'Odyssey of Hope': The role of carers in mental health tribunal processes and systems of mental health care

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‘Odyssey of Hope’: The role of carers in mental health tribunal processes and systems of mental health care

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This article examines carers’ involvement in the interconnected processes of mental health care planning and mental health tribunal hearings, decision-making processes which often dramatically impact on carer–service-user relationships and effectively impose obligations on some carers to assist in implementing legally binding orders. It explores concerns expressed by carers about difficulties accessing information about, and contributing to, these processes, and identifies associated dilemmas and conflicts. Whilst carer involvement may not be appropriate in all cases, the article concludes that carers should be better engaged at the service delivery level from the first point of contact and on an ongoing basis. It argues that a more consistent approach which assists and encourages carer participation in tribunal processes should be adopted. It also suggests that there is a need for additional processes and efforts to deal with conflicts arising between service-users, carers, and health services in the mental health context.

Key words: carers; involuntary mental health treatment; mental health care; mental health tribunals.

Introduction

The patient does not present in a vacuum. Often other community agencies, family and friends are involved in the presentation. Some of these will advocate for the patient and argue against a need for recommendation, and others will emphasise the need for treatment, containment, and removal. Part of the decision-making process is to both seek, and weigh up, the advice and information provided by others. The level of social support and supervision is of particular importance in determining whether a patient can be safely followed-up at home.

The increasing influence of human rights and therapeutic jurisprudence discourses in the mental health field has meant that greater consideration has been given to issues such as fairness, freedom, protection, and treatment within the context of involuntary treatment and mental health tribunal processes. Part of this trend has involved recognizing the rights of mental health service users to play a meaningful role in processes of legal review or determination relating to clinical decisions affecting their lives, including mental health tribunal processes. This suggests a move away from paternalism toward citizen participation. An interconnected dilemma is how individuals can effectively participate in broader decisions about their mental health care and other decisions affecting their lives. Ensuring the
participation of affected citizens in mental health governance is now an explicit goal of mental health policy, as set out in the priority themes of the National Mental Health Plan 2003–2008, although there are concerns regarding the extent to which this goal is realized in practice.

This article deals with the involvement of “carers” in mental health governance, taking mental health tribunal processes as the starting point. It stems from a comparative study of Australian mental health tribunals, the findings of which demonstrate that for citizens affected by mental health tribunal processes these processes are often viewed as inseparable from their wider experience of navigating the mental health system. In fact, making sense of the intertwined legal, ethical, and social issues arising in mental health tribunal processes calls for a holistic examination of these processes, acknowledging that they are embedded within the wider arena of mental health governance, as well as comprising discrete legal decision-making processes.

Service users are the citizens most affected by the various decision-making processes involved in mental health governance. However, they do not generally live in a vacuum or without some social network of support, whether recognized or not, as Barbara Vine suggests in the quotation at the beginning of this article. In fact, individuals’ social networks are often relied upon by health and social services to assist those services to perform their formal treatment, care, and support roles. In times of mental health crisis, carers are often the ones to “pick up the pieces”, or so it is felt. In fact, there have been studies that indicate that greater participation by carers from the outset of service users’ contact with the mental health system can be beneficial in a number of ways: family involvement can reduce relapse rates and hospitalisation, and family interventions can be cost-effective, and improve service users’ functioning and recovery.

Where an individual’s social network plays some role in supporting, supervising or caring for them, then they too are citizens who have a stake in mental health governance. In this article, the term “carer” is used to refer to the various individuals and bodies providing care and support to service users. It appears that giving a name to people and bodies performing such supportive roles has facilitated the development of a valid identity for this group. Thinking about carers as a group is valuable because of the often critical part they play in assisting service users to deal with mental health services and cope with their condition and recovery on an ongoing basis. This process also assists in identifying carers’ functions and needs, which inevitably have legal as well as social and ethical implications for the delivery of mental health care and experiences of service users. Carers may play a range of supportive roles beyond the provision of “care” as traditionally understood. Not all carers are parents, partners or family members, although in this research most were. The “carer” category may encompass non-government organisations that provide community support services.

The “carer” category is not, however, universally accepted. It has been suggested that the term “carer” is inappropriate in the mental health context, given that the majority of people with mental health issues are able to manage and make decisions independently in the community much of the time. An approach which speaks of “consumers” and “carers” as if their rights and interests are identical is indeed questionable. In some situations, conflict between the views of mental health service users and their carers may raise particular dilemmas for mental health tribunals and clinicians and is of concern for consumers, in particular regarding involuntary mental health treatment.

Our aim is to give consideration to how carers’ concerns may be addressed without
impinging on the rights and needs of individuals with mental health issues. However, where there is tension between the wishes of carers and the wishes of their loved ones, achieving this goal may not be straightforward. Relationships of care are often characterized by ambivalence, rather than involving “either-or” stereotypical paradigms of the “noble carer” or the “abusive carer”.¹⁹

Based on interviews conducted with participants in tribunal processes, and looking mainly at interviews with carers, and also fieldwork observations of these processes,²⁰ this article analyses the nature of carers’ involvement in mental health governance, discusses carers’ concerns about involvement in mental health care and tribunal processes, and identifies associated dilemmas and conflicts that may arise. Foremost among concerns expressed by carers was the experience of being marginalized in the mental health care system. Experiences of mental health tribunal processes and subsequent dealings with those involved in these processes were often experienced as part of a general sense of being devalued and ignored by a mental health system which in fact relies on them to bear much of the “burden of care”. The concerns of carers interviewed for the present study revolved around:

- the quality of care and services provided to loved ones and barriers to achieving a more holistic approach to care;
- accessing information about the mental health system, involuntary treatment, and mental health tribunal processes and accessing support to help them navigate these processes;
- accessing information about and being involved in care and service delivery planning;
- finding out about and being allowed a meaningful opportunity to participate in tribunal hearings; and
- lack of support for service users to enable them to participate in mental health tribunal processes effectively, such that carers must often take on pseudo-advocacy roles.

Mental health tribunals are affected by the broader social and policy dynamics at play within the mental health sector. This article in part considers the extent to which these broader dynamics interact with tribunal processes and how social relationships, such as between service users, carers, and services, should be factored into tribunal and care-planning processes. Protecting the various rights and interests, and meeting the needs, of both individuals with mental health issues and their support networks within and across medical and legal decision-making processes is a complex task, and one that requires diligence, dialogue, and care. The challenge is how to foster opportunities to hear voices of different affected individuals and groups in the governance of mental health care and to create environments enhancing recovery through participation and collaboration.²¹ Although legislative regimes form a critical foundation for effective mental health governance, this article is primarily concerned with the practices and cultures which may enhance or detract from carer involvement in service delivery and tribunal processes.

Legal and Social Policy Context: The Burden of Care and Need for Cultural Change

Contemporary mental health policies have been instrumental in shifting the responsibility for the provision of care from the state to the individual, their families or the non-governmental sector and remodelling the relationship between service providers and the state, and users and the state, in terms of contractual obligations.²² This development has seen increasing demands
placed on carers, who are treated as a silent partner of sorts, relied on by mental health and social services to provide for shortfalls in services or assist in implementing decisions made by services or legal decision-makers such as mental health tribunals.23

The World Fellowship for Schizophrenia and Allied Disorders (WFSAD) outlines three significant associated problems:

- inadequate community support and rehabilitation services;
- lack of support and training for families/carers in treatment and care plans; and
- inadequate training of mental health professionals to work with community groups, consumers and carers in an inclusive treatment strategy and approach.24

Interviews with carers identified each of these problems when reflecting on their personal experiences in dealing with clinical services and mental health tribunals. These problems are connected to systemic issues which also affect the way in which services are delivered at an individual level, in relation to access to appropriate and holistic care and inclusion of service users and carers in care planning. When there are inadequate resources or limited provisions, these systemic issues affect how each sector or group operates individually and collectively. The high ratio of clients to individual clinicians may limit the time for, and level of engagement when, discussing treatment and options. Confusion can be caused and options limited where a particular health care sector operates differently to other health or social service sectors or in other regions. The restricted availability of services, from housing to clinical placement, may influence decisions regarding the length of hospitalization or treatment, including the options which are put forward to or considered by mental health tribunals.

