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Families and Mental Illness: Contested Perspectives and Implications for Practice and Policy

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Abstract
Mental health research, policy, and service provision over the last 50 years have constructed families and their connections with mental illness in various and contradictory ways. Three distinct but intersecting perspectives derive from the clinical mental illness literature, the family advocacy movement, and mental health policy. Within the clinical literature, the perspective of families is largely one of blame and pathology. By contrast, the family advocacy movement has generated the perspective of the burdened family, whereas mental health policy has created the perspective of the obligated caregiver. The result is an ambiguous understanding of the role of the family in both contributing and responding to mental illness. Implications for policy and practice include the need for a commitment to the principles of partnership with families, a recognition of diversity within families, recognising the difference between carer and family positions, and a need for policy to reflect the position of family as both intimately concerned, but not necessarily responsible, for patient care.

Keywords: Family Interventions; Mental Health; Social Work Practice; Social Policy

Families are central to understanding the experience of mental illness and identifying effective strategies for enhancing outcomes. Families represent a primary dimension of the social context for the individual in which illness develops and treatment is provided. Yet, review of the research and literature reveals a history of conflicting perceptions of families of people with mental illness in both the clinical and policy domains, and general contestation as to what constitutes “the family”. In part, the contested understandings of families reflect the changing research and treatment agendas evident in the era of deinstitutionalisation and beyond. However, the way that families are described and understood in relation to mental illness reflects also broad social movements and political change, particularly relating to expectations of citizens and the monitoring and promotion of the wellbeing of citizens (Henderson, 2008).

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Within the clinical literature, families have been seen as causing mental illness in a family member, as sustaining mental illness and contributing to relapse, or as carrying the burden of caring for the person with mental illness (Bland, 1998). With the rise of the family advocacy movement, an alternative view of family has emerged stressing the impact of illness on the family and the role of family as caregivers for the patient. This perspective argues that serious mental illness has an impact on the individual and their family across all domains of life. In the mental health and social policy of recent years, while the emphasis has been the role of family as partners in the care of the patient in the community, families have also been constructed as “carers”, endowed with caring obligations and subject to privacy legislation that diminishes both the partnership and caring relationship (Heaton, 1999). Notwithstanding these competing perspectives, it is widely accepted that while broader social processes such as culture, economy, and education are central and relevant to aetiology and response, mental illness emerges within the context of the network of the individual’s family and other relationships. Treatment and care is provided within this social context in which family relationships are central and primary. In view of this, a critical review of perspectives of the family and the implications for policy and practice is warranted.

In this paper, we consider the competing perspectives of families and mental illness that derive from three areas: the clinical mental illness literature, the family advocacy movement, and mental health policy; and how these perspectives generate varied service system and professional responses to families. While there are some overlaps in the literature from these three areas, there are also distinct differences in the ways that families and mental illness are understood and dealt with. We argue that the ambiguity surrounding perceptions of the family remains a significant barrier to developing positive and constructive policy and practice approaches that are inclusive and respectful of boundaries and diversity. Moreover, the notion of families as informal carers creates unreasonable expectations of the family to provide long-term care. The paper includes a discussion of the implications for policy and practice that derive from the contested perspectives of families and mental illness. These include the need for a commitment to the principles of inclusion and partnership with families so that professionals find creative ways to deal with matters of agency, privacy, and confidentiality, a recognition of the diversity of family, and the difference between carer and family positions, a need for policy to reflect the position of family as both intimately concerned, but not necessarily responsible, for patient care.

**Defining Key Concepts—Disorder, Illness, and Family**

The concept of mental illness is highly contested, as are the tensions between positivist and constructivist models of illness (Pritchard, 2006). We acknowledge the debates about which of the syndromes of symptoms are properly identified as disorders (Horwitz & Wakefield, 2007) and the contested nature of diagnosis. Within the psychiatric literature a distinction is drawn between high prevalence and low
prevalence disorders. The “high prevalence” disorders such as anxiety and depression are more common in the community, and extreme forms of these disorders can cause disabling impacts on individuals and their families (Andrews, Hall, Teeson, & Henderson, 1999). However, it is the low prevalence disorders, schizophrenia, major depression, and bipolar disorder, for which the impact of illness is most likely to be severe and enduring (Jablensky et al., 1999) and is most likely to impact on the patient’s family. For the purpose of our discussion in this paper, we have chosen to focus on this more severe end of the spectrum of disorders. This group has attracted much focus in mental health research, mental health policy and service development, and nearly all the literature on families and mental illness has been concerned with this group of disorders. For the purposes of the review of the family research, we will adopt a language of illness and treatments to describe this group of serious disorders.

