3. LITERATURE REVIEW

3.1 RATIONALE AND METHODOLOGY

As part of the current project, the Department of Health and Ageing requested an update of a previous review related to the '*Identifying the Carer*' project. This review was undertaken of international literature and focussed on current policies and good practice protocols in regard to the process of identification and to determine the nature of the information sought by carers at the time of admission to services.

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 (2010) 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, carer rights and provision of information to carers of people with mental illness.

- **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; and
- carer information.

3.2 LITERATURE FINDINGS: KEY THEMES

Literature available on identification of the carer continues to be 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.

Some of the information presented in this section is an update of that presented in the Network's '*Identification of the Carer*' Project completed by the same author for DoHA in 2007.

Literature searches of the United Kingdom (UK) literature provided the most recent information regarding processes for identification. These relate primarily to identification of all carers, not specifically those who care for people with a mental illness. The literature also almost exclusively related to general practice rather than mental health services. Nevertheless, the practices are worth examining as they could be applied across a range of sectors. The good practice protocols identified in the search also related to general practice.

GPs practice in Australia is significantly different than that delivered by the National Health Service (NHS) in the UK. However, the 'good practice' protocols that have been implemented, albeit in a rather ad hoc manner in the UK, could form the basis for discussion with the College of GPs in Australia.

The UK National Strategy for Carers (1999) identified the NHS as being the most important point of contact for adult carers and it specified some key roles for primary care staff. They recognised that the most important point of contact for young carers was within education, but, acknowledged that primary care staff working with families/parents offers obvious opportunities for identifying young carers. The strategy highlighted the primary care roles as being ideal for identifying patients who are carers or who have a carer; checking carers' physical and emotional health; informing carers of their rights to an assessment and other support services; sign–posting and referring carers to other sources of support and developing carer friendly practice based services.

Both carer specific and mental health legislation were also re–examined however there has been minimal changes over the last two years and the majority continue to be dependent on people self identifying, or assume a process has already taken place.

For completeness this section of the project report has been updated and re–describes the following.

- The rationale for carer identification and engagement
    - Carer rights.
    - Impact of carer identification and engagement in relapse prevention for consumers.

- Impediments to identification
    - Use of the term carer.
    - Privacy and confidentiality.
    - Workforce education and training.
    - Organisational and cultural issues.

- Advance Directives

However, given the areas of overlap it continues to be difficult to address these topics in isolation.

The issues examined specifically in the literature related to processes for identification and have been categorised into the following broad themes.

Key findings around each of these themes are provided below.

3.3 THE RATIONALE FOR CARER IDENTIFICATION AND INVOLVEMENT

3.3.1 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, revised 2008), has been the cornerstone of the *National Mental Health Strategy* since its inception in 1992. The *Mental Health Statement of Rights and Responsibilities,1991* 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 that:

> *"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, counselling and community nursing facilities;*
> * *exchange information with those providing treatment concerning the consumer's lifestyles and their relationships with others."*
>
> [Page 17, Mental Health Statement of 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]

This Statement has been flagged for review as part of the *Fourth National Mental Health Plan – An agenda for collaborative government action in mental health – 2009 – 2014.*

A search of available literature continues to reiterate these rights. However, the reports of various projects undertaken over the last fifteen years highlight not only the extensive roles played by carers and their ongoing needs; but also the fact that services continue to ignore, and in some cases actively exclude, carers from assessment and care processes.

A study undertaken jointly by Carers Australia and The Mental Health Council of Australia (MHCA) in 2000 detailed the extensive role played by carers of people with a mental illness and comprehensively described their needs in relation to their caring role. This was subsequently reinforced by the extensive consultations undertaken nationally by the MHCA in 2009 resulting in the report *'Adversity to Advocacy'.* It is tragic to read that in 2008 and 2009, more than 1500 carers consulted on a national basis at 116 locations, including those in rural and remote areas and carers as young as nine years old reported the same issues that were identified in the following reports.

- The *1993 National Inquiry into the Human Rights of People with Mental Illness* ('the Burdekin report').

- The 2005 *Not for Service Report*, undertaken by the MHCA.

- The report of the Senate Inquiry in Mental Health, *From Crisis to Community, (*2006).

- The 2007 *Identification of the Carer Report,* undertaken by the Private Mental Health Sector Consumer and Carer Network.

- The 2009 House of Representatives *Inquiry into Better Support for Carers.*

Only Australian reports have been specifically listed. The content of these reports is reflected in the international literature.

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

The needs and rights of carers of people with a mental illness have been very comprehensively described over a number of years both in Australia and internationally. However, the literature indicates that the rhetoric far outweighs the action. In the UK, carers have been entitled to an assessment of their own needs since 1995. However, numerous reports indicate that in the majority of cases, carers are still not even offered this opportunity. Many would argue this relates to lack of processes to identify who carers actually are.