The legal situation can confound these problems as there are various Acts and policies which often do not complement each other regarding the carer’s roles and entitlements, such as mental health laws as well as general health and privacy legislation, guardianship laws, and social security laws. There is substantial variation between state and territory mental health legal frameworks in relation to carers’ involvement in care planning and tribunal processes. This is due in part to the breadth of decision-making responsibilities conferred on both tribunals and clinicians, depending on the jurisdiction, and possible approaches that may be taken within the dominant decision-making categories of: (1) assessment of need for compulsory treatment; (2) authorization of compulsory treatment; (3) specific treatment decisions; and (4) administration and property management.25 A recent legislative development in Victoria and the ACT, which may affect involvement of carers in mental health governance into the future, is the enactment of human rights legislation imposing requirements on government bodies to comply with human rights principles when performing certain functions and developing new laws and policies.26

The impact of care planning and related legal decision-making processes on carers has gained increasing attention in mental health policy debates. The third and most recent national Mental Health Plan in Australia included a specific outcome measure of “improved support for families and carers”.27 The appropriate recognition of carers by mental health and related laws has been a central topic in recent legislative reviews.28 Certain reforms have been directed towards addressing carers’ concerns, in particular relating to: (1) access to information about service users’ interaction with the mental health system and treatment provided to them; and (2) active involvement in care planning processes.
Whilst all these reviews considered what kinds of legislative changes might be needed, there was some consensus that cultural change within the workings of health services and other decision-makers is needed to ensure carers are given access to relevant information and appropriately involved in care planning.

The following sections contain a brief comparative overview of legislative provisions regarding carer involvement in mental health service delivery and tribunal processes in the jurisdictions of New South Wales (NSW), Victoria, and the Australian Capital Territory (ACT), where the present study was primarily conducted. Quite different positions are taken in each of these jurisdictions, with Victoria and now also NSW (but not the ACT) making legislative provision for clinical obligations specifically to involve carers in service delivery in certain respects. However, aside from limited notification requirements, carer involvement in mental health tribunal processes is left largely to the discretion of tribunals, as legal decision-makers with a broad inquisitorial mandate to gather written and oral information as appropriate in each case. However, prior to carers attending a tribunal hearing during which the tribunal panel will control their level of involvement, whether carers find out about the tribunal process and how they might contribute in the first place is largely dependent upon the their relationships with service users and clinicians within the care planning process.

**Access to Information and Involvement in Care Planning**

A project run by the Mental Health Council of Australia in tandem with the Carers Association Australia – one of four studies commissioned by the Commonwealth Department of Health and Family Services in 1998–1999 in response to ongoing criticisms of mental health services for negative attitudes towards carers – made a number of recommendations, including: (1) carer-sensitive service delivery; and (2) carer education and information development. In recognition of concerns regarding these areas, state, territory, and federal governments have implemented initiatives aimed at fostering carer inclusion in the provision of mental health services and providing them with necessary educational and social supports, including the establishment of carer advocacy and support bodies and programs. However, interviews and fieldwork observations conducted for the present study indicate that whilst progress has been made, there is some way to go before such policy goals are fully realized in the everyday world of mental health and related social service delivery.

A large debate in the New South Wales Government’s review of the Mental Health Act 1990 (NSW) concerned carers’ access to information and involvement in care planning as part of a broader focus on privacy and information sharing in the mental health context. The review considered possible legislative changes, such as appropriate recognition of a “carer” role, but especially general changes in policy, practice and legislation “to encourage a culture of involvement” for families and other support people. A number of associated changes were introduced with the Mental Health Act 2007 (NSW MHA), notably the creation of a new “primary carer” role. “Primary carers” are people nominated by the consumer, who must be notified of important events relating to that person’s care, provided with information about medication administered to inpatients and follow up care, and given an opportunity to be consulted about discharge and ongoing care planning. In the absence of such nomination, the NSW MHA provides a hierarchy of people who are default primary carers. Provision for patients to nominate a person or people to
be excluded from being given information about them is intended to safeguard patient privacy and autonomy. However, such protection is not absolute: who is treated as a primary carer is ultimately a matter for clinical discretion, which considers possible harm caused by giving effect to a patient’s nominations and their capability to make such nominations.37

The Mental Health Act 1986 (Victoria) (Victorian MHA) has contained a “primary carer” role for some time.38 However, this is not a role which is intended to cover the field in terms of access for and involvement of support people like the New South Wales primary carer role. Rather, primary carers are recognized alongside guardians and family members of patients as being entitled to be notified of certain events relating to a patient’s care, and consulted about care planning unless the patient objects,39 whilst having some additional entitlements where involvement relates to their ongoing caring role.40 Similarly, the confidentiality provision in the Victorian MHA restricting disclosure of information, except in specified circumstances, allows for the provision of information to guardians, family members or primary carers, if necessary for ongoing care of the person which the support person will be involved in providing.41

The review of the Victorian MHA considered whether additional legislative entitlements should be given to carers in line with the new New South Wales primary carer provisions and comparable New Zealand provisions.42

Unlike the NSW and Victorian mental health statutes, the Mental Health (Treatment and Care) Act 1994 (ACT) (ACT MHA) and related legislation do not specifically entitle carers to information or opportunities to be involved in care planning. The combined effect of the Health Records (Privacy & Access) Act 1997 (ACT) (HRPA Act) and the ACT MHA is that mental health practitioners are authorized to disclose information about a person’s care and treatment without their consent where necessary to prevent or lessen a significant risk to the life or physical, mental or emotional health of the consumer or another person.43 This is equivalent to the position taken in ACT health legislation generally, regardless of whom the information is being provided to. The ACT approach is therefore one which does not discriminate where clinical service provision takes place in the mental health context or differentiate “carers” from others who may have an interest in the information in question. The review of the ACT MHA did, however, raise the question whether the Act should be amended to include a provision authorizing disclosure of information specifically to carers.44

Carer Involvement in Involuntary Treatment and Mental Health Tribunal Review Processes

In addition to access to information and involvement in care planning, mental health legislation may provide for other specific roles or entitlements for carers, specifically regarding commencement of, or discharge from, involuntary treatment and involvement in discharge and follow up care and support services. Carers may be involved in making an initial request for compulsory treatment which will then be followed by a formal clinical assessment, and in some jurisdictions have specific entitlements to make certain applications or appeals to mental health tribunals. The default position, however, is that carers can influence events by virtue of the limited number of legislative provisions allowing any “third party” – over and above consumers and clinicians – to initiate specific decision-making processes within mental health governance, including some mental health tribunal processes.

