



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

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IDENTIFYING THE CARER PROJECT

FINAL REPORT AND RECOMMENDATIONS

FOR

THE COMMONWEALTH DEPARTMENT OF HEALTH AND AGEING

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CONTENTS

	PAGE
EXECUTIVE SUMMARY AND RECOMMENDATIONS	2
FINDINGS	2
RECOMMENDATIONS	4
Standards	
National identification and participation policies	
Legislation	
Data Development	
Changes in Clinical Practice	
Education/Training and Skill Development	
1. CONTEXT	7
2. METHODOLOGY	9
3. LITERATURE REVIEW	10
3.1 LITERATURE FINDINGS: KEY THEMES	10
3.2 THE RATIONALE FOR CARER IDENTIFICATION AND INVOLVEMENT	11
3.2.1 Carer rights	11
3.2.2 Impact of carer identification and participation in relapse prevention for consumers	12
3.3 IMPEDIMENTS TO IDENTIFICATION	12
3.3.1 Use of the term 'carer'	13
3.3.2 Confidentiality	13
3.3.3 Workforce education and training	15
3.4 ADVANCE DIRECTIVES/STATEMENTS/CARE PLANNING	16
3.5 EXAMPLES THAT PROVIDE SOME GUIDANCE FOR PRACTICE	17
3.5.1 Family therapy – psychoeducation programs	17
3.5.2 Surrey-wide Operational Partnership Group in Mental Health (SWOP), UK	18
3.6 CONCLUSION	18

4.	INTERNATIONAL POLICY AND PROGRAM CONTEXT	20
4.1	BACKGROUND	20
4.2	UNITED KINGDOM POLICY AND LEGISLATIVE CONTEXT	20
4.2.1	Carer Assessments	21
4.2.2	UK Mental health legislation	22
4.3	USA POLICY AND LEGISLATIVE CONTEXT	23
4.4	CANADIAN LEGISLATIVE AND POLICY CONTEXT	23
4.5	NEW ZEALAND POLICY AND LEGISLATIVE CONTEXT	25
4.6	EUROPEAN COMMUNITY POLICY AND LEGISLATIVE CONTEXT	25
4.7	EXAMPLES OF GOOD PRACTICE	27
4.7.1	Lambeth Early Onset Service – UK	27
4.7.2	Processes to assist identification of hidden carers	28
4.7.3	Home from hospital initiative	29
4.7.4	Screening tools to assist identification	29
4.8	CONCLUSION	29
5.	AUSTRALIAN POLICY AND LEGISLATIVE CONTEXT	31
5.1	PUBLIC SECTOR	31
5.2	NATIONAL STANDARDS FOR MENTAL HEALTH SERVICES	32
5.3	STATE AND TERRITORY POLICIES	33
5.3.1	Queensland	33
5.3.2	New South Wales (NSW)	33
5.3.3	Australian Capital Territory (ACT)	33
5.3.4	Northern Territory	34
5.3.5	Western Australia (WA)	34
5.3.6	Victoria	34
5.3.7	Tasmania	35
5.3.8	South Australia (SA)	35
5.4	PRIVATE HOSPITAL SECTOR	36

5.5	MENTAL HEALTH AND CARERS RECOGNITION LEGISLATION	36
5.5.1	Impact of legislation on carers	38
5.5.2	Consistency between Acts	39
5.6	CONCLUSION	39
6.	SUMMARY OF CONSULTATION	40
6.1	PROCESS	40
6.2	CURRENT EXPERIENCE OF CARERS	40
6.3	GENERAL COMMENTS REGARDING IDENTIFICATION	42
6.3.1	Use of the term Carer	42
6.4	SUMMARY OF DISCUSSION	45
6.4.1	The consumer voluntarily identifies carers	45
6.4.2	The consumer refuses to identify carers with whom information can be shared.	45
6.4.3	The consumer is unable to identify carers because of their mental state	46
6.4.4	The consumer is a child and their ability to consent is in question	46
6.5	MECHANISMS SUGGESTED DURING CONSULTATION TO ENCOURAGE IDENTIFICATION	47
7.	DISCUSSION	51
7.1	WHO IS A CARER	51
7.2	DEFINITIONS CURRENTLY IN EXISTENCE	51
7.3	DEFINITION ON THE BASIS OF RELATIONSHIP	52
7.4	DEFINITION ON THE BASIS OF SUPPORT PROVIDED	54
7.4.1	Support required for ongoing maintenance in the community	54
7.4.2	Support required during acute episodes	55
7.5	ISSUES THAT IMPACT ON IDENTIFICATION OF CARERS OF PEOPLE WITH A MENTAL ILLNESS	55
7.5.1	The role of carers in recovery focused care	56
7.6	WHY IDENTIFICATION IS IMPORTANT	57
7.6.1	Improvement in consumer outcomes	58
7.6.2	Benefits for carers associated with identification	59

7.7	CRITICAL TIME–FRAMES FOR IDENTIFICATION	59
7.7.1	Early stages of the illness	60
7.7.2	Following diagnosis when the consumer is well – Relapse Prevention	60
7.7.3	On admission	61
7.7.4	On discharge	62
7.7.5	Complaints Processes	63
7.8	CHALLENGES FOR STAFF	63

REFERENCES

APPENDIX A

Project Reference Group Membership

APPENDIX B

Focus Groups and Consultations

APPENDIX C

New Farm Clinic Approved Carer Form

EXECUTIVE SUMMARY AND RECOMMENDATIONS

The Australian Government funded the Private Mental Health Consumer Carer Network (Australia) to undertake a project examining issues associated with identification of carers, prior to the future development of a burden of care measures for carers.

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 has proved difficult to examine the issue of identification as a stand alone project. Very little has been written about the process of identification as much of the work undertaken to date assumes identification. 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 this issue.

The project aimed to address the following issues, in both the public and private sectors:

- Current practice regarding identification of carers,
- Policy and legislation impacting on the identification of carers, and
- Preferred processes for identification.

Information was obtained by way of an international literature search, policy and legislative analysis and focus group and individual consultation with carers, consumers and service providers. However, it was not possible to obtain information regarding the practice of individual psychiatrists in their office-based practice.

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

The major following issues were identified from both the literature and from national consultation with carers, consumers and service providers.

- 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 a extended period of time such as when they are caring for a person with a long term mental illness.
- 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 lesson 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.
- 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,
 - A specific Carer Standard within the *National Standards for Mental Health Services*,
 - 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,
 - Development of a specific carer standard for inclusion in the revised *National Standards for Mental Health Services*,
 - 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 Advanced Directives or relapse prevention plans that include identification and desired level of involvement of carers,
- Development of specific Carer Assessment legislation and protocols.

RECOMMENDATIONS

The recommendations have been grouped according to the following headings, however, they are not presented in any particular order of importance.

Standards

- ***A specific standard addressing the issue of carer identification and participation to be developed for inclusion in the revised National Standards for Mental Health Services. This should also include the following.***
 - ***Inclusion of mechanisms for specific measurement of this standard in accreditation survey processes, including the Australian Council on Healthcare Standards (ACHS) EQUIP.***
 - ***Additional training to be made available for surveyors of mental health services.***

National identification and participation policies

- ***Nationally consistent carer identification and participation policies and good practice protocols to be developed for implementation in all public and private mental health services.***

Legislation

- ***State and Territory Mental Health Legislation to be amended to mandate identification and support of carers/primary support persons.***
- ***Development of Carer Recognition legislation in all States and Territories. At the time of submission, Carer Recognition legislation was in place in WA, SA, and NT.***
- ***Implementation processes to be developed for Carer Recognition legislation which provides particular attention to mental health carers.***
- ***Development of Carer Assessment legislation requiring all services to identify mental health carers in order to offer assessment of their needs.***
- ***Development of national policy and practice guidelines to accompany the enactment of mental health and carer recognition or carers' rights legislation. This will require provision of adequate financial and human resources to promote and ensure adoption of legislative requirements regarding carers as partners in the provision of mental health care and recovery.***
- ***Legislation governing Carer Payment, Carer Allowance and new programs funded through the Council of Australian Governments' (COAG) National Action Plan on Mental Health 2006-2011 (July 2006) to be reviewed to***

ensure that identification and eligibility requirements are suitable to meet the needs of carers of people with a mental illness.

Data Development

- *Mandatory carer identification fields to be built into data collection software. This would include the following:*
 - *Modification of State and Territory mental health data systems to make collection of 'carer' identification mandatory and separate to data related to 'next of kin';*
 - *Inclusion of carer identification fields in General Practice software; and*
 - *Development of suitable questions for inclusion in data collection protocols to inform identification of the carer.*

Changes in Clinical Practice

- *Public and private mental health services to encourage the identification of carers through the development and distribution of nationally consistent information packages to carers as a compulsory component of the admission procedure.*
- *Admission procedures to public and private mental health services be modified to include development of standardised forms that:*
 - *highlight the benefits of consumers involving others in their care;*
 - *seek specific permission to identify family members or significant other persons who have ongoing input to their lives;*
 - *nominate the level of information to be shared;*
 - *are colour coded, updated on every admission and remain in the health care notes; and*
 - *make note of the distribution of information packs to carers, family members or significant other persons.*
- *All public and private mental health services to review their admission, discharge and referral policies to ensure carers are identified, supported and allowed to make informed choices.*
- *Clinical practice standards which promote an inclusive approach to identifying and working with carers are established by all public and private mental health services. This approach will promote identification and engagement to enable carers' strengths to be promoted, their difficulties to be acknowledged and to encourage empowerment.*
- *Public and private mental health clinicians to encourage consumers with long term illnesses to develop Relapse Prevention Plans and Advance Directives regarding care preferences, identification and involvement of carers. This process should occur when the consumer is functioning at the best possible level, become part of the health file and the information be transferred to other services as appropriate.*

- ***Carer Consultants/Liaison Officers to be appointed to all public and private mental health services to assist with carer identification and assessment, staff support and training, linkages to carer support mechanisms and to be a specific point of contact for carers following discharge of the consumer.***

Education/Training and Skill Development

- ***Comprehensive training to be provided for 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. This would include the following.***
 - ***Liaison with the Australian Divisions of General Practice to develop protocols/good practice guidelines to increase General Practitioners (GPs) awareness regarding the important role they play in the identification of carers.***
 - ***Liaison with the Royal Australian New Zealand College of Psychiatrists to develop family/carers focused training modules and good practice protocols.***
 - ***Recognition of additional training modules in family/carers oriented practice by relevant Colleges as a component of skill maintenance.***

1. CONTEXT

The Private Mental Health Consumer Carer Network (Australia) [Network] has been aware of discussions undertaken at the AHMAC Mental Health Standing Committee's Mental Health Information Strategy Subcommittee to progress the development of Carer Measures.

The Network was of the opinion that consideration needed to be given as to the identification of who the carer actually is as a pre-requisite to the development of any carer measure. Issues requiring examination include:

- How is the carer ascertained in the first place?
- Whose responsibility is it to identify and recognize who is the carer?

It was considered that these are issues of concern to all mental health carers whether involved in the private or public mental health systems.

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.

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, current service delivery continues to be individually focussed with carers largely unidentified and uninvolved.

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. The Australian Government as part of their activities designed to improve outcomes for both consumers and carers has funded this project examining identification of carers as a pre cursor to additional work that will lead to changes in clinical practice in this area.

It has been very difficult to examine the issue of identification as a stand alone project. Very little has been written about how the process of identification has occurred. The majority of work undertaken to date assumes identification and moves on from there.

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 in order to achieve better outcomes for consumers.

Change needs to occur at all levels. This will take time. The information collected during this project provides a basis for systemic change. A simultaneous process of carer empowerment will assist to drive this change.

It is anticipated that recommendations from this Project when implemented, will change mental health services practices including private psychiatrists and GPs, in first identifying the carer. Hopefully a consequence will be facilitating greater engagement with them.

Implementation of recommendations may have implications for allocation of financial resources, organisational change and staff training. This may have short term costs, but is expected to lead to longer term savings through improvement in services. Implementation will also be enhanced by the improved ability to identify, engage and involve carers in governance of mental health services such as policy development, planning, service reviews and staff training.

2. METHODOLOGY

A variety of mechanisms were used to obtain information for this project.

These included the following.

- 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 examined in consultations included:
 - processes for identification;
 - processes for review of engagement; and
 - identification of issues of concern for consumers and possible solutions.

Face-to-face focus groups were held in Adelaide [24th April 2007], Perth [2 and 3 July], Brisbane [6 June 2007] and Darwin [July 12th]. Specific invitations were provided to carers identified as having interest and expertise in pursuing this topic as well as carer focused non government organisations. A limited number of service providers and consumers were also invited to participate in this process to achieve balanced views.

The focus groups were conducted by the Project Officer with the assistance of the Chair of the Network.

In addition, telephone consultation was undertaken with Carer groups in other States and Territories and specifically identified individuals with a long history of working with carers.

The needs of carers were acknowledged, however, participants were encouraged to focus on the process of identification as much as possible.

3. LITERATURE REVIEW

As part of the current project, the Department of Health and Ageing requested a review be undertaken of International literature with the focus on the United Kingdom, USA, Canada, New Zealand, Germany, Sweden and the Netherlands to determine current policy and practices regarding identification of the carer.

The literature search encompassed both peer-reviewed journals and other published literature. The search methodology incorporated the following elements.

Electronic database searches. Subject and text words were used in searching databases for relevant research concerning Carer identification with English language limits and a publication date from 1990 to present (2007) being applied.

Internet searches. A search was made of internet resources in Australia and internationally using search criteria, such as Carers, carer identification, hidden carers and carer rights.

Scanning of reference lists. Reference lists of publications (primary studies and reviews) found through database searches were scanned to identify further studies for consideration.

Grey literature and conference proceedings. The internet was also searched for examples of recent conference proceedings that discussed the topic.

The review strategy involved a detailed examination of the material that had been identified as part of the search strategy. In this stage, the literature was excluded if the subject matter was insufficiently described and therefore the documentation did not contribute important information to the project.

Key words used in the literature search were:

- carer;
- carer identification;
- carer recognition;
- mental health;
- mental health legislation; and
- carer recognition legislation.

3.1 LITERATURE FINDINGS: KEY THEMES

Literature available on identification of the carer is extremely limited both within Australia and internationally. Information related to rights and needs is well documented, however, the process of identification is generally not addressed. Definitions are many and varied and they primarily require self identification by way of relationship to the consumer or by the tasks undertaken for the consumer. Some of the literature explores the difficulties associated with the process of self identification particularly for carers of people with a mental illness.

Literature searches of the UK, USA and NZ provided the most useful information however, the issue of identification continues to be elusive. Some of the legislation requirements require a process of identification, or assume a process but this is not well documented.

In examining the literature it proved difficult to separate identification from what should occur after identification has taken place, for example provision of information, participation in assessment and service delivery. Some information was found regarding issues associated with confidentiality in the mental health area.

The international search of literature was further complicated by the differences in terminology and differing legislation and service delivery systems in each country.

This section of the project report will attempt to focus on identification but given the areas of overlap it is difficult to address this topic in isolation.