3.3.2 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 now good evidence to demonstrate that providing support and education to families/carers provides direct health benefits to consumers.

Dr Margaret Leggatt, a key figure in carer issues, both in Australia and internationally, in 2009 summarised the current evidence for inclusion of families and other carers in delivery of care, in the following statement:

> *"We now have powerful evidence from over 40 randomized controlled trials carried out over 30 years that supports the inclusion of family and other carers in the treatment and care of their unwell relative, leading to better outcomes for consumers, their carers and for clinicians. These studies meet the 'gold standard' for research; meta–analyses of these studies are included in Pharoah et al (2006), Pitschel–Walz et al (2001) and Cuijpers.P (1999). Briefly summarised, the evidence reveals:*

> - *a reduction in relapse rates (up to 20%) – resulting in a reduced number of hospitalisations*
> - *better adherence to medication*
> - *reduced psychiatric symptoms*

> *Further research studies show other significant outcomes, such as:*
> - *improved social functioning of the consumer*
> - *increased employment rates*
> - *increased involvement in community*
> - *reduction in the burden experienced by family carers*
> - *improved relationships between family members, including improved relationships with the consumer*
> - *cost effectiveness*

Leggatt also reports that studies in China, Spain, Scandinavia and Britain have demonstrated that family interventions are effective across different cultures. This is important for consideration of our own culturally and linguistically diverse (CALD) communities in Australia.

> *All of the research studies utilised three important techniques not usually found in clinical settings. Consumers, family carers and clinicians met together and worked on plans of action that were mutually agreed by all parties. Working together was carried out over an extended period of time until effective communication styles and problem–solving techniques had been achieved. This process combined the experiential knowledge of the consumer and carers with the professional knowledge of the clinician/s. This method of working together overcame situations where fear of breaching confidentiality was used by clinicians to avoid communicating with family carers.*

It is surprising then to find that these research findings are not generally known about, let alone implemented into routine clinical mental health care. The late

Professor Ian Falloon (2001), a pioneer and international champion of 'integrated' mental health care, has commented:

> 'All recent authoritative reviews of this body of research have reached a consistent conclusion that further delays in implementing these methods in clinical practice can no longer be justified, either on the grounds of insufficient scientific evidence for their effectiveness, or on account of problems with securing additional manpower resources for implementation.'

3.4 CONTINUED 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 continue to include:

- Use of the term carer;

- Privacy and confidentiality;

- Lack of training in a carer oriented approach to clinical practice; and

- Organisational structures and cultures that impede 'carer friendly' practice.

3.4.1 Use of the term carer

Becoming a carer is usually not based on a conscious decision of the carer but on an event in the life of someone else. Sometimes the onset of caring is very sudden, for instance when one's partner, child or parent is involved in an accident and is seriously injured. In other cases, especially with the development of mental illness, it may be a slower process, particularly in situations complicated by substance abuse where diagnosis can take some time. Here the carer begins by giving slight assistance but may end up with a heavy care load. For most people caring is a matter of course.

Carers do not tend to think of themselves as carers but rather as the mother of a person with a mental illness or the child of a parent with a mental illness who has never known any other situation. They are often referred to as 'hidden carers' and are not identified by schools or health services. That makes it difficult to reach them and to provide them with the recognition and support they need. This situation is compounded when the carers are children.

In undertaking both this and our previous *Identifying the Carer Project* in 2007 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 reported as far back as 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."

Identification is a major issue for young carers. If young carers do not identify – or are not identified by others as carers – they and the person for whom they are caring, can miss out on the support that may be available.

The 2009 Carers Australia Budget Submission states:

> *In most countries community awareness of young carers is very limited, even among those in the health, education and social service professions who have most regular contact with the families of young carers. The idea that young people, even children under age 10, are undertaking caring responsibilities goes against general societal norms where children should themselves be looked after, rather than looking after someone. As a result those administering adult services often fail to recognise that a young person is taking an active caring role in the family, often excluding them from discussion about patient treatment or services for the family and, as a result, their particular needs are ignored...*

> *...Young carers have also reported that they are often not recognised as carers 'by adults in authority'. Increasing identification of young carers requires legislative frameworks of equity and fairness with developed welfare support, community awareness and respect. It also requires clear pathways of referral to supporting organisations for those most likely to be in contact with families.*

Use of the term 'carer is also a problem for Indigenous communities. Carers Australia convened a roundtable with Indigenous elders and Indigenous support workers. The report of these discussions indicated that identification of carers is difficult because:

- Indigenous carers are more likely to be women and less likely to see themselves as 'carers' because caring 'for their own' is what they do;

- an individual carer is likely to be caring for several people across generations; and

- often people with a disability or mental illness have low status in Indigenous communities, and consequently carers also have a low status

Other issues that impact on identification of Indigenous carers are:

- the cultural background of Indigenous carers , including their kinship relationships; and

- lack of cultural awareness and competent practices of many mainstream services, which means in urban centres Indigenous people are unlikely to access the service.