Mental health tribunals play an important role in overseeing the implementation
of mental health laws and reviewing or approving clinical decisions in the mental health context. The primary types of decisions that these administrative tribunals make are authorizing either a person’s detention in hospital, or their compulsory treatment in the community under a community treatment order (CTO), generally as a result of a hearing conducted by a multidisciplinary three-member panel (or sometimes of fewer than three members). The affected person must be notified of the hearing, and the affected person and a representative of the health service will usually attend the hearing. Other health workers, carers, and third parties may also attend, depending upon the situation.

There are requirements for carers to be notified in relation to some hearings, depending upon the jurisdiction – which provide an opportunity to attend in theory. In practice, carers’ access to hearings is mediated in many cases by health service staff, taking into account service users’ preferences, given that hearings for the most part take place on hospital or health service premises, or sometimes by tribunal staff. If carers are notified and given access to this forum, tribunal panels have the discretion to allow carers to attend hearings and provide information as they see fit, and in line with their broad inquisitorial powers. Carers are not always aware of or involved in tribunal processes, and the extent to which relevant information from sources beyond clinicians and consumers – such as carers – is available to, or specifically sought by, tribunals varies from case to case.

Carers’ Concerns about Involvement in Mental Health Care and Tribunal Processes

Mental health tribunals are in many respects part of the overall mental health system owing to a range of factors, including: their administrative position within health departments in some jurisdictions; their practical location within and reliance upon health services for the conduct of much of their business; and perhaps most importantly, the way in which their substantive decisions are dependent upon clinical decision-making and wider service-delivery contexts. As such, they embody some of the patterns of behaviour and actions evident in the wider field. The environments in which they operate on a daily basis are heavily suffused with medical cultures, and their decision-making is frequently reliant on the adequacy or otherwise of clinical reports – with the consultant psychiatrist’s report frequently constituting the only or main written evidence before them – and the services available in hospitals and communities to meet patient needs. The extent to which carers are involved in service delivery and the social relationships that develop between service users, carers, and health workers in individual cases is also likely to carry over into tribunal processes, in terms of whether carers are informed about hearings and positively encouraged to attend and made aware of what to expect and how they may be able to contribute. Their level of participation may vary depending upon the approach of individual carers and health services, as well as the wishes of services users and the dynamics in relationships between individual service users, service providers, and carers.

The caring role in the mental health context is a complex and sensitive one that varies according to the unique social circumstances, relationships and networks in individual cases. Carers may play a range of formal and informal roles in caring for and sometimes advocating on behalf of loved ones, including arguing for particular care or service outcomes or attending and providing information during tribunal hearings. In discussing the concerns of carers in this paper, we are not suggesting that their views about whether a service user needs treatment, and the type
of care they need, are always right or should override those of service users. However, in many cases, carers’ views comprise a critical part of the spectrum of views that together determine care and service outcomes. As such, it is important to engage these views in a productive way, even if contrary decisions are ultimately made. Such an inclusive dialogical process can improve the quality of decision-making and also ensure that citizen participation in mental health governance decisions affecting their lives is as supportive a process for affected citizens as possible.

How well service users can cope with their mental health issues is dependent to some extent upon the ability of their social networks to assist them, and whether the people in those networks feel they have the knowledge, time, and strength to provide needed assistance. In times of crisis when carers feel that additional professional support services are needed, this view will be one which may significantly influence the nature of service users’ interaction with mental health services. Where a service user is receiving involuntary treatment, a carer’s willingness, or otherwise, to support a service user to live in the community may be an important consideration for clinicians and mental health tribunal panels when deciding whether there is a less restrictive alternative to involuntary treatment.

Tribunal decisions and care planning may in turn dramatically impact on the relationships between carers and consumers and effectively impose obligations on some carers to assist in implementing legally binding orders. These factors heighten the need to carefully assess whether carers are given sufficient opportunity to be involved in such decisions. The support of carers may be critical for the effective implementation of CTOs in particular, which generally require at a minimum adherence to a medication regime and sometimes also participation in rehabilitation programs. Carer involvement may be crucial to ensure that a consumer meets their obligations under a CTO, such as where they need assistance to make and keep appointments or buy and take medication:

Now he has to have an injection every fortnight, that’s not a problem. I’ve organized it with our local doctor. And that is actually what I had to do. I had to go to our local doctor, make an appointment for myself. L didn’t come. So I had to go to our local doctor. I had to give him a copy of the community treatment order which I’d got a copy of by this stage from the mental health team, explain to him what the situation was – that L was now having to have an IMI [intramuscular injection] of Clopixol fortnightly, and I needed a script. ‘Cause they didn’t give me a script here so I had to [get one]. So he gave me a script on behalf of L. I then took it to the pharmacy, ordered it, and picked it up the next day, took it back to the doctor’s, so all L had to do was come to the doctor’s on the Friday and... it was all there waiting.52

Although our interview questions related primarily to tribunal hearings, responses inevitably drew in the issue of carer and service user participation in mental health governance more broadly, with tribunal processes viewed as one aspect of this wider governance context. Major problems were felt to lie in inadequate systems for the provision of care and participation of consumers and carers in shaping the nature their recovery. The main concerns carers identified are:

- not being recognized as an integral part of the person’s support network;
- a lack of communication by the mental health services, or reliance on supposed confidentiality obligations to justify not communicating with families;53
- not feeling listened to or believed;
- feeling reluctant to complain because things may get worse in terms
of care provided or they may be perceived as troublemakers and ignored completely;

- not advocating for their own needs or wanting another battle because they feel exhausted, or already have too many struggles in their lives, or feel too defeated to speak up; and
- not being informed about changes to medication, treatment, or mental health tribunal hearing dates and processes in an intelligible way.

The overarching concerns expressed by carers related to mental health services and the “system” in which they operate, rather than issues specific to mental health tribunal processes. Following a brief overview of these concerns, more detailed perspectives of carers are discussed within the themes of: seeking care and resorting to involuntary treatment; carer involvement in treatment planning; carer involvement in tribunal processes; and finally, lack of holistic care planning and the relative powerlessness of tribunals to facilitate better outcomes in relation to care planning.

**Navigating an Amorphous “System”: Disconnected Sectors and Inadequate Safety Nets**

Carers often found it difficult to navigate a pathway through the “system” as it is difficult to understand what kind of services are available, where assistance can be sourced, as well as what role, rights, and responsibilities a carer has within this system.

My mother and I and the rest of my family (I’ve got a large family)... were desperately trying to seek assistance through any avenues we could... But it’s a very opaque system. It’s very difficult to actually understand where you can get assistance.54

The mental health “system” was viewed by many carers as being an amorphous mass comprising various disconnected parts which do not operate as a coherent and collaborative network.55 Not knowing how the sectors work separately, as well as collectively, in terms of services provided, the rights and responsibilities of particular people, and who to seek assistance from, all contribute to carers feeling unsupported or confused, especially when first entering the mental health system. It was acknowledged, however, that this sense of anxiety and confusion is exacerbated by coming to terms with the changing behaviour of a loved one, as well as feeling helpless in not being able to alleviate any mental distress experienced. And carers are also dealing with their own personal distress, such as feelings of a loved one being lost to them temporarily or permanently, an overwhelming sadness for a future of diminishing possibilities for that person and themselves, a sense of guilt as to how they may have contributed to the person’s suffering, and some anger about the injustice of “the situation”. Such feelings may limit the ability of a carer to effectively participate in the service delivery context and mental health tribunal processes – to defend the needs of their loved one or accentuate their own relevant needs.

