

## EXECUTIVE SUMMARY AND RECOMMENDATIONS

In 2007 the Australian Government funded the Private Mental Health Consumer Carer Network (Australia), (hereafter the Network) to undertake a project *Identifying the Carer*, examining issues associated with identification of carers as a precursor to the future development of a burden of care measures for carers.

In addition, a number of other activities at national, state and territory levels have occurred in recent years that mandate carer engagement in all levels of service delivery. These changes include the following.

- Development in some states of state-based Carers Recognition Legislation.
- Development of the national *Carer Recognition Act 2010*.
- Development of a specific Carer Standard in the revised *National Standards for Mental Health Services, 2010*.
- Revision of mental health legislation in some States and Territories to mandate identification in a variety of forms.
- Revision of the *National Mental Health Policy [2009]* and funding of the *Fourth National Mental Health Plan, an agenda for collaborative government action in mental health 2009–2014*.
- Publication of the Royal Australian and New Zealand College of Psychiatrists (RANZCP) Guidance Notes, *Involving Families, 2000*.

**The needs and rights of carers of people with a mental illness have now been very comprehensively described in both legislation and policies. Following such comprehensive description one would expect a plethora of information and activities designed to meet these needs. This does not appear to be the case and while some States and Territories have developed guidelines for consumers, family carers and mental health professionals to work together in collaboration and partnership few changes have occurred at a practical level. Many have argued this relates to lack of processes to identify who carers actually are.**

In an attempt to progress these issues the Australian Government in 2009 funded the Network to undertake a further short term project with the following deliverables.

- **Development of draft nationally consistent identification policies and good practice protocols.**
- **Development of draft nationally consistent information packages for carers.**
- A search of the international literature revealed a continued focus on carer needs and rights for engagement. Increased evidence is available that

substantiates the benefits of carer engagement in all processes of care and treatment. However information related to managing the complexities associated with carer identification is limited with the Network's Report of the *Identifying the Carer Project, 2007* prepared by the same author appearing as the primary new work in this area. Some literature is also available regarding identification of general carers in GP practice in the National Health Service in the United Kingdom that has relevance to the carers of people with a mental illness.

For completeness the literature search has been updated and re-describes the following.

- The rationale for carer identification and engagement, including:
  - Carer rights; and
  - Impact of carer identification and engagement in relapse prevention for consumers.
- Impediments to identification, including:
  - Use of the term carer;
  - Privacy and confidentiality;
  - Workforce education and training; and
  - Organisational and cultural issues.
- Advance Directives.

Consultation was undertaken nationally by way of face to face focus groups in Melbourne, Adelaide, Brisbane and Launceston. Specific invitations were provided to carers identified as having interest and expertise in pursuing this topic as well as carer focused non-government organisations. Service providers and consumers from both public and private services were also invited to participate in this process to achieve balanced views. Telephone consultation was undertaken with Carer groups in other States and Territories and specifically identified individuals with a long history of working with carers. In recognition of their time and expertise, participants were paid a per diem rate for their participation in the focus groups.

In addition, individual meetings were held with representatives from the Royal Australian College of General Practitioners, Medicare Australia, Australian Council of Health Care Standards (ACHS), senior staff from MIND in the United Kingdom and representatives from relevant professional and non-government organisations such as the RANZCP and the Association of Relatives and Friends of the Mentally Ill.

The input of the many carers, consumers and health professionals who gave us their time and wisdom during the consultation phase of the project has been invaluable in exploring the issues.

The overwhelming experience of consultation participants was that, despite the existence of legislation and policies, health services continue to make little or no

effort to identify or involve carers. Some stated they felt that the majority of clinicians did not seem to know how to go about this process. Organisational structures and culture were also reported to be counter productive to the processes of identification and engagement.

In addition, in situations where consumers voluntarily identified their carers or carers self identified there continues to be significant reluctance by many clinicians to include them in care processes. '*Consumer confidentiality or privacy legislation*' continues to be cited as reasons for non engagement. It was the experience of participants that individual clinician attitudes and practices prevail in contravention of existing service policies.

