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Participation and Partnership:

The development of a social work model of service delivery

for consumers and carers living with schizophrenia

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ABSTRACT

The primary intention of the research reported in this thesis was to develop a model of social work service delivery within one mental health service, Lantana Integrated Mental Health Service (LIMHS), that would prioritise the development of participation and partnerships in service delivery, planning and evaluation for consumers diagnosed with schizophrenia and their carers as stipulated under Standard 3 of the *National Standards for Mental Health Services (1996)*. In order to undertake this task, ethnographic case study research was employed which incorporated focus group discussions and individual semi-structured interviews. The intent was that any proposed model, arising from the research would be capable of operationalisation within the existing structure of LIMHS. Research participants consisted of three members of management, a community development worker, twelve social workers, fourteen consumers and fourteen carers either working or receiving services at LIMHS.

The findings of this study indicate that LIMHS experiences many constraints to implementing participation and partnership policy expectations. The primary themes which emerged from the consumers' and carers' discourses were about their powerlessness in relation to psychiatry and bureaucracy, and the importance of mental health professionals, including psychiatrists, to help them address their social, emotional and material needs rather than continue a strict focus on bio-medical issues and solutions. This research uncovered a more respectful stance towards social work as demonstrated by consumers and carers than the respect social workers afford themselves. Using structuration theory (Giddens, 1984) this study found that social workers position themselves precariously between an overt demonstration of collusion with psychiatry in the workplace and a more covert alliance with their own codes and methods of practice in the intimate shared space of consumer and carer engagement.

This study found many anomalies and tensions within a third way (Giddens, 1998) politics when applied to the field of mental health. The findings of this case study suggest that consumers and carers are exposed to legal, medical and social structures, and third way policies which fail them. These conclusions have implications for socially just social work practice. This thesis culminates in the presentation of a proposed model of social work practice at LIMHS.

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ABBREVIATIONS

AASW	Australian Association of Social Workers
AHMAC	Australian Health Ministers Advisory Committee
AMHAC	Australian Mental Health Advisory Council
CAG	Consumer Advisory Group
GPs	General Practitioners
LCAG	Lantana Consumer Advisory Group
LIMHS	Lantana Integrated Mental Health Service
MHPs	Mental Health Professionals
MHS	Mental Health Service
NCAG	National Consumer Advisory Group
NHMRC	National Health and Medical Research Council
NSMHS	National Standards for Mental Health Services

KEY CONCEPTS OF THE STUDY

This section clarifies the overarching philosophical distinctions that underlie some commonly used terms of this study. Commonly used terms are often weighed with different meanings for different people. The interpretation of these concepts is a reflection of my experience and philosophical orientation. The definitions borrowed from other authors are identified and referenced accordingly.

Binary	a distinction that is black and white so that things are thought of as only one way or the other.
Biopower	has two poles or components. First is the pole of scientific categories of human beings (i.e., species, population, race, gender). This pole is tied to the practice of confession. The second pole is disciplinary power. Danaher, Schirato & Webb, 2000).
Carer	any person who is involved with unpaid caring for a person diagnosed with schizophrenia.
Carer's framework	the way that a carer of a person with mental illness would like to be treated by mental health professionals.
Caring	any duty carried out by a carer which contributes to the overall well-being of a person diagnosed with schizophrenia.
Consumer	any male or female 18 years and over who has been diagnosed with schizophrenia and who does not manage their life without assistance from others. Throughout this research, people with schizophrenia have been referred to as consumers. The term consumer however, is now common to all stakeholders in mental health services, including consumers and carers.
Consumer's framework	the way that consumers would like to be treated by mental health professionals.
Disciplinary power	a form of surveillance that is internalised. With disciplinary power, each person disciplines him- or herself. The basic goal of disciplinary power is to produce a person who is docile (Dreyfus & Rabinow, 1982, p.13).
Disciplinary technologies	techniques for producing docile people who may be subjected, used, transformed and improved (Dreyfus & Rabinow, 1982, p.135).
Discursive formation	roles within a particular field that precede the people who now occupy the roles Foucault (1972).
Empowerment	a process through which people become more able to influence those people and organisations that affect their lives (Meagher, 1995, p. 20).
Governmentality	a centralisation and increase in government power. This power is not negative. In fact, it produces reality through 'rituals of truth' (Dean, 1999).

Mainstreaming	The management of people who are seriously mentally ill, under the same organisational arrangements as those applied to general health services (*Australian Health Ministers,* 1993).
Panopticon	a method of surveillance used in modern prisons. It involves the observation of those incarcerated at all times in order to coerce obedience to a dominant order (Bentham, 1995).
Partnership	is multiple people as groups or individuals associating in a common endeavour, moving forward together through the process of learning about each others skills, knowledge, strengths and abilities in mutual growth (Meagher, 1995, p. 20).
Role	the part played by persons attending to myriad duties required of them through formal or informal processes and/or structures of organisation.
The Medical Model	a general term describing the power of the medical profession in terms of its control over its own work, the work of other mental health workers, mental health resource allocation, mental health policy, and the ways that psychiatric hospitals and community mental health services operate. This term is commonly used instead of the more descriptive term, medical dominance (Germov, 2000).
Technologies of the self	specific practices by which people identify themselves within and through systems of power, and which often seem to be either 'natural' or imposed from above (Danaher, Shirato, Webb, 2000).
Tokenism	processes whereby a dominant group promotes a few members of an oppressed group to high positions and then uses them to claim there are no barriers preventing any member of that group reaching a position of power and status. The people promoted are 'tokens', and the process of their engagement is 'tokenism' (Bishop, 2002).
Transdiscursive	a paradigm reclaimed from the past and represented as new and progressive (Foucault (1977b).