The term “family”, in both the clinical and policy literature is also open to multiple interpretations and hence there is no precise meaning. Although much of the research literature has been based on family as meaning the individual patient and close relatives, typically parents and to a lesser extent siblings, spouse, or children (Wasow, 1995), we acknowledge that the term family can be applied to the wide range of intimate relationships that can include close friends, same sex relationships, and blended family groupings.

**Perspective One: The Clinical Mental Illness Literature**

Deinstitutionalisation in western democracies was given impetus with a series of social developments, including developments in medicine and pharmacology, and major policy reforms, which shifted management of mental illness from the institution to the community (Richmond & Savy, 2005). Much of the research interest in families through the six decades following World War II is based on a recognition that community care for people with severe mental illness depended on the support provided by families (Hatfield, 1987). Two themes that emerge from early interest in families are the idea that families might be to blame for the development of illness, and secondly that families carry the burden of community care (Goldstein & Miklowitz, 1994; Hoenig & Hamilton, 1969; Laing & Esterson, 1970; Lidz, 1958). These themes re-emerge in subsequent research and policy through the rest of the century.

Emerging from the era of what Terkelsen (1987) called *radical environmentalism* were a group of theories that sought to locate the emergence of mental illness within disordered family structure or communication. Hatfield (1987) reviewed these theories, distinguishing a number of approaches including speculative psychodynamic theory, theories of double-bind communication, theories of marital schism and skew, and theories of hierarchical incongruity. The central assumption was that individual patient pathology was located within disturbed family structure and dynamics, and amenable to change through family therapy. In this context, patients were viewed as victims, families as persecutors, and treatment staff as rescuers (Bland,
1997). Though now largely discredited and discounted, the theories were popular with mental health professionals through the 1960s and 1970s (Hatfield, 1987).

This construction of the family and the subsequent focus on the family environment as a fundamental target for intervention was also occurring against the context of social and political change at the time. Developments in public health focused on social relations both as a means of understanding illness and a way of intervening to promote the health of the nation, while liberal welfare doctrine supported professional intrusion into family life as a way of preventing social problems and reinforcing the imperatives of citizenship (Henderson, 2008). The intersection of these changes and ideas about family pathology legitimised policies and practices targeting parenting and family behaviour, both as a way of avoiding mental illness but also ensuring responsibilities relating to care (Crossley, 1998). It also served as a vital backdrop for a growing interest in understanding the connection between family traits and the prevention of relapse in patients being discharged from long-term hospital care into the community through the 1960s and 1970s.

The discharge of long-term hospitalised patients with schizophrenia into the community offered the opportunity for research into patient outcomes and variables that could predict patient relapse. Studies in Britain and the United States (Brown, Birley, & Wing, 1972; Vaughn & Leff, 1976) proposed that certain family traits, such as criticism, hostility, and emotional over-involvement, created a form of chronic stress for the patient that led to patient relapse. Measurement of expressed emotion was refined to valid and reliable scales, although the conceptualisation and theorising about the exact nature of expressed emotion and its connection with relapse remained uncertain (Strachan, 1986). Reviewing the expressed emotion literature, Kavanagh (1992) defined expressed emotion as a measure of negative or intrusive attitudes that relatives express about the patient. The original research on patients with schizophrenia was extended to other diagnostic groups such as major depression and bipolar disorder (Goldstein & Miklowitz, 1994).

