution to CALD communities.

#### **3.4.4 Young carers**

There are at least 384,000 young carers in Australia who care for someone with an illness, a disability, a mental illness or who has an alcohol or other drug problem. Of these, 170,600 young carers are under the age of 18, and 177,400 are aged between 18 and 25 years.

Over half of young primary carers provide care for a parent, who is likely to be their sole-parent mother. A third of young primary carers provide care for their own child or partner. Approximately 25 per cent of all young carers provide care for someone with a mental illness – although this figure is thought to be underestimated (Carers Australia 2002).

Carers Australia data indicate mental illness ranks third behind physical and intellectual conditions in reasons young carers provide care (Carers Australia 2007b).

Young carers are often socially and economically disadvantaged because of their caring responsibilities and their family situations. They have poorer education than non carers, and are less likely to complete secondary school or undertake tertiary education. Only four per cent of primary young carers between the ages of 15-25 are still at school, compared to 23 per cent of the general population (ABS 2004 and Carers Australia 2002). The consequences of this poorer education can have lifelong consequences for young carers, their families and the Australian taxpayers that may have to support them.

Sixty per cent of older young carers (18-25 years) in Australia were not employed compared with 38 per cent of non carers in this age group (ABS 2004). International research supports this trend that caring reduces access to education, and consequently leads to their reduced employment opportunities.

A report released earlier this year by the Australian National Council on Drugs (ANCD) highlights the high number of young Australians living in households with substance users. The report estimates that over 550,000 children aged 12 years or younger live in households where at least one adult binge drinks, at least one adult uses cannabis daily, or they live in a household with an adult who uses methamphetamine at least monthly. The report highlights the likely correlation of substance abuse and mental health problems of their parents or adults living in the household.

“Key point 5. Parental substance misuse might be seen as a possible marker of co-morbid parental psychopathology, which may in itself contribute to greater impairments to child outcomes than substance use alone. To improve child outcomes in substance-abusing families, treatment programs need to attend to the management of parental mental health issues and their corresponding impact on the parenting role.

Key point 6. To improve child outcome in substance abusing families, treatment programs need to attend to the management of parental mental health issues and their corresponding impact on the parenting role. In practice, this might translate into both improved training opportunities for alcohol and other drug (AOD) workers to help better address mental health issues, and improved liaison with mental health services. It appears likely that employing experienced mental health workers in AOD services will increase the use of such treatment options within substance using families.”

The report recommends that the interplay between parental substance use, mental health and child outcome should be a particular research focus. The report also indicated a clear pattern that showed the highest rates of binge drinking amongst those with children are single mothers and the lowest rates are amongst women in couple households (ANCD 2006).

As young carers are a vulnerable group, strategies need to address the family context of young caring as well as young carers’ separate need for support. In particular, coordination of policy and practice between services for young carers and mental health services, alcohol and drug dependant persons

services, family support services and child protection services need to be considered under the COAG national action plan.

There is a need to consolidate and extend the initiatives targeting children of parents with a mental illness recently developed in most states and territories. Programs under the Children of Parents with a Mental Illness (COPMI) and CHAMPS raise worker and parent awareness of consumers' children's needs, and provide interventions to support parenting and build resilience in all children.

Strategies are also needed to increase recognition and additional support for children and young people who have substantial caring responsibilities for a parent or sibling with mental illness. These include:

- Training for general practitioners and mental health staff to raise awareness of and capacity to engage and work with young carers.
- Employment of young carer workers on a regional basis to work directly with young carers from the sector, on an outreach and ongoing basis, to address the often complex family needs and ensure links to appropriate local family support services which can support the maintenance of families during crisis periods.
- Resources for the development of a range of peer based programs in the region, including groups, camps, social activities and networks.
- Building on existing school based mental health or young carer programs to increase awareness of young people caring for a relative with mental illness and develop school based support opportunities.

In addition there is a need to increase awareness and support for siblings of young mental health consumers through worker and parent education, and dedicated sibling support programs. Some of the COAG Individual Implementation Plans on Mental Health include funding for this support.

Carers Australia recommends the Australian Government:

17. commit additional funding to address the identified gaps in resources and access for Indigenous, CALD and young carers of people with mental illness
18. fund Carers Australia to coordinate a national program for young carers of people with mental illness, to sit within the FaCSIA-funded national Support for Young Carers Program
19. through the COAG national action plan coordinate policy and practice between services for young carers and mental health services, alcohol and drug dependant persons services, family support services and child protection services
20. develop a communication strategy for the distribution and delivery of information and education resources that takes into account the diversity of carers of people with a mental illness, key entry and transition points in the carer journey and many carers' preference for personalised discussion of available information

## **3.5 Education and training**

### **3.5.1 Introduction**

Carers' access to support is critically linked to the recognition of, and response to, their needs by workers in clinical and psychiatric disability support services. There is a need for clearer local policy directives, practice guidelines and accompanying tools and training to generate more supportive relationships and carer referrals as part of mental health service delivery.