CHAPTER ONE
Introduction

People with schizophrenia, their carers, and social workers in Australian mental health services often face disempowering organisations. The current push for the genericism of all disciplines within mental health services has severe ethical implications for social workers practising in this domain. Opportunities for social workers to pursue principles of social justice have been seriously eroded through incremental changes brought about by neo-liberal mental health reforms and the subsequent revamp of the mental health workforce. People with schizophrenia and their families are increasingly forced to take responsibility for their own care and treatment. Social work is one of several professions engaged to implement these government policies. Many social workers are aware of this dilemma; however, with the genericism of mental health professions, there is a danger that social workers are allowing themselves to be co-opted into a role of social control. Social workers have long been aware of the dilemmas of care and control and their position as employees of the state which itself can privilege control over care and social justice.

The discourse of recent mental health policy has framed consumers and carers as no longer willing to be submissive beneficiaries of services designed for them by MHPs (*National Standards for Mental Health Services,* 1996). Further, this discourse claims that consumers and carers want to be partners in the decision-making about problems that personally affect them. This suggests that consumers and carers are not only to be involved in the designing, managing and evaluation of mental health care services but that they wish to do so. These current policies imply that government has suddenly recognised the importance and value of the contribution of the consumer and carer view. At best, this may be a progressive policy change that has been long overdue. At worst, government is abrogating responsibility for decisions about rationing mental health resources, and the use of expensive pharmacology, by implicating consumers and carers themselves in these decisions as partners with government .

Focusing social work research on people with schizophrenia and the people, who care for them, adheres to the social work mission of working with the most vulnerable members of society (Burdekin, 1993; Crocker, 1990). People with schizophrenia and people experiencing mental ill health in general have been at the centre of numerous public inquiries into abusive practices by mental health professionals (MHPs) and the organisations that employ them (see Burdekin Inquiry, 1993; Chelmsford Inquiry

1988-1990; Inquiry into Ward 10b, Carter, 1991). Subsequent changes in policy direction (e.g., institutionalisation to deinstitutionalisation and community care) have so far failed to improve their circumstances. The promises of health ministers (Whiteford, 1999; Wooldridge, 1999) and directives from current policies (*First National Mental Health Report,* 1993; *National Standards for Mental Health Services*, 1996; *Second National Mental Health Plan*, 1998) towards partnership and participation indicate a sea change. Under these policies, people experiencing mental ill health are to engage with the planning, delivery and evaluation of the services that intimately involve them.

The importance of the case to unravel whether or not practices of participation and partnership will contribute to improving the circumstances of people experiencing mental ill health, including a reversal of abusive practices between mentally ill people and their carers, and those who purport to serve them. This thesis, examines the potential for participation and partnership practices to contribute to the development of a social work model of service delivery intent on improving the lives of consumers and carers living with schizophrenia. It also unearths the effects of the genericism of the mental health professions on social work and mental health social workers, and how genericism influences social work practise with consumers and carers.

Research aim and questions

This study had one major aim. This was to develop and articulate a model of social work service delivery within one mental health service, Lantana Integrated Mental Health Service (LIMHS), which would prioritise participation and partnerships between LIMHS and consumers diagnosed with schizophrenia and their carers. Three research questions were used to inform the development of this model. These were:

1. what is the policy environment of the mental health service, Lantana, which either invites or constrains participation and partnership building between this mental health service and consumers and carers?

2. how is social work structured into and/or out of Lantana mental health service and how do social workers provide a social work service?

3. to what extent do people diagnosed with schizophrenia and their carers, perceive mental health services in Lantana to be involving them in meeting their needs?

The remainder of this introductory chapter outlines the context of consumers and carers living with schizophrenia in their interaction with large, bureaucratic mental health services and explores past and current policies that impact on this group. The personal location of the researcher is described and the chapter concludes with an outline of the research methodology which guided this study.

It is noted from the outset, that consumer and carer needs and experiences in the context of living with schizophrenia are both similar and different (Onyett, 2003). It is not my intent to gloss over this. However, from a mental health service perspective, carers are also consumers and are therefore confronted with most of the issues explored in this research simultaneously. Consumers and carers are both recognised as consumers of mental health services and have a right to participate in all aspects of mental health planning, service delivery and evaluation.

Myths, stigma and the media

Over the past 44 years, since attention was initially drawn to the negative effects of having a psychiatric consumer identity (Goffman, 1961; Scheff, 1966), numerous studies have addressed public attitudes towards people experiencing mental ill health. These studies emphasise the difficulties faced by current and former consumers (Bord, 1970; D'Arcy & Brockman, 1961; Farina & Ring, 1965; Lamy, 1966; Nunnally, 1961; Taylor, Dear & Hall, 1979; Trute & Loewen, 1978; Whatley, 1959). The myths, misunderstandings, negative stereotypes and attitudes that surround schizophrenia often result in stigmatisation, isolation and discrimination directed at the sufferers and the people who care for them (Clayer, McFarlane, Czechowicz, & Wright, 1991). In the UK, Nieradzik and Cochrane (1985) presented evidence in their study on public attitudes towards mental illness, that the general public are substantially more rejecting of psychiatrically diagnosed people than accepting, and that such social rejection increases the diagnosed person's disturbed behaviour.

Reports from the United Kingdom (Crocker, 1990) and Australia (Burdekin, 1993) inform us that people experiencing mental ill health are the most stigmatised group of people in society. In the United States, Lopez (1991) found that 87 per cent of a community's attitudes and beliefs were gained from newspapers. He went on to say that "the stigma attached to mental illness ... persists insidiously in everyday language ... and comes from false beliefs that stem from a lack of understanding" (p.

272). The destructive nature of stigma affects both the sufferer and those who encounter such stigma.

Research into social distance reactions or the extent to which social interactions are acceptable, suggest that although better informed, the public's attitudes and beliefs about people experiencing mental ill health has undergone little change since the days of institutionalisation (Lopez, 1991; Williams & Taylor, 1995). Goldman, Adams and Taube (1983) and Sherman, Newman and Frenkel (1984) suggested that community acceptance is vital to the successful placement of people experiencing mental ill health in the community.