However there are few services and supports in communities to call on, especially in regional and remote centres. This makes identification even more important as it is likely to result in significant increases in carer burden.

The Social Policy Research Centre at the University of New South Wales has been commissioned to determine what information is known about Indigenous carers and what further information is needed. It is hoped that this study will also examine mechanisms for identification.

3.4.2 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.

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 (Etzoni, 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 frequently espoused as vital components of mental health recovery. However, privacy and autonomy principles are subject to restrictions when there are:

- Doubts about an individual's capacity to make rational judgements;

- Public and personal safety considerations;

- Treatment criteria of mental health legislation (where a person is detained on an involuntary basis); and

- Groups of people with severe mental illness who could not survive without significant assistance from others.

The carer's need for information to support the caring role further threatens consumer autonomy and privacy. Firstly, 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 the following.

- Disaffected and abusive relationships.

- Connotations of overprotection associated with the term carer, that conflict with the ethos of independence fostered by community care.

- 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 patients 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.

The Australian Law Reform Commission undertook a review of privacy law in 2008 and recognized that disclosure of information to 'a person responsible for an individual' can occur within privacy law. The need for legislative reform in this area was also recognized by the 2009 House of Representatives Inquiry into Better Support for Carers. Recommendation 14 of that report called for investigation of whether privacy and mental health legislation 'adequately allows carers to be involved in the treatment of the individuals for whom they care'.

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.

SANE Research investigating the effects of caring for someone with a mental illness, 2007 produced the *SANE Guide for Families, the essential resource for families, friends and other carers of people with a mental illness*. 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, drew 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."

Diane Froggat, in examining issues of confidentiality and privacy in *Families as Partners in Mental Health Care* states:

The difficulty arises when those who are caring for a severely ill person are told by the clinician that he or she cannot discuss the patient. In most cases carers are not looking for personal details of the clinical relationship, but only for information that will help them carry out their responsibilities as caregivers. This is not privileged information unless the patient has specifically asked the clinician not to talk to his/her relatives about anything, a circumstance that is very rare in the families who bring their relative to treatment.

The concept of confidentiality is often a concern to clinicians training in mental health. One effective way of raising the profile of the needs of carers that has been reported, 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.

The development of a specific carer standard in the revised National Standards for Mental Health, 2010, that requires services to actively engage with carers highlights the urgency of finding mechanisms to address this situation.

3.4.3 Lack of training in a carer oriented approach to clinical practice

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.*

Staff training remains primarily individually focused however the evidence in the mental health area for adopting a partnership approach to care that is inclusive of the consumer and their carers is overwhelming. Changing training and practice to a partnership approach is not a simple matter. Legislation and standards now mandate behaviour that clinicians are not adequately trained to provide at this point in time.

Changing training programs is a protracted activity and whilst it will have benefits in the long term, the literature indicates that strategies are required to facilitate change in current clinical practice to be more carer and family focussed.

Recent literature from centres that have incorporated 'Family Interventions' (the name given to programs that utilise the methods used in the research), now document the barriers to implementation and how they are attempting to meet these challenges.

While some patients and families reject this intensive form of help, most welcome it. The major challenges to be tackled for new models of evidence–based mental health service delivery to be implemented, relate to the training of the workforce and changing the organizational culture to accommodate a radically different way of working.

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.

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, DoHA and the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) are funding local and community programs through the COAG national action plan.

Workforce training for professionals who deliver mental health care need to address a number of key barriers carers encounter. Formal protocols for identification are considered key in overcoming these barriers.

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.

There are now excellent and effective training programmes that have been developed in the UK and America, where mental health clinicians – psychiatric nurses, psychologists, occupational therapists, social workers, a few psychiatrists and family carers – have been trained in the methods developed from the research studies. These programs have also been tried in Australia but have been largely unsupported, and have not developed to any great extent.

Set out below, are two models of working with families that have developed from the evidence–base reported in the literature and for which training manuals ('Family Work Manual' – Falloon et al, 2006 and 'The Management of Major Mental Illness with Families in Group Interaction' – Lambert and Leggatt, 1999) are now available.

- Behavioural Family therapy. This model has been adapted and is being implemented as 'Building Family Skills Together,' in conjunction with North West Area Mental Health Service, the Centre for Psycho–Social Research and the Bouverie Centre. All of these services are located In Victoria.