As part of the Carers of People with Mental Health Project report, the MHCA and Carers Australia identified that although organisations are dedicated to making valuable contributions and effort, the Australian mental health community develops education, training and information resources for carers in a generally fragmented manner. This effort occurs in the absence of a sector wide common or shared approach to needs analysis, educational design and learning methodologies, curriculum and resource development (including the concept of core and specific knowledge), overall standards setting and the effective monitoring of education and information service delivery.

The report called for urgent action to promote collaboration by mental health organisations on education and information development for carers within an agreed framework of national standards. This process must practically support day to day service delivery in states and territories and involve carers in all phases of product and resource development (MHCA and Carers Australia 2000). Carers also benefit from specialised carer education and training programs developed for carers of people with mental illness.

### **3.5.2 Workforce education and training**

A major plank in the successful implementation of any carer participation policy is the planned and coordinated education of mental health professionals and service providers driven by governments and professional bodies.

The present level of education provided in some states and territories through public sector staff orientation, in-service seminars, targeted workforce training, psychiatric trainee education and general practitioner education under the Better Outcomes in Mental Health program is inadequate to achieve and sustain culture change regarding carers. However, with the funding now available through the COAG national action plan across national and state and territory levels this may now improve. Also, DoHA and the Australian Government Department of Families, Community Services and Indigenous Affairs (FaCSIA) are funding local and community programs through the COAG national action plan.

Workforce training for professionals who deliver mental health care will need to address a number of key barriers carers encounter. These include training in a better understanding of the range of mental illnesses, carer sensitive practice and avenues for carer support.

General practitioners, mental health professionals in public and private sectors, and other key primary and acute health care providers need skills, knowledge and the right attitude to build partnerships with carers. This will require an ongoing education strategy through undergraduate, postgraduate and continuing education programs targeted to professionals delivering specific programs or employed in public and private mental health systems.

DoHA, through its Sharing Health Care Initiative, is having some of this engagement through its 'Analyse the Training and Information Options to Support Chronic Disease Prevention and Self-Management in Primary Health Care' project. This project will investigate the knowledge and skills

required by health professionals to support patients in the prevention and self-management of chronic disease. There are other health professional education initiatives included in the individual implementation plans under the COAG national action plan.

At present there is little systematic or in-depth training in working with and supporting carers. Although, a number of distinct programs exist in some states and territories, eg New South Wales, Victoria and the Australian Capital Territory offer one-off training to mental health staff of differing length and focus. These programs have positive impacts, but generally lack the capacity to reinforce practice changes through follow-up training, in-service sessions or consultation.

### **3.5.3 Compliance with national standards for mental health services**

Carers NSW stated in its recent submission on the review of national standards for mental health services conducted by the Australian Council for Healthcare Standard that:

... feedback provided to Carers NSW through its consultation processes has highlighted the need to ensure that services actually understand and, most importantly, implement the standards. Without implementation and compliance, the standards are merely a set of guidelines that identifies 'best practice' for mental health services rather than a realistic blueprint for action and improvement.

This failure to implement policy is endemic within the mental health system, as highlighted by Kathy Griffiths, Associate Professor and Director of the Depression and Anxiety Consumer Research Unit and Co-Director of ehub: research and development at the Australian National University:

"As noted by the evaluators of the outcomes of the Second National Mental Health Plan, the problem is not with the policy but with its implementation and in particular with "failures in investment and commitment" (Steering Committee for the Evaluation of the Second national mental Health Plan 1998 – 2003, p. 3)" in Health Issues Journal, Summer 2006, Issue 89 - Griffiths K. "Policies without Progress: Two Decades of Mental Health Services in Australia".

Implementation and compliance is an unrealistic expectation without "investment and commitment". If the standards depict the quality measures that are required to be met by a mental health service, support must be provided to the service to enable it to meet these requirements.

Such support should primarily focus on education and training for services to encourage and sustain a commitment to the standards through all levels of staffing. Increased funding may also be required to enable services to engage or assign adequate resources to effect any required adaptation of internal policies or processes (Carers NSW 2007).

### **3.5.4 Training for staff outside the mental health sector**

Carers come into contact with staff from a wide range of services outside the mental health sector in seeking treatment and support for the consumer, and in seeking assistance with their own needs. Low understanding of and skills in mental illness and carer support needs of these workers can form significant barriers to carers' access to supportive relationships and practical assistance.