The expressed emotion theories were very influential clinically as they generated a wide range of interventions designed to modify family behaviour in order to prevent patient relapse (Goldstein, 1981; Hatfield, 1987, 1994). These interventions largely relied on principles of psychoeducation, seeking to modify family behaviour through teaching communication and problem-solving skills (Hatfield, 1994). Moreover, expressed emotion was influential in shaping the therapeutic imagination of mental health workers over the ensuing decades (Bland, Renouf, & Tullgren, 2009). The extensive therapeutic literature in this area suggests a range of psychoeducational approaches; with individual families, in small groups, using brief or extended treatment, all of which appeared to show good patient outcomes (Mueser, Glynn, & Liberman, 1994; Strachan, 1986). While these programs recognised that families could be distressed or burdened, the primary focus of therapeutic concern remains on the impact of the family on the patient.

In the last 10 years, the published research literature on expressed emotion has declined significantly as more comprehensive ways of understanding the connections among patient, family, and environmental variables are sought. Ohaeri (2003), in her
review of recent research, suggested that high expressed emotion may indicate the family's attempts to help the patient, and is mediated by controlling behaviour, stigma, burden, and caregivers' perception of the patient's control over their own behaviour. Wuerker, Long, Haas, and Bellack (2002) argued that expressed emotion might be better understood as an indicator of family responsiveness to symptoms, rather than either a cause or result of symptoms.

The very large body of research literature on expressed emotion, and the subsequent criticism of the theory from the family movement, constitutes a consistent and influential concern with families as somehow contributing to the course of mental illness. Families were seen as a source of stress for the recovering patient, and the potential target of therapeutic endeavour. The strong positivist approach to measuring family traits apparent in the expressed emotion concept reflects the growing influence of scientific approaches to psychiatry. The enthusiasm to use expressed emotion measures to test the effectiveness of treatment anticipates the rise of evidence-based practice as a central organising principle in psychiatry that has become important over the last 20 years (Gilgun, 2005). For many families, this scientific positivism was experienced as a continuation of the family blaming of earlier decades. There was little concern for the needs of families in their own right and very little compassion for the family experience. Family blaming might also be an unanticipated consequence of other clinical research such as the emerging interest in the connection between childhood trauma and abuse and subsequent mental illness (Coates, 2010). If parental abuse can contribute to mental illness then clinicians might look more critically at the parents of their patients.

Various reviews of the literature on the impact of family caring on the health and wellbeing of carers have consistently found caregiving to be stressful and potentially harmful to carers (Robinson, Rogers, & Butterworth, 2008; Savage & Bailey, 2004). A review by Schultz, O'Brien, Bookwala, and Fleissner (1995) of the broader caregiving literature found increased levels of psychiatric morbidity in carers, including elevated levels of depression. Robinson et al. (2008) identified a number of aspects of the burden of caring relevant to family health and wellbeing. These included the recognition of the impact of illness on the family as well as the patient; the high rate of undiagnosed mental illness requiring family, but not formal, care; the reliance on informal family care; the long-term nature of severe mental illness; and the high risk of mental health problems among carers themselves (Robinson et al., 2008). Recent research by Cummins et al. (2007) helped to put this psychological stress for families within a broader social context. Their study found that carers also experienced higher levels of unemployment, more physical health problems, lack of positive social support, and higher levels of financial problems than non-carer counterparts.

Perspective Two: The Family Advocacy Movement

An alternative literature about families and mental illness emerged with the development of the family movement in the United States, Australia, and elsewhere.
Similar to the early studies of deinstitutionalisation, which evoked the concept of *family burden* (Hoenig & Hamilton, 1969), this literature reoriented the perspective on families by acknowledging and documenting the impact of mental illness (Hatfield, 1978; Hatfield & Lefley, 1987). Hatfield’s (1978) seminal paper on the psychological costs to the family of schizophrenia alerted mental health workers to the previously unacknowledged distress that many families were dealing with, as they provided care for a family member with schizophrenia. In the United States, the National Alliance for the Mentally Ill (NAMI) encouraged families to share, and write about their experiences. Within the leadership of NAMI there emerged a number of writers and researchers who were themselves parents of people with severe mental illness, and for whom the dominant discourse around families as sustainers of mental illness was offensive. Their writing offered an alternative way of understanding families, offering not simply an insight into neglected aspects of family emotional response to illness, but alternative theoretical explanations for the connections among patient symptoms and family response. The language of this body of writing was direct and challenging. For example, Vine (1982) wrote of *Families in Pain*, a contrast in style to the academic detachment of clinical writers. Similarly, Deveson (1991) detailed the family response to the emergence of schizophrenic illness in her son. The influential journal *Schizophrenia Bulletin* included in each of its editions, a first person account of schizophrenia, and many family perspectives and stories are included here. These direct personal accounts of family response to illness are in direct contrast to the scientific positivism of the expressed emotion theories.