The range of sectors and bodies contributing to the delivery of mental health services include community care services, the hospital sector, GPs and private practitioners, housing services, the psychiatric disability rehabilitation sector, financial protectorates such as State Trustees or Protective Commissioners, the police, and mental health tribunals. When first in contact with one or more of these services, carers’ expectations can be that they will erect “a safety net” for the consumer and themselves. However, their experiences are often that such safety nets are temporary, inadequate or inconsistent. It may come down to individual clinicians or service types as to whether effective services are
provided, and there are often inconsistencies in approach between services and across sectors. The links between clinical services and their relationships with other social services, rehabilitation programs or housing projects can be difficult to understand.

**Seeking Care and Resorting to Involuntary Treatment**

Being a carer has been described as “tough love” and a “hard place to be”. The often long journey for carers – their “odyssey of hope” – can range from searching for a cure, securing ongoing services or treatment, maintaining stability for the person in need, and seeking information, recognition, and support in distressing times (or to prevent such situations from repeating). The initial hope is that contact with a mental health service will result in “stability” and needed care and support for a loved one and those affected by the situation, but obtaining effective services and continuing care is not always so straightforward. The imposition of an involuntary treatment order may seem the best or necessary way to ensure treatment or contact with a clinical service. Yet, an order can also be viewed as a heavy-handed approach to secure care. It can become a point of contention or difference between the carer and the consumer or with the treating team. It can mean that a carer feels that they are playing a dual role, being complicit with the treating team, or unable to convey their concerns through fear of damaging their relationship with their loved one. An order can change the social dynamics between all involved. In many cases, however, the relationships between carers and consumers do not involve straightforward agreement or disagreement around issues such as the need for involuntary treatment, but rather constant fluctuation in the level of consensus or conflict – as with any social relationship.

Most carers interviewed for this project described difficulties accessing assistance in times of crisis and were unhappy with the services their loved one was receiving. Families and carers will often try to manage without assistance for some time. Most carers interviewed for this research explained that involuntary treatment is sought in acute situations where things have escalated to breaking point, and some felt that the way in which the law is structured and the lack of support and effective services can force them into the somewhat uncomfortable position of having to instigate involuntary hospitalization. Carers may end up arguing for involuntary treatment, when in fact what they want is better and more consistent attention and care – it can seem that an involuntary order is the only way to achieve this goal. This dilemma is well exemplified by the following extract from an interview:

“We weren’t so worried about actually making an order against D, we were wanting to make an order against the system. We wanted them to say: ‘The system must provide this man with some help.’ And that was the major outcome we were after . . . [Y]ou can’t just keep on letting this guy out of jail, not provide him with any support and services, and not expect a bad thing to happen.”

On the other hand, many carers want the person to remain on an involuntary order on an ongoing basis as this seems the most effective way to ensure some stability for the consumer and themselves.

“We don’t want him to come off his order because we know that, and there is evidence of this going back many times, that if he does come off the order, he will go off [his] medication anyway and we are left then to pick up the pieces and then we have to go through that unbelievable business of watching someone become unwell . . . we have to go through it all again.”
Developing a culture, and providing the necessary resources, to enable health and related support services in the mental health sector to be more responsive to the needs of service users and carers before a crisis point has been reached – through the use of early intervention and voluntary treatment – would go a long way to addressing some of these problems. Technically, of course, indefinite use of an involuntary order is not legally permissible, although finite orders may be extended through the making of new applications on expiry. Effective communication with carers about the services and legal options available is equally important for both service users and for themselves.

**Carer Involvement in Treatment Planning**

As part of broader attempts to navigate an amorphous mental health “system” and be better engaged at the level of service delivery, of particular concern is what role a carer should or could play in individual treatment or care plans. There is the impression that the one-on-one relationship between clinicians and their clients is paramount, with little attention given to the information carers may be able to provide to assist in care planning, the information they may require to enable them to provide needed support in the community, or their own needs as individuals who may be more fragile as a result of trying to cope with a loved one’s changed behaviour. It was expressed that there is an individualistic view taken toward treatment.

We have a psychiatric system in Western countries that pretty much excludes family members from the treatment and care of their mentally unwell relative. I think this is very poor and drastically needs to be improved. Why we exclude families in the West has quite a long history which has to do with what I call individualistic models of care ... We have had this idea that the way for people with psychiatric problems to improve or become well is to develop a very strong therapeutic reliance or relationship between the patient and the clinician and that has lead to the idea that we should exclude third parties ... Our mental health clinicians are not trained to work with families. In mental health that just simply doesn’t work ...

This individualistic view can exist at two levels:

- the way in which “mental illness” may be understood as an event localized “in” or “to” the person; and
- the way in which individuals with mental health issues may be treated as an individual living within a vacuum, with little contact with or inclusion of the social milieu within which the person exists.

The perceived effect is one of marginalizing the social network of the person most affected, which may ironically cause detriment to that person where their mental health is to some degree dependent on the coherence of their social network. This feeling of exclusion is heightened with the medical language used, the irregular or erratic contact made between health services and carers, the lack of ongoing support for carers to discuss issues or concerns, and uncertainty about whether carers’ views are perceived as informative or rather with some suspicion by clinicians. Clinical services may be wary of, or indifferent to, carers’ views, sometimes understandably such as where service users’ perspectives regarding their carers’ involvement are at odds with those of their carers. In addition, other government and non-government service providers may operate their own distinct policies in relation to carers; and such service providers, in particular non-profit community organizations, may themselves fall into the...
carer category when needing to liaise with mental health services in planning how best to assist individuals.

Froggatt states that it is important for the consumer’s lived experience to be recognized and respected, as well as to “...see [them] in context with their surroundings, and not as the embodiment of difficult symptoms and behaviours”. In a similar fashion, carers who participated in the present study felt that their experiences of the situation could be much better respected, both as part of consumer’s lived experience and social context, and as part of their own lived experience in coming to terms with the mental health issues of a loved one.

People with mental illness and their families have experiential knowledge, lived experience and the knowledge that comes from actually going through a process of illness or going through a process of caring, and that knowledge is equally as valid and equally as important as professional knowledge. Unless you utilise peoples’ experiences in your development of their treatment and care, you are not going to get far or get the right services. You can’t deny peoples’ experiences, and you can’t have a didactic clinical service that believes it knows what is right for you. And that is still very much the model.

Many carers expressed the view that a carer’s involvement in mental health treatment may not be perceived to be of value and that carers are not viewed as relevant or helpful agents in care planning. A frequent criticism levelled directly at clinicians is that carers are unable to access information needed to enable them to fulfil their caring roles, which may work to the detriment of service users’ recovery.

There are some fabulous clinicians, who perhaps through common sense believe that families have to be involved. But an awful lot don’t and they hide behind this huge problem of confidentiality, which has become a great mount in the way of efforts to communicate with families.

A predominant concern for carers was lack of involvement in care planning as between mental health services and their clients, and many carers experienced a parallel and closely related difficulty in aiming to participate in and share their views during tribunal proceedings.

**Carer Involvement in Tribunal Processes**

It was raised in the interviews that the lack of a comprehensive approach to carers at the clinical service level could mean that the tribunal process may be the first time a carer has a chance to raise issues of concern to them. Similarly, based on fieldwork observations, it appeared that clinicians sometimes used tribunal hearings as the primary focal point for consultation with carers – sometimes for a very brief period prior to the hearing – where a bare overview of the proposed care plan and purpose of the hearing was provided. Ideally, the tribunal process itself should not be used a means of keeping carers up to date with important decisions about treatment and recovery. The views discussed in this section indicate that carers need to be far better involved from the point at which a consumer enters “the system” and beyond the point of discharge from hospital: they should be engaged in ongoing care planning and discharge planning as now provided for in some mental health statutes. Better incorporating carers at the service delivery level may minimize conflicts likely to occur during tribunal hearings, as some of these conflicts may be able to be resolved prior to hearings or be more amenable to ongoing discussion as part of care planning. In turn, such ongoing inclusion of carers in care planning where appropriate may put clients and carers in a better position to
participate in tribunal processes as they will know where they stand in relation to other participants, their views, and the options being considered.