This report presents the findings of the project. The literature search, summary of Australian mental health and carer recognition policy and legislation, and report of the consultations provide the evidence base for the following.

- The draft policies and protocols regarding carer identification.
- The content of the information brochure for families and other carers.

Both products are contained within this report and with minimal editing can be re-produced as stand alone documents suitable for further consultation on a national basis with service providers, carers and consumers.

This report presents the findings of the project and summarises these into a series of recommendations for consideration by governments, professional organisations and public and private services. The recommendations are designed to strengthen the identification of, and support for, the important group of people who provide significant and sustained contribution to the care of people with a mental illness.

## **FINDINGS**

- All participants were of the view that identification and engagement of carers is crucial in any recovery based approach to care. This position is substantiated by the literature. They also agreed that change in clinical practice will only occur if it is mandated by legislation, well grounded in policy and protocols, compliance is audited on a regular basis and incentives are associated with positive changes in practice.
- Research that recognises that carers play a critical role in the process of recovery and relapse prevention is continuing to be largely ignored by both public and private specialist mental health services.
- The professional judgement of clinicians is recognised, however no single clinician or carer can meet all the needs of all consumers. A partnership and recovery approach to care will improve consumer outcomes and decrease the burden on services and carers.
- The ideal process for identification is by the consumer. These discussions together with the degree of involvement should be negotiated, documented and regularly reviewed. The experience of staff currently working in a carer inclusive

manner is that if approached in this manner then the majority of consumers recognise and welcome the involvement of their support network.

- Some carers who self identify are not necessarily the best people to be involved in the ongoing care and recovery of consumers, either because of their past history with the consumer, or their own particular needs. However, these carers continue to have rights and mechanisms need to be developed to ensure their needs are met.
- Some consumers will, from time-to-time, because of the nature of their illness, refuse to identify or to involve carers. All professional interactions with them and written information provided to them needs to reinforce the importance of their support network being actively involved in their care.
- 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 and privacy legislation is NOT a basis for preventing clinical staff across a range of settings from having a working relationship with the family/carer. Carers still 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 at all levels, on the basis of existing policies, Carer Recognition Legislation, mental health legislation and National Standards for Mental Health Services have a responsibility to identify and support carers. Cultural and organisational change, policies, protocols, education and support will be necessary to encourage changes in clinical practice.
- Policies and protocols to identify carers are essential and will vary according to service setting. The following settings provide opportunities and “trigger points” for identification to occur.
  - Primary care – specifically GP practices.
  - Public and private assessment services.
  - Formal Admission to a specialist public or private mental health service.
  - Formal discharge from a service.
  - Continuing care in both the public and private sectors.
- A nationally consistent information brochure for families and other carers is highly desirable as it will improve mental health carer literacy and opportunities for engagement. It was acknowledged that on first admission to a mental health services the information required needs to be simple, specific and practical however given that all carers are at different stages in their journey when the opportunity arises to obtain this information it was considered important to develop a brochure that was more comprehensive that could be referred to as carers were able to absorb the information. It was decided that this should be presented primarily in one booklet however should refer people to additional information related to specific diagnosed and medication once these were

established. The brochure has been developed on the basis of information provided by carers, consumers and service providers, all of whom are participating in the varying stages that accompany in the treatment and recovery process.

The brochure will:

- Provide an introduction to the mental health service, explaining the processes that would be followed;
  - Provide some general information about what the symptoms of mental illness might be;
  - Outline in question and answer form some of the concerns they may have;
  - Provide examples using the stories of family members and friends to assist them to feel less alone;
  - Introduce the new language, eg ‘consumer’, ‘carer’;
  - Introduce the concept of carers rights and complaints processes;
  - Introduce the issues associated with the consumers rights to confidentiality and what this might mean for the sharing of information; and
  - Provide information on where to go for additional information and support.
- This information brochure could be augmented by the diagnosis specific guidelines prepared by the RANZCP once a specific diagnosis is agreed and a treatment process implemented.
  - Carer identification and support will be enhanced by the appointment of a nominated person/Carer Consultant/Family Support Worker on staff, with whom they can personally interact, discuss and clarify information needs as required and generally use as a point of contact for future needs.