Early work by Bernheim, Lewine, and Beale (1982) encouraged a compassionate view of families struggling not just with difficult patient behaviour at home, but also with a treatment system that was ignorant or uncaring of family distress. Hatfield and Lefley (1987) drew together a range of family writers under a theoretical framework of family coping and adaptation. Family response to emerging mental illness in a family member was conceptualised as family coping, response to crisis, response to stigma, and as family caregiving. These themes were further developed in the literature (Bland, 1987; Hatfield, 1990; Lefley, 1989; Wasow, 1995) in which the ideas of instrumental, cognitive, and affective dimensions of caregiving emerge. McGregor (1994) and Bland (1998) have written about grief and guilt in families coping with mental illness, and Terkelsen (1987) described the collapse of hope in families and the emergence of grief as stages in family response to illness over time.

The family advocacy movement has generated a range of group-based treatment programs based on helping families to understand the nature of mental illness and ways in which they might deal effectively with common problems associated with the illness (Bernheim & Lehman, 1985; Hatfield, 1991; Lefley & Johnson, 2002). These programs were developed not just in the resource rich research centres, but also in the self-help advocacy groups for families in the United States, Australia, and elsewhere (Alexander, 1991; Bland, 1986). The aim of these programs has been to apply an educative, rather than a therapeutic, focus to working with families. Learning about the illness and about ways to manage stress for the family has the goal of empowering families and restoring...
family wellbeing. Evaluation of these programs has emphasised family, rather than patient, outcomes.

Family advocates have successfully challenged some of the very influential but potentially blaming expressed emotion theories, including the tendency to categorise families as either high or low expressed emotion so that mental health workers see families as either “good” or “bad” (Lefley, 1992), and to blame, misunderstand, or ignore families, and to overlook the clear connections between disturbed patient behaviour and distressed family response (Bland et al., 2009). Hatfield and other writers from the family advocacy movement in the United States have argued that these theories continue the blaming of families for mental illness, overlooking all the good things that families do to support patients (Hatfield, 1994; Hatfield, Spaniol, & Zipple, 1987).

In recent years there has been a convergence of this family advocacy and expressed emotion theory approaches, emphasising families and treatment staff working together in partnership towards good outcomes for both patients and families. Falloon (1999) and Froggatt, Fadden, Johnson, Leggatt, and Shankar (2007), for example, have reviewed the family work literature to identify a number of common principles of effective, evidence-based family work. These principles include giving information about mental illness, tailoring sessions to meet specific family needs, longer rather than shorter interventions, and encouraging a low-stress environment (Froggatt et al., 2007). Mottaghipour and Bickerton (2005) argued that effective family work does not have to be the province of highly trained specialist clinicians. Rather, the evidence from family advocates is that the simple tasks of engaging with families, providing education, and collaborating in treatment decisions is well within the skill set of all mental health professionals.

The perspective of families as caregivers with needs in their own right and, in fact, with rights of their own within the treatment system for support, inclusion, and respect offers an important contrast to the view of families as potential sustainers of mental illness that underpins the expressed emotion literature. These differences in ways of understanding families are reflected in the language used. Significantly, literature from the self-help movement uses more direct and emotive language to capture family experience. As suggested, many of these writers have direct personal experience of living with mental illness and are not speaking from places of academic distance.