The word schizophrenia has been hijacked and abused by the media (Buckland, 2005), and often depicts people with this disorder as dangerously violent. This contributes to a misunderstanding about the behaviour exhibited by people with this disorder (Crocker, 1990; Lopez, 1991; Williams & Taylor, 1995). This form of abuse by the media has become a major barrier to better community acceptance (Buckland, 2005; Burdekin, 1993; Crocker, 1990). An Australian Mental Health Advisory Council (AMHAC; McGrath, 2000) study demonstrated that 18 per cent of 980 people with schizophrenia, who participated in their research, were victims of violence and were more likely to be victims of violence than to victimise other people (Jablensky et al., 1999). McGrath (2000) also pointed out the inadequacies of a mental health system where those who need treatment and supervision for their own and others' safety are neglected, denied hospitalisation and/or received inadequate follow-up after discharge.

In the UK, Philo (1996) described the role media played in influencing negative public perceptions of people suffering schizophrenia. *Me, Myself and Irene* is an American movie about people who present as different personalities existing within one body. This type of movie reinforces a popular misconception of schizophrenia by conflating multiple personality disorder with schizophrenia. In Australia, McGrath's (2000) critique of this movie focused on its repugnance and insensitivity towards people with mental illness. In McGrath's (2000) opinion, the film destroyed years of intense education of the community regarding the realities of schizophrenia.

Similar to Philo (1996) and McGrath (2000), a study by Williams and Taylor (1995) demonstrated the existence of a remarkably negative and stereotypical attitude toward people experiencing mental ill health, in the Australian. The media's

unchallenged portrayal of people experiencing mental ill health perpetuates this myth (Crocker, 1990; Williams & Taylor, 1995).

The myths propagated about the inherent violence of people experiencing mental ill health, is not only prevalent in the mass media and through community attitudes, it can be spread by actions of mental health services themselves. For example, a memorandum from Dr. Robert Stable (personal communication October 10, 2002) the Federal Director General of Health in 2002, regarding the execution style shooting of the Director of Mental Health Services in South Australia, stated that she was "shot presumably by a mental health client" (p. 1). This memorandum went on to say "Queensland health staff working in mental health services need to be vigilant of a possible increased risk to themselves once this tragedy is reported in the media" (p. 1). This memo was sent through the e-mail system to individual state managers, to regional district managers, to individual team leaders who then sent it to all mental health staff around Australia. Six weeks later, it emerged that the person charged for this appalling murder was a former senior psychiatrist with an 'axe-to-grind' (The Advertiser, 2002, p. 1). Furthermore, no 'copycat' type activity by psychiatric consumers towards mental health staff occurred after the media report. This prejudicial statement by the Minister was made worse by the failure of senior managers and subsequently team leaders, to ameliorate the official statement before sending on an amended version to staff.

The abuse of carers and families

It is not only people diagnosed with mental illness who experience discrimination and stigma. Rejection of people with mental illness inevitably spills over to carer and family members (Freeman & Simmons, 1961; Segal, Baumohi & Moyies, 1980), including the pain and social stigma of deinstitutionalisation (Bland, 1986; 1987). The blame theories of the 1960s which invoke family dysfunction to explain schizophrenia, both initiate and perpetuate this stigma (Jacobs, Crichton & Visotina, 1989; Lidz, 1973; Twigg & Atkin, 1994). Bland (1987) perceived this blame as leading to ongoing difficulties for families living with schizophrenia including feelings of guilt.

From the 1950's there was mounting interest on the impact of the environment in the aetiology of psychiatric disorders. The family as an element of environment, and through family therapy, was regarded as a primary domain for maintenance and management of schizophrenia (Jacobs et al., 1989). In the opinion of Lidz (1973) service providers blaming parents for their offspring's illness fail to recognise that parents do not intentionally impose schizophrenia on their offspring. This blaming

outlook prevails despite increasing evidence that recognises biochemical and, in some instances, genetic factors as fundamental to the aetiology of schizophrenia (Taylor, 1987; Torrey, 1983).

This pattern of familial blame continues today, with studies on highly expressed emotion. These studies focus on three aspects of family interaction:

(i)   criticism of offspring;

(ii)   hostility toward offspring; and

(iii)   over involvement with offspring (Rosenhan & Seligman, 1989).

The concept of highly expressed emotion assumes importance given that males with chronic schizophrenia returning to live with their families after hospitalisation are more prone to relapse than their counterparts who return to community facilities, or live with more distant relatives (Falloon, Boyd & McGill, 1982; Gamble & Mildence, 1994). This approach, while not necessarily regarding the family as a source of illness, does view the conduct of family members as implicated in psychotic relapse. Methodological problems and resistance to contemplating anything other than parental blame are cited as major criticisms of studies on highly expressed emotion (Torrey, 1983). Further, all of these studies looked at emotional connection after a person had been diagnosed and incarcerated (Kanter, Lamb & Loeper, 1987).

Criticism was heavily directed at the mother in emergent family systems theory, which depicted psychotic symptoms as a consequence of double-bind communication or an inappropriate enmeshment on the part of the mother (Rosenhan & Seligman, 1989; Wedenoja, 1991). A classic paper outlining this phenomenon, entitled, *Toward a Theory of Schizophrenia,* made a distinction between situations where it was possible for family members to clearly choose one course of action over another, and situations where choice appeared to be offered, but in reality either choice would lead to the same end thus negating real choice (Bateson, Jackson & Haley, 1956). This distortion of the young person's reality influenced family therapy in the psychoanalytic model (Jacobs et al., 1989), through a focus on helping families, especially families living with schizophrenia, overcome double-bind communication.