Relatives, family members or friends of a mental health service user may have been key instigators of involuntary treatment in some cases, as described above. Yet in other cases they may rally behind the person to argue against the proposed order. Sometimes they may simply be concerned onlookers. Depending on these factors and any previous involvement in care planning, carers may seek different types of involvement in tribunal hearings, and service users may have different views about such involvement.

Carers had different experiences regarding participation in hearings. Overall, a number of carers felt that – if they were notified of and able to attend tribunal hearings – tribunals treated them respectfully and sought their views.

"I think there’s an attempt to involve. And I’m quite impressed by the fact that they do ask me what I think. “How do you think S has been on this order?” I mean they ask me that. Her case worker doesn’t ask me that. I see S at least twice a week. Her case worker doesn’t ask me that." 66

Several carers who participated in the study themselves felt unprepared for hearings for a range of reasons. The level of attendance by carers at tribunal hearings is, on average, quite low. Often, carers have not been informed that a hearing will take place. In other cases, they do not understand what a tribunal hearing might involve and so cannot think in advance about how they might meaningfully contribute to the discussion.

"I know many, many instances when the mental health clinicians don’t even really inform the family that there is a hearing or if the family does know, in that they get to hear that there is a hearing, they are not prepared for it, they don’t know how to present." 67

Sometimes carers want to attend a hearing, but cannot get time off work. Scheduling arrangements often prevent people in full-time employment from attending hearings because only a vague morning or afternoon time frame is provided rather than a specific commencement time. Better planning at the outset by tribunal panels, health service staff, and lawyers’ staff to ensure carers are given an opportunity to participate wherever possible is recommended, although this is not always straightforward due to the complexities of fitting individual hearings around the daily and often unpredictable work of mental health services and individual clinicians, as well as patients’ fluctuating needs.

If carers have not been included in care planning until the stage of the hearing, they are often not sure whether they will be heard or taken seriously if given an opportunity to participate in the hearing. Some carers explained that they did not understand how they could contribute to the hearing or that once in the hearing room they could not get the right words out or say it the way it really is at home and so they gave up. A number of carers were also concerned that their loved one did not sufficiently understand the tribunal hearing process and its implications and were not given enough information about what it would involve beforehand in a sensitive fashion. Some felt that legal and other formal advocacy arrangements for service users did not provide adequate support and that they consequently had to perform a pseudo-advocacy role or were, in any case, better advocates for their loved one.

A number of carers came to hearings simply to find out what was happening with a person’s treatment as they felt they had not been kept up to date with important information about care planning. The hearing was often viewed as their only vehicle by which to become better informed and attempt to exert some influence over the quality of care and
services provided to a loved one. Whilst some carers expressed concerns about lack of information about tribunal processes or difficulties participating effectively in such processes, for those who were able to attend hearings, failure to act on carer and service user concerns relating to service delivery raised in the course of hearings was considered a major problem. However, this was generally seen as a problem owing to tribunals’ lack of powers to influence treatment outcomes or more broadly as part of general inadequacies in service systems such that optimal treatments and services were simply unavailable.

The Circumscribed Role of Mental Health Tribunals and Need for Holistic Care Plans

When carers feel unable to secure quality care for a loved one they may resort to mental health tribunal processes as a possible avenue for achieving particular treatment outcomes. However, tribunal processes are not necessarily intended or designed to address concerns about care planning and this can cause tensions for carers – and also service users – who may attend the hearing with these goals in mind. A number of carers questioned why tribunals do not have more power to improve the provision of treatment in individual cases and pave the way for a more holistic care plan, especially where there have been difficulties or disagreements between carers, consumers, and clinicians regarding care planning.

One of my concerns with the tribunals is that they decide whether or not to continue a community treatment order. And a community treatment order basically is giving the person medication whether they want it or not. Very often it’s depot medication, which is a fortnightly injection, because they don’t trust the person to take oral medication . . . But the problem is this community treatment order seems itself to be restricted to medication. And in the modern sense of the word, treatment – if you were looking up best practice for psychiatric treatment – doesn’t confine itself to psychiatric drugs. It’s psycho-social rehabilitation, psychology. I think they see their job as keeping this person out of the hospital . . . Now what the tribunal should be doing, if they decide to allow a community treatment order, is to also make sure this person is the recipient of best practice. They have no power.

For many carers, hearings understandably seem a wasted opportunity to get it right: “Why wouldn’t you look at what a person needs and make an order to ensure they get that, rather than simply saying they’re in or out?” Tribunals are often perceived by themselves and others as powerless to consider consumer and carer concerns about treatment planning. However, even though not all mental health tribunals have express care plan review roles, it is arguable that such a role is implied in mental health legislation and is in any case not precluded, especially given that tribunals are administrative and not judicial decision-makers. The extent to which tribunal panels can and should be active in exploring different treatment planning and recovery options and attempting to influence the course of treatment is a question that has been raised in some reviews of mental health legislation and one that continues to vex tribunals and participants in their processes.

The focus of the hearing is primarily on addressing the criteria of the relevant mental health statute and not necessarily on the issues of most concern for the parties. This can cause frustration and dissatisfaction with the process. However, such negative experiences are accentuated when there is not a clear understanding of the purpose of the hearing or there is a lack of clarity as to why certain issues are not relevant or addressed. In addition, issues of most concern for carers and service users do, in many cases, affect how the statutory criteria should be applied in a given case,
but where there is little time and assistance for those citizens to explain their views clearly during tribunal proceedings, the connection may not be immediately obvious and consequently may not be addressed. Fieldwork observations and interviews conducted by the study provided some understanding of the experiences of both carers and consumers in negotiating their relationships given the sometimes all encompassing element of mental illness or distress, and the way in which these relationships interacted with clinical service provision and were factored into tribunal processes. Legal and ethical dilemmas may arise in cases where there is disagreement between consumers and family members or carers about the best way forward.

**Conflict, Fairness and Communication: Involving Carers Whilst Respecting the Autonomy and Privacy Rights of Consumers**

The family rings up because something terrible is happening at home, but the client doesn’t want Mum or Dad to be involved. The clinician needs information from the family to see if... what they are hearing from their client is actually what is happening. J doesn’t want them to talk. Do they talk, do they not talk? If they talk to the parents do they tell their client that they are going to talk – he is going to be angry ... And then it escalates into this torment in many ways for the clinician because they don’t know quite what to do.71

This quotation illustrates some of the dilemmas faced by health services in deciding the appropriate level of carer involvement in service delivery and care planning, dilemmas which are often carried though to the forum of the tribunal hearing. This section will consider how well tribunal processes deal with and can accommodate conflicting interests and views between carers and consumers.

There is reluctance amongst some carers to attend tribunal hearings because they are concerned about saying things in front of their loved one – such as how difficult they have been at home or how they have been unable to look after themselves – as this may place unnecessary stress on their relationship. They may not want to describe their concerns as doing so would affect the relationship once the person has “returned home”. “A lot of families in order to protect themselves don’t talk in front of the person or they want to protect their relationship.”72 Such concerns sometimes led carers to seek to provide information to tribunal panels on a confidential basis or through clinical reports rather than having to appear before tribunals and explain their views in front of service users. Such practices obviously raise the issue of fairness for service users and their ability to effectively participate in tribunal processes where they may not be made aware of information the tribunal panel will rely on in reaching a decision.