The issues examined in the literature identified can be categorised into the following broad themes.

- *The rationale for carer identification and involvement*
 - Impact of carer identification and participation in relapse prevention for consumers
- *Impediments to identification*
 - Use of the term carer
 - Confidentiality
 - Workforce education and training
- *Advance directives*

Key findings around each of these themes are provided below.

3.2 THE RATIONALE FOR CARER IDENTIFICATION AND INVOLVEMENT

3.2.1 Carer rights

Australian and international policy and legislation support carers as a partner in the delivery of services to improve outcomes for people with a mental illness.

The contribution that carers make to the support and care of people with mental illness was recognised by the Australian Government in the *Mental Health Statement of Rights and Responsibilities* (1991). This document, together with the *National Mental Health Policy* (1992), has been the cornerstone of the National Mental Health Strategy since its inception in 1992.

The *Mental Health Statement of Rights and Responsibilities* acknowledges that caring and advocacy roles are complex and the relationship between carers and consumers can change frequently and may also vary according to the age of the consumer. The following statement, taken directly from the document, assumes identification but clearly states it as a right:

“With the consent of the consumer, carers and advocates are entitled to:

- *have access to the consumer;*
- *be consulted by service providers about measures under consideration for treatment of the consumer or for his or her welfare;*

- *arrange support services such as respite care, counseling and community nursing facilities;*
- *exchange information with those providing treatment concerning the consumer's lifestyles and their relationships with others."*

page 17, Mental Health Rights and Responsibilities, 1991

The document also acknowledges that there may be circumstances where the consumer is unable to give consent or may refuse consent because of their disturbed mental state. In such cases it may be appropriate for service providers and carers to initiate contact and involve those who may be able to assist with the consumer's diagnosis and care.

"Carers and advocates have the right to put information concerning family relationships and any matters relating to the mental state of the consumer to health service providers.

Carers and advocates have a right to help with their own difficulties which may be generated by the process of caring for or acting as an advocate for a person with a mental health problem or mental disorder."

page 17, Mental Health Rights and Responsibilities, 1991

A search of available literature continues to reiterate these rights. A study undertaken jointly by Carers Australia and The Mental Health Council of Australia (2000) details the extensive role played by carers of people with a mental illness and comprehensively describes their needs in relation to their caring role.

Carer rights have also been recognised both internationally and in some parts of Australia in the form of Carer Recognition Legislation.

3.2.2 Impact of carer identification and participation in relapse prevention for consumers

The literature is clear that the support needs of consumers and carers are interdependent. There is good evidence to demonstrate that providing support and education to families/carers provides direct health benefits to consumers.

Dixon and Lehman (1995) showed that psychoeducational programs with families reduce relapse rates for consumers and similarly psychotic symptoms are decreased significantly following family education. Adherence to medication regimes has also been reported to be higher following education (McFarlane, 1995). Similar reports have been made by Falloon et al as early as 1982. Tarrier et al, (1988) and Pharoah et al. (2003). Randomised control trials have repeatedly demonstrated that family interventions that provide some combination of mental illness education, support, problem solving training and crisis intervention, in combination with appropriate medication, reduce one-year relapse rates from a 40 to 53 per cent range to a 2 to 23 per cent range (Dixon and Lehman, 1995).

Carers are partners in the provision of healthcare to those they care for. Supporting them is a sound investment in continuity of care and recovery.

States and Territories in their policies support this position. However, it has been difficult to identify protocols for identification of carers to enable the *Mental Health Statement of Rights and Responsibilities* (1991) and subsequent documents to be implemented.

3.3 IMPEDIMENTS TO IDENTIFICATION

The literature acknowledges the importance of carers as partners in the delivery of services to people with a mental illness and primarily focuses on impediments to inclusion. These include:

- use of the term 'carer';
- confusion regarding confidentiality; and
- lack of training in a carer oriented approach to clinical practice.

A UK based study, *Positive and Inclusive: Effective ways for professionals to involve carers in information sharing, Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation Research and Development (NCCSDO) (2004)* was examined. This study was a collaborative project between Rethink severe mental illness (the largest mental health charity in England providing support to 7000 people daily through 380 services and 135 support groups) and the Health Services Research Department at the Institute of Psychiatry. The primary focus of the paper is on the process of sharing information with Carers. The issue of identification was not addressed specifically, however, a number of issues that impinge on identification were addressed and contributed to the literature search. These included the following.

3.3.1 Use of the term 'carer'

In undertaking the project the practical difficulties that can arise when using the term 'carer' were highlighted. The term 'carer' was seen as controversial. It was reported that some carers disliked it because it implied they did not *care* before the person they support became unwell, or because it unhelpfully professionalised the relationships. Others did not recognize that the *regular and substantial* support they provided entitled them to specific *carer's rights* such as carer assessments. Others queried as to when their role of a mother, father, wife, husband, partner, neighbour or friend ended and the role of *carer* began? Equally, it was noted, there are consumers who do not recognise their carers as such and who do not want them involved with their mental health care.

This position was also supported in 1997 in the Pfizer Journal, Perspectives on Health Care and Biomedical Research which was devoted to care giving in America. This document describes how carers define themselves differently depending on their relationship to the consumer. The adult child will come to see himself as a carer before a spouse does, because the spouse will see their role as a good husband or wife, and the parent will see the role as that of a good parent. The carer designation often does not come in until a crisis changes the situation. It clicks in at different times for people in different relationships.

The Journal goes on to state:

Carers do not self-identify or seek out carer organizations because the word is not well recognized.

3.3.2 Confidentiality

The issue of confidentiality is frequently cited as an impediment by Australian clinicians as a reason for not sharing information. If this position is adopted it negates the need to identify people with whom one might have concerns about sharing information. This position leads to an exploration of issues associated with privacy and confidentiality.

It appears that the protection and use of information in general, and specifically in relation to carers, is deeply embedded in ethics and professional codes, policy and law, values and professional practice.

Health professionals believe in the right of an individual's privacy in relation to his or her psychiatric condition, and are trained in *patient confidentiality* rather than information sharing (Leggatt, 2001). They are concerned to keep the trust of the patient (British Medical Association, 1999) and fear being sued (Montgomery, 1997; Leggatt, 2001), although litigation is rare (Department of Health, 2001). Yet rights to confidentiality are not absolute, may be breached in cases of societal and public interest (*W v Edgell*, 1990), and need to reflect social responsibilities (Etzioni, 1999). Backlar (2001) contends that although in Western societies confidentiality in healthcare is implied and broadly assumed, providers should be clear about what information can be divulged to families and under what circumstances the patient has privacy rights. Furlong and Leggatt (1996) suggest a conceptual framework is needed to balance the rights and interests of patients with the needs and responsibilities of carers. Confidentiality is seen as a particularly taxing ethical issue when the family's involvement appears justified but the service user is withholding consent (Szmukler and Bloch, 1997).

Mental health service consumers face particular restrictions on their private lives. The right to privacy is essential in the interests of maintaining self-respect and enabling human interaction without constant social breakdown (Nagel, 1998 cited in Backlar, 2001).

Patient privacy and autonomy are vital components of mental health recovery. However, privacy and autonomy principles are subject to restrictions because of:

- Doubts about an individual's capacity to make rational judgments;
- Public and personal safety considerations; and/or
- The treatment criteria of mental health legislation (where a person is detained on an involuntary basis).

The carer's need for information to support the caring role further threatens consumer autonomy and privacy. The consumer may have no choice about the identity of the carer, or the right to refuse to have one. The position is further complicated by:

- disaffected and abusive relationships;
- connotations of overprotection associated with the term carer, that conflict with the ethos of independence fostered by community care; and
- potential vested interests exist in close relationships (Brazier, 1992).

Beauchamp and Childress (1994) observe that professional organisations impose obligations to ensure the trustworthiness of their members. However, traditionally, professional codes have been generated without scrutiny or acceptance by consumers and the public (Beauchamp and Childress, 1994). Many are now being revised with stakeholder assistance (namely consumers, carers and mental health professionals). As a result, professionals with entrenched attitudes could be seen to be breaching the new guidance of their own professional bodies. (RANZCP Guidance Notes for Involving Families, 2000). In theory, clinicians now run the risk of carer litigation where harm to carers (Zinn, 2003), or depriving carers of information to enable them to exercise their role (*S v City*, 2002), can be shown as a result of failures to communicate appropriately.

Public mental health services in Australia are generally delivered by teams of people from different disciplines subject to different professional codes. The literature acknowledges that little examination or discussion has occurred regarding these differences. Given the critical

impact of the carer and consumer relationship, professional skill in managing the interface is of utmost importance, particularly in situations where consent for involvement is an issue.

This stance is supported by Experts by Experience (EbE), a group of service users and carers who advise National Institute for Mental Health in England on their concerns. An unpublished discussion paper (2003) noted:

...Handling tensions between users and carers should be regarded as a core skill for mental health professionals and included in all qualifying training programmes and continuing professional development.

SANE Research investigating the effects of caring for someone with a mental illness produced the *SANE Guide for Families, the essential resource for families, friends and other carers of people with a mental illness* (2007). The Guide explains how everyone in a family can be affected, the services available, and the skills needed to help support their relative's recovery. The Guide does not address the issue of identification per se, however, it draws attention to the need for this and the role that 'confidentiality' plays in excluding carers from services. The report states:

Many health professionals still exclude family carers from treatment planning, and withhold information, inappropriately citing confidentiality. This is despite changes to legislation and new policies on inclusion of carers. Health professionals need training and supervision to ensure these attitudes to family carers are improved.

3.3.3 Workforce education and training

Carers Australia in their submission to the *Senate Inquiry into Mental Health (2007)*, highlight the fact that 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. Identification is a precursor to participation.

They clearly state that the present level of education provided in some states and territories through 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. They were optimistic, however, that with the funding now available through the COAG *National Action Plan on Mental Health 2006-2011* across national and state and territory levels this may now improve. Also, the Department of Health and Ageing (DoHA) and the Australian Government Department of Families, Community Services and Indigenous Affairs (FACSI) 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. Formal protocols for identification could be described as one such barrier.

Carers Australia acknowledge that 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.

The concept of confidentiality is often a concern to clinicians training in this work and one effective way of raising the profile of the needs of carers has been to involve carers directly in the teaching and training process to 'tell their story' of their own experience. Carers are usually very willing to do this and clinicians repeatedly report this has major impact on how they go on to engage families following the training in family interventions. One main component of the model is information sharing between the consumer and the family members.

This often takes the form of the consumer describing to the other family members their experience of being unwell. During this process, information about the service and the particular difficulty the consumer identifies is discussed. With this approach both the consumer and the carer have control over what information is divulged. However, the evidence base for this work maintains that, by encouraging greater effective communication between people who significantly influence each other, outcomes for both parties are dramatic. Service satisfaction through a positive experience is well known to enhance future relationships between consumers, carers and clinicians.

3.4 ADVANCE DIRECTIVES/STATEMENTS/CARE PLANNING

An exploration of the literature to determine mechanisms for identification indicated that Advanced Directives had some potential for use in this area.

Advance care planning refers to the process of preparing for likely scenarios and usually includes assessment of, and dialogue about, a person's understanding of their medical history and condition, values, preferences, and personal and family resources. An Advance Directive, sometimes called a 'living will', is a document that describes a person's future preferences for medical treatment in anticipation of a time when they are unable to express those preferences because of illness or injury.

Advance Directives are most commonly used in situations towards the end of life, however, there are some anecdotal reports of an increasing use in the mental health area as a means for consumers to have more input into their care at times when they have acute episodes and are considered unfit to make decisions on their own behalf.

They have been used successfully to help people to plan ahead and maintain a degree of autonomy and control during crisis (Diggins, 1993) with beneficial outcomes on rates of hospital admission. (Sutherby *et al.*, 1999). They also enable the consumer to nominate people to have control over their affairs. This may enhance the carer's position in decision-making where he or she is nominated.

They have received widespread international support and, in the United States, Advance Directives now have a statutory basis in all 50 States. Three Australian States (Victoria, South Australia and Queensland) and two Territories (the Northern Territory and the Australian Capital Territory) now have legislation which provides for Advance Directives. Although New South Wales, Tasmania and Western Australia do not have similar legislation, Advance Directives may still be valid under common (judge-made) law in these States, but this is something that cannot be relied upon.

Recommendation 18 of the Australian Government Senate Select Committee on Mental Health (2006) also states:

That the HREOC be requested to complete its important work on advance directives and protocols that would recognize the rights of consumers to, for instance, identify substitute decision makers, appropriate treatments and

other financial, medical and personal decisions, particularly for the care of children.

However, despite their prevalence in the United States, Advance Directives have, in many instances, failed to guide clinical decision-making, and their utility has been questioned. Of particular concern is the dilemma facing clinicians when the Advance Directive rules out treatment which the doctor believes is in the patient's best interests. Currently in Australia, Mental Health Legislation can over-ride an Advance Directive.

In the UK, Advance Statements are recommended by the Expert Committee (Department of Health, 1999), and actively promoted as part of a reformed Mental Health Act by the 60 organisations of the Mental Health Alliance (2003). However,, as yet advance statements are not recognised in mental health law in the UK. Prudent professionals may of course choose to state why they have acted against an individual's wishes. Advance statements are recognised in UK case law and healthcare policy and usefully promote consumer values and autonomy. They can also avoid the problem of paternalism associated with best interests.

Families and others often shoulder significant burdens when consumers are acutely psychotic. Reflective discussion in a non-crisis situation can identify options regarding treatment and the role that carers will play. This process, if carried out as part of the development of a relapse prevention plan, would justify the identification of carers and publicly acknowledge their role in future treatment.

3.5 EXAMPLES THAT PROVIDE SOME GUIDANCE FOR PRACTICE

3.5.1 Family therapy – psychoeducation programs

Within the frame of family therapy Szmukler and Bloch (1997) acknowledge the potential ethical dilemma of observing patient confidentiality and involving the family in the service user's care. To avoid damaging *patient* autonomy and the therapeutic relationship the authors suggest a set of guiding principles to structure information sharing practice.

The approach involves a clear explanation at the outset about information sharing, and recognition that service user consent can be renegotiated as part of a dynamic process during the journey from breakdown to recovery. Where the service user refuses to give consent the professional should persevere in seeking the service user's agreement, clarify why the information is needed and seek to understand the reasons behind the refusal. If these approaches fail the professional can negotiate restricted conditions of disclosure. As a last resort, factors to be weighed in deciding to act against the service user's wishes are identified as follows:

- The nature and magnitude of the harm to be avoided;
- The availability of alternative courses acceptable to the service user;
- The service user's capacity to make choices based on his or her understanding of the proposed treatment;
- An assessment of the quality of family relationships and the longer term concerns;
- The feasibility of using less restrictive care alternatives where the family is involved; and

- A duty of care on the part of professionals to help families, given the huge impact mental health problems can have on their lives.

In addition, considering nearest relatives who abuse, the authors acknowledge that professionals need to discriminate against families and carers who have an inappropriate relationship with the service user. This stepwise approach provides professionals with a set of principles to guide discernment and discretion in identifying and communicating with families and carers.