## **RECOMMENDATIONS**

The recommendations have been grouped according to the following headings.

### **DRAFT IDENTIFICATION POLICIES AND PROTOCOLS**

The following policies and protocols to identify carers during all stages of care be distributed widely to public and private sector mental health services for comment and feedback on the feasibility of introduction on a progressive basis.

#### **Policies**

Identification and participation of carers in a partnership approach will be acknowledged and respected as crucial to the facilitation of early intervention, treatment and recovery of people with a mental illness.

Carer identification and levels of participation in ongoing care will take account of social and cultural differences and will be reviewed with consumers and carers on a regular basis.

Carer levels of identification and satisfaction with their engagement will form part of the regular reporting of all mental health services.

## **Protocols**

### Identification of Carers in Primary Care Settings

1. The following protocols to identify carers be discussed with the Royal Australian College of General Practitioners (RACGP) for consideration during the 2010 review of Standards.
  - Provision of general information encouraging self identification on electronic and paper notice boards including posters and leaflets.
  - New Patient Forms to identify carers.
  - Utilise normal practice appointment consultations.
  - Practice newsletters to feature articles regarding carers.
  - Utilise patients' personal health checks to identify if they undertake care for another person.
  - Have a named member of staff responsible for maintaining the practice's procedure for identification of carers – a carer specialist or champion.
2. Medicare Australia be asked to consider the placement of messages to assist with the identification of carers on benefit cheques issued during Carers Week held annually in Australia.
3. Pharmacists be asked to consider the placement of messages to assist with the identification of carers on all folders containing repeat prescriptions during Carers Week held annually in Australia.

### Identification of Carers in Assessment Settings

- Generic information encouraging self identification by carers be provided in waiting areas on electronic and paper notice boards including posters and leaflets.
- New patient questionnaire data systems be expanded to include carer identification by a series of questions phrased in a positive manner designed to encourage consumers to recognise who their carers are and the importance of their ongoing contribution.
- Triage processes ask appropriately worded questions emphasising the positive aspects of family/carers participation in all aspects of care.

- Interviewing doctor/nurse ask appropriately worded questions to determine identification of carers and their level of involvement.
- A specific member of staff be allocated responsibility for maintaining procedures for identification of carers – a carer specialist or champion.
- Information packs be provided for both consumers and carers that include rationale and encouragement for identification of carers.
- ‘Carer corners’ be established in waiting rooms.
- Identification of Carers during Formal Admission to a Public or Private Mental Health Service.
- Generic information encouraging self identification by carers be provided in waiting areas on electronic and paper notice boards including posters and leaflets.
- Colour coded forms inviting consumers to identify carers and nominate the level of involvement be included in all admission procedures. Forms to be completed as soon as practicable and audited on a regular basis.
- In circumstances where a consumer refuses to identify their carer(s), the Mental Health Service will review this status at regular intervals during the episode of care in accordance with Australian and state/territory jurisdictional and legislative requirements.
- A specific member of staff be allocated responsibility for maintaining procedures for identification of carers – a carer specialist or champion. This may be a carer consultant/liaison officer/family support worker with the following responsibilities.

### **Staff support and training**

- Liaison point between staff, consumers and carers, for example, assistance with completion of admission protocols regarding identification of carers; advocacy for individual carers with staff/services.
- Information and linkage to alternative options for information and support for carers such as referral to carer support organisations.
- Provision of carer specific perspectives to staff meetings.
- Assistance with carer assessments.
- Specific point of contact following discharge for carers.
- Ensure accreditation and reporting systems in health and community sectors incorporate the National Standards for Mental Health Services and, in particular, Standard 7 relating to the identification and participation of carers at all areas in service delivery.

- Consumer information packs to include a rationale and encouragement for identification of carers, including the identification of children who are carers.
- Services to report on the provision of information packs to carers.
- Staff to receive 'carer sensitivity' and skills development training.