In such situations, it was sometimes clear that the carer’s views had been discussed with the person prior to the hearing, whereas in others it seemed that the person had not been made privy to this information or its depth or were unjustifiably kept in the dark about their carers’ views. Not disclosing such information to service users can seriously limit their ability to participate in and influence the outcome of a hearing. A simple example is where the tribunal has information that a carer does not want a person to return home, but the person is arguing that there is a less restrictive alternative to involuntary detention because they can return home: the person in this scenario has not been given any opportunity to submit a less restrictive alternative for the tribunal’s consideration that they might have been able to arrange if they had known of their carer’s views.

Of concern was the lack of a formalized process for dealing with situations where carers wanted to keep certain information...
or opinions from service users and that information or its source was in fact not disclosed. Mental health laws and the requirements of procedural fairness more generally allow for some flexibility in the extent of information to be conveyed to ensure a ‘fair’ hearing. Some mental health statutes expressly allow disclosure of information to patients to be limited in certain circumstances, such as to prevent harm being caused to patients or others.73

Although tribunals have the option of a pre-hearing conference to determine the question of confidential submissions,74 this process was almost never used in the hearings observed for the present study. It is important that if an application has not been made, tribunals nonetheless engage such processes where appropriate and keep a record of reasons for determinations to ensure future panels looking at the person’s case are properly informed and to ensure accountability in case of appeal.

A related question is whether, as is often maintained, sharing certain information with consumers is really going to be harmful as suggested, or whether more damage to a patient’s wellbeing might not be caused by withholding the information. Consumers are often aware when they are being kept in the dark and may justifiably feel an acute sense of unfairness about discussions between their carers and health services and/or tribunals, which may in turn lead to loss of trust in their relationships with clinicians and people upon whom they must depend for emotional and material support. The potential damage caused by excluding patients from discussions which will inform important decisions about their life is evident, for example, from the experience of one patient who felt ongoing mistrust towards both his parents and clinicians after they had a meeting without him. During the subsequent hearing he could not be certain that information he did not know about had been conveyed to the tribunal and he consequently came to view his parents’ behaviour as somewhat manipulative.75

In a number of hearings observed by the study, when the views of carers and consumers conflicted during hearings, this led to tension or even arguments. Usually this was where carers were close family members or people who were very involved in providing care on a day-to-day basis and considered that compulsory treatment was necessary, contrary to the view of the consumer. This kind of dynamic is one that tribunal panels need to be skilled to manage so as to ensure that appropriate views are heard whilst not letting the situation escalate out of control. Some carers express concerns that conflicts between themselves and a loved one in relation to care planning may be exacerbated in the context of tribunal hearings. It appeared, however, that this difficulty was often connected more to communication and systems failures at the pre-hearing stage, such as inadequate provision of information to carers or clients about what hearings involved or ineffective communication between service users, clients, and carers as part of wider care planning processes.

One carer was critical of the fact that she was not told that information she provided to the ACT tribunal in an application for an involuntary treatment order would be disclosed to her brother.76 In retrospect she understood the reasons why this had to happen, but she explained that if she had known this she would have been more careful in wording her application and prepared for what might follow. In addition, she said that the way in which her application was disclosed to her brother (he received it in the post) was insensitive and likely to upset him more than necessary. She felt that a process where someone sat down with her brother in person and explained what the application meant would have been a less damaging one. This experience raises the broader issue of
improving communication with clients and carers to ensure that information about rights and processes is shared in a way that is sensitive to the complex social dynamics involved.

Tribunal panels dealt with conflicts between clients and carers during hearings in differing ways. Whilst tribunals need to take into account any objections consumers have to their carers attending or participating in hearings, tribunals may need to collect information from a carer in order to make an informed decision, even where carers’ views conflict with those of consumers. This situation requires tribunals to exercise discretion in managing the process to ensure carers’ involvement does not unduly interfere with the privacy rights of consumers. Many carers know a great deal about the condition and treatment of the person and their information will have varying degrees of relevance to the decisions which tribunals have to make. At the same time, in actively engaging carers in hearings processes where appropriate, it is ultimately for the tribunal to determine the relevance of any information provided by carers for the decision at hand. Where carers want to attend a hearing and provide their views to the tribunal, but consumers object to their presence, one option is for carers to attend solely for the purpose of providing their opinion to the tribunal, but be excluded from the rest of the hearing on the basis that clients objected to them hearing other private information.

The possibility of abuse or manipulation of a client by a carer or someone holding themselves out to be a carer, or a carer having ulterior motives which may work against the clients’ wishes and needs, should also be remembered. Similarly, where clinicians feel that carer involvement may be positively harmful for a client, it can be difficult for tribunals to know how best to involve carers or respond to their concerns. Above all, however, the tribunal hearing is a forum which can consider a range of different perspectives, although ultimately a decision may need to be made as to which perspectives are more “truthful” in order to reach the most appropriate decision.

There are different, sometimes conflicting, valid interests between carers and consumers, and the treating team and carers and/or consumers and part of the role of tribunal members is to assess those various interests to ensure the best legal outcome in each case, which includes taking into consideration the relationships of the parties involved. In addition to the tribunal process, there may be a need for additional processes that can address the conflicts that can arise in the course of mental health treatment and planning in different ways – to bring concerns out into the open in a more informal and sensitive, and perhaps more appropriate, environment than the tribunal hearing.

What Enhanced Role Could Carers Play in Tribunal Hearings and Mental Health Governance

Our reflections on how the involvement of carers in mental health governance could be enhanced relate to two interconnected levels as alluded to above: (1) involvement in care planning and decisions about treatment and recovery; and (2) involvement in mental health tribunal hearings.

Mental health services could play a greater role in providing support to carers in terms of their involvement in care and treatment planning, as well as in tribunal hearings. As documented by Johnson, in studies where families have been involved in “family psychoeducation” with the consumer as “co-participant” some of the outcomes that have resulted are reduced relapses for consumers, a decrease in family stress, and greater satisfaction with clinical services. The other benefits of such
education programs facilitated by trained mental health professionals are that they improve communication and problem-solving among carers, consumers, and clinicians. Involving carers early and regularly in care and treatment planning and providing training for them alongside consumers may also result in better representation of the carers’ perspective and set of circumstances at tribunal hearings, as well as generally lead to more productive and inclusive hearings, because consumers, carers, and clinicians will better understand their respective positions and options with respect to any involuntary treatment order proposed and ongoing care planning.

A more comprehensive approach to involving carers in the hearing process is also needed which may require allocating funds to train tribunal staff, health service staff, and carer advocates to provide assistance to carers and develop guidelines about the boundaries of such assistance to ensure that such an approach does not diminish protection of service users’ rights. Although existing carer advocacy bodies may in some cases assist carers in relation to tribunal hearings, there is no one-stop-shop where carers can get information about tribunal processes or assist them to make a meaningful contribution to these processes. Carers must frequently rely on ad hoc information, access and support that may be provided by some mental health clinicians, whose primary duties are owed to consumers.