3.5.2 Surrey-wide Operational Partnership Group in Mental Health (SWOP), UK

In 2001, the group produced a multi-agency policy document with four main interactive parts, which covered the following:

- The partnership ethos and mechanisms for multi-agency working;
- The key principles and procedures on confidentiality and information exchange;
- The duties of healthcare staff and basic procedures; and
- Carers' issues and confidentiality.

The document was expressly written for staff and volunteers in statutory and voluntary organisations with mental healthcare responsibilities. The separate carers' section was designed in collaboration with a local carers' group. The section identifies the carer role, context of care and carers' rights under mental health and carer legislation. It links with the sections on principles and procedures and responsibilities of staff in a wide range of health and welfare areas such as security of records, welfare benefits and housing. The policy attempts to provide workers with general guidance regarding the circumstances in which information should be protected and shared and to clarify the steps that should be taken in the decision-making process. These include obtaining the service user's consent wherever possible, consulting colleagues and in extreme cases taking legal advice. The document attempts to address the factors professionals should consider when sharing information with carers and what carers might wish to consider when imparting information to professionals. The importance of recording the decision-making process so that actions can be justified if so required is also emphasised. The first edition of the policy (SWOP, 1999) was promoted in the government consultation document *Guidance on the Section 31 Partnership Arrangements* (Department of Health and Department of Environment, Transport and the Regions, 1999, p.30), UK.

3.6 CONCLUSION

The literature is mostly silent on how to achieve identification. However, there is plenty of evidence to support the various activities that flow from identification. Existing literature focuses on the problems associated with implementing these processes. It can be assumed the resistance that exists in current practice relates to implementation of activities that flow from identification. Therefore it appears necessary to address impediments to implementation of existing policies if the issue of identification is to be addressed.

In summary, the literature identifies that a substantial commitment is required from all stakeholders across the mental health system in years to come, if the widespread current poor practices in identification and support of carers are to be rectified. Improvements in practice depend on the following:

- Clear policy guidance and service delivery protocols,

- Improved knowledge and training regarding the issues of confidentiality;
- Routine identification of carers preferably by consumer consent via Advance Directive or relapse prevention plans;
- A cultural shift within mental health services, including a change in attitude towards identification and working with carers;
- A process for addressing practical constraints that restrict professional involvement with carers within services;
- Access to carers' assessments and general information packs; and
- Carers self identifying and becoming pro-active in the development of effective relationships with professionals.

4. INTERNATIONAL POLICY AND PROGRAM CONTEXT

In discussing identification, it is essential to consider the current international context in terms of legislation, mental health policy and currently operating programs. This chapter provides a description of the international legal and policy context in relation to carers and describes a small number of projects which have been conducted in a variety of international settings that focus on carer identification.

4.1 BACKGROUND

Following the de-institutionalisation of mental health care throughout the world, an increasing number of consumers are cared for in community settings but primarily by family and friends who fulfill the role of carer. Over the last 15 years there has been a major focus on development of policies and legislation to protect consumer rights. Services have become more consumer focused and consumer participation in policy development and service delivery in mental health has provided a model for other areas of health care. The degree to which this has happened has varied internationally and has been influenced by mental health and carer recognition legislation.

The rights and needs of carers have also been addressed internationally, however, the majority of work in this area has taken place in relation to carers of people with an intellectual or physical disability or in aged care. Most legislation developed to enshrine these rights include carers of people with a mental illness. However, the guidelines governing implementation of this legislation is heavily weighted towards carers whose tasks are constant and primarily physical in nature. All carers share some common experiences, however, the episodic nature of mental illness, lack of recognition of the term carer, and issues associated with interpretation of privacy legislation make identification of carers of people with a mental illness a more complex process than in the general health area.

An examination of international policy, legislation and literature has revealed a plethora of information relating to carer rights and needs, policy support for inclusion of carers as an integral component of the treatment team and changes in legislation to support these activities. However, very little exists in relation to actual identification of carers of people with a mental illness.

Literature searches of the UK, NZ and Canada provided the most useful information, however, the issue of identification continues to be elusive. Some of the legislation requirements require a process of identification, or assume a process although this is not well documented.

4.2 UNITED KINGDOM POLICY AND LEGISLATIVE CONTEXT

The UK appears to have the most comprehensive legislation and policies concerning carers. Like many developed countries, the United Kingdom's Mental Health Policy is developing an increased emphasis on the involvement of carers in mental health services. Carer participation has been emphasised in a variety of general and mental health-specific policy documents and legislation. Mental health was identified as one of three clinical priority areas in the general National Health Service (NHS) Plan released in July 2000. This was followed by the Patient's Charter (Department of Health, 1992) that states:

if you agree, you can expect your relatives and friends to be kept up to date with the progress of your treatment.

The Carers (Recognition and Services) Act 1995 introduced the carer's right to an assessment of his/her own needs. This was subsequently extended under Standard 6 of the

National Service Framework (NSF) for Mental Health (Department of Health, 1999a) which states:

All individuals who provide regular and substantial care for a person on CPA should:

- *have an assessment of their caring, physical and mental health needs, repeated on at least an annual basis*
- *have their own written care plan which is given to them and implemented in discussion with them.*

In addition, a new Carers (Equal Opportunities) Bill focuses on carers' health, employment and life-long learning issues. The Bill places duties on local authority social services departments (SSDs) to:

- *inform carers about their rights to an assessment*
- *develop information strategies to ensure that carers know about their rights*
- *promote the health and welfare of carers*
- *ensure other parts of the local authority works with social services to deliver information strategies to help carers.*

There was also support noted for the development of advance statements registering the preferred contact. Carer organizations have recommended that question protocols be developed to assist psychiatrists, consumers and carers to promote meaningful interaction.

It is of interest to note, however, that although carers have the right to have their needs assessed in the UK, they are still not entitled to have their needs met.

The document, *Developing Services for Carers and Families of People with Mental Illness* (Department of Health, 2002a) also emphasises the importance of engaging carers as soon as possible during or after the first episode of mental illness of the individual concerned. However, no guidance was provided regarding how the process of identification should occur.

4.2.1 Carer Assessments

In the UK, Carers have a right to an assessment of their needs – and this right has been extended by successive pieces of legislation. This assessment is undertaken by the Local Authority, and is the passport to a number of support services for carers. (Carers (Recognition and Services) Act 1995, Carers and Disabled Childrens Act 2000, Carers (Equal Opportunities) Act 2004.) Health services have a key role in ensuring carers can access these rights and services. The 2004 Act places a duty in primary care to give *due consideration* to a request from Local Authorities for the planning or provision of services to carers.

In establishing this standard on carers in the NSF for Mental Health, the Department of Health acknowledged that the implementation of the carers' right to an assessment was:

....patchy. Assessments are not always carried out. Some carers are offered very sensitive practical and emotional support. But others receive very little, or no help.

The Framework goes on to say that Carers of people with long term conditions should have access to appropriate support and services that recognise their needs, both in their role as a carer and in their own right. They are to be supported by health services, involved in the planning of care, treated as partners and receive a range of services. Staff working with carers are to receive carer awareness training.

Policy guidance for the 2004 Act advises that the NHS and Local Authorities develop a multi-agency strategy and ensure that agreed protocols are in place from partner organisations in providing support to carers.

Of great interest is the fact that the new General Medical Service contract for GPs offers 3 points if *the practice has a protocol for the identification of carers and a mechanism for referral of carers for Social Services Assessment*. The new contract offers a mechanism for inclusion of carers in contractual requirements.

In addition, the following two core standards from the new performance framework for the NHS in place from April 2005 relate to carers.

- C14 relates to systems to ensure that patients, relatives and carers have suitable and accessible information about services and complaints.
- C17 requires organizations to take account of the views of patients and carers in planning and delivering services.

4.2.2 UK Mental health legislation

The current mental health legislation identifies the nearest relative as the main carer. This identification is identified using a hierarchy based on British genealogical traditions underpinned by principles of *kindred and affinity*. This excluded same sex partners until changes made by case law in 2002.

Hospital authorities are only required by the Mental Health Act 1983 to provide information to the nearest relative if the patient agrees. Evidence suggests that carers and healthcare staff generally do not know about the nearest relative role (Hart 1998; Gregor, 1999) and that the powers are rarely implemented (Rapaport, 2002).

The government appointed an Expert Committee to advise on legislative reform (Department of Health, 1999). While the reform has been delayed to allow for a further period of consultation it is anticipated that the nearest relative will not feature in a new Act. Under the current proposals (Department of Health, 2002b and 2002c), the nearest relative will be replaced by the roles of 'carer' and 'nominated person'. The latter will be appointed by the patient subject to the approval of the approved mental health professional. The carer and nominated person (who may be one and the same) will have rights that even when combined in no way equate with the nearest relative's powers. However, carers will be consulted about care plans and discharge, and staff will have duties to provide information about services and how these can be accessed.

The literature notes that the consumer's capacity to make an informed and rational decision allowing his or her carer to receive personal information is fundamental to information sharing between professionals and carers.

It is acknowledged that problems occur because of the fluctuating nature of mental health problems and the consumer's hostile reaction to his or her carers arising from mental illness. The law is currently silent on this issue. Proposals issued by the Lord Chancellor's Department (1997) to clarify the carer's position in respect of people whose ability to make

decisions is temporarily or permanently impaired were deferred. However, in this regard a Mental Capacity Bill was issued in June 2004 (followed by the Mental Capacity Act 2005). This gives carers, who have been appointed as lasting power of attorney, powers to make decisions about the patient's finances and welfare. If enacted, the patient would have the power to appoint his or her carer as attorney when he or she was well, thus in some measure addressing weaknesses in current carer and mental health law.

4.3 USA POLICY AND LEGISLATIVE CONTEXT

The development in the USA which clearly acknowledged the importance of carer involvement in mental health services was the President's New Freedom Commission on Mental Health, launched in 2002, with a mission to conduct a comprehensive study of the US mental health service delivery system. The Commission's membership included consumers and carers. The findings of the Commission reported that a fundamental transformation of America's mental health system was necessary and proposed six goals required to facilitate this transformation. One of these goals was that mental health care becomes consumer and family driven. To achieve this, the final report of the Commission recommended that carers should be directly involved in designing and developing the systems in which they receive care.

In response to the final report of the New Freedom Commission, the US Department of Health and Human Services partnered with various federal departments to launch the Federal Mental Health Action Agenda. This agenda calls for:

fundamental transformation of the mental health care delivery system in the United States—from one dictated by outmoded bureaucratic and financial incentives to one driven by consumer and family needs that focuses on building resilience and facilitating recovery.

The agenda represented the first steps towards fundamental transformation of US policy on mental health towards more carer inclusive service delivery.

4.4 CANADIAN LEGISLATIVE AND POLICY CONTEXT

The Senate Standing Committee on Social Affairs, Science and Technology published in 2006 a document: 'Out of the Shadows at Last. Transforming Mental Health, Mental Illness and Addiction Services in Canada.' That report made far reaching recommendations in relation to carers and, if implemented, would cover many of the issues associated with identification. The recommendations relating to carers have been reported in full because of their potential for consideration within the Australian context.

Recommendation 2 (page 69)

That health care professionals take an active role in promoting communication between persons living with mental illness and their families. This includes asking persons living with mental illness if they wish to share personal health information with their families, providing them with copies of the necessary consent forms, and assisting them in filling them out.

Recommendation 3 (page 69)

- *That health care professionals have discretion to release personal health information, without consent, in circumstances of clear, serious and imminent danger for the purposes of warning third parties and protecting the safety of the patient.*

- *That this discretion be governed by a clearly defined legal standard set out in legislation, and subject to review by privacy commissioners and the courts.*

Recommendation 4 (page 70–71)

- *That all provinces and territories empower mentally capable persons, through legislation, to appoint substitute decision makers and to give advance directives regarding access to their personal health information.*
- *That provisions in any provincial legislation that have the effect of barring persons from giving advance directives regarding mental health treatment decisions be repealed.*
- *That all provinces and territories make available forms and information kits explaining how to appoint substitute decision makers and make advance directives.*
- *That all provinces and territories make available community-based legal services to assist individuals in appointing substitute decision makers and making advance directives.*
- *That all provinces and territories undertake public education campaigns to educate persons with mental illness, and their families, about the right to appoint a substitute decision maker and make an advance directive.*

Recommendation 5 (pages 71–72)

- *That where a person is diagnosed with a mental illness that results in his/her being found mentally incapable, and where there is no previous history of mental illness or finding of mental incapacity, and where there is no named substitute decision maker or advance directive, the law create a presumption in favour of disclosure of personal health information to the affected person's family caregiver(s).*
- *That the provinces and territories enact uniform legislation setting out this presumption.*
- *That the legislation specify an "order of precedence" for relatives (i.e., if the person is married, or living in a common-law relationship, disclosure would be to his or her spouse or common-law partner, and if there is no spouse or common-law partner, to the person's children, etc.).*
- *That the legislation specify the information to be disclosed, including: diagnosis, prognosis, care plan (including treatment options, treatment prescribed, and management of side-effects), level of compliance with the treatment regime, and safety issues (e.g., risk of suicide).*
- *That the legislation specifically bar the release of counseling records.*
- *That the legislation oblige the person disclosing the personal health information to notify the mentally incapable person, in writing, of the information disclosed, and to whom it was disclosed.*

A recent (2007) Election Paper on mental health and addiction reinforced these recommendations.

The Canadian Association for Mental Health has also undertaken some interesting work examining supports it offers to family members of people with mental illness and the ways in which it involves families in client care. Family members, the Family Council, clinical staff representatives and the Community Support and Research Unit collaborated on a consultative process to develop an Action Plan that clinical staff could use to review their programs and identify strengths and weaknesses in how they work with families. The report titled, *Putting Family Centered Care Philosophy into Practice December 17, 2004*, synthesizes the literature on evidence-based best practices for involving families in client care and supporting them more generally.

The literature review was guided by the following four key questions.

- What are best practices for a family philosophy?
- What are best practices for involving families in client care?
- What are best practices for designing and delivering professional mental health support services to families?
- What are best practices for facilitating families helping families?

4.5 NEW ZEALAND POLICY AND LEGISLATIVE CONTEXT

The Mental Health Commission of New Zealand (MHCNZ) developed a Blueprint document in 1998 that outlines the steps required to achieve the implementation of the Government's National Mental Health Strategy at the time. The Blueprint states that

There are significant advantages when support for families is provided as part of a continuing care programme. Services are more likely to be effective when they utilise the knowledge and experience of the people closest to the person who is ill.

The Second New Zealand Mental Health and Addiction Plan, 2005–2015, outlined action priorities, which focused on improving New Zealand's mental health system. Within action priorities is a need for services to recognise that family and whānau must be involved in service delivery and treatment.