Prior to this, Freud and his followers studied interactions between children and their parents. With no apparent regard for their feelings, culpability for psychological disturbance was attributed to the parents, particularly the mother (Jacobs et al., 1989). Feminists considered Freud's view of women as mercurial creatures with a deficient sense of moral standards, as downright misogynistic (Elson, 1992). Another

early psychoanalytic theory that gained recognition, despite a lack of empirical evidence to support it (Jacobs et al., 1989), was that of Fromm-Reichman (1948). He believed that a mother who was either indifferent and uncaring towards her child/ren, or over involved, fostered the emergence of schizophrenia in her offspring. He even applied the term "schizophrogenic mother" to these women. As knowledge developed about schizophrenia, new theories surfaced to explain this phenomenon and older theories that no longer fit have been set aside and eventually discarded.

Unfortunately, censuring the mother for her offspring's schizophrenia persists among some Mental Health Providers (MHPs; Burdekin, 1993; Twigg & Atkin, 1994). It may be due to MHPs early training or rigidity towards change in the mental health sector. Whatever the reason for this censure of mothers, blame and an inability to support them, results in multiple problems for families living with schizophrenia (Carey & Leggat, 1985; Lidz, 1973). These problems in turn affect the way carers are perceived (Twigg & Atkin, 1994).

As a result of blame theories, Wedenoja (1991) believed generations of mothers who have experienced their offsprings' distress and anguish caused by sudden and unexplained persistent psychotic disorders have been held responsible for those disorders and scorned by MHPs, other relatives and the community at large rather than being recognised for the significant role they undertake on behalf of the community to care for community members diagnosed with mental illness. Twigg and Atkin (1994) urged an empathic stance be taken in relation to these carers and stressed the importance of MHPs to partner with carers through their own (carers') framework. They felt this framework would help MHPs concentrate on carers' needs and roles as vital members of a helping mental health network.

Suicide and schizophrenia

People with serious mental disorders are at a higher risk of suicide than people without mental disorders. Fifty per cent of people with schizophrenia attempt suicide and 10 to 15 per cent are successful (Kaplan & Sadock, 1998). A study from the United States by Cohen, Test and Brown (1990) reported that young men with early onset schizophrenia are at highest risk of suicide, particularly those with immediate signs of profound distress, feelings of despondency, isolation and dissatisfaction with life. Bartels, Drake and McHugo (1992) also emphasised depression and high alcohol consumption as predictive of suicidal behaviour in people diagnosed with schizophrenia. Likewise, Kosky and Goldney (1994) reported "studies that

demonstrate convincingly that at least 90 per cent of those who commit suicide have evidence of a psychiatric illness before their death" (p. 186). They further pointed out that people with severe psychiatric illness commonly have their onset during teenage years, with the majority of suicides occurring in the first few years after the onset of the illness. These studies suggest that the most effective way to suicide prevention may be the provision of specialised mental health services to address the underlying vulnerability of young people to psychiatric disorder.

Both Australia and New Zealand show significant increases in youth suicide (World Health Statistics Annual Report, 1983-93). Queensland has the highest rate of youth suicide in Australia, at 34 per 100,000 (non-Indigenous) and 70 per 100,000 (Indigenous), increasing by 150 per cent over the last three decades and continuing to rise. Indigenous suicide rates of males aged 15 to 29 in Queensland are nearly 4 times higher than their non-Indigenous peers and this largely reflects patterns of male alcohol associated behaviours embedded in a context of widespread and tenacious social disadvantage (Hunter, 1993). In 2006, during a sentinel review following the death by hanging of an Indigenous 16 year old female, Professor Ernest Hunter (Cairns Post, April, 2006, p. 3) claimed that a high rate of self-harm and completed suicide of Indigenous youth on Cape York endures, with many of these youth younger than the female under review.

One third of young men under 25 diagnosed with schizophrenia attempted suicide during 1992-93, and 1 attempt in 10 was successful (Commonwealth Department of Human Services and Health, 1995). Australian Health Ministers (AHM) targeted the growing incidence of these deaths in 1992. Their objective was a reduction in the suicide rate of people with schizophrenia by 25 per cent over 10 years (AHM, 1993).

An analysis of urban and rural differences by the Commonwealth Department of Human Services and Health (1995) indicates that suicide rates are generally lower in major cities and tend to increase in more isolated, rural areas. Brian Burdekin (1993) had previously acknowledged the link between rural disadvantage, including lack of service provision, and suicidal behaviour.

In June 1995, a voluntary group, which included representatives from Lifeline Australia, was convened in response to the appalling frequency of youth suicide in Queensland including the fact that from 1992 Cape York and the Torres Strait region had the highest youth suicide mortality rate in Queensland (Duplock, 1996). . Under the name of the Far North Queensland Taskforce for the Prevention of Youth Suicide

the group received funding from Queensland Health for a six-month project. A report based on community consultation and released during October 1996, stated: "while the region is not without services, it must be stressed that existing services are working to capacity and beyond. The need for human services is far greater than existing agencies, workers and funding levels can meet" (Duplock, 1996, p.8). If studies like those of Cohen, Test and Brown (1990), which showed a high relationship between suicide and schizophrenia are generalisable to the Australian context, then lack of service provision in mental health services (including suicide prevention) has a specific and unique (detrimental) impact on those who suffer with schizophrenia compared to those who do not.

The First National Mental Health Report (AHM, 1993) target of a 25 per cent reduction in suicide rates by people with schizophrenia over a 10 year period appears to have been unsuccessful. A report by Pezzullo (2002), released during August 2002, showed a disturbing increase in suicide by people with schizophrenia. The report found that "84 per cent of Australians with schizophrenia who died during 2001 took their own lives" (p. 1). It also stated that "over the past 40 years the rate of suicide has increased by 400 per cent [and] people with schizophrenia are now 12 times more likely to die by suicide than the general population" (p. 6). Professor Carr, a psychiatrist at the University of Newcastle and a key contributor to the report, stated, "early diagnosis and ongoing treatment and support in the community are the keys to reducing the suicide rate and the cost of the illness. We are lagging way behind other comparable Western countries ... Australia spends only 6 per cent [of its health budget] on mental health, whereas countries like Canada, the United Kingdom and New Zealand spend around 10 to 12 per cent."