**Perspective Three: Families and Carers in Australian Mental Health Policy**

Alongside these divergent views of families in the mental health research literature, the concept of family-as-carer has emerged as the dominant perspective in the mental health policies in Australia and elsewhere (Lefley, 1997; Sevenhuijsen, 2000). The term carer, as applied in mental health policy, appears to derive from the caregiving literature in which Hatfield (1978) and her colleagues in the NAMI movement have been so influential. Lefley (1997), for example, has argued that families became caregivers in response to the deinstitutionalisation movement, assuming care for family members who were formerly cared for in hospital. Carers of family members with mental illness
were then included with the larger group of informal care providers, caring for ageing family members or people with disabilities. Thus the family care of someone with schizophrenia became equated, for example, with the care of ageing relatives or of children with severe physical or intellectual disabilities. In Australia, mental health carers became part of the broader caring community represented by groups such as Carers Australia and were eligible for the same social security benefits (Carer Payment and Carer Allowance) as other informal carers in the Australian welfare system. Recent research by Pirkis, Hardy, Burgess, Harris, Slade, and Johnston (2010) estimated that there may be as many 15% of the adult population of Australia who are caregivers of relatives with a mental disorder. They found that most carers are older women, a reminder of the gendered nature of caregiving.

The perspective of families with caring responsibilities was given political impetus through community care policies framed by neoliberal ideas. A move away from public provision towards a mixed economy of welfare (Dean, 1996) elevated the importance of informal care networks. In doing so, community care policy sought to delimit the scope of action by the state in respect to families (Offer, 1999) and to incorporate the family into new governance arrangements relating to the provision of care in the community (Henderson, 2005). Alongside this, the care of people with mental illness was enacted in a new framework of responsibilities and rights, and new relationships with government and the professions (Sevenhuijsen, 2000). The aim was to encourage families to care for family members. Review of the national mental health policy documents, and those of the various states, reveals a central interest in the concept of carer, and recognition over time of the importance of a broader concept of families and carers. The early policy documents, the National Mental Health Policy (Australian Health Ministers, 1992a) and the first National Mental Health Plan (1993–1998) (Australian Health Ministers, 1992b), expressed a strong and pioneering interest in the importance and welfare of carers. These documents define a carer as “a person whose life is affected by virtue of his or her close relationship with a consumer, or who has a chosen and contracted caring role with a consumer” (Australian Health Ministers, 1991).

While there is very little attention given to carers in these early policy documents, the Mental Health Statements of Rights and Responsibilities (Australian Health Ministers, 1991), gives extensive attention to the rights and responsibilities of carers. These include “the right to respect for individual human worth, dignity, and privacy” (p. 17) and “the right to comprehensive information, education, training and support to facilitate the understanding, advocacy and care of those consumers they care for” (p. 17). It is significant that the two-page section on carers’ rights does not mention the term family. However, it does acknowledge the need to respect, inform, and include carers in mental health care—themes that underpin the policy view of family and carers in subsequent mental health policy documents. Most significantly, the list of rights includes that “carers and advocates have a right to place limits on their availability to consumers”, and the “carers... have a right to help with their own difficulties that may be generated by the process of caring” (p. 18). These rights,
together with the definition of carers provided in the policy, emphasise that families and others choose to be carers, and have a right to support from mental health services in meeting the needs associated with caring. These radical ideas are less evident in subsequent National Mental Health Plans.

A dominant theme in the First National Mental Health Plan (1992), covering the period of 1993–1998, was the principle of consumer participation in all aspects of service delivery and evaluation, and in the education of the mental health workforce. The Second National Mental Health Plan (1998–2003) (Australian Health Ministers, 1998) extended the participation principle to include carers and emphasised the importance of partnerships among service providers, consumers, and carers in service delivery. The Third National Mental Health Plan (2003–2008) argued that “consumer and carer participation and partnership at all levels in policy, planning and treatment is a hallmark of a quality mental health system” (Australian Health Ministers, 2003). The principle of participation is reflected in other policy documents—the National Practice Standards for Mental Health Services (Australian Health Ministers’ Advisory Council National Mental Health Working Group, 1996), and the National Practice Standards for the Mental Health Workforce (Australian Health Ministers Advisory Council’s National Mental Health Working Group, 2002). All documents appear to see participation by consumers and carers as a right to be protected, rather than as a way of ensuring that services are responsive to consumer and carer need.