New Zealand also developed a strategy for carer involvement in mental health that was championed at ministerial level (Mental Health Commission, 1998). This followed a statement by the country's Privacy Commissioner regarding his frustration at *the refusal of some hospitals to adopt sensible policies governing the release of information about mentally disordered patients to their care-givers* (Office of the Privacy Commissioner, 1998). The model of carer involvement at strategic and care planning levels was largely influenced by the strong family traditions of the Maori community. Subsequent guidance issued by the New Zealand Ministry of Health (Royal Australian and New Zealand College of Psychiatrists, 2000) supports close co-operation with families and *sharing information, planning, decision-making, and providing support and education when necessary*. The guidance identifies the complex cultural, ethical, legal, financial, organisational and treatment issues which affect the involvement of families in *patient care* and the potential for conflict over the rights and responsibilities of consumer privacy and family concerns. While consumer consent is upheld, the document states that the country's Privacy Act 1993 and Health Information Privacy Code 1994 do not prevent most aspects of working with families.

4.6 EUROPEAN COMMUNITY POLICY AND LEGISLATIVE CONTEXT

The result of de-institutionalisation and the move to community based care in Sweden, France, Germany and the Netherlands has seen a de-centralisation of service delivery and cost to regions and municipalities. Within those frameworks there may be individual programs or services that address the issue of how a carer is identified, but as yet they are not part of the available literature.

The Council of Europe and the European Commission, which encompass a number of the countries stipulated in the terms of reference for this project make reference to *Patients and their families* with no specific reference to carers. It is clear, however, that the thrust of service delivery is toward the community environment with municipalities being responsible for costs. No literature was able to be sourced regarding identification.

The literature and legislation primarily focuses on *people with disabilities* who are “entitled to support under the Social Services Act, but also under special legislation. The Act Concerning Support and Services for persons with Certain Functioning Impairments (1993) provides for items such as personal assistance particularly in daily activities” It does not in its content define a carer—but only the user and only in terms of entitlement. In the same country, the National Board of Health and Welfare refers to patients and “their relatives”

One effect of the shift from hospital care to primary care has been that *General practitioners either makes an appointment for an appropriate caregiver for the patient or - - -*. It is, however, stated that there is no legal obligation for people to provide care for their relatives. This assertion appears mostly to apply to those caring for the elderly.

Investigating the area of Health in Transition (Glenngard, Hjalte, Svensson et al 2005) discussion concerns the quality of life for mental health patients, and places the responsibility on the municipalities. Move to a *continuity of care* direction does not elicit a determination specifically as to who the carer is.

Nonetheless, in accessing the minutes of the Assemble Parlementaire (May 2005), the Social Health and Policy Affairs committee refers constantly to *the views of users and their families* (Berger :Germany): *associations/ professionals, users and their relatives*: while further is re-iterated, the responsibility to *ensure independent monitoring and evaluation of mental health programs in close co-operation with mental health services, professionals, users and their relatives.*

The status of relatives (not relationships per se) in a discussion, which in seeking more representatives of users and their relatives, acknowledges that families require support when **caring for their relatives**

The European Union (2006) in considering written informed consent states, *when written informed consent has been given by the patient, or a person, counselor or guardian chosen by the patient as his or her representative*. It was also of interest that this decision has to be confirmed by a select committee not composed exclusively by psychiatric experts. However, the reference to users, their relatives and their families identifies the most commonly found relationship. It seems to be a taken-for-granted position with no immediate suggestion of extending the scope.

Stultz, Williams and Uten in *Qualitative Health Research* (2006) discuss the impact of care upon families—most particularly family carers. Additionally, Torgalshoen and Rund (1998), in investigating recovery said

“Factors like willpower and a supportive family were discussed as positive contributors in the process of recovery”,

while the European Commission (2006) referred to:

“family carers of those with a mental illness who are themselves at risk of burnout and depression.”

Part resolution was seen as the involvement of patient groups as well as that of families and nearby carers. This was the only reference to a broader definition of carer but did not make reference to the process of identification.

German law appears to take a strongly prescriptive stance about confidentiality. Under Section 203 of the German criminal code which deals with confidentiality (Die Schweigepflicht: Juristische Grundlagen/Confidentiality: Legal Basics), professionals are forbidden from sharing information that they have discovered in the course of their work or that has been found out in any other way. However, echoing the British *Spycatcher judgement* (Attorney General v Guardian Newspaper, 1990) only *secrets* are protected by confidentiality, not well-known facts. Thus, in respect of families where consumers refuse to consent to information being shared, only passing on *secrets* is forbidden. Where the family is aware that the patient is in hospital professionals may:

- contact the relatives and discuss facts that are already known to the family; and/or
- ask the family for information without the consent of the consumer

The family can also ask for a conversation with the professional without the service user being present. The policy advises professionals, in conversing with families, to allow family members to talk to establish how much they know. For example, do they know the diagnosis? Passing on the diagnosis can be a *secret* under Section 203, especially if it is the first diagnosis. If the family knows the diagnosis, this can be passed on and the doctor can provide general information about the illness. The family must also observe confidentiality in respect of information received and the doctor must not tell the consumer what he has told the family.

4.7 EXAMPLES OF GOOD PRACTICE

Literature regarding clinical practice internationally is mostly silent on the issue of identification and it was only possible to identify a small number of programs where the identification of carers is a key component of the service. This is not an exhaustive selection and is provided to indicate a range of current activities for identifying carers.

4.7.1 Lambeth Early Onset Service – UK

The UK government had a target of establishing 50 Early Intervention Services (EIS) to proactively support young people managing mental health problems in England by December 2004. It is not known if this was achieved. However, information was obtained regarding how well supported family members felt by Lambeth Early Onset Service (LEO).

The LEO service is for younger people (16–35), particularly those in their first or second episode of psychotic experience. The ethos is to provide early intervention, individual help and treatment to reduce the duration of untreated psychosis and to inform, empower and involve the client and their family in all aspects of their care. Their approach to working with carers is to:

- engage with families as soon as possible after crisis;
- provide written and verbal general information for the carer on the service, psychosis and their rights;

- explain to the consumer the importance of engaging their carers;
- provide more specific client information where the consumer gives consent;
- review consumer consent where this has been withheld;
- obtain information from families about what has led to the crisis;
- explain the role of the primary nurse in the context of 'patient care' and keeping the family up to date with weekly appointments;
- work with carers and consumers separately and together;
- address carers' anxieties by finding ways of helping them;
- facilitate carer/family access to an appointment with professionals including psychiatrists;
- involve the carer where appropriate in giving medication before discharge; and
- provide information about carer groups.

4.7.2 Processes to assist identification of hidden carers

The area of general practice has been targeted in the UK and the following examples are provided of mechanisms for identifying hidden carers within primary care settings.

Mailshot Identification. This method identifies carers through the use of a letter and short questionnaire being sent directly from the GP to an agreed set of patients. This may be a particular age group or those with particular illnesses or medical conditions. However, from experience of using this approach the return rate was on average 6% of the total patients contacted.

On-site identification. This method of working places staff within a health centre or practice setting for an agreed number of hours per day generally over a four to six week period. During that time they approach all patients entering the practice, or whilst they are waiting for their appointment, and ask if they are carers.

Using notice boards and general publicity material to raise awareness. A notice board and a range of publicity material was used throughout the health settings for patients to take away or read. It was thought this could become a permanent feature of a practice or health centre.

Direct awareness-raising. Staff worked with community-based health staff such as district nurses or health visitors in direct awareness raising sessions. This provided health service staff with details of service provision and contact cards and letters to distribute to patients and/or their carers where appropriate.

It was also suggested that 'carers' surgeries' be held on a regular basis for two hours two days per week, providing information and advice on-site in the surgery. This would enable GPs to make quick referrals and give carers immediate contact with the carers' support worker.

Pharmacists role in identification. The Carers Organisation in Scotland also reported on the possibility of community pharmacists being well placed to identify carers and to provide information to them regarding options for information and support. This suggestion was

based on the fact that it is frequently the carers who collect repeat prescriptions for psychotropic medication.

This is not an issue that was raised during consultation, However, it has merit for further exploration in the Australian situation.

4.7.3 Home from hospital initiative

The Home from Hospital Initiative NHS Scotland White Paper (Scottish Executive 2003) reported recognition at the point of discharge from hospital as an important opportunity to identify and support carers at the start or resumption of their caring responsibilities. However, no processes to assist with identification were suggested.

4.7.4 Screening tools to assist identification

Alison Jarvis, lecturer in Nursing Studies, University of Scotland, in the Journal of Clinical Nursing (2005) described the development of a screening tool to identify carers in a general practice by a large-scale mailed survey. This took place in one Scottish general practice.

The study noted that identifying carers is a fundamental precondition to providing them with support. Studies often recruit carers who are members of carers' organisations or via the care recipient in receipt of services. However, as nearly 60% of carers receive no support from the statutory services, this group of carers may not be representative of the majority of carers. This paper describes the results of a study undertaken to identify a broader group of carers in a general practice in a large Scottish city.

A quantitative research design was employed using a mailed screening survey to identify carers within a general practice. Carers were systematically identified, independent of the care recipient, using a screening tool developed by the researcher which was sent to all adult patients registered with the practice.

The response rate was 69%. Overall, 11% of the surgery population identified themselves as carers with a mean age of 55 years. The carers were involved in a range of caring activities of varying levels and duration. However, it was concluded that the screening exercise was time consuming and costly.

The project did emphasise, however, that when carers are systematically identified early in their caring career the primary health care team is more able to support them proactively.

4.8 CONCLUSION

Plentiful information is available regarding the following:

- Documents that identify and explain the rights and responsibilities of consumers and carers;
- Documents that outline various professional roles and responsibilities with regard to patient confidentiality and the central role of consent;
- Helpful contact points;
- Reference to the unique needs of young carers;
- A conceptual framework to support appropriate information sharing between professionals and carers;

- Summaries of the law and government policy on carer issues; and
- Examples of situations where information may be shared without the consumer's consent, for example by order of a court or in cases of risk.

Carer oriented policies also identified the following professional responsibilities:

- To provide an explanation of confidentiality and the agency protocol to all parties;
- To seek consumer consent to disclosure of personal information to support carer 'need to know';
- To review consent at regular intervals;
- In the event of the consumer withholding consent, where appropriate persevere with seeking consent working with the consumer to help them understand why their carer may 'need to know' specific personal information regarding their care and treatment;
- To assess the capacity of the consumer to give consent;
- To ensure information is accurately recorded; and
- To assess the nature of the care context and relationships.

In conclusion, there is little information available that specifically addresses the issue of identification.

5. AUSTRALIAN POLICY AND LEGISLATIVE CONTEXT

5.1 PUBLIC SECTOR

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 fifteen years. Policies of non institutionalisation and mainstreaming of mental health services with general health have resulted in families and carers playing a major role in the community based care of people with a mental illness.

Carers' rights and needs and avenues for their involvement as key stakeholders in all levels of mental health care are outlined in various NMHS documents. These include the following:

- Mental Health Statement of Rights and Responsibilities (MHSRR) (1991);
- National Standards for Mental Health Services (NSMHS) (1996);
- National Practice Standards for the Mental Health Workforce (NPSMHW) (2002); and
- National Mental Health Plan (NMHP) 2003–2008.

These documents support involvement of carers at both individual and organisational levels. Over this period there has been an increase in consumer specific activity at local and state levels. However, opportunities for carer participation in activities that effect them at local and state levels have not continued to develop in the manner initially hoped.

At the individual care level the policies require carer participation in all aspects of care with the consumers consent or at the clinician's discretion in certain circumstances such as involuntary detention. These policies also require that services assist carers to manage their caring role and the impacts of mental illness on them and their family.

The policies also recognise carers as key stakeholders in the planning, development, delivery and evaluation of mental health services at a system-wide and local service level.

Feedback from carers indicates that both public and private mental health systems have been slow to implement these policies at either level. However, new publications are emerging that reinforce the benefits of participation.

None of these documents address the issue of how to identify carers.

During the implementation period of the third National Mental Health Plan, the Mental Health Council of Australia, together with the Australian Human Rights and Equal Opportunity Commission, published a nationally consulted report detailing experiences of injustice and despair in mental health care in Australia. The *'Not for Service'* report was published in 2005 and a senate inquiry into mental health services in Australia was announced. The Senate Inquiry Report, published in 2006, listed a wide range of recommendations for action to improve mental health services in Australia. In April 2006, the Commonwealth Government announced an additional \$1.9 billion funding commitment to mental health over five years. This was soon followed in July 2006 by the Council of Australian Government's endorsement of the *National Action Plan on Mental Health 2006-2011*. The COAG *National Action Plan* represents a landmark in the development of mental health services in Australia and an unprecedented collective investment in mental health by all Australian governments to date.

The Plan outlines five areas for action and proposed the formation of a COAG Mental Health Group in each state and territory. These state and territory Mental Health Groups provide a forum for oversight and collaboration related to the COAG Commonwealth and State/Territory initiatives. COAG has committed to carer participation in each of these Mental Health Groups, acknowledging the importance of carer involvement in the successful implementation of the National Action Plan.

The Individual Implementation Plans, which form part of the National Action Plan, represent the areas of focus as determined by each state and territory. Whilst some states have committed a specific focus on carers they have not addressed the area of identification in their implementation plans.

Carers Australia research has also indicated that a vast array of mental health information and education resources for carers 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.

Some distinct policies and programs exist in some states and territories including the offer of one-off training to mental health staff of differing length and focus. These programs have positive impacts, but generally appear to lack the capacity to reinforce practice changes through follow-up training, in-service sessions or consultation.

5.2 National Standards for Mental Health Services

The *National Standards for Mental Health Services* were endorsed in 1996 as a guide for service enhancement and continuous quality improvement. The focus of the current standards is on consumers with a number of standards referring to both consumers and carers. Implementation of these standards was initially slow to progress, however, this has now improved, particularly in the public sector. The external review and monitoring processes involved in services achieving accreditation against the standards have tended to focus more on consumers with little or no attention being paid to the interactions between mental health services and carers.

The continued implementation of the Standards was reinforced in the *National Mental Health Plan 2003–2008* that lists as key direction 27.2.

Establish continuous quality improvement cycles and public reporting based on the Mental Health Service Standards and the National Practice Standards for the Mental Health Workforce, including comprehensive implementation and ongoing accreditation and review.

The 1996 Standards are currently undergoing a process of review and there has been significant lobbying to ensure a specific standard is devoted to identification and support of carers in their own right.

Recommendation

- **A specific standard addressing the issue of carer identification and participation to be developed for inclusion in the revised National Standards for Mental Health Services. This should also include the following:**
 - **Mechanisms for specific measurement of this standard in accreditation survey processes, including ACHS EQUIP; and.**

- ***Additional training to be made available for surveyors of mental health services.***

5.3 STATE AND TERRITORY POLICIES

5.3.1 Queensland

Queensland Health does not currently have a statewide policy regarding identification of carers. Identification is dealt with on a case by case basis and processes vary between individual Health Service Districts.

However, the Queensland Government does have a *Carer Action Plan 2006–10*, which has been developed following endorsement in 2003 of the Queensland Government Carer Recognition Policy to formally recognise the contribution of carers. The Carer Action Plan focuses on addressing issues regarding work/life balance, young carers, ageing carers and carers as partners in care. As part of this Plan, Disabilities Queensland and the Department of Communities are undertaking a collaborative project in the area of youth carer identification, understanding and support of young carers in education. The project is currently in its initial scoping phase.