The dominant view of suicide is that it is a symptom of mental illness (Smith, 1998). This view results in alienating and pathologising people who suicide and decontextualises their subjective experience. This propensity to pathologise suicide, rather than view it as a social problem, is detrimental to reducing suicide statistics.

An alternate view to suicide as a pathology, is that of Foucault (1978) who considered suicide as empowering; an act of defiance against total domination (biopower). Foucault (1978) implied that there was a measured proportionality between the 'power' of death and the 'power' of biopower. As the power over one's body increases through an outside factor, the power of death also increases. Indeed, Foucault (1988) stated that absolute "power can only be exercised over another to the extent that the other still has the possibility of committing suicide" (p. 12).

Foucault (1984) therefore reminds society that suicide may be a form of resistance to the power some exercise over the life and body of others including mental health practices of forced treatment and incarceration.

<center>Caring for people with schizophrenia</center>

Since human service organisations have shifted their emphasis from institutions to the community, caring for people with severe mental illness has fallen heavily on families. Manthorpe (1994) highlighted the lack of research on this topic outside of that care to do with dementia and the aged. Nonetheless, research literature about carers and the caring experience, offers various ways of classifying carers (Manthorpe, 1994; Perring et al., 1990). Carers can be classified by personal attributes (e.g., age, gender) or by their relationship to the person cared for (e.g., parent, daughter, spouse, sibling). An alternative is to use the diagnosis of the person being cared for (e.g., dementia, physical disability). For the purposes of this study two variables were used; relationship and diagnosis.

Three basic elements permeated the literature on caring. One was that caring was burdensome (Lloyd & King, 2003). A focus on the nature and difficulty of duties performed was exemplified in studies by Fadden, Bebbington and Kuipers (1987), and Winefield and Harvey (1993). A second element was the kinship obligation, focusing on relationships between the carer and the cared-for, illustrated in the works of Finch (1989), and Qureshi and Walker (1989). A third approach was to view caring as a responsibility, focusing on the supervision of recurrent crises. This approach was elaborated in the works of Perring et al. (1992) and was especially prominent in mental health literature (Twigg and Atkin, 1994). It was these last two theoretical constructs, kinship obligation and responsibility during crisis, which seemed most appropriate to this study.

American research on care-giving across a variety of relationships and conditions was undertaken by Twigg and Atkin (1994). They recognised that carers have become the focus of government policy directives and this has brought about a shift, in the last fifteen years, from the rhetoric of community care, to that of strengthening and supporting carers (or carer care). An emphasis is placed on identifying breakdowns in caring networks and filling the gaps with appropriate social services. Women are perceived by government as part of the social services. By supporting the caring work of families, the government claims this work as its own. This is a hallmark of Giddens (1998) "Third Way"; that government is not separate from the

people, but directly performed through myriad persons. In this sense, government is not a noun, but an adjective. This active view of government where each member of society is part of government through the acts it engages each with the other is a revitalisation of community which allows government to claim the work of carers as its own. In this relationship, though, government (formal) has responsibility towards this energising and reinvigoration of society.

It is in this sense that Twigg and Atkin (1994) discussed an increase in the profile of carers' about whom governments (formal, institutionalised) show genuine concern and to whom rights to service provision are extended. This is a tenuous relationship between government and carers, however, since there is lack of precision about the amount and type of provision that can accrue to carers through government (formal). What was clear to Twigg and Atkin (1994) was that carers would continue to provide the majority of care, but "... how they were perceived by service providers would continue to determine the level and pattern of help they will receive in doing so" (p. 156). This was explicated through the work of Pilgrim (1992) and Chapman and Goodwin (1992). These authors suggested that the family is still viewed by policy formulators as primarily responsible for its members, outside of any Giddensian notion of family as a site of government. Any innovations in caring and how this is constructed still remains the discretion of service provision at a local level. Since a gendered division of labour exists within Australian households (though this is not quite as clear cut as 15 years ago), the carer more often than not is a woman (Chapman & Goodwin, 1992; Pilgrim, 1992). Service providers at local levels are likely to construct community caring as more possible when there are women available to undertake this caring work.

The Australian Mental Health Advisory Council (AMHAC, 2000) reported that individual carers contribute approximately 104 hours per week to a family member with a mental illness. Not only is there a cost of time in caring, but carers are also "financially burdened; bearing one third of all financial costs associated with (mental) illness" (Pezzullo, 2002, p. 1).

Besides these physical burdens, the onset of chronic illness confronts the carer with variations in the cared for person's personality and behaviour:

> There is always the sense of loss, almost like a death. Schizophrenia cuts down young people just as they are realising their potential and the person left often seems a pale shadow of the person they were before. There is a grieving that needs to be done for this lost person, a grieving that will help the carer adjust to the new person the sufferer has become (Berry, 1997, p. 26).

Hockley (1985) viewed the grieving process as lifelong. This is due to constant change, with regression producing intense feelings of loss and sadness. Loss is constantly renewed and grief reworked. This non-finite grief continues for the duration of the cared-for's life. The carer becomes increasingly aware that the person will not return to the person they knew before the onset of the illness. This often means carers needing to give up the hopes and dreams they previously held for the person and for themselves.

Fadden, Bebbington and Kuipers (1987) estimated that between 50 and 70 per cent of families experience significant levels of distress as a result of their caring for a psychiatrically diagnosed member. Families report that interactions with MHPs make them feel guilty, frustrated and helpless (Bernheim & Switalski, 1988). Schodel's (1994) study showed that carers were left out of the decision-making process with regard to their offspring. Sometimes they were not given feedback on the treatment regimen or the general welfare of their adult children with schizophrenia. This resulted in carers being unable to care or communicate with their offspring, which led to increased feelings of distress. Lloyd and King (2003) believed that carers often see MHPs hiding behind "confidentiality", to justify not including them with their offspring or cared-for in service planning processes.