There is a need for systematic cross sector training about mental illness, caring experiences, ways of positively responding to consumers and providing relevant carer support. Regional carer services and state- and territory-wide carer organisations can play a significant role in enhancing services capacity to



work sensitively with carers when appropriately resourced. The Chronic Illness Peer Support Program (CHIPS) program delivered by Carers NSW as part of its mental health project is an example of a consistent and planned approach to worker training.

### **3.5.5 The need for carer education and training**

Caring can last a long time, and negative impacts of caring may be ongoing, or spread over many years. Australian Bureau of Statistics (ABS 2004) data indicate that 60 per cent of primary carers over the age of 15 have cared for five years or more and a third have cared for 10 or more years. In some cases caring lasts more than 30 years. Negative impacts of caring may be ongoing, or spread over many years.

The National Survey of Carer Health and Wellbeing research undertaken by Carers Australia found that the physical, mental and emotional health and wellbeing of most carers was poorer than non carers because of their caring responsibilities. As a result of caring:

- over half of all carers suffered a decline in their physical health
- one-third of all carers had been physically injured providing care
- two-thirds of carers felt their mental and emotional health had been affected by providing care
- constant pressure of caring, stress, disturbed or lost sleep and providing mobility such as lifting and transferring were the most common reasons affecting health
- around one-third of carers reported that they found it difficult to undertake or delayed having treatment such as visits to the doctor, hospital treatments, operations, and therapies such as physiotherapy because of their caring duties (Briggs H and Fisher D 2000).

The Independent Living Centre of WA (2006) surveyed over 1,600 carers in Western Australia in 2006 and found similar results. Providing care was demanding and had a significant impact on a carer's health:

- 43 per cent of carers had been physically injured as a result of providing care
- 65 per cent of carers said that they had a health condition after becoming a carer
- 42 per cent of carers who had been injured while caring required extra assistance to continue caring
- the higher demands on the carer the more likely they were affected by continuing to provide care.

Of major significance to this inquiry is research undertaken by Carers Queensland and the University of Queensland (2005) that found 25 per cent of 1,200 carers surveyed were clinically distressed (Pakenham et al 2005).

Carers Australia has begun to collect data on carers coming for counselling who are experiencing suicidal ideation over July 2007 to June 2008. This initiative arose from counsellors concern over the incidences of carers talking of 'ending it all'. It may be that very few people really intend to take their own life, but many do want their current life to 'stop'. Both our in-house and brokered counsellors have been asked to be alert for behaviour that may reflect suicidal intent. Exploration of suicidal intent and possible plans, and lethality of such plans is imperative. At the conclusion of the research period, a report will be collated and presented to DoHA, with an analysis of the effectiveness of the counselling intervention, and appropriate recommendations.

The above findings demonstrate that carers can become physically and emotionally exhausted influencing their capacity to care, and the quality of care they are able to offer. Research and feedback from carers indicate that specialised carer education and training can reduce the injury caused by

caring, and also improve their wellbeing, particularly mental wellbeing (Pagnini 2005 and Carers Australia 2007a).

Carers Australia recommends the Australian Government:

21. in collaboration with professional and industry bodies, fund and ensure coordinated, comprehensive workforce training for mental health services provides on carer issues consistent with the National Standards for Mental Health Services
22. commit funds to increase sustainable undergraduate and continuing education programs targeting mental health care providers to ensure adequate knowledge and skills to appropriately identify and respond to carer and family support needs, including the needs of specific population groups of carers of people with a mental illness
23. fund national sustainable education and training programs to be delivered through Carers Australia for all carers to minimise the adverse affects of caring, including mental, emotional and physical wellbeing
24. continue and expand funding for initiatives to improve carers' health and wellbeing, including professional education and training, and carer access to MBS Chronic Condition programs

### **3.6 Information and carer resources**

#### **3.6.1 Introduction**

The National Mental Health Strategy 2003-2008 (and its companion documents such as the Mental Health Statement of Rights and Responsibilities and the National Standards for Mental Health Services) outlines the policy base for the provision of funding and program resources to respond to the needs of carers and consumers. One of the 11 principles underpinning the national strategy is directed at the provision of resources. It specifically states that these must recognise the impacts of mental health problems and illnesses and be directed at interventions ranging from promoting mental health through to prevention and recovery.

Carers Australia research has indicated that a vast array of mental health information and education resources exist. Many of these are duplicated, and there is no central repository listing available information and resources. They are provided to carers by a range of national, and state or territory based government and non-government bodies in the mental health sector and other sectors. Research also identified that the development and distribution of resources was uncoordinated and fragmented. Development, distribution and delivery of information and educational resources are strongly influenced by the nature of the program developer and the auspice under which it is developed.

The MHCA argued in 2003 in its *Out of Hospital, Out of Mind* report for nationally consistent, but locally relevant training and education programs for carers.