Within the detail of some documents there is some recognition of the requirement for services to address directly the needs of carers. For example, Standard Two “Consumer and Carer Participation” of the National Practice Standards (Australian Health Ministers’ Advisory Council National Mental Health Working Group, 1996) insists that workers should identify “the needs of family members and/or carers in unique or special circumstances and ensure that services are provided to these families by the mental health service or another appropriate service” (p. 12). In this document too there is the recognition of the needs of children of consumers. The Third National Health Plan (2003–2008) continued this trend to recognise the needs of family carers and required services to develop carer plans in conjunction with consumer plans, emphasises regular review of the needs of carers including the need for respite and the needs of children of a parent with a mental illness. The Fourth National Mental Health Plan (Commonwealth of Australia, 2009) continued this focus on carers and families, identifying respect for the rights and needs of consumers, carers, and families as the first principle underpinning the Plan.

The themes of participation and inclusion evident in the national mental health policy are reflected in the various state policies. All the state plans and policy documents adopt a similar definition of carer and use the terms carer and family, or family and other carers. Perhaps the best articulation of a rationale for working with families and carers comes from the Victorian Mental Health Services Clinical Practice Guidelines: Working together with Families and Carers (April, 2005). The Guidelines acknowledged the diversity of family members and others who adopt caregiving roles, and stressed the importance of services working in partnership with family and
carers. They argued that the rationale for working with families and carers includes acknowledgement of the benefits for patient outcomes of including families and carers in assessment and treatment, and also identifies the importance of meeting the needs of families and carers through support and education. Other aspects of the Victorian Mental Health Plan (Department of Human Services Victoria, 2009) recognised the importance of supporting families to promote prevention of mental illness, another example of recognising families beyond a carer role.

As a whole, the national policy documents emphasise the role and importance of families as carers, though there is an emerging recognition of broader needs of families, not just as carers supporting consumers, but as having needs in their own right. The needs of children are a case in point. While older children might adopt carer roles, younger children represent a concern for family welfare that is not about caring for the consumer. At the same time, within national policy there is an inherent tension evident by incorporating on the one hand, the notion of families as willing partners in the care of the patient, and on the other, carers with caring responsibilities and obligations.

**Implications for Practice and Policy**

The competing perspectives deriving from the clinical mental health literature, family advocacy literature, and government mental health policy have left a legacy of confusion about the appropriate place of families in policy and service delivery. On the one hand, the blaming perspective would indicate that policy and service delivery privilege the rights and wellbeing of the individual and limit the involvement of the family, including putting restrictions on what families are told and the information they have access to. On the other hand, the recognition that families are burdened by caring responsibilities but also pivotal to the caring process would suggest that policy and service delivery be targeted toward enabling the involvement of the family and ensuring they have access to information and resources to assist them, not only in the caring task but also to ensure their wellbeing. The current lack of consensus about the position of the family points to a number of key implications for individual workers and service managers, as well as for policy makers.

**The Need for a Commitment to the Principles of Inclusion and Partnership with Families**

The principles of inclusion and partnership must frame the approach to families in mental health policy, and be translated into practice through appropriate resourcing and development of universal protocols and guidelines. There is evidence that despite the good intentions of policy makers in Australia, many families continue to experience difficulties in relationships with service providers and in accessing services (Groom, Hickie, & Davenport, 2003). The failure of services to address the needs of families was a key finding of the Report of the National Inquiry into the Human Rights of People with Mental Illness (Human Rights and Equal Opportunity Commission,
1993), and the Senate Select Committee Report *A national approach to mental health: From crisis to community* (Commonwealth of Australia, 2006). Submissions from individuals and family carer groups stressed the exclusion of families from treatment systems and problems with the interpretation of confidentiality and privacy principles when applied by treatment staff. “It is common for carers of people with a mental illness to experience a lot of rejection of their caring role, not only from their family member but also from the mental health system” (Carers Association of SA Submission #30)