In Lantana during September 2004, after the data for the research reported in this study had been collected, a strategic review (Seymour, 2004) of LIMHS was released. It found the extent to which carers were not involved or informed of decisions about the care of consumers, was a major source of concern. Seymour (2004) considered that the majority of MHPs acknowledged the value of involving carers, however, this had not translated into practice. From the MHPs point of view the issues of 'confidentiality' and maintaining the consumers' right to privacy were raised. Alternatively, the families and carers reported that they were ignored and undervalued by MHPs. They were not listened to and not offered advice on how they were to assist or support the cared-for when they were discharged from hospital.

Despite this lack of engagement by mental health services, Winefield and Harvey (1993) remind us that the immediate family of people with chronic schizophrenia, suffer psychological distress and interference in daily life from the burden of caring. This was especially so for those caring for females with schizophrenia. The Burdekin Report (1993) also focused explicitly on the plight of females, particularly their vulnerability to rape and abuse, not only in the community but also in hospitals. Burdekin (1993) requested immediate action, not only for the women, but also their

families in these circumstances. The carriage of his words conveyed recognition of the anguish and helplessness that carers and families suffer when unable to protect their offspring.

In the last fifteen years, the theoretical shift away from psychoanalysis has seen a growth in psycho-educational programmes designed to offer support to carers (Alexander, 1991; Bland, 1986; Hatfield & Lefley, 1987). Psycho-educational programmes teach carers about the nature of schizophrenia and medications used in its treatment. It also teaches practical coping skills in communication and problem-solving and provides some recognition of the caring role. The growth in psycho-education programmes corresponds with government promotion of partnerships and participation. While psycho-education is undoubtedly the better option, it can also be viewed as training carers to cope with their ongoing unpaid responsibility towards the cared-for (Bentley, 2002), and developing knowledge and skills that carers require in an environment of increased psycho-pharmacological solutions.

Indigenous ways of caring

It is the opinion of Pargiter (1991) that psychiatry was practised in Australia before European settlement. The holistic way of viewing mental illness and caring with cultural beliefs, was part of Indigenous Australian society. Indigenous ways of understanding mental health and mental illness revolved around their association with the land and was regulated by sophisticated and diverse beliefs. Rowley (1972) and Willis (1983), Australian historians, documented stories of Indigenous women, using products of the land to assist European women with their caring duties.

Burdekin (1993) highlighted the need for cultural sensitivity when diagnosing psychiatric disorders. This is due to the holistic way in which Indigenous carers view mental illness and the possible meaninglessness of European diagnoses. Furthermore Burdekin (1993) emphasised the detrimental effects of psychiatric labelling, particularly when the name of the disorder (e.g., schizophrenia) does not, of itself, describe what is happening. To Sailor (1987), the Aboriginal way of thinking defines mental health in a more complex way and the greatest method of coping is through spiritual engagement. In the context of schizophrenia, Aboriginal carers, from reports in *The National Consultancy Report on Aboriginal and Torres Strait Islander Mental Health "Ways Forward"* (Swan and Raphael, 1995) had concerns about the potential for bizarre behaviour to be misdiagnosed. Spiritual things, for example, Indigenous persons talking to the spirits of those deceased, can be misconstrued as

delusional, while delusions can be misconstrued as spiritual processes. Following the National Aboriginal Mental Health Conference in Sydney in 1993, Swan and Raphael (1995) documented many of the insights and recommendations of Aboriginal people. The report was built on Aboriginal views of health as holistic, involving spiritual, social, emotional, cultural, physical and mental wellbeing, and issues that relate to land and way of life. It supported the view that Aboriginal mental health bears a direct relationship to colonisation, history, racism and social factors.

The AMHAC (McGrath, 2000) in consultation with Indigenous mental health workers identified specific needs and service support requirements for carers in Aboriginal communities. They remind us that carer support is enhanced when Indigenous mental health workers are based in their community. This also assists trust building and community accountability. Furthermore, Indigenous mental health workers are in a position to approach their work with a point of reference and proficiency to interpret mental illness within a cultural context. This enables the worker to facilitate both Indigenous and non-Indigenous approaches. The AMHAC also believed that help for a person with a mental illness in Aboriginal communities is more likely to be provided by an extended group of carers, rather than by a primary carer, which is more common in non-Indigenous communities.

Paxinos (1999) provided specific examples of a person's cultural background being paid lip service and in some instances being viewed by MHPs as having a detrimental effect on the person's recovery. In particular, it was noted that MHPs do not often acknowledge family networks, traditions and various loyalties. In these situations, trauma may escalate. Sometimes the protest from families is disregarded by MHPs or interpreted as "overprotective" behaviour. These concerns are consistent with the findings of Swan and Raphael (1995) who advised that:

> MHPs must consult with family and community members before deciding that any individual affected by mental illness requires care or treatment away from the community. Community members should be kept informed about the treatment, progress and likely return of anyone removed from their community (p. 13).

The DSM-IV (1994) recognised that a clinician who is unfamiliar with the nuances of an individual's cultural frame of reference may pathologise normal variations in behaviour, belief or experience that are culturally specific. Similarly, Smallwood (1996) reported on culturally inappropriate methods of assessment that lead to a disproportionate diagnosis of major mental disorders in the Indigenous community. Smallwood (1996) believed there was a danger that the pervasive Anglo-Celtic dominant culture inherent in the Australian Health Care System would not allow

cultural safety unless practitioners were overtly aware of their need to demonstrate cultural competence.

The Second National Mental Health Plan (AHM, 1998) proposed that universal preventative measures should target Indigenous people, particularly those removed as children from their families, as they warranted attention for selective preventative mental health measures. This document recognised the 'stolen generation' and the related on-going trauma of Indigenous families from violent past policies.

