



Private Mental Health
Consumer Carer Network (Australia)
engage, empower, enable choice in private mental health

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Submission to the Inquiry into better support for carers June 2008

We thank the House of Representatives Standing Committee on Family, Community, Housing and Youth for the opportunity to provide comment on the consultation to the Inquiry into better support for carers.

The *Private Mental Health Consumer Carer Network (Australia)* (hereafter Network) represents Australians who have private health insurance and/or who receive their treatment and care, and those that care for them, from private sector settings for their *mental illnesses or disorders*. As our title implies, the Network is the authoritative voice for consumers and carers of private mental health settings.

The Network is committed to working with Government and would be pleased to work with the Inquiry Committee and relevant others in addressing the needs of carers. Mental Health brings with it many challenges, not the least for carers. As a consumer and carer organisation we are in a unique position to provide direct lived experiences to the Committee and would welcome the opportunity to engage in further consultations, either independently or with other relevant organisations.

To add to our credentials, in 2007 The Australian Government, Department of Health and Ageing funded the Network to undertake a project examining issues associated with the identification of carers, prior to the future development of burden of care measures for carers. This entailed international literary search and extensive consultations throughout Australia with mental health carers, consumers and both public and private service providers. A number of key recommendations emerged from this Project.

1) Role and contribution of carers in society and how this should be recognised

Much has been written over a number of years regarding the desirability of involving carers in the care and treatment of people with a mental illness. Policies and legislation have been developed to reflect this philosophy. A large volume of literature also exists clearly describing the needs of carers. However, service delivery in Australia continues to be individually focussed with carers largely unidentified and uninvolved.

It is recognised that the whole area of carer involvement is very complex. It is known that consumers can sometimes feel very differently about whether they actually want a carer involved in their treatment, who that person should be, and in what capacity, and to what extent someone can, or should, act on their behalf. This is particularly relevant when a consumer is subject to mental health legislation.

It is also recognised that most carers currently view their involvement within mental health service processes as very inadequate and often tokenistic.

The National Mental Health Strategy, implemented over the last 15 years, has had a primary focus on consumer rights. Unfortunately, carer rights have not received the same level of attention.

Consumers, carers and service providers share the common goal of improved treatment outcomes, relapse prevention and recovery. The achievement of these goals will be greatly facilitated by all parties working in partnership. This is currently the exception rather than the rule. Carers are increasingly vocal in their need for recognition and inclusion.

First task – Formal identification at health service level

The process of identification of carers is complicated at an individual and community level because of continuing stigma associated with mental illness. At a service delivery level it is complicated by poor understanding of privacy legislation, lack of skills and organisational structures that perpetuate current practice. These issues must be addressed as a first step toward recognising the role and contributions of carers.

Carers have an important role to play in all situations where a person has an illness, however, specific identification of carers is most important in situations where their role is likely to be ongoing over an extended period of time such as when they are caring for a person with a long term mental illness.

Second task – How can this be accomplished

- The ideal process for identification is by the consumer. These discussions together with the degree of involvement should be negotiated, documented and regularly reviewed at times when the consumer is well.
- Some consumers will, from time to time, because of the nature of their illness, refuse to identify or to involve carers.
- Consumer refusal to identify does not lessen the burden on carers. It may in some cases increase the burden of care.
- Consumer refusal to identify carers should not prevent clinical staff from having a working relationship with the family/carer. Carers have a right to give information to clinical staff to assist in assessment, treatment and ongoing care.
- Identification is not a one-off process. Service providers need policies, training, support, regular monitoring and legislative backing to enable them to develop the skills to build the process of identification, and participation, into every day practice.
- The use of the term 'carer' reduces the likelihood that people will self identify. Many people see themselves as supporting a person with a mental illness because of their close caring relationship with the person, not as their carer. The majority of people in this role don't feel they need the label of carer – unless they need to apply for the Carer Allowance or Carer Payment. There is, however, a need identified for a common description.
- Few identification policies exist in current services and practice varies significantly from one location to another. In general, health services make little effort to identify or involve carers.

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- Clinicians who are recent graduates are more open to actively identifying carers than longer practicing/more experienced clinicians, especially in their early years in service delivery.
 - Identification is hampered by lack of the following:
 - Legislative requirements to identify carers within the mental health service systems with accompanying government policies for implementation,
 - Policies and protocols to guide practice

Understanding of the Privacy Legislation and its practical application, within both public and private inpatient and community mental health settings.

- Change in clinical practice will take time and may be assisted by the following:
 - Modification of data collection systems to facilitate identification of primary supports for consumers,
 - Development of carer identification forms for inclusion as a standard component of all health records,
 - Amendments to Mental Health Legislation to mandate identification and support of carers,
 - Appointment of Carer Consultants/Liaison Officers in public and private health services to support change in practice,
 - Development of carer packs of information for distribution by public and private mental health services, carer organisations, non-government organisations, pharmacies, and for downloading by carers from identified web sites,
 - Encouragement of people with long term mental illness to develop Advance Directives or relapse prevention plans that include identification and desired level of involvement of carers,
 - Development of specific Carer Assessment legislation and protocols.

2) Barriers to social and economic participation for carers

The experience and nature of a mental illness is obscure and difficult to understand. Family members are generally the first people to witness the emotional, personality and behavioural changes that accompany the onset of mental illness. In the case of psychosis, the individual's lack of insight and loss of touch with reality, together with the absence of an obvious physical illness, can be frightening and bewildering for the family. Families of people with mental illness experience great stress and confusion because they can not see what is happening, don't know what to do or how to help. Unpredictable bouts of extreme behaviour can result in contact with the judicial system, family conflict and breakdown.