The Queensland Government is also currently finalising the draft *Queensland Plan for Mental Health 2007–17*, which outlines a focus on the consumer, family and carers as a key underlying principle to ensure improved outcomes for consumers.

5.3.2 New South Wales (NSW)

Mental Health Services in NSW are currently delivered within the context of the five year plan launched by NSW Health in 2006 and summarised in the document: *NSW: A new direction for Mental Health – a five year plan to improve care for people with mental illness*.

In addition, NSW has a whole of government approach to identifying, recognising the needs of, and supporting carers. This is documented in the *NSW Carers Action Plan 2007–2012*. A *Family and Carer Mental Health Program* commenced in 2005 within the Mental Health and Drug and Alcohol Office. Policy positions and clinical practice frame works are currently under development.

Individual Area Mental Health Services generally have specific local policy documents associated with carer participation although it is not known if these specifically address the issue of identification.

5.3.3 Australian Capital Territory (ACT)

ACT Mental Health Services are currently directed in their service delivery by the *ACT Mental Health Strategy and Action Plan 2003–2008*. Four broad principles were identified out of the consultations conducted for the Strategic Plan which were then used to guide the development of the Strategic and Action Plans. The last of these principles highlights the prominence of carers in the delivery of mental health services in the ACT:

active support and encouragement for consumer and carer participation in the planning, development, delivery and review of mental health services.

Recent correspondence from the Director of Mental Health indicates that Mental Health ACT does not currently have a policy regarding identification of carers. The current practice adopted by the treating teams involves the consumer nominating who their carer is, if appropriate. This is formalised by the consumer completing a form authorising the treating

team to exchange information with the carer. Consumer instructions not to involve carers must be respected under the legislative framework.

5.3.4 Northern Territory

The Northern Territory in the current strategic direction document: *Building Healthier Communities: A Framework for Health and Community Services 2004–2009* demonstrated a need for more carer involvement in service delivery. Consultations undertaken as part of the preparation of the report *Mental Health Service System Development Strategy Project for the Northern Territory* identified a lack of consistent carer and consumer input into the planning, development and operation of services within the public sector.

5.3.5 Western Australia (WA)

Currently, WA mental health services are delivered in the context of *Delivering a Healthy WA: Western Australia's Mental Health Strategy 2004–2009*. The focus on carers in this document is minimal. However, WA was the first State in Australia to pass the Carers Recognition Act in 2004. This legislation recognises the significant role that carers play in the community and provides a mechanism for their involvement in services that impact on them. All public health services are obliged to comply with the Act.

The following information guides specifically for use in the mental health area were published in 2007 as part of the implementation of the Act:

- *Carers guide to information sharing with mental health clinicians;* and
- *Communicating with Carers and Families.*

5.3.6 Victoria

New Directions for Mental Health Services, The Next Five Years (2002), represents the Victorian Government's priorities for mental health services and encompasses as a core goal the strengthening of services for carers and the development of systems for carer involvement in policy and planning. The need to understand and acknowledge the carer's contributions is clearly articulated.

Caring Together: An action plan for carer involvement in Victorian public mental health services, August 2004, further articulates strategies for improving carer involvement.

In 2006, the Victorian Department of Human Services released a number of policy documents, including:

- *'Doing it with us not for us';*
- *Caring together – An action plan for carer involvement in Victorian public mental health services;* and
- *Recognising and supporting care relationships.*

These documents move carer policy towards a relationship focused model. They move away from focusing on the needs of carers or the people being cared for and towards an integrated approach that looks at the dynamic interconnections between people in caring relationships. The documents outline a set of overarching principles that capture the most important elements of supporting caring relationships within a human services context. The Action Plan emphasises that the consent of the consumer is relevant in determining the

extent of participation of the carer , as outlined in the *Mental Health Statement of Rights and Responsibilities* document, the Plan also emphasises that without consent the carers still have the right to:

- *Provide information concerning family relationships and any other matters relating to the mental state of the consumer to health service providers; and*
- *Assistance with their own difficulties that may be generated by the process of caring for people with a mental disorder.*

The documents are silent on the issue of processes for identification.

5.3.7 Tasmania

The *Tasmanian Mental Health Services Strategic Plan 2006–2011*, developed by the Department of Health and Human Services outlines six Strategic Priorities. One of these Strategic Priorities for 2006–2011 is Customer focus. According to the following priority, carers are included as customers of the mental health service.

.....Maintaining the customer as the primary focus ensures services are relevant and responsive. Mental Health Services has a broader range of customers than its consumers. Carers, families, non-government organisations, other services in the community that consumers access and government are all “customers” of Mental Health Services and commitment to working effectively with these customers is critical to the best possible outcomes for our consumers.

The Tasmanian Mental Health Services report that they routinely request information from consumers at their point of entry to the service system. This is collected on the basis that the consumer becomes acutely unwell and unable to provide informed consent rather than a process for identifying and supporting carers.

5.3.8 South Australia (SA)

Strategies 7 (Mainstreaming Mental Health Beds) and 10 (Carer Support) outlined in the report *A New Millennium– A New Beginning. Mental Health in South Australia. 2000–2005 Implementation Plan* outline the commitment to carers in SA.

Strategy 7: Work in Partnership with Key Stakeholders: Promote increased involvement of consumers, carers, the non-government sector, and public and private providers at all levels of service planning, implementation and delivery. This should occur utilising the advisory structures developed as part of the service delivery networks.

Strategy 10: Carer Support: Non government organisations to provide increased assistance to Carers through the provision of information and advocacy which aims to empower carers to participate in partnership with government for the provision of better services and to improve the conditions under which carers work.

Strategy 10 is inclusive of young carers and those from Aboriginal and culturally and linguistically diverse backgrounds.

A practical example of this commitment has been increased funding to Carers SA for additional education, advocacy and community liaison projects and the appointment of a number of carer consultants to specialist inpatient services in SA.

5.4 PRIVATE HOSPITAL SECTOR

Letters were sent to Chief Executive Officers (CEO's) of all private psychiatric hospitals [46] seeking information regarding current policies and practice regarding identification of carers. Responses were received from 13 hospitals [28%].

The majority of responses indicated that no policies currently exist except to identify next of kin. However, the point was made by a number of hospitals that information regarding identification of family, significant others or support people was sought as part of the practice of taking a psychosocial history on admission. Some hospitals, in explaining the policy regarding collection of information also sought information regarding the identification of people who should/or should not be provided with information regarding the patient.

One hospital referred us to their statement of Carers Rights and Responsibilities, however, had relied on displaying this information at locations within the hospital to enable carers to self identify. This was also the avenue for carers to identify themselves to participate in carer specific psychoeducation and support programs.

Another hospital asked patients to identify *family members or loved ones* to participate in a week long program of *education and supported processing*.

One hospital provided extensive documentation including a Carer Participation and Carer Rights and Responsibilities Policies together with a variety of brochures provided to carers. As part of their quality improvement activities, they audited carer involvement and satisfaction. The audit tools and the results provided were interesting as they indicated that 15% of the carer section of the admission checklist being completed, however, 80% had the carer section on the care plan completed. This information was presented to staff as a reminder to involve carers in care and discharge planning. These activities and audits were undertaken as part of the hospitals obligations for the EQUIP process of quality improvement.

In some hospitals, carers have access to resources located in patient's lounges and brochure stands with some information provided in a number of languages other than english. Reference was made in documentation to a variety of carer policies that outline the rights and needs of carers. Identification in these policies hinges on consumer consent. In this same hospital copies of admission forms were provided that provided a space for the following question:

Does the consumer consent to family/carers involvement/external health care provider in put into assessment/care/discharge plan? Yes/No.

Space was also made to record the input.

Of most relevance to this project were the two private hospitals which provided information and examples of forms that have been developed to specifically address the issue of carer identification. One such form is discussed in greater detail in the report of consultations and was considered by participants in consultation to be an example of good practice.

Additional comments received from hospitals included the following.

We would appreciate any input regarding the initiation of a suitable policy regarding the identification and engagement of carers.

5.5 MENTAL HEALTH AND CARERS RECOGNITION LEGISLATION

Review of State and Territory Mental Health Legislation in Australia is an ongoing process. The process of review and drafting amendment bills requires extensive consultation, may be contentious and sometimes take years to come to fruition.

The significant role that all carers play in Australian society has been recognised in recent years by the development of generic Carer Recognition Legislation in WA, SA, and NT. Government Departments in jurisdictions who have this legislation are required to develop implementation plans and to report on this process at regular intervals. Some States have recognised the special needs of mental health carers in their mental health legislation. These include Victoria, NSW and NT. In jurisdictions where Carer Recognition Legislation exists, there have also been subsequent changes to mental health legislation to encompass the spirit of the Carer Recognition Legislation. States have generally achieved this by way of amendments to existing legislation.

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. However, carers also have needs in their own right and this has not been adequately or consistently addressed in mental health legislation nationally.

The current position in relation to State and Territory Legislation has been summarised by Carers Australia in their submission [July 2007) to the Senate Select Committee Inquiry into Mental Health Services in the following table:

STATE/TERRITORY	MENTAL HEALTH ACT REVIEW	NAME	CARER RECOGNITION ACT
New South Wales	Review completed. Mental Health Amendment Bill 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 Whole of Government Carer Policy Implementation Plan 2006
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 rights, articulate treatment, assessment and care provisions of the consumer. The purpose of these Acts is not primarily to identify or 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 role of carers and their access to information which allows them to provide care but do not address the issue of identification.

Some Mental Health Acts specifically define carers, however, 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 process for identifying or defining 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 focus on notification of information, usually after an event such as an involuntary admission and do not say how carers will be identified in order to fulfill this provision of the legislation.

The Northern Territory's *Mental Health and Related Services Act 1998, Amendment Bill 2007* addresses the issue of carers' rights in relation to information, admission, treatment and discharge of the patient. The Amendment Bill, 2007 made provision to balance the rights of both carer and consumer for the first time in Mental Health Legislation in Australia. Procedures for implementation are currently being drafted. It is currently not known if these procedures will address the issue of identification.

NSW has very recently passed a Mental Health Amendment Bill, which has provisions for a primary carer to receive information. The primary carer is defined primarily according to their relationship with the consumer with the emphasis on family, however, the concept of that relationship being ‘close and continuing’ is introduced which is relatively new. People consulted during the project felt this was an important component of the identification process as there is potential for identification of short term acquaintances if consumers are asked to do this when unwell.

The Queensland Mental Health Act 2000 does not specifically identify carers although involuntary patients are entitled to nominate an ‘allied person’.

5.5.1 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 for other legislation that addresses rights to also address the issue of identification.

There is now a move towards a whole of government approach to recognise, support and meet the needs of carers. The table above illustrates the fact that 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 Carers Australia Senate Inquiry submission [2007] states:

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.

They go on to say:

...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.

Attempts have been made in the public sector in Victoria in the Chief Psychiatrists Guidelines regarding confidentiality and in the private sector by way of the *Privacy Kit for Mental Health Service Providers* to clarify issues regarding confidentiality for clinicians. However, current practice indicates that the legislation continues to be used as the reason for not sharing information with carers. Identification is a pre-cursor to sharing information and providing support.

Some states and territories already support carers and provide information to assist them understand their rights to access information within the existing legislative framework. However, these processes pre-suppose identification.

5.5.2 Consistency between Acts

The National Mental Health Strategy has provided a framework for legislative reform. However, it has never been possible to achieve consistency in all areas nationally, or national Mental Health Legislation as has been recommended by consumers and carers for many years.

Australia continues to have 8 separate Mental Health Acts. Relationships between consumers, carers and service providers vary according to the State or Territory. 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.

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.

5.6 CONCLUSION

While government policy has attempted to promote the role of carers in care planning to sustain community care, policy guidance on identification and information sharing between health professionals and carers is either non-existent or has in most cases failed to address the problems that occur because of the fluctuating nature of mental illness and its effects on decision-making.

The difficulties associated with changing eight separate Mental Health Acts to obtain consistency in approach to identification and inclusion of carers is acknowledged however

this is considered necessary if carers are to become true partners in the delivery of services to consumers.

Recommendations

National identification and participation policies

- ***Nationally consistent carer identification and participation policies and good practice protocols to be developed for implementation in all public and private mental health services***

Legislation

- ***State and Territory Mental Health Legislation to be amended to mandate identification and support of carers/primary support persons.***
- ***Development of Carers Recognition legislation in all States and Territories. At the time of submission, Carer Recognition legislation was in place in WA, SA, and NT.***
- ***Implementation processes to be developed for Carer Recognition legislation which pay particular attention to mental health carers.***
- ***Development of Carer Assessment legislation requiring all services to identify mental health carers in order to offer assessment of their needs.***
- ***Development of 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 as partners in the provision of mental health care.***

6. SUMMARY OF CONSULTATION

It is not only the consumer who is suffering. The care giver is too.

Carer participant in consultation, 2007

6.1 PROCESS

Issues regarding identification of carers of people with a mental illness were discussed in focus groups and with telephone consultations with a wide range of stakeholders [see 2. Methodology]. The following information emerged during this process.

6.2 CURRENT EXPERIENCE OF CARERS

Participants reported that they were generally unaware of policies regarding identification of carers and that current practice varies significantly from one location to another. In fact, the overwhelming experience of participants was that they felt health services make little or no effort to identify or involve carers. Some stated they felt that clinicians did not seem to know how to go about this process. In addition, in situations where consumers voluntarily identified their carers or carers self identified there was still reluctance by many clinicians to include them in care processes. *Consumer confidentiality or privacy legislation* was usually cited as reasons for non involvement. It was the experience of participants that individual clinician attitudes and practices prevail in the absence of service policies or protocols.

It was felt that the focus of training for the majority of health professionals in Australia is on the individual consumer. Individuals who have had additional family and/or group training were seen as the exception and were perceived as having a more family focused clinical approach.

Some examples were provided where clinicians were making early attempts at identification and participation of families and other carers. These included ORYGEN, Australia's leading youth mental health service and Research Centre within the University of Melbourne.

Regardless of the illness, participants identified a critical need for a framework that highlights the psychosocial demands of chronic conditions, particularly those that have intermittent acute episodes. In other words major changes are required in training if attitudes and practice of clinicians is to change. The individual approach marginalises carers and minimises their likelihood of identification and thus their participation in treatment processes.

Participants also expressed the view that asking consumers to identify their carers was frequently counter productive as if they were to do this it would be an admission that they were unable to care for themselves. Consumers' identifying their children as their carers was also considered to be problematic as some believed that by revealing this it may lead to the involvement of child protection agencies.

Participants stated that clinicians who are recent graduates are more open to actively identifying carers than older clinicians, especially in their early years. They felt that current training continues to focus on the individual consumer while the attitudes of recent graduates appears to be more open to considering the views of a wider range of people. There are a number of well documented issues associated with obtaining and retaining appropriately qualified and experienced staff particularly in public mental health systems. Organisational systems are not conducive to ongoing education and attitudes of staff to both consumer and carer participation have proven difficult to change. Existing staffing practice and systems do not facilitate young clinicians practicing in the manner in which they have been trained.