- Multiple Family Groups. A research project was implemented through the Inner West Area Mental health Service in Victoria, and the results of this work have been published (Bradley G et al, 2006). Multiple family groups have been commenced in two other Victorian Mental Health Services.

3.4.4 Organisational change necessary to accommodate new ways of working

Margaret Leggatt in her article, *New thinking and acting for turbulent and challenging times, 2010,* sees organizational change as probably the greatest challenge to identification and engagement with family members and other carers.

In brief, the major barriers that have to be overcome are:

- *changing outdated clinical attitudes to families as the cause of mental illness*

- *implementing better methods of case–load management*

- *finding resources, both in terms of funding but significantly more important has been the need to gain the support of management. Once this occurs, funding seems to become available.*

- *finding 'culture change carriers' who will advocate and push for innovation*

- *making time available to implement the change process*

- *finding ways to ensure sustainability; this has happened primarily through ongoing clinical supervision to build and maintain confidence and expertise.*

Leggatt goes on to say that there is now substantial literature from clinical researchers in other countries where family work has been implemented, who have

confronted and overcome the barriers to this implementation (Brooker C, 2001; Drake et al, 2001; Fadden G, 2006; Grol and Wensing, 2004).

One method for overcoming these barriers is to undertake a 'Barrier Analysis' as described by Leggatt in the chapter *Meeting the Challenges* in *Families as Partners in Mental Health Care.*

A 'barrier analysis' enables major individuals and groups that are critically important in making changes within an organization to be identified. This type of analysis can be undertaken by groups comprising clinicians, consumers and carers.

When the National Institute of Clinical Studies (NICS) used this process in Australia they identified the following individuals and groups as most important to making change succeed:

- Area managers;

- Directors on clinical services;

- Team leaders/program managers;

- Frontline clinicians (interdisciplinary case managers);

- Doctors; and

- "Known obstructors".

It is clearly very critical that known obstructors are identified and involved if change is to occur. Focus groups with frontline clinical staff were also seen as an important tool in addressing the barriers to implementing changes in clinical practice towards a partnership model of care.

Leggatt also notes the importance of involving experts in family interventions when making changes in clinical practice. Dr Grainne Fadden, in a workshop in Melbourne in 2005 emphasized the following key principles to ensure change occurs:

- *Evolving family work into routine clinical practice is a practice that takes time and perseverance.*

- *Central funding is needed to get family work started – not necessarily to have it in the longer term.*

- *Model of intervention should be relatively simple and part of the workload of all clinicians.*

- *Ongoing supervision of clinicians after training is vital.*

- *Uptake of the intervention by clinicians will be minimal at first (working in depth with only one or two families if working with a single family model, or one group if a "multi–family group" model is adopted.*

The literature reports that consumers, family or carers and clinicians working together collaboratively, provide an excellent opportunity for incentive–based

learning. Staff start to find that they are 'thanked' by families, rather than having to cope with families that are angry, frustrated, and therefore seen as difficult and 'dysfunctional.' Less staff burn–out, less absenteeism, and fewer resignations have also been reported. Including the family and other carers is much more satisfying in that they are now 'allies', and not 'enemies.' Clinicians also find that issues such as confidentiality disappear when carers become part of the treatment and care team. Cost effectiveness of these interventions has been reported in several cases, including in Australia (Mihalopoulos, 2004).

Family Interventions are a proven way of helping families stay together. Rather than focussing treatment solely on the consumer, new ways of thinking and acting must incorporate the consumer's social network, most particularly his or her family and friends. This is undoubtedly in the consumer's best interests for optimum recovery.

Diane Froggatt in her introduction to *Families as Partners in mental health Care, A Guidebook for Implementing Family Work (2007)*, provided the following quote:

> *Asked about what single change would substantially improve quality of psychiatric care, Professor Julian Leff replied: "Listening to and implementing what patients and their carers want." In answer to what single area of psychiatric practice was most in need of development, he replied: "Including the family in any consideration of the patient's problems, needs and strengths"*

3.5   ADVANCE DIRECTIVES/STATEMENTS/CARE PLANNING

An exploration of the literature to determine mechanisms for identification indicated that Advanced Directives and Ulysses Agreements have 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 one's future preferences for medical treatment in anticipation of a time when one is 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.

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 AD 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, 1999d), 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.

3.6   CONCLUSION

The literature is mostly silent on how to achieve identification, however there is plenty of evidence to support the activities that flow from identification. Existing literature focuses on the problems associated with implementing these processes. One can assume 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 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.

- Increase in carer mental health literacy via access to specifically tailored information packs.

- Carers self identifying and becoming pro–active in the development of effective relationships with professionals.