Ensuring that legitimate carers can present their views at hearings may require the bolstering of independent bodies such as carer advocacy groups so that they are trained, and have the time, to assist carers in relation to tribunal hearings, there is no one-stop-shop where carers can get information about tribunal processes or assist them to make a meaningful contribution to these processes. Carers must frequently rely on ad hoc information, access and support that may be provided by some mental health clinicians, whose primary duties are owed to consumers.

What information and views carers could present at hearings and how to present them, as well as answering phone calls from carers in order to provide such assistance. Carers’ involvement in hearings could be better facilitated by uniformly checking whether a carer has an interest in contributing to the process and seeking their views in appropriate cases, including by sourcing written submissions in advance.

Whilst a cultural shift to better include carers in the hearing process is recommended, ultimately health services and tribunals will need to determine the level of access to, and involvement in, the service delivery context and tribunal processes that carers should have. The appropriate level of involvement, if any, will vary from case to case. Such a cultural shift is, therefore, likely to require the development of protocols and possibly legislative changes to establish the processes whereby the tribunals – potentially in liaison with health services – can establish: who can be considered a “carer” for the purpose of providing information to them and assisting them to participate in hearings in appropriate cases; exactly what information can be provided to them; and any limitations on their involvement in hearing processes.

Coming out of the Australian Research Council comparative research findings, there are two future direction changes for the role of mental health tribunals which could ensure that citizens are better able to participate in mental health governance decisions affecting their lives:

- Mental health tribunals could be more active in both monitoring treatment planning and delivery and/or recommending other processes to address conflicts and concerns that arise at hearing. This could involve tribunals dealing more thoroughly with issues raised
by consumers and carers and the various options for treatment and recovery put forward by them, including greater scrutiny and follow up of the treatment plan and relationships between the parties, and may require more active case management prior to or during the conduct of proceedings.

- More broadly, policy-makers should consider whether discrete processes such as mediation and conferencing, to deal with conflict in the course of care planning as often surfaces in the course of tribunal hearings, should be incorporated into the overall governance of mental health care. Such additional conflict resolution processes could then become one of the options which could be recommended by mental health tribunals to deal with issues that cannot be addressed during hearings.

Such alternative conflict resolution processes, however, should always remain optional and supportive for service users and carers; care would need to be taken in their design and implementation to avoid them becoming an additional coercive or punitive measure used to monitor the progress of service users. Such processes should be aimed at improving communication and problem-solving between service providers, service users, and carers in order to work towards better service and social outcomes.

There have been a number of inquiries and policy statement papers from state and federal Attorneys-General and Law Reform Committees highlighting new directions for the justice system to improve participation in legal processes and access to justice generally. Some of the considerations relate to addressing disadvantage, creating an engaged and unified legal system, enhancing greater participation and validation in legal processes, along with addressing the emotional and social concerns and issues that affect the people involved. Enhancing carers’ participation in mental health governance may be viewed as part of this wider trend towards legal processes that are more accessible for affected citizens and more accommodating of the social relationships in which legal problems are embedded.

**Conclusion**

This article has considered how carers’ rights and responsibilities are factored into mental health governance in relation to the interconnected processes of care planning and mental health tribunal processes and how they may be better addressed in the future, an enquiry consistent with the contemporary policy agenda to enhance citizen participation in legal processes. Carers’ wishes, needs, and varying abilities to provide needed support to service users in the community significantly influence, and are impacted upon by, the mental health governance decisions in question. Where carers are excluded from decision-making processes or engaged in them in a fragmented or careless fashion, there may be a number of negative consequences in terms of both the quality of decision-making and the ongoing social relationships between affected parties.

A sense of being marginalized by the mental health “system” and concern about the inability of under-resourced and disconnected mental health and social services to provide effective care to loved ones were the dominant themes in interviews with carers for the present research. These perspectives superseded specific concerns about mental health tribunal processes, which often came to be viewed as one of very limited opportunities to have some input into decisions affecting their lives as well as those of service users. A number of carers interviewed for the present research,
however, explained that they were ill-informed about tribunal processes and how they might contribute to them, a situation stemming in part from barriers to their involvement in the wider service delivery context.

Our analysis and the views of carers interviewed for this research leads us to conclude that there is a need:

- to better include carers at the service delivery level from the first point of contact with mental health services and on an ongoing basis;
- for health services and mental health tribunals to adopt a more consistent approach which will assist and encourage carer participation in mental health tribunal processes in appropriate cases, which will require development of protocols to clarify the relevant responsibilities and any limitations on them;
- to enhance carer advocacy bodies to enable them to provide independent advice and assistance to carers involved in mental health tribunal processes, as well as in their dealings with mental health and social services; and
- to use a formal, consistent, and transparent approach where there may be withholding of information from service users that mental health tribunals will rely on to make their decisions.

Whilst mental health tribunal processes were generally viewed as a critical part of the ongoing journey of navigating the mental health “system”, hearings were often viewed as a squandered opportunity to resolve pressing issues requiring attention and action. It was felt that such issues – which are likely to involve some level of disagreement between service providers, service users, and carers – are often aired during tribunal hearings, but then remain unresolved. This experience was frustrating for carers as tribunal processes seemingly exacerbated conflict in relationships of care rather than representing a positive step forward in terms of treatment and recovery. These problems appear to be in part due to persistent uncertainty about the boundaries between tribunal and clinical decision-making, and an understandable failure to confront the reality and sometimes uncomfortable implications of the symbiotic nature of the relationship between these two levels of decision-making.

Service users equally experience a range of barriers in terms of accessing relevant information, support, and advocacy to assist them to participate in both tribunal and care planning processes (even though they are the citizens most directly affected by mental health governance decisions), issues which have been addressed in other papers produced as a result of this research. Discussing the concerns of their carers in this context is part of developing a holistic understanding of the cultural, practical, and legal barriers to effective citizen participation in mental health governance with a view to working towards the kind of overall response necessary to remove those barriers. Our final suggestions about possible future directions involve practical, but also cultural, shifts in mental health governance in order to enhance participation and better address the interconnected nature of the legal, practical and social issues and relationships involved:

- existing processes to deal with conflicts between service users, service providers, and carers and address service user and carer concerns about care planning should be examined with a view to possible development of conflict resolution processes specifically designed to meet the needs of mental health service users and their carers to
enhance problem-solving about service and recovery options; and

- mental health tribunals could play an enhanced role in considering and making recommendations about care planning issues relevant to their decision-making – as is already prescribed in some jurisdictions – which could include referral to conflict resolution processes in situations where the tribunal process is not the appropriate forum for dealing with such concerns.

These suggestions are intended to open up much-needed discussion about how to achieve a more holistic response in mental health governance, involving inclusive dialogue between affected citizens and other interested parties, in order to improve outcomes for service users and those within their social networks.

Notes
1. A phrase used by Anne Deveson in her book Tell Me I'm Here, which recounts the journey that she and her family took with her son who was diagnosed with schizophrenia. The ‘odyssey of hope’ is one where a carer is searching for what they think is best for the person who is distressed, disoriented or disconnected. The hope can be for a cure, for protection, for safety, for peace – as well as understanding and support: Anne Deveson, Tell Me I'm Here (Penguin, Ringwood 1998) 101.
2. This is a revised version of a paper presented at Families in Law: Investigation, Intervention and Protection, 29th Annual ANZAPPL Congress, 26–29 November 2009, Fremantle, Western Australia.
5. Carney and others (n 4) 4.
9. This research is a collaboration between the Universities of Sydney and Canberra, funded by an Australian Research Council (ARC) Linkage Grant, with industry partners the Law and Justice Foundation of New South Wales, the New South Wales Mental Health Review Tribunal, the Victorian Mental Health Review Board and the ACT Mental Health Tribunal, comparing the operation of Australian mental health tribunals (ARC study). Both authors are part of the research team. Some of the themes and all of the interviews and observations presented derive from the ARC study. Other ideas and considerations come from each author’s respective doctoral thesis: Beaupert’s thesis entitled ‘Dispensing Justice in a Tablet?: Communication and Participation in the Context of Mental Health Tribunal Processes’ with the University of Sydney and Vernon’s on ‘Mental Health Tribunals and Governance: The Use of Conflict Management and Restorative Processes for Dealing with Mental Health Issues’ with La Trobe University.