The theme of exclusion and problems with privacy is evident in the submissions to the Mental Health Council of Australia for their report *Not For Service; Experiences of injustice and despair in mental health care in Australia* (Mental Health Council of Australia, 2005). Carer groups such as Carers Australia claimed that treatment staff invoked concerns about privacy and confidentiality to deny family members access to support and information that they needed in order to care for their family member. For example, the ARAFMI Tasmania submission argued that:

> Family members indicate they have all responsibility but no rights. They are key players in caring for sick family members. The confidentiality/privacy act is an aberration...Professionals deny themselves access to the wisdom of carers and hinder early diagnosis and accurate diagnosis. (MHCA, 2005; ARAFMI Tasmania, Submission #245)

These problems exist despite the spirit of the various state and Commonwealth mental health policies that proclaim partnership between family carers and service providers, and various reports in the research literature about the management of confidentiality matters with family (Furlong & Leggatt, 1996; Veccio, Stephens, and Cybinski [2007]) studied Australian carer perceptions of service delivery and found that most carers reported that they received insufficient support from service providers. A recent survey of family carers by the Mental Health Council of Australia (MHCA, 2009) also confirmed that carers continue to feel ignored and excluded by treatment services. This survey identifies 15 issues for carers, including the physical and mental health of carers, the need to be listened to and treated with respect by service providers, the need for information and support from service providers, and the need for financial support for carers. Significantly, carers claimed that their rights to be part of the care team were denied on the erroneous grounds of privacy and confidentiality (MHCA, 2009, p. 4). Carers surveyed also identified a number of difficulties that their family members experienced in accessing treatment services.

In practice, the extent to which confidentiality and privacy issues are problematic depends on the clinical situation of the particular patient. Where the patient is working closely with treatment staff and is living independently of family, there is not a justifiable argument for sharing details of patient treatment with anyone else. Where patients are living with family members and their behaviours are considered dangerous to themselves or family members, mental health workers are ethically obliged to engage and inform the family in planning for patient care and ensuring
safety (Leggatt, 2002; Szmukler & Bloch, 1997). Between these extremes is a range of
care situations in which the needs and rights of the patient compete with the needs
and rights of the family. The seminal work of Furlong and Leggatt (1996) remains
relevant to managing this tension. They suggested that dealing with the question of
confidentiality sensitively presents clinicians with an opportunity to develop quality
relationships with both clients and their families (Furlong & Leggatt, 1996). Furlong
(2001) challenged the assumption that clients’ needs and family needs compete and
argued that clinicians should work from a position that acknowledges that the
interests of clients and families are correlated over the longer term. This argument
was supported by Machin (2004) in an analysis of the legal dimensions of patient
confidentiality.

Where patients are dependent on family support for care in the community,
partnership between treatment staff and families is possible only if the treatment staff
respect the family’s need for reasonable information and advice about treatment.
Treatment services need to find creative solutions to this dilemma, which are based
on forming treatment alliances among families, patients, and workers. For example,
in treatment teams it may be possible to assign a staff member to work closely with
families of patients who insist on keeping treatment matters confidential and separate
from families. In other teams, staff can insist on meeting with the patient and their
family to review treatment so that families have an opportunity to feel heard about
decision-making, and patients can determine what information is shared.

The issue may also be addressed by law as well as policy. In Victoria, the Government
is proposing changes to the mental health legislation to establish a nominated persons
scheme in order to “enhance carer involvement while protecting patient privacy”