### **Identification of Carers during Discharge Processes**

- Generic information encouraging self identification by carers be provided in waiting areas on electronic and paper notice boards including posters and leaflets.
- Colour coded forms requesting consumers to identify carers and the level of involvement they want them to have be checked for completion.
- Ensure carers have personalised information packs including:
  - Diagnosis;
  - Medication – dosage, purpose and possible side effects;
  - This is what you can expect;
  - Who to contact to discuss concerns; and
  - What supports are available to you locally, eg your GP, Carers Australia, ARAFMI.
- Encourage the routine identification of carers, including children, in the development of relapse prevention plans emphasising the benefits of information sharing and support.
- A specific member of staff be allocated responsibility for maintaining the Service's procedure for identification of carers to inform carers of continued points of contact for information and support.
- Ensure accreditation and reporting systems incorporate the National Standards for Mental Health Services and in particular Standard 7 relating to the identification and participation of carers at all areas in service delivery.
- Discharge letters, with the permission of the consumer and the carer, to identify carers, their willingness to continue in this role and an outline of potential support required.
- Services to undertake regular satisfaction surveys regarding their level of engagement with carers.

### **Identification of Carers in Continuing Care Settings**

- Relapse prevention plans to emphasise the benefits of information sharing and support and contain a specific component for identification of carers. Carers need to give permission for their names and contact numbers to be included in the Plan.

- Encourage the identification of carers in the development of Advanced Directives.
- Ensure the development of Ulysses Agreements in situations where children are carers.

### **Information Brochure for Families and other Carers**

1. The Information Brochure contained within the report:
  - be edited to a 'plain English' format; and
  - be edited by a graphic designer for transmission by email and to be web based; to enable wide distribution nationally to carers for consideration and feedback.
2. The revised brochure be published in hard copy and placed on the DoHA website for national use.

### **Good Practice Checklist**

The following 'good practice checklist for identification and engagement of carers' be adopted nationally by public and private services.

# CARER IDENTIFICATION AND ENGAGEMENT

## A GOOD PRACTICE CHECKLIST FOR STAFF

### Choice

Allow carers time to make choices about:

- Taking on the role of carer;
- Whether to continue caring; and
- How much and what type of care, taking into consideration family and caring commitments, health, work education, social activities

### Identification

- Throughout the service admission and discharge process and at the earliest opportunity, ensure there are triggers in place to identify carers.
- Be aware that carers may not view themselves as carers but as partners, parents, sons, daughters, etc.

### Information

Actively seek permission from consumer to share information with the carer and provide carers with information about the following.

- Discharge plan in writing and verbally.
- Medical condition of consumer.
- What is likely to be involved in caring
- Benefits.
- Financial implications of caring.
- Other sources of help and other organisations, such as *Carers Australia* and self help groups.
- Access to interpreters to enable effective understanding and communication.
- Challenging decisions and complaints procedures.

### Assessment

- Involve carers in assessments, including those carried out by allied mental health professionals' and community nurses.

### Planning for future service delivery

- Ensure carers feel fully involved at all stages of service delivery including the decision to discharge the person and making sure practical arrangements are in place
- View carers as partners, respect and listen to their views – longer term carers are likely to have considerable expertise and skill in how to care for the consumer
- Acknowledge carers' individual needs, consider cultural differences, age, race, disability, health, religious background, sexual orientation, gender assumptions, geography
- Ensure carers have been involved in drawing up, monitoring and reviewing policy and its implementation
- Develop different types of consultation procedures

### Support

- Be flexible: provide services that carers want, when they want them
- Ensure practical help is in place prior to discharge
- Offer information on how to care safely: eg administering medications, dealing with difficult behaviour
- Improve co-ordination between health and *Centrelink* and other government agencies to ensure carers receive a seamless service
- Refer carers to support groups

### Monitoring

Find out whether carers' outcomes were met by the service delivery process.

Methods of carrying this out could include:

- Carer satisfaction surveys;
- Audits of discharge documentation provided to carers;
- Carer outcome measures; and
- Review policies regularly in consultation with carer consultants, *Carers Australia*, *ARAFMI* etc.