14. The New South Wales Consumer Advisory Group is of the view that although consumer rights are paramount, there is a need to acknowledge and support the role of carers because ‘[c]aring for carers ensures better, and longer term, care for consumers’: New South Wales Consumer Advisory Group, ‘Issues Paper: Privacy and Confidentiality’ (1 June 2004), 25.

15. Carers themselves may have specific needs to be met, both for them to provide effective support to service users and to maintain their own physical and mental wellbeing: Sane Australia, ‘SANE Research Bulletin 5: Family Carers and Mental Illness’ (SANE Australia website 2007) <http://www.sane.org/information/research.html> accessed 1 December 2009.


19. Yeates (n 17) 455.

20. Fieldwork conducted for the study included interviews with service users, tribunal members, clinicians, legal and non-legal advocates, and carers in NSW, Victoria, and the ACT, as well as focus or discussion groups with service users, tribunal members, and advocates. Data were also collected through observations of tribunal hearings and the working environment of tribunals and other stakeholders, such as tribunal premises and clinical service contexts, in these jurisdictions. The majority of interviews referred to in this paper are interviews with carers who provide support to a service user who is at the centre of tribunal proceedings, although some of the carers interviewed in NSW had only been involved in Magistrates, rather than tribunal, hearings pursuant to the NSW MHA. In NSW, there is an additional legal review process alongside the mental health tribunal process, which involves initial review of a person’s involuntary treatment by local court Magistrates before regular review by the NSW Mental Health Review Tribunal is initiated. Ten interviews with carers across the jurisdictions of NSW, Victoria, and the ACT were examined in writing this analysis. Those interviewed are numbered chronologically, which is an identification method unique to this paper and does not correspond to the method used for the purposes of other publications coming out of this study.

21. See Alikki Vernon, ‘Fostering Participation in Mental Health Tribunal Hearings: The Use of Restorative Justice Practices’ (unpublished paper, 2009), for a fuller discussion regarding how to consider using other complementary processes alongside the tribunal hearing to deal more effectively with mental health issues more broadly.

22. Henderson (n 8); Froggatt (n 11) 1; Select Committee on Mental Health (n 16) 27–28, 104–07.

23. Froggatt (n 11) 1.

24. Froggatt (n 11) 3.


27. Australian Health Ministers (n 7) 23–24.


32. One example is the NSW model for service delivery to carers of people with mental illnesses, known as the Family and Carer Mental Health Program and funded by the Centre for Mental Health since July 2006, which provides funding to the Area Health Services to provide carer-friendly mental health services and also to a number of organizations to provide statewide carer education and support services.


34. NSW Health (n 33).

35. It was considered that the previous provisions relating to entitlements for different support people to be notified of events – variously including “nearest relatives”, nominated relatives and friends at different times – were inconsistent and confusing: NSW Health (n 33) 11.

36. However, for a person under guardianship their guardian, and for children whose parents, are their primary carers: NSW MHA s 71(1)(a)–(c).

37. NSW MHA ss 71–79.

38. Vic MHA, s 3.

39. See eg Vic MHA s 19A, requiring consultation with guardians, family members, and primary carers involved in providing care and support to the person about treatment plans.

40. See eg Vic MHA s 73, requiring clinicians to make reasonable attempts to notify primary carers of the proposed performance of electroconvulsive therapy.

41. Vic MHA s 120A(3)(ca).


43. HRPA Act, Sch 1, Principle 10(2)(d).

45. Mental health tribunals have additional functions in some jurisdictions. For a comparison of community treatment order (CTO) or compulsory outpatient treatment regimes in different Australian and overseas jurisdictions, see Michael Dawson, *Community Treatment Orders: International Comparisons* (Otago University Print, Dunedin 2005).

46. For a discussion of the composition of tribunal panels in different jurisdictions and the possible human rights implications of downsizing from three-member to one-member panels in some situations, as has recently happened or been contemplated in some jurisdictions, see Carney and Beaupert (n 27).

47. See, John Lesser, ‘All Care and Whose Responsibility?’ (2004) 11 Psychiatry, Psychology and Law 236, 239–241, regarding the lack of any obligation for the Victorian Mental Health Review Board to provide information about its clients to carers, as well as legal and practical limitations on the Board’s ability to involve carers appropriately in hearings.

48. In Victoria, the executive officer may give notice of a Mental Health Review Board hearing to “any other person” – which would include a carer – as the Board directs: Vic MHA s 32. However, in practice such notification would often be given by health service staff involved in hearing administration or carers may find out by being told directly by consumers or their treating team if actively involved in care planning.


50. This trend was, on average, more apparent in Victoria and the ACT than NSW where a greater range of health worker perspectives – such as the social worker perspective – were more frequently presented in hearings observed for the present study and according to data collected from paper files of the tribunals.


52. Carer 1 (NSW, 2006).

53. See also, Select Committee on Mental Health (n 15) 99–100.


55. Select Committee on Mental Health (n 16) 27.

56. Carer 8 (Victoria, 2008).

57. Deveson (n 1) 1.

58. Carer 5 (n 54).

59. Carer 9 (Victoria, 2008).

60. NSW Health (n 33).

61. Mihalopoulos and others write: “Many health professionals still exclude family carers from treatment planning, and withhold information, in appropriately citing confidentiality” (n 11) 513. Carers appear to have a range of unmet needs relating to access to respite and home care services, to counselling and debriefing and to general support in their caring roles: NSW Health (n 33) 14.

62. Carer 9 (n 59).

63. See Froggatt (n 11) 8.

64. Carer 9 (n 59).

65. Carer 9 (n 59).

66. Carer 3 (ACT, 2006).

67. Carer 9 (n 59).

68. Carer 8 (n 56).

69. Carer 1 (n 52).


71. Carer 9 (n 59).

72. Carer 8 (n 56).

73. See MHA NSW s 156, providing for a person to have access to their medical records subject to any order of the tribunal, and providing for a medical representative of the person to have regard to any warning of a medical practitioner that it may be harmful to communicate this information; the Vic MHA s 26(7)(8) enumerates in more detail circumstances when the Board may limit a person’s access to their files. The Victorian and ACT mental health
statutes expressly provide that the relevant tribunal is bound by the rules of natural justice: MHA Vic s 24(1)(b); MHA ACT s 96.

74. See NSW MHA s 156; Vic MHA s 26(8).

75. Consumer 12 (NSW, August 2007)

76. Carer 5 (n 54).


78. See Lesser (n 47) 240–43, discussing some of the legal and practical dilemmas in this regard, and specifically considering whether mental health tribunals should have a similar obligation to clinicians to provide information about service users (such as whether they are subject to an involuntary treatment order) directly to carers where required for a carer to fulfil their caring role. Our recommendation relates more narrowly to health services and tribunals providing general information and assistance to carers about the hearing process and how to participate in it.


80. Carney, Tait and Beaupert (n 26).