Mental illness frequently manifests in adolescence and, if complicated by concurrent substance abuse, may take some time to diagnose. The losses, grief and

adaptations that families of people with a mental illness usually face are frequently different to families where there is a congenital or birth related condition, or one which is evidenced in early childhood. They are different again from the losses associated with care of an ageing parent or partner. Due to this different age of onset and the unpredictable course of mental illness, roles and relationships need to be changed and re-formed on an ongoing basis. The responsibility for recognising the profound sense of grief that families experience must rest with all health professionals encountered during their search for help.

The cyclical and episodic nature of some mental illnesses and the effects of variations in treatment compliance can also create additional stresses for carers of people with a mental illness. It complicates the grief process for family and friends and can impact on their ability to continue to in any meaningful employment. Uncertainty, the emotional roller coaster and need to adjust relationships and care responsibilities can place different demands than when the individual's condition is stable or progressively deteriorating. For most other long-term carers, adaptations tend to occur with life stage changes or functional decline.

In addition, the stigma, guilt and isolation experienced by those providing care for people with a mental illness are much greater than for most other conditions, and create significant barriers to people self identifying by asking for help from both formal and informal sources. Cultural factors may intensify these experiences. Carers of people with a mental illness are often deeply affected by adverse responses by neighbours, friends, school communities and extended family members. Blame and shame, and lack of support have a significant negative impact on the carer's wellbeing in turn affecting their willingness to support the consumer in an ongoing manner.

In the mental health area the policy of non institutionalisation has created a situation where a significant portion of care is provided by unpaid carers – with the biggest burden falling on women, many of whom are becoming older. Some alarming projections have been made about the dwindling supply of carers. The decline can be traced to decreased birth rates, a greater number of older family members than younger ones, more working women, increased divorce rates, and more families having children later in life. This makes it all the more important to identify, involve and value carers of people with long term mental illnesses

In recent years one of the most significant groups of carers to be recognised is children and young people. Often in single parent families, children or young people have to take on significant caring responsibilities in the absence of other family and community support. They form an even more hidden group of carers, making identification essential in order to minimise the impact on their social, educational, emotional and health needs, and on their future life opportunities. A sub group of these carers are young people who are thrust into this role via way of their being the interpreter in situations where parents have limited English language skills.

3) Practical measures required to better support carers

Carers tell us that staff in mental health services do not feel comfortable in actively working with consumers to identify carers or in working in a partnership manner with carers.

Staff in both public and private mental health services require access to practical guidelines for implementation of privacy legislation and additional training in their

implementation. The disclosure of information by clinicians about consumers is governed by legislation that varies from State to State. Clinicians must routinely seek a consumer's permission to share information. However, even when permission is denied, carers can be listened to and given sufficient knowledge for them to provide effective care. The essential component of this process is the identification of the carers.

Adoption of a partnership approach to care that is inclusive of carers will save time for service providers in the long run. If carers feel supported they will be able to maintain consumers for longer periods of time in the community thus reducing re-admissions.

The role of carers needs to be recognised by all practitioners, but currently professionals admit there is reluctance among some staff to work with carers. This reluctance has its roots in structural problems: lack of professional training (and hence confidence) to work with carers; insufficient capacity (acknowledged as lack of time) to work effectively with carers as well as service users on their caseloads; and the environment (most notably on wards) not being conducive to sharing information with carers. However, it also stems from stereotypes of carers and family members as over-involved, difficult and better avoided.

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.

4) Strategies to assist carers

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. This ensures a whole of government approach to ensuring that policy, program and service development meets the needs of carers. However, while these Carer Recognition Acts provide legislative recognition for carers they do not address the issue of identification particularly in the mental health area where there is a balance that has to be achieved between the right to privacy for the consumer and the carers' need for information in order to achieve better outcomes for the consumer.

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.

Caring responsibilities exact a price and provision of support will minimize the impact on the following:

- The emotional and physical wellbeing of carers;
- Employment opportunities strains placed on daily working life;

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- Educational activities and opportunities, particularly for younger carers;
 - Social relationships;
 - Family roles and relationships;
 - Financial costs associated with the illness; and
 - Long-term care prospects.

Carer empowerment is crucial. It will also:

- diminish the sense of isolation and of carrying the burden alone; and
- improve long term care prospects for consumers in the absence of limited support from service systems.

Identification is also necessary if carers want to seek financial assistance to support them in their caring role. Carers of people with a mental illness can potentially apply for either a Carer Payment or a Carer Allowance. The Guidelines for funding state:

The person(s) being cared for must be:

- *likely to suffer from the disability permanently or for an extended period of at least 12 months (unless their condition is terminal) assessed by a medical practitioner or other approved person as meeting the medical eligibility criteria.*

In order to apply for either of these benefits, the carer must first identify as such, or be identified by a health professional. There is then an in depth process to be completed. The questions asked as part of this process do not take account of the episodic nature of many mental illnesses. Similar processes are a requirement for application of funding for respite care funded as part of the COAG National Action Plan. This matter has been brought to the attention of the Government on many occasions, however, processes continue to discriminate against carers of people with a mental illness.

Conclusion

The Network has been pleased to provide this Submission to inform the Inquiry into better support for carers. We would be very pleased to discuss this submission or aspects of the Committee's Inquiry directly from a carer 'lived' experience.

We also believe it crucial that we brief the Inquiry Committee on the findings and recommendations of the Network's *Identifying the Carer Project, 30 September 2007*, the outcomes of which are extremely relevant. The content of this Submission has been taken from portions of that Report. We formally request, the opportunity to expand upon this submission and brief the Inquiry Committee.



Janne McMahon OAM
Independent Chair
4th July, 2008