Families differ in many ways, ethnicity, culture, core beliefs, religion, gender defined roles, communication styles, secrets etc. It was felt that before any health professional could help they would have to find out who were the carers. This takes time, and commitment. Participants also felt there was a need for clinicians to recognise that the concept of family is also changing. In many cases family means others who care, protect, and share concern about the ill person.

Substance abuse is increasingly pervasive and it was felt that this may further complicate family relationships and impact on the level to which people wish to be identified as caring for a consumer who may have the double stigma of mental illness, and substance abuse. This was particularly noted in situations where the consumer's behaviour has resulted in contact with the law. It was also mentioned that significant numbers of young children are the 'hidden carers' of people, in particular single mothers, who have substance abuse problems. The issue of co-morbidity also impacts on access to services for consumers thus potentially increasing the burden of care for family and carers.

6.3 GENERAL COMMENTS REGARDING IDENTIFICATION

Both carers and service providers agreed that it is necessary to ask a range of questions in a non threatening manner to both identify carers and to seek approval for their participation in care. It was seen as preferable not to use the term 'carer' in these discussions.

The time at which these questions were asked was also crucial. Seeking information from the consumer on admission for an acute episode was perceived to be problematic, however, this is one of the times when collateral information supplied by carers could provide assistance with diagnosis and early formation of treatment plans.

There was unanimous support for the need for carers to be identified and to actively participate in all discharge processes.

It was felt that in situations where a consumer has an ongoing relationship with a service then information regarding carers was best sought when the consumer was relatively well by a series of well formulated sensitive questions. This information should be recorded in the notes and regularly up-dated. The degree to which involvement was allowed should also be determined at this stage.

6.3.1 Use of the term Carer

Participants unanimously expressed the position that use of the term 'carer' in the mental health area is problematic as it has evolved from use in the disability and aged care areas where the emphasis has been on physical tasks associated with the caring role. Many people see themselves as supporting a person with a mental illness because of their close caring relationship with the person and, not as their carer. The majority of people in this role do not feel they need the label of 'carer' unless they need to apply for the Carer Payment and/or Carer Allowance.

Carer Recognition Legislation also enshrines this term although existing Mental Health Legislation uses a variety of terms including 'carer', 'primary support person', 'close friend or relative', 'allied person' or in the case of children or young people 'person responsible'. Participants identified a need for common terminology and descriptions but acknowledged that in current circumstances given the whole of government approach it was preferable that the term 'carer' continue to be used. However, the term 'Primary Support Person' was favoured for practical use within services particularly in situations where service providers were seeking to identify carers.

Use of the term 'carer' without explanation/interpretation is rejected by consumers as it has a 'paternalistic' flavour to it and is at odds with the current philosophy of recovery oriented care where the emphasis is on caring for one's self. This in turn reduces the willingness of consumers to identify the people who support them. The rejection of the notion of a carer is reportedly used by many clinicians as a refusal by consumers to give permission for services to actively involve a wider range of people in the care and treatment programs. Many reports were provided by carers who did self identify and challenged this situation. Almost universally the consumer's refusal was acted upon with clinicians most frequently citing 'privacy laws' as the reason for not sharing information. In most cases this also extended to their refusal to accept information from carers, much of which could have been useful in processes of assessment and diagnosis.

One carer stated:

The doctor gave my son a diagnosis of 'severe psychosis' and then proceeded to believe everything he said.

This behaviour was confirmed by the majority of carers who participated in the consultations.

Participants stated that the use of the term carer has grown in currency and been somewhat enshrined by the development of the *Australian Government Payment Systems and Guidelines*. The criteria for these guidelines primarily focus on the completion of physical tasks.

A range of community based programs such as the Respite Programs have also been funded by the Australian Government through the COAG *National Action Plan*. These programs have gone some way to meeting the needs of some carers for short term replacement care, however, current guidelines and style of service delivery fail to meet the ongoing needs of carers of people with a mental illness.

Participants felt that identification requires recognition of a role:

- By self
- By others

Self identification by carers was seen as difficult, particularly in the early stages of an illness because:

- They may be overwhelmed by the situation if they have not had any previous experience with mental illness;
- Community stigma can result in denial of the diagnosis;
- They see it as a duty or family responsibility and would be reluctant to accept help from outside;
- They may be wary of statutory services involvement;
- They may view asking for help as a reflection of failure or an inability to cope on their part;
- They become buried in the tasks at hand and may not be aware there is help available or how it might make a difference; and
- They despair anyone could help them

Self identification is also hampered by the use of the term 'carer'.

Participants reported that a number of programs exist at both state and national levels to provide information, support and respite to carers, however, until carers self identify or until they are identified by other people such as clinicians then none of these programs are going to have a great deal of impact.

The question was then discussed that if people are reluctant to self identify then who should have this responsibility, and what would be needed to ensure this occurs?

Some participants saw this as a responsibility of Carers Organisations in each State. However, in general they felt that these organisations could only be effective once a process of identification had occurred. There was general consensus that Carers Organisations did a good job in supporting carers once they were identified.

How do people get to contact a Carers Organisation?

- Self referral; or
- Referral by others

Self referral requires self identification with all the inherent problems as listed above. This leaves referral by others. This was seen as dependent on a process of identification having occurred.

Given that carers only become such when a person requires care then the clinicians tasked with the care of the individual were seen as best placed to also identify the carers. In order to achieve this, participants felt that they must broaden their focus away from the individual consumer to a more holistic approach to care. They believed clinicians need to realise this will save time in the long run and provide better outcomes for consumers.

For many years, public mental health services have recognised that a team approach is the most appropriate and cost effective when providing care for people with long term mental illnesses. Participants in consultations felt strongly that carers are essential members of that team. In most cases they spend more time with the consumer than any other member of the team.

The following reasons were identified by participants as the basis for current resistance by staff to identifying carers.

- Time – not paid to do this.
- Don't know how – lack of skills.
- Don't know the questions to ask.
- Privacy – consumer wont give consent.
- No policies or protocols in place to guide practice.
- Legislation does not insist on it.
- No specific standard in National Mental Health Standards to guide clinical practice.

It was concerning to note that the majority of people consulted felt that specific mechanisms would be necessary to mandate the identification and inclusion of carers in ongoing care of

consumers. They also felt that these processes would need to be monitored and audited on a regular basis if they were to result in changes to clinical practice.

6.4 SUMMARY OF DISCUSSION

Participants unanimously supported the need to identify carers and stressed that no single process could achieve this. It was felt that processes fall into the following categories:

6.4.1 The consumer voluntarily identifies carers

This was seen as the ideal although it was felt that this could only be achieved under the following conditions:

- Development of standardised lists of question prompts to identify who provides support in an ongoing way to the consumer;
- A willingness to ask the questions and record the information when the consumer is well. Many consumers will need to develop a trusting relationship with service delivery staff if they are to reveal sensitive information, particularly if their carer is a young person;
- A willingness to update the information regularly;
- A recognition by clinicians of the value of seeking to obtain this information;
- Staff possess the appropriate knowledge and skills to work with carers. This is particularly difficult when providing care to people whose carers may come from culturally and linguistically diverse backgrounds;
- Mandatory requirements such as legislation and standards that would require this; and
- Regular monitoring by way of accreditation surveys to examine compliance with the process of identification.

6.4.2 The consumer refuses to identify carers with whom information can be shared.

Identification of carers in order to obtain information from them to assist with assessment and diagnosis and to refer them for support, was seen as separate from identification in order to share personal information.

Participants also felt it was a staff responsibility to identify people involved in supporting the consumer via a sensitive set of questions and then to initiate contact to obtain information that could assist with development of plans that would lead to a positive outcome for the consumer. It was also felt that this was a role that could be facilitated by Carer Consultants.

Staff should also clarify with the carers what information they would like shared with the consumer. Carers also have a right to respect for privacy and confidentiality.

It was acknowledged that consumers have the right to refuse to identify carers, however, all participants felt that obtaining this information is part of a process, not a one off event. It is necessary to regularly review these views with consumers. It was also considered important to inform carers that consent for involvement would be reviewed on a regular basis and the consumer may change their view as the treatment progresses.

It was interesting to note that it was the experience of service providers who participated in this project that consumers rarely refused to identify people who supported them. Identification depended rather on when and how the questions were asked and the reasons provided for asking.

Consultation participants were also clear that even if consumers continue to refuse to identify 'carers' it does not prevent mental health staff from working with families who self identify via their presentation or continued relationship with the consumer. The family/carers are still entitled to information of a general nature, support and referral to carers support organisations. Many examples were provided of the support obtained by carers from being referred to NGOs.

Some mental health legislation requires that carers be notified regarding specific events or clinicians are required to show just cause as to why they have not done so. This is difficult to do until they have been identified. Even where this exists, such as Victoria, participants felt that only minimal changes had occurred in practice. These changes were primarily seen as a result of greater carer empowerment.

In addition, it was felt that at any stage of the treatment process carers who self identify should be entitled to provide information to staff to assist with diagnosis and treatment.

6.4.3 The consumer is unable to identify carers because of their mental state

Participants felt that many such situations could be avoided if Advanced Directives or Relapse Prevention Plans identifying carers and the desired roles they are to play had been negotiated and documented at an appropriate earlier stage of the consumer's illness. Where this had not occurred participants suggested staff should make a decision in the best interests of the consumer. In such situations it is essential to obtain information to assist with diagnosis and the development of a treatment plan.

It was noted that in some cases if the consumer has no history with the service and they were transported to the hospital by the police it may be difficult to actually identify who the carers are unless they accompany the person. Information may be obtained from the GP if one can be identified. This issue is of particular concern in situations where the carer is a young person and there are no mechanisms in place to identify and inform them what has happened to their parent.

Participants felt that in situations where the consumers mental state is not stable staff should err on the side of caution regarding sharing of information until the consumer becomes well enough to hold an informed discussion regarding this matter. However, the same conditions should apply as in 6.4.2. (above) regarding provision of support to carers.

6.4.4 The consumer is a child and their ability to consent is in question

Mechanisms have been in place for some time within child and adolescent services to address this issue. These situations are governed by a range of legislation. Issues arise, however, when the age of consent varies or when the child lives independently despite being considered a 'minor'. This issue is currently being addressed in some jurisdictions where legislation is being considered to introduce the concept of a mature minor i.e. a person aged 14 to 17 years who is deemed to be able to accept responsibility for their own welfare and presumably "identify" their carer who may not be their legal guardian. In this situation, a child is then defined as a person under the age of 14.

Participants suggest that the same principles contained in the report relating to adults identifying carers should be applied except where legislation specifically provides otherwise.

6.5 MECHANISMS SUGGESTED DURING CONSULTATION TO ENCOURAGE IDENTIFICATION

- Development of Carers Recognition legislation in those States that do not have such legislation at this time. Implementation processes developed for this legislation should pay particular attention to mental health carers.
- All State and Territory Mental Health Legislation should be amended to mandate identification and support of carers/primary support persons. Directors of Mental Health should be required to report on the implementation of this section of the legislation on a regular basis
- Development of a carer standard in the revised *National Standards for Mental Health Services* together with mechanisms for specific measurement built into accreditation survey processes such as ACHS EQuIP. This requires additional training for surveyors. The development of a specific standard addressing the issue of carer identification and participation was supported as assisting with this process.
- Data systems to be modified to make collection of 'carer' information mandatory. It was also felt that a short list of 'sample' questions would need to be developed to assist this process. Asking about 'carers' will not illicit the information required.

Child and adolescent services are required to collect information regarding parents/guardians/etc. Electronic data collection forms are frequently organised in such a way that it is not possible to move on to the next section until this section has been completed. Participants supported a similar process being developed for all admissions. It was also considered important that these questions be re-asked at every admission as just copying the information from the last admission would lead to situations where clinicians are left trying to contact relatives or friends who are no longer involved, or who have moved.

It was also felt that asking for Next of Kin does not cover this issue.

- Inclusion of carer identification in referral processes. GPs were seen as having a crucial role to play in the identification of carers as they frequently treated the whole family. They are also well placed to keep this information up to date and to transfer the information when making referrals. The Australian Government's GP Better Outcomes in Mental Health Program for people with mental illness was seen as potentially playing a positive role in identification of carers.

Participants highlighted the need for all referral processes/forms to identify carers. This information should be an integral component of all referrals including:

- GP to psychiatrist;
- Psychiatrist to hospital; and
- Hospital to community service.

In some States/Territories data collection systems mitigate against the sharing of information between inpatient and community services.

- Development of carer packages of information similar to those given to consumers. Admission protocols should require noting that they have been given. The content of these packs could include basic information regarding the service the consumer has been admitted to, rights and responsibilities of carers and contacts for additional supports such as Carers organisations etc. It was felt that basis information such as this should be provided to all people who accompany a consumer to hospital and does not

require the permission of the consumer. The availability of a Carer Consultant to support new carers to 'talk through' this information was seen as highly desirable.

- Permission from the consumer to identify carers to be sought via a structured set of questions. This form needs to be regularly updated and form an integral part of each admission or re-admission procedure. It was also highlighted that it may not be possible to complete this component of the admission procedure immediately upon admission. In fact, it may be desirable to return to complete the form once the consumer has had a chance to develop a relationship with staff. Completion and review of this form should be an ongoing process that is used as the basis of discussion between all parties. The form should highlight the benefits of involvement of a wider range of people in the care and support of the consumer and seek to clarify the level of involvement that the consumer feels comfortable with each person having. These levels may change over time.

Case example, *New Farm Clinic*, a private hospital in Brisbane, was identified as a model of good practice in this area. They have developed a standard form for use during all admissions. This form highlights the benefits of consumers involving others in their care and seeks specific permission to involve family members or significant other persons in discussion of the treatment plan and progress. The consumer is also asked to nominate the level of information he/she would be happy for the staff to share with these people. The form records the following information:

- Name;
- Relationship;
- Contact details;
- Level of information:
 - Full disclosure, or
 - General information – treatment plan and medication but not personal information disclosed in the course of therapy, or
 - No information at all without my permission.

Consumers are encouraged to inform nursing staff if they would like to change any of this information during their admission. This form is colour coded and forms part of the admission procedures for each admission. It remains in the case notes and should be up-dated on every admission. The form is completed as soon as possible after admission and the collection of this information is audited on a regular basis.

Workshop participants supported the development of a form such as this, noting the importance of a process to ensure the form remained up to date. Participants felt that the audit process was critical in changing clinical practice over time.

- Encouragement of people with long term illnesses to develop Relapse Prevention Plans regarding care preferences and identification and involvement of carers. The development of such Plans was seen as needing to take place when the consumer was functioning at the best possible level and involve discussion with case managers and clinicians including private psychiatrists. Participants expressed the view that the majority of people with a long term mental illness know they need to have varying levels of support at different stages of their illness. However, very few are encouraged to prepare for this when they are well by developing Relapse Prevention Plans that could ensure they have more say in what happens to them during acute episodes.