**Recognition of the Diversity of Family and the Difference between Carer and
Family Positions**

Service providers and policy makers need to be inclusive and mindful about the
whole range of important family-like relationships that comprise an individual’s
social context when developing policy, and making assessments and treatment plans
with patients. As our review of the literature has revealed, mental illness emerges for
individuals within the complex network of intimate relationships. The caregiving
response occurs within these relationships and the impact of illness is across all these
relationships, not just a parental relationship. In recent years there has been
recognition of the impact of mental illness on the children of ill parents (Cowling,
2004), spouses, and extended family (Wasow, 1995), and there is limited research
interest in the same-sex, friendship, and blended-family relationships. These
important relationships are significant in terms both of understanding the broader
impact of serious illness and of the potential supports for the patient in their recovery
journey.
The current approach to defining families as carers in mental health policy, with its emphasis on partnership and inclusion, is superficially attractive but inherently problematic. For example, the language of the Second National Mental Health Plan (Australian Health Ministers, 1998) consistently uses the term carers to describe family. Later policy documents use the terms carers and carers and families interchangeably (Australian Health Ministers Advisory Council’s National Mental Health Working Group, 2002). At one level, this acknowledges that families provide extensive and ongoing care for an ill family member. Yet it also reduces the complexity of family relationships and obligations to a single role—that of caregiving, and it conveys an expectation that families will continue to be carers. Reducing family response to the caring role is to deny the range of other important activities and roles that families provide—the conferring of identity, emotional intimacy, transitions through life stages, and mutual interdependence. A service preoccupation with caregiving allows services to ignore family members, such as siblings, children, and grandparents, who may not be primary carers but for whom the impact of illness may yet be great.

However, the relationships may not be captured within the narrow concept of “family carer” central to mental health policy. For example, siblings of the patient might be severely stressed over many years by the patient’s illness but are not really carers. Our argument is that services and policy makers need to hold a broader view of families and their connection with the patient’s illness than simply the caregiving role.

**Mental Health and Social Policy that Values and Acknowledges Care as Central to Humanity and Inclusive Citizenship**

A reorientation of service provision to incorporate an acceptance of the diversity and uniqueness of families will ultimately require mental health and social policy to uphold the notion that care is both a valued and central part of not only human activity but inclusive citizenship (Fine, 2007; Sevenhuijsen, 2000). The loss of sense of self and the abandonment of additional social activities such as full-time employment is often commonplace for families caring for people with mental illness, as acknowledged by the Senate Select Committee, 2006). Moreover, it is the case that carers needs are interpreted, both at the service and policy levels, primarily in terms of a caregiving role, rather than a more inclusive citizenship (Sevenhuijsen, 2000). The latter acknowledges the many and varied contributions individuals negotiate and make in society and the right of individuals to choose how they make these contributions.

Therefore, from a more inclusive perspective, care is not understood simply in terms of a family caring for an individual, but more so as integral to a multitude of social practices and relationships in a changing social, economic, and political environment (Sevenhuijsen, 2000). Sevenhuijsen (2000) advocated for policies that incorporate a democratic “ethics of care” such that they enable all citizens to express both their need for care and capability to give care across many domains of social life.
without reducing the meaning of care to a burden from which individuals seek liberation.

For the families of people with mental illness, this perspective accepts families may be both intimately concerned, but not necessarily responsible, for patient care. It emphasises the social importance of care while also understanding the needs of families in relation to other human activities such as work and leisure. Hence, care within private relationships is not considered separately, negatively, or outside of other human activities that occur in public domains; rather there is explicit recognition of how these varied activities intersect. Social policies that tackle issues of care in this way, Williams (2001) argued, are integral to social justice but also imperative if there is to be a more progressive and holistic socioeconomic orientation to social life in the twenty-first century.

Conclusions

Review of the mental health literature on treatment and policy has revealed a range of competing perspectives about families of people with serious mental illness. These perspectives, though drawing on extensive and sometimes overlapping research areas, reflect clinical positions, the family advocacy movement, and government policy. It is imperative that the next stage of mental health reform in Australia, both in policy and service delivery, reflects a more considered and compassionate understanding of the concept of family of people with mental illness. Adopting the perspective that caring happens within the complexity and interdependencies of family relationships that are unique to each family is fundamental to rethinking service provision and the manner in which service providers engage with families and people with mental illness. More so, situating these complex interrelationships within broader roles and responsibilities of citizenship is essential to move away from the view that care is a private concern of individual families caring for a person with mental illness and that there is a moral imperative for families to undertake that care. Policy reform that engenders such perspectives views policy solutions as addressing these moral dilemmas within a broader network of caring relationships rather than through strategies that aim to ensure the caring conduct of individual family members (Sevenhuijsen, 2000).

References