The policy setting

The development of mental health services in Australia is unique. No other nation has its origins as a British penal colony in such an isolated country. Mental illness has been evident in Australia since the beginning of European settlement. In 1788, Governor Phillip was assigned the care of lunatics in the same manner as they were provided for under the *Great Seal of Great Britain* in the United Kingdom. By the mid to late nineteenth century, asylums for people experiencing mental ill health and handicapped had been erected in all Australian colonies (Pargiter, 1991). Whether these were for their care or for other reasons is debateable. Foucault, for example believed that "after the Renaissance psychiatric institutions had nothing to do with any medical concept, but with power" (p. 40). They were not concerned with turning mad people into sane people but with maintaining power and the social order (Foucault, 1967).

Be that as it may, asylums continued, in Australia, as the main institution for care and treatment of psychiatric disorder during the first half of the twentieth century. Towards the middle of the twentieth century, however, incarceration was deemed detrimental and no longer considered the best option for people experiencing mental ill health. It had become increasingly clear that large mental institutions had contributed to a loss of social skills, were excessively restrictive, violated human rights, increased dependency and reduced opportunities for rehabilitation (Garton, 1985). However, in 1961 shortly after the beginning of the closure of institutions in the UK, Enoch Powell forewarned that the major problem of deinstitutionalisation was not so much the physical change, but the cultural change that would be difficult to initiate and sustain:

> This is a colossal undertaking, not so much in the physical provision, which it involves but the sheer inertia of mind and matter, which it requires to be overcome. There they stand, isolated, majestic, imperious, brooded over by the gigantic water tower and chimney combined, rising unmistakable and daunting out of the countryside – the asylums which our

forefathers built with such immense solidity. Do not for a moment underestimate their power of resistance to our assault (as cited in Gilbert, 2003, p13).

The trend from institutional to community care in Australia commenced in 1950, due in part to the development of new anti-psychotic drugs such as thorazine, haldol and more recently, clozapine, risperidone and olanzapine. These drugs were heralded for their ability to control symptoms like confused thinking and auditory hallucinations, enabling people experiencing mental ill health to live in the community (Scull, 1984). Psychopharmacological response and community care has been the predominant theme of government mental health policies since the 1960s, and resulted in large numbers of people being discharged from mental health institutions (Jacobs, Crichton & Visotina, 1989). This process of deinstitutionalisation occurs regardless of the strength and availability of community supports needed to support people experiencing mental ill health (Flynn, 1984; Murphy, 1991).

The practice of deinstitutionalisation has become embedded in another concept, that of mainstreaming. *The First National Mental Health Report* (AHM, 1993) regarded a mental health service as mainstream, "when it is managed under the same organisational arrangements as those that apply to the general health services" (p. 62). The AHM (1993) advocated for the replacement of traditional stand-alone psychiatric hospitals with a mix of general hospital, residential, community treatment and support services. The central debate within this shift focused on whether community care was advanced for its financial efficiency or its therapeutic potential. Several authors (Baines, Evans & Neysmith, 1993; Goodwin, 1990; Scull, 1984) have argued, however, that the fundamental driving force behind deinstitutionalisation was not quality of life for people experiencing mental ill health, but the escalating cost of mental health services

The emptying of institutions in Australia increased homelessness and contributed to hardship for many families with mentally ill members (Burdekin, 1993). By the late 1970s, the rumblings of disquiet surfaced in Australia, as the plight of people experiencing mental ill health who were also homeless, and the plight of carers emerged (Andrews, 1991, as cited in Burdekin, 1993; Burdekin, 1993). The publication of reports on the homeless and mentally ill during the 1980s and 1990s disgraced Australia in the international arena (Burdekin, 1989; *Chelmsford Inquiry 1988-1990*; Carter, 1991; Burdekin, 1993) and caused public outrage which the government could not ignore. *The Burdekin Report* (1993), a comprehensive review on human rights and mental illness in Australia, gave an account of the lack of resources as 'bedevilling' community-based care.

Reforms began to emerge as federal and state governments were obliged to meet universal standards for mental health care. The re-emergence of criticism against mental institutions in the contemporary sense (Burdekin, 1993; Carter, 1991) had allowed governments to save money while simultaneously giving their policy a humanitarian gloss (Baines, Evans and Neysmith, 1993; Goodwin, 1990; Scull, 1984). Furthermore, the release of the Burdekin Report coincided with major economic reforms. The social services were overshadowed by market forces, reinforced by an economic agenda (Stephens & Warren, 1997).

Heading the Federal Labor government of the day, Paul Keating committed Australians to a business, or managerialist approach, with the prevailing and pervasive ethos of cost effectiveness, efficiency and accountability (*National Health Strategy, 1993*). In the opinion of Yeatman (1990), the managerialist language and the rosy promises of consumer consultation, social justice, client rights and participation, effectively defused those in search of democratic reform. This idea was reflected in publications such as, *Developing a Casemix Classification for Mental Health Services* (Australian Health Ministers Advisory Council, 1997). Language in this document was inclusive of the consumer approach, incorporating cost benchmarking; best practice and quality management.

The 1960s and 1970s witnessed a rise in international human rights advocacy with a focus on civil rights and oppressed minority groups in the area of mental health (Brown, 1982). In March 1991, The *United Nations Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care* (1991) specified the ways in which human rights recognised in other legislation applied to people with mental illness and to situations affecting people with mental illness. In 1991, the Australian Health Ministers endorsed the *National Mental Health Statement of Rights and Responsibilities.* This document defined the rights and responsibilities of consumers, carers, advocates, service providers and the community. Although the United Nations principles were not officially embodied within Australian legislation, they were endorsed in the *National Mental Health Policy* (1992). This policy documented and endorsed the strategies underpinning the major reform programme and framed a national commitment to transform the mental health system in Australia.