Some States also have legislation in place that allows the development of Advance Directives. Historically these have been used primarily regarding specific instructions regarding treatment for physical illnesses and ageing, however, they could also be used by people with ongoing mental illnesses to identify who the carers are and the role the consumer wants them to play in any crisis situations and in their ongoing care.

Participants acknowledged that not all States have this legislation available and that even where it does exist it can be superseded by Mental Health Legislation. They felt that this situation needs to be re-visited, however, if Relapse Prevention Plans or Advance Directives were developed as described and placed in health files this would assist with the identification of carers whilst also supporting consumer driven care.

It was thought that the encouragement of the development of Relapse Prevention Plans and Advance Directives, including the identification of Carers should rest with all public mental health services and private psychiatrists in situations where consumers have ongoing contact because of the long term nature of their illnesses.

- Development of legislation to provide for separate Carers Assessments as is currently available in the UK, would require services to identify carers.
- An option for the development of Identification Cards or bracelets for carers. Some carers who participated in consultations raised the issue of cards/bracelets such as those used when people have allergies etc or as available in the USA. This would be one way of self identifying plus it would be added protection, particularly for older carers in ensuring that the person they care for will be notified and attended to in the event they are unable to do so. Information that could be recorded on the card/bracelet could include the following:
 - I am a family caregiver for my (relationship);
 - Caregiver's name;
 - Care recipient's name;
 - Relationship—mother, father, spouse, sister, etc.;
 - Urgent needs and instructions for the recipient;
 - Who to contact in your absence.
- Development of carer identification and participation policies and protocols in each service would be necessary to support changes in clinical practice.
- Opportunities for staff to receive 'carer sensitivity' and skills development training was seen as an essential for any change to be made in clinical practice regarding identification of carers.
- Appointment of Carer Consultants/Liaison Officers. The role of such people was compared to the current consumer consultants that are employed in a number of services. Participants saw the role of Carer Consultants as including the following:
 - Staff support and training;
 - Liaison point between staff, consumers and carers, e.g. 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.

These positions could ideally be filled by carers, provided they have appropriate skills and support. Some services have appointed 'carer friendly' staff to specifically fill this role.

The desirability of locating Carer Consultants in Emergency Departments, where this is the main point of entry to mental health services, was also highlighted as being important in the process of identification of carers.

7. DISCUSSION

7.1 WHO IS A CARER

If carers are to be identified, then it is necessary to be able to describe who they are, or to define what they do.

It is recognised that a large variety of definitions exist in relation to carers. In some situations other terms such as 'primary support person' or 'allied person' has been used interchangeably with that of 'carer'. Historically these definitions were primarily based on the relationship of the care-giver to the person receiving care. This has more recently expanded to include people other than family. However, most policies and legislation such as Carer Recognition Legislation continue to define carers according to the services they provide, particularly those that are physical in nature.

Carer Recognition Legislation recognises the significant role that carers play in the community and provides a mechanism for their involvement in services that impact on them. This Legislation, as with most other pieces of legislation that refer to carers and their rights, specifically excludes people who receive remuneration for their caring except those who meet the requirements of the Australian Government Carers Allowances or Benefits.

The definition is important if it is used as the basis for access to, or exclusion from, funding or services. This is particularly relevant for carers wishing to access Carers Allowances or Benefits or Respite Programs.

Most definitions are generic in nature and focus on the person receiving care requiring this care over a long period of time. Guidelines for funding and service delivery based on meeting these guidelines do not in general identify or differentiate between the needs of the different carer groups. Organisations such as Carers Australia have in a number of submissions to Senate Inquiries and budget processes in recent years pointed out the difference in the needs of carers of people with a mental illness. [2006, 2007]

If carers of people with a mental illness are different from other carers, does this make the process of identification more difficult?

7.2 DEFINITIONS CURRENTLY IN EXISTENCE

The following selection has been chosen from published reports of international projects, selected Australian Mental Health Legislation and that used by the Australian Council on Healthcare Standards (ACHS). This is in no way an exhaustive list. There are as many different definitions as there are pieces of legislation.

European Carers Charter (June 2007)

Carers are non-professional people who take care of patients at home. Carers can be relatives of the sick person or other voluntaries. They usually give help or support to relatives or friends because of a long term physical or mental illness or disability.

Canadian Palliative Care Association, (1988)

those closest to the patient in knowledge, care and affection. This includes the biological family, the family of acquisition (related by marriage/contract), the family of choice and friends (not related biologically by marriage/contract).

United Hospital Fund Families and Health Care Project, New York (2006)

Family caregivers include relatives, partners, friends, or neighbors who provide essential assistance to an adult or child with chronic illness or disability or to a frail or cognitively impaired older person. Some of the ways in which the family may respond are emotional support, surrogate decision making, financial contributions, care management, and hands-on care. (Parents of well children or children without disabilities are not considered family caregivers in this sense.) Family caregivers may provide or manage all or some of the care, either part-time or full-time, and may or may not live with the care recipient.

ACHS

Nominated carer refers to either the family member or other person (partner or friend) that has been identified by the consumer as being in a caring or supportive role.

Northern Territory, Mental Health and Related Services Act 2005

primary care provider means a person who because of his or her relationship with a person, whether that is through kinship, familiarity, marriage or a de facto relationship, has a sense of responsibility for that person and provides care and support for that person, whether or not the person lives with that person;

Queensland Carers Recognition Policy

A person of any age, who without being paid, cares for another person who needs ongoing support because of a long-term medical condition, a mental illness, a disability, frailty or the need for palliative care. A carer may or may not be a family member and may or may not live with the person. Volunteers under the auspices of a voluntary organisation are not included.

7.3 DEFINITION ON THE BASIS OF RELATIONSHIP

Identifying carers by their relationship to a person receiving services is problematic for a variety of reasons.

With increasing fragmentation in family networks, many carers caring for vulnerable and needy people are not caring for members of their immediate family. This has become most obvious in recent years in the situation of carers in the HIV community, where the stigma of the virus has meant that many people with the virus are not cared for by family members.

Who provides care is dependant on the types of relationship that the person with a chronic illness or disability has with their family and friends. This depends on how close they live to family, what relationship they have with family and whether external support networks meet their needs.

Australian families are frequently geographically separated and this creates particular problems in the identification of carers.

Long distance care giving, whether it be in the next suburb or interstate, is more complicated than just the distance between people. Long distance carers need to plan carefully since when crises occur they will need more time off work and more funds for travel.

Carers, irrespective of their relationship, are people that provide support to someone that needs help. It doesn't matter how many hours per week are spent providing support. Carers may live with the person they are caring for, providing assistance with daily needs, or may visit the person weekly or call regularly. Being a carer involves an investment in time, energy and support.

The following case examples illustrate these situations.

- A man has lived in Darwin for several years. He has mental illness. There are periods when his medication and stress in his life are better controlled and he is able to take a full part in life. However, he has bouts of more severe illness. He lives hundreds of miles away from his family. His friends are the ones who support him, not his family who are too far away to provide day to day help.
- A man lives in Sydney, he has depression, is blind and has severe alcoholism. A close friend takes care of his paperwork, buys him essentials and visits every three or so days. Again, his family live miles away.

Identification of carers can be even more problematic for those groups of people who have a different concept of family and community and for those who rely on certain networks of support because they suffer from discrimination and prejudice in some form or another. This includes communities where there are significant cultural and language barriers that prevent individuals from accessing services and the problem that the right services are in very short supply if they exist at all. Examples include the following.

Indigenous communities

The concept of carer in Indigenous communities has been well documented as, in general, being whole of community or kinship based rather than individually based. However, individual communities have unique patterns of cultural values and traditions. This impacts on processes required for identification.

Culturally diverse communities

Approximately 40% of Australians were born overseas or have at least one parent who is from a non-English speaking background (Burgell, 2000). Prevalence of mental illness varies but is known to be significantly higher for people with a history of torture or trauma as experienced by many recent refugees. However, people from non-English speaking backgrounds are under represented in both public and private mental health services. Services that are received are often culturally inappropriate. This has significant implications for the carers many of whom remain hidden because of high levels of stigma, lack of information about access to services, lack of culturally appropriate services and shortages of interpreters and bilingual staff.

Older immigrants have varying degrees of English language skills and some revert to their original language as they age or become unwell. The shortage of interpreters has led to the use of children in this role. In general however, staff have failed to identify the fact that in many cases the children are also the carers when a parent develops a mental illness.

Recent refugees are far more likely to be cared for by people who are not their relatives and do not necessarily live together. This makes identification of carers very complex. Currently this task mainly falls to ethno-specific welfare agencies that suffer from lack of resources and appropriately trained staff.

Complex family situations

These include situations where people with mental illness have sought alternative sources of support and accommodation as a result of a history of sexual abuse or physical violence. Identification of carers in these situations requires extreme sensitivity and recognition of the issues involved for the consumer.

Same sex communities

Many gay and lesbian people experience prejudice and as a result experience difficulty in seeking support from families and neighbours. In some cases this has also been the experience of people of the same sex who share houses and close friendships even when the relationship is non sexual. Identification of same sex carers requires particular attention.

Rural and Remote communities

Self identification by carers in rural and remote communities can be determined by the nature of the community and its understanding and acceptance of mental illness. Greater challenges are faced by people living in these areas to obtain appropriate services particularly for the maintenance of people with long term mental illnesses. In such situations the carers are probably the most important component of the treatment and support partnership. Identification and support of carers of people with a mental illness in rural and remote areas is a critical component of community based care.

Carers come from all ages and socioeconomic groups. Many would not identify with the term 'carer' and are thus best described by the term 'hidden carers'.

7.4 DEFINITION ON THE BASIS OF SUPPORT PROVIDED

Identifying a carer on the basis of what they do for a consumer is also problematic. However, this does provide a framework to assist clinicians with the process of identification and to highlight areas for the targeting of assistance. Carers of people with a mental illness provide a range of support. This includes, but is not limited to the following.

7.4.1 Support required for ongoing maintenance in the community

- Providing emotional support, sometimes for protracted periods each day.
- Encouraging the use of medication, checking compliance and observing for side effects.
- Assistance with personal business affairs, such as bill paying, Medicare claims.
- Reminding the consumer of appointments and ensuring they get to them.
- Helping with understanding of medical decisions about treatment.
- Checking to see if there is food in the fridge, and sometimes making meals.
- Helping with household chores such as cleaning, grocery shopping, lawn care, etc.
- Making regular phone calls to the consumer to "check in" on them.

- Assisting with the maintenance of social activities.

7.4.2 Support required during acute episodes

- Management of unpredictable and sometimes paranoid and/or violent behaviour of the consumer.
- Notifying treating staff and negotiating appointments in situations where the consumer has an ongoing relationship with a private psychiatrist or community team.
- Transportation to services. In some cases this may require negotiations with the police.
- Visiting the consumer if they are hospitalised.
- Assistance to other family members and carers to enable them to understand what is happening..

All of these requirements are particularly difficult in rural and remote areas and in situations where children are the carers.

In many cases the nature of the illness, together with the absence of assistance with the support tasks resulting from their lack of identification as a carer, results in a situation where they:

- Lay awake at night worrying about the person.
- Dread the phone ringing or the doorbell going because of the feelings of *What will I do if....*
- Have had to stop work because their attendance is 'patchy' when the person they care for is having an acute episode.
- Withdraw from friends because it is just too hard to explain.
- Experience deterioration in physical health and/or their financial resources.
- Spend a lot of time thinking who will care when I am no longer here to do it?

7.5 ISSUES THAT IMPACT ON IDENTIFICATION OF CARERS OF PEOPLE WITH A MENTAL ILLNESS

Identification of carers of people with a mental illness is frequently complex. This relates to:

- The time between onset of the illness and diagnosis;
- Lack of community knowledge and understanding regarding mental illness;
- Masking of symptoms via substance abuse;
- The episodic nature of mental illness;
- Service and clinician interpretations of Recovery Models of care; and
- Inadequate understanding of privacy legislation.

The need to identify carers is often not recognised as a priority during the time that frequently elapses between onset of symptoms and diagnosis of a mental illness.

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. Early identification of both consumers and families will result in better long term outcomes for all.

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 support the consumer. 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.

Yvonne Shipp in her unpublished paper *The Journey Towards Recovery* 2000 states:

In the case of mental illness, we grieve but cannot say goodbye as we do when a loved one has died. The healing process and the road to recovery is more difficult and complex. The mourning is about the pre-illness personality, once bright with promise and the loss of the person who was, and the person who might have been.

7.5.1 The role of carers in recovery focused care

The recognition of the concept of recovery and development of recovery oriented practices are well advanced in a number of other countries including the United States and New Zealand. Current policies in Australia support the adoption of this approach as one that can result in significant positive outcomes for consumers.

Historically people with mental illness were expected by many, including mental health professionals, to be passive recipients of care and to never fully recover or have the capacity to take control over their own lives. Such negative perceptions not only contribute to the stigma associated with mental illness and adversely impact upon the lives of consumers and their families and friends but are now known to be incorrect.

Recovery has been described in many different ways as a process, an outlook, a vision, a guiding principle. Instead of only focusing on symptoms and treatment of illness, a recovery approach aims to support an individual in his / her own personal development, building self esteem, identity and finding a meaningful role in society to their highest positive level. However, it is this very focus that in a number of situations is used by both consumers and clinicians to exclude the identification of carers.

This was never the intention of the model. A true Recovery Model provides holistic treatment and care within an active and assertive partnership between the consumer, carer and the necessary support agencies delivering goal orientated and assertive care and treatment. In order to achieve this it is necessary to have policies and protocols in place that support identification and participation of carers.

A focus on recovery means that mental illness need not be a barrier to a satisfying and hopeful life of full participation in the world. This approach is fundamentally about strengthening hope and optimism not only for individuals with mental illness, but also for their carers and for the service providers who work with them.

7.6. WHY IDENTIFICATION IS IMPORTANT

Research has conclusively shown that there are significant clinical, social and economic advantages in providing mental health services in a family inclusive way.

[World Schizophrenia Fellowship 1998]

Identification of carers will result in:

- Improved outcomes for consumers; and
- Opportunities for provision of improved information, education and support of carers.

Carers have been recognised in Disability legislation at national and state levels since inception. In addition, the significant role that all carers play in Australian society has been further recognised in recent years by the development of specific Carer Recognition Legislation in four Australian States and Territories. Amendments are also progressively being developed for State and Territory Mental Health Legislation that recognise mental health carers.

All Acts and Amendment Bills contain definitions but none address the issue of identification.

Other jurisdictions, such as Queensland, have Carer Participation and Support Policies in place.

The Australian Government has specific programs devoted to providing benefits and services to carers. Funding has been allocated as a result of the COAG National Action Plan to support additional provision of services to carers who meet the specific criteria. The episodic nature of mental illness and the nature of the support required does not easily enable carers of a person with mental illness to meet these criteria.

Over the last decade in particular, mental health carers have emerged as important members of the consumer's healthcare team. Services that once were provided by nurses and other health professionals are now provided by carers. Not only do carers provide unpaid care and in many cases avoid or delay institutional care they also save the cost of health professionals providing these services.