The individual implementation plans by national, state and territory governments that form part of the COAG national mental health plan all allocate funding to develop and distribute information and resources. The challenge to governments will be to ensure national consistency of services, and their adequate development, distribution and access across Australia to carers and consumers.

#### **3.6.2 Gaps in information and resources**

Although Carers Australia has identified there is a plethora of information and carer resources available, carers consistently indicate difficulty in finding relevant information and report it is not offered to them.

Particular disadvantage is experienced by CALD carers, and carers of a person with a mental illness who receives treatment and care from general practitioners and private psychiatric services.

Barriers carers face in accessing information and services are outlined in Table 3 below.

<b>Table 3 Barriers to accessing carer information and resources</b>	
<b>Gaps in Information provided</b>	Information needs of carers as they change over time
	Information needs of carers arising out of specific carer/consumer relationships
	Information needs of carers in relation to certain mental illness
	Information needs of carers from CALD communities
	Information needs of carers for coping strategies
<b>Access issues</b>	Identification as carer
	Diagnosis of mental illness
	Stigma and denial
	Information poorly distributed through sector <ul style="list-style-type: none"> <li>▪ General practitioners rarely give out information</li> <li>▪ Carers of consumers in private care may have difficulty accessing some information</li> </ul>
	Information on Internet restricted to those with access
	Information on Internet limited by language and availability of translation
	Written information assumes literacy
	Written information not provided in wide enough range of languages
	Written information assumes preference to learn by reading
	Lack of cultural awareness and sensitivity by service providers
	Lack of culturally and linguistically sensitive material

*(Reproduced from Carers of People with a Mental Illness Project report, Carers Australia (2006).)*

Gaps in the availability or provision of resources to carers were identified relating to carer coping strategies and for particular sub-groups of carers of people with a mental illness. Information and resources needed at the different phases of the caring journey were lacking.

It has been found that the resources available do not meet the information needs of carers as they change over time, and resources are mostly general (Pagnini 2005). Education programs were particularly lacking for carers of people whose mental illness has not yet been diagnosed, and for long-term and ageing carers. Other carers for whom there is limited information include specific relationship groups (partners, siblings and young offspring, grandparents), diagnostic groups (high prevalence disorders and other non-psychotic disorders) and CALD families.

In addition to the need to be supported in the practicalities of caring for a person with mental illness in physical, legal and financial dimensions, carers have additional needs which arise out of the enormous toll that caring places on them. These include managing stress, anxiety, interpersonal relationships, financial and legal matters and their own health. Carers unequivocally say that their job would be made easier if they received extra information and support.

Options to address these issues include:

- Commitment to sector-wide and cross-sector collaboration on the development and distribution of information and education resources, drawing on the varied expertise across the sector, eg non-government organisations, Carers Associations, government mental health services, professional bodies, academics and other independent bodies.

- Commitment to address gaps and deficiencies in information and education resources that have already been identified.
- Commitment to non-government organisations and other community organisations collaboration for the development and distribution and delivery of resources for carers from CALD communities.
- Initiatives to engage general practitioners and primary health care providers as vital first point of contact by carers for information and referral.
- Commitment to continue to raise mental health literacy in the community, and awareness of caring experiences and avenues for further information and help.
- Education of mental health care providers about carers' need for information and key access points for information and education.
- Commitment to provide information using different learning styles and the use of different media such as audiovisual and personal delivery.
- Commitment to continue to resource support groups, which are generally led by carers and provide a supportive environment in which information and experiences can be shared.

Information, education and support for the carer have direct and positive impacts on the health benefits for the person with a mental illness. These include:

- reducing the incidence of relapse
- improving adherence to treatment
- improving family functioning
- increasing periods of wellness
- improving the consumer's quality of life and social adjustment.

### **3.6.3 Lack of specific mental health information and resources**

A range of information and education is provided for carers about the services that are available to support them in their role. Similarly, information is available about serious mental illness. Carers indicate that less information and education is available on non-psychotic disorders such as anxiety, depressive, eating and borderline personality disorders. Carers of people with these disorders are less likely to engage in programs directed at carers of consumers with a more serious and less prevalent mental disorder.

Carers also identified that there was no routine approach to incorporating ongoing prevention within the mental health system. Consumers, their families and carers had no expectation of receiving an holistic, ongoing and planned approach to continuing care.

Carers Australia recommends the Australian Government:

25. commit to, and resource, the coordinated development, distribution and evaluation of information and education resources for carers of people with a mental illness as a priority
26. commit funds to address the identified gaps in resources and access for specific population groups of carers of people with a mental illness
27. monitor the inclusion of carers and people with a mental illness by mental health service providers in the development of ongoing and future care plans, and the provision of adequate information and resources to maintain these care plans
28. fund an ongoing national information campaign to destigmatise mental health, and to inform consumers and carers about available services and access points.

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