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.

A report by Carers Australia and the Mental Health Council of Australia (June 2000) identified that carers of people with a mental illness on average contribute 104 hours per week caring for that person. That report did not address the issue of how to identify who the carers are, however, the report did make a series of recommendations largely relating to the urgent need of carers for better information, support, counseling and recognition of carers of people with a mental illness and their inclusion within the mental health system.

The report noted that: *it is primarily carers who are sustaining the fabric of operational effectiveness of mental health services systems across Australia.* (Page 4)

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.

The issue of identification of carers is crucial if State and Territory Governments are to develop appropriate implementation plans for legislation.

7.6.1 Improvement in consumer outcomes

The support needs of consumers and carers are interdependent. There is now good evidence to demonstrate that providing support and education to families/carers provides direct health benefits to consumers. These were clearly described in the *Carers Australia submission to the Australian Government Inquiry into Mental Health Services* (July 2007) and include the following:

- Reducing the incidence of relapse;
- Improving adherence to treatment;
- Improving family functioning;
- Increasing periods of wellness; and
- Improving the consumers quality of life and social adjustment.

However, the literature search revealed references as far back as 1982 (Falloon) that clearly substantiated these claims.

Carers are partners in the provision of healthcare to those they care for. Identifying and supporting them is a sound investment in continuity of care.

7.6.2 Benefits for carers associated with identification

Caring responsibilities exact a price and identification 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;
- 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.

Identification will assist empowerment. 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.

Recommendation

- ***Legislation governing Carer Payment, Carer Allowance and new programs funded under the COAG National Action Plan to be reviewed to ensure that identification and eligibility requirements are suitable to meet the needs of carers of people with a mental illness.***

7.7 CRITICAL TIME-FRAMES FOR IDENTIFICATION

When people have a one-off episode of illness hopefully they will have someone who fulfils the role of carer for them. One also hopes this is a short term responsibility with impacts that can be managed.

When an illness is profound and has potential to be life long, the early identification of carers becomes crucial. Options for identification exist at all stages of the illness with early identification being more likely to lead to improved outcomes for both consumers and carers.

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

Early identification is particularly important for young carers as caring responsibilities can reduce a young person's access to parental support, guidance and control as the nature of the traditional relationship between the parent and the child is changed. If not identified early the quality of a young carers childhood is likely to be compromised as they assume the additional responsibilities of caring and a perceived need to protect the family.

Key times/opportunities for identification include the following.

7.7.1 Early stages of the illness

In many cases, it will be the family or close friends who have an ongoing supportive relationship that initially identify a change in behaviour of a person in the early stages of a mental illness. Hopefully, they will seek advice regarding this from a GP or community health centre. This is the ideal time for services to identify the role the family and close friends play in supporting the person, recording this information and referring them for assistance.

In other situations school counsellors may contact families if a change in behaviour has been brought to their attention. Identification and support of family carers at this early stage could lead to early diagnosis and better outcomes for both consumers and carers.

All referral processes provide an opportunity to identify carers for involvement in future service delivery.

Recommendations

- ***Carer identification fields to be built into GP software used for electronic data collection.***
- ***Liaison to occur with the Divisions of GPs to develop protocols/good practice guidelines to increase GP awareness regarding the important role they play in the identification of carers.***
- ***Liaison to occur with the RANZCP to develop family/carers focused training modules and good practice protocols.***
- ***Recognition be given to additional training modules in family/carers oriented practice by relevant Colleges as a component of skill maintenance***

7.7.2 Following diagnosis when the consumer is well – Relapse Prevention

Mental illness can cause sudden psychotic crises often outside normal working hours. These times can be extremely stressful for carers. The development of relapse prevention plans provide a key opportunity to identify carers.

The majority of consumers, when their health is stable, readily recognise that from time to time they require some assistance and support. At this stage they are also more likely to be able to discuss the nature of the support they receive and its importance in the prevention of relapses. It was the experience of all consulted during this project that identification and consent for involvement was rarely refused if these issues were discussed in a sensitive manner during periods of optimum health of the consumer. The participation of carers at this stage will facilitate a definition in roles and a partnership approach to relapse prevention and future service delivery. Processes need to be developed to document and transfer this information if necessary.

Relapse prevention plans are particularly important in the public sector where there is a high turnover of staff. Private sector services often provide a greater degree of stability, however, this does not negate the necessity of such plans and the opportunities they provide for identification.

Opportunities to develop relapse prevention plans will be facilitated by the development of good practice guidelines and additional training to ensure appropriate implementation.

Organisational structures and processes need to be reviewed to ensure relapse prevention plans are a key component of all service delivery in both public and private sectors.

Recommendation

- ***Public and private mental health clinicians to encourage consumers with long term illnesses to develop Relapse Prevention Plans and Advance Directives regarding care preferences, identification and involvement of carers. This process should occur when the consumer is functioning at the best possible level, become part of the health file and the information be transferred to other services as appropriate.***

7.7.3 On admission

Asking for information regarding carers on admission is difficult because of the acuteness of the episode necessitating admission is the time when it will be most difficult to obtain accurate information. However, it is a time when collateral information provided by support persons could provide valuable assistance with diagnosis and treatment.

The majority of specialised mental health services in Australia now collect information on admission electronically. A data collection field exists for next of kin. In many cases the person listed may not be the carer. Examples of this would include where an adult with a mental illness lists their elderly mother who resides in a nursing home as NOK although, they are supported on a day by day basis by close friends.

Recommendation

- ***Mandatory carer identification fields to be built into data collection software. This would include the following.***
 - ***Modification of State and Territory mental health data systems to make collection of 'carer' identification mandatory and separate to data related to 'next of kin'.***

- ***Development of suitable questions for inclusion in data collection protocols to inform identification of the carer.***

Comprehensive intake processes are usually completed on, or shortly after admission, primarily by nursing staff. This process provides opportunities for identification of carers via a range of sensitively worded questions. Use of the term carer may not be fully understood therefore questions could be framed in terms of support provided prior to admission. Emphasising the importance that family and significant other people play in recovery will assist with identification. Care needs to be taken that people who have an ongoing supportive relationship are identified rather than people who have had a chance meeting, perhaps when the consumer was close to admission.

During consultation an example was provided to us of a form that has been developed to obtain this information. Completion of this form is an integral component of the admission process even where completion may take some days depending on the consumer's state of mind. The form and its contents are described more fully in the report of the consultations. A copy of the New Farm Clinic Form is contained in the Appendix.

At admission it is current practice for both public and private services to provide information packs specifically to consumers outlining their rights and general information regarding the service. Ideally these documents should be reviewed with a view to including information regarding the importance of identification of carers.

There is also an opportunity for the development of similar information packs specifically for carers. The content of these packs should include basic information regarding the service the consumer has been admitted to, rights and responsibilities of carers and contacts for additional supports such as carers organisations.

Recommendations

- ***Public and private mental health services to encourage the identification of carers through the development and distribution of information packs to carers as a compulsory component of the admission procedure.***
- ***Admission procedures to public and private mental health services be modified to include development of standardised forms that:***
 - ***highlight the benefits of consumers involving others in their care;***
 - ***seek specific permission to identify family members or significant other persons who have ongoing input to their lives;***
 - ***nominate the level of information to be shared;***
 - ***are colour coded, updated on every admission and remain in the health care notes; and***
 - ***make note of the distribution of information packs to carers, family members or significant other persons.***

7.7.4 On discharge

The hospital discharge process is a crucial time for identification and involvement of carers. In the case of a first episode they may be confronted for the first time with taking on a more formalised caring role. This is the time when carers have to make important decisions that

can affect their relationship with the consumer, other members of their family and their employment status. However, it is important for staff to be aware that at this stage carers may not view themselves as carers but as partners, parents, children or friends. It is also important that assumptions are not made about their ability or willingness to care.

The issue of a history of providing support and a continuing ability to do so needs to be addressed. During consultation examples were provided of situations where consumers, when asked to nominate their carers had provided the names of people they had met for the first time when acutely unwell in the inpatient unit.

Unless appropriate carers, who have an ongoing commitment to the consumer are identified, fully involved and properly supported then the transfer from hospital to home can have significant consequences for both consumers' and carers' health, well-being and quality of life.

Some discharge policies discuss the need to involve carers but none provided to this project make any specific mention or provided guidance on how to identify carers.

Nationally consistent discharge policies are needed not only to identify carers but also ensure mechanisms are in place to talk to carers about what is likely to be involved in caring and the potential impact on their lives. This process could be facilitated by the employment of specific people to support carers through the transition from hospital to home.

Discharge policies also need to address protocols for identifying the carers that are to assist the consumer in their transition and maintenance in the community in situations where the consumer refuses for personal information to be passed on to the carers.

However, producing discharge policies that identify carers can too easily become a paper exercise unless accompanied by staff training and monitoring to ensure effective implementation.

Recommendations

- ***All public and private mental health services to review their discharge policies to ensure carers are identified, supported and allowed to make informed choices.***
- ***Carer Consultants/Liaison Officers to be appointed to all public and private mental health services to assist with carer identification and assessment, staff support and training, linkages to carer support mechanisms and to be a specific point of contact for carers following discharge of the consumer***

7.7.5 Complaints Processes

Information is provided on a routine basis to consumers regarding complaints procedures. Currently no mechanisms appear to exist to ensure carers are identified to ensure they also have an ability to access complaints procedures.

7.8 CHALLENGES FOR STAFF

Information provided during consultation indicated 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. The literature reviewed substantiated these views.

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.

Recommendations

- ***Clinical practice standards, which promote an inclusive approach to identifying and working with carers are established by all public and private mental health services. This approach will promote identification and engagement to enable carers strengths to be promoted, their difficulties to be acknowledged and to encourage empowerment.***
- ***Comprehensive training be provided for 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.***

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APPENDIX A.

PROJECT REFERENCE GROUP MEMBERSHIP

Ms. Janne McMahon (Chair) – and representing private sector consumers;

Ms. Pat Sutton – representing public sector carers;

Ms. Julie Hutson – representing private sector carers;

Mr. Tony Fowke – representing carers nationally;

Ms. Ruth Carson – representing national organisations;

Mr. Michael Burge – representing national consumer organisation, public sector consumers


Ms. Rosemary Warmington – representing Carers Australia-SA;

Dr. Bill Pring – representing service providers; and

Ms. Michelle Warwick – representing the Australian Government, Department of Health and Ageing

ICP CONSULTATION	PARTICIPANTS	TOTAL
Adelaide Workshop Date: Tuesday, 24 April, 2007 Chair: Ms Janne McMahon Facilitator: Mrs Judy Hardy	5 carers representing the public sector 1 carer representing the private sector 2 consumers representing the public sector 1 consumer representing the private sector 2 public sector service providers 1 private sector service provider 3 NGO representatives (Carers SA, Comic, Chair Australian Mental Health Consumers Network)	15
Brisbane Workshop Date: Wednesday, 6 June, 2007 Chair: Ms Janne McMahon Facilitator: Mrs Judy Hardy	5 carers representing the public sector 1 carer representing the private sector 3 consumers representing the public sector 2 consumers representing the private sector 1 public sector service provider 1 private sector service provider 2 NGO representatives (Carers QLD, ARAFMI QLD)	15
Perth Workshop Date: Tuesday, 3 July, 2007 Chair: Ms Janne McMahon Facilitator: Mrs Judy Hardy	4 carers representing the public sector 2 carer representing the private sector 0 consumers representing the public sector 2 consumers representing the private sector 1 public sector service provider 4 private sector service providers 5 NGO representatives (Commonwealth Respite & Carelink Centre, Ruah Inreach Peer and Recovery Programs, Carers WA, ARAFMI WA, ARAFMI Australia)	18
Darwin Workshop Date: Thursday, 12 July, 2007 Chair: Ms Janne McMahon Facilitator: Mrs Judy Hardy	1 public sector service provider 2 NGO (Carers NT) (Mental Health Coalition of NT) 1 Carer also representing ARAFMI	4
Central Northern Adelaide Health Service Date: Wednesday, 23 May, 2007	7 Carer Consultants 1 NGO – Carers SA	8
Carer Assessment Working Group South Australia Date: Tuesday, 5 June, 2007	3 public sector carer consultants 7 public sector service providers	10
Carer Connect South Australia Date: Tuesday, 5 June, 2007	4 carer consultants 3 carers 8 public sector service providers	15
Perth Clinic Date: Monday, 2 July, 2007	1 private sector service provider 1 public sector service provider	2
St Vincent's Hospital Date: Monday, May 7 2007	1 Mr Douglas Holmes	1
Australian Mental Health Consumers Network Date: Thursday 7 th June, 2007	1 Executive Director, Ms Helen Connor	1
Teleconference NSW and ACT Date: Monday, 30 July, 2007	1 private sector consumer 3 private sector service providers 3 carer public sector (Carers NSW, NMHCCF member, ARAFMI) 2 public sector consumers (ACT Mental Health Consumers Network)(St. Vincent Hospital, Sydney)	9
Teleconference VIC and TAS Date: Tuesday, 31 July, 2007	1 carer Academic 4 Carer Consultants public- Vic 1 consumer consultant public - Vic 1 NGO (Carers Vic) 2 carers public sector (NMHCCF) 2 carers private 1 private sector consumer consultant 1 public sector service provider	13
Teleconference Key People Date: Tuesday, 2 August, 2007	1 Ms. Margaret Springgay - Executive Director, Mental Illness Fellowship Australia 1 Dr. Margaret Leggett - Past President WFSAD 1 Dr. Paul Morgan - Deputy Director, Sane Australia 1 Patricia Jones - MHCA 1 Ms Joan Hughes - Executive Director, Carers Australia	5
TOTAL PARTICIPANTS		116

APPENDIX C.

 <p>Approved Carer</p>	UR No: _____ Name: _____ Address: _____ Dr: _____ DOB: ____/____/____ Sex: M / F (Please circle)
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The Mental Health Standards recommend that we maintain privacy and confidentiality for consumers and carers. However,, they also recommend that we “encourage, and provide opportunities for, the consumer to involve others in their care” for example, family, carer(s), significant others.

Close family members or significant others are often vital in the recovery from mental health conditions and due to privacy legislation, often feel very left out of the care when a patient is in hospital.

Therefore, in order to meet your needs for privacy and confidentiality and to ensure that we facilitate your recovery and return to your home, it would be helpful for us to know if there is a family member or significant other person with whom you would be happy for us to discuss your treatment plan and progress.

Please nominate the person or persons that we can include in discussions about your treatment plan and progress and identify the level of information you would be happy for the staff to share with these people.

Name	Relationship	Level of information*	Contact details

1. Full disclosure – can discuss anything with this person
2. General information – treatment plan & medications but not personal information disclosed in the course of therapy.

NB: Personal information about your thoughts and feelings or your history will not be discussed with anyone without your express permission.

If you would like to change the approved carer during your admission, please see the nursing staff.

Name: _____

Date: __/__/__

Signature: _____

Witness: _____

Signature: _____