The Mental Health Statement of Rights and Responsibilities (AHMAC, 1991) was an official federal government document. It acknowledged that previously people with a mental illness had limited input into the types of services available to them. It also stressed that a diagnosis of mental illness is not a justification for inappropriately

limiting a person's rights. The statement made proclamations ranging from the nugatory (the right to treatment), via the obvious (the right to access relatives and friends), to the faddish (the right to information, consultation and participation in respect of decisions affecting the interests of consumers and carers). Pleasing as these rights were, it remained whimsical to think that they would put an end to the abuse of consumers and carers. Human rights charters stake out the boundaries of human morality, and therefore seem to offer an independent check on the disengaging power of the state. Brian Burdekin (1993) claimed the assertion of rights without effective monitoring of their implementation, or remedies for their violation, were of little effect, as his inquiry demonstrated. Therefore, it came as no surprise when *the Evaluation of the National Mental Health Strategy* (1997) discovered that the protection of consumer and carer rights, were regarded as the area that had least changed over the previous five years.

It has only been since the 1990s that concentrated attention has been given to policy development in the area of Indigenous mental health. The *Inquiry into the Human Rights of People with Mental Illness* (Burdekin, 1993) highlighted principles to be taken into account in the development of mental health services. This report stressed the importance of self-determination in the planning and implementation of mental health services for Indigenous people and the need for culturally appropriate services. It recommended the employment of liaison officers and specialist Indigenous mental health workers. It drew attention to the importance of training of Indigenous mental health workers and the provision of adequate funding for this training and support for these workers, especially those in remote locations.

Policies of inclusion

Over the past 15 years, Australia has established and endorsed various policy and strategy documents under the *National Mental Health Strategy*. A commitment of interest in the *National Mental Health Policy* (1992) was the endorsement of consumer participation. This new reading of consumer rights was listed in two of 12 policy areas. Objectives for consumer rights were to ensure they were affirmed in mental health legislation and that Commonwealth and State governments had mechanisms for protecting these rights. Objectives for the promotion of mental health and the prevention of mental illness focused on public education to improve knowledge about mental illness, minimise stigma and to develop primary, secondary and tertiary programmes for people at risk of developing mental disorders. It also supported further research into both causality and the development of effective ways

to evaluate preventative work. This document reflected a predominant focus on preventing mental illness rather than promoting mental health.

The importance of Australian consumers and carers participating in the planning and implementation of mental health care has also been recognised in the *Queensland Mental Health Plan* (1994). One of the key objectives is to ensure that mental health services deliver high quality care that best meets the needs of consumers and is accountable to them for the efficient and effective use of resources. This is seen within the planning context of the establishment of formal consumer advisory processes at all levels to ensure participation of consumers and carers in mental health service evaluation and planning. The *Ten Year Mental Health Strategy for Queensland* (1996) further emphasised formal consumer advisory processes and the adoption of a consumer-focused service programme.

The Australian Health Ministers Advisory Committee (AHMAC) endorsed the *National Standards for Mental Health Services* (NSMHS) in December 1996. They are outcome oriented and developed to both inform consumers and carers about what to expect from a mental health service, and as a basis for the development of external review tools, specific for the mental health sector. In this document, Standard 3 (see appendix one) is about consumer and carer participation and it states that consumers and carers are to be involved in the planning, implementation and evaluation of the mental health service. There are seven criteria related to this Standard, which cover such issues as policies and procedures, undertaking a range of activities that maximise consumer and carer participation in the service, training and support, reimbursement, roles and responsibilities and representation. As part of their funding agreement, all Commonwealth, State and Territory funded mental health services would undergo external review during the course of the *Second National Mental Health Plan* (AHM, 1998).

By 1998, when the *Second National Mental Health Plan* was launched, the Commonwealth estimated that since the early 1990s progress had occurred in consumer and carer participation at national and state levels in advising on strategy implementation and decision-making. More tools and training programmes were developed for consumers and carers to enhance their skills in consultation, advocacy and media work. Consumers were to have greater involvement in shaping professional education and training, community education and consultation and frameworks for promotion and prevention (AHM, 1998).

The *Third National Mental Health Plan (*AHM, 2003) was introduced in July 2003*.* The 2003-2008 plan consolidated the successes of the first and second plans and identified four priority themes. These themes emphasise mental health promotion and prevention, increasing responsiveness to consumers and carers, strengthening quality outcomes and fostering research, innovation and sustainability. However, this plan also recognises the need to strengthen the mechanisms to assist genuine participation of consumers, families and carers in decision-making at all levels. Thus:

> Consumers and carers report that there have been increased opportunities for participation in policy and planning, particularly at a national level. However, participation at other policy and planning levels, and participation in service planning and delivery across the spectrum of care from promotion and prevention to recovery, has not yet been achieved. Further work is required to ensure that meaningful participation by all consumers, and their carers and families, is realised (AHM, 2003, p. 24).

The admission by the Australian Health Ministers in 2003, that consumer and carer participation, endorsed by them in 1992, had not been taken up by individual state mental health services, may highlight the level of resistance or disinterest by MHPs and management towards these policies. Seymour (2004) found that the LIMHS could be similarly criticised for its inadequate links and poor communication with consumers and carers. Furthermore, Seymour (2004) discovered that the implementation of consumer and carer partnerships and participation remained in its infancy stage at LIMHS.

From consultation conducted as part of the *Enhancing Relationships Project* (Mugford & Walters, 1998) participants felt that the *National Standards for Mental Health Services* (Australian Health Ministers Advisory Committee, 1996) are significant in terms of enhancing relationships between consumers and carers and those who purport to serve them. The NSMHS (AHMAC, 1996) clearly outlined how participation should occur.

The extent to which the NSMHS translate into effective and respectful consumer involvement is yet to be determined and will undoubtedly be scrutinised through particular views of participation. Croft and Beresford (1992, 1994) and Ife (1997) described two approaches to consumer participation; the consumerist approach and the democratic approach. The consumerist approach is associated with the politics of the New Right, designed to promote the efficiency and effectiveness of services. The democratic approach is concerned with the rights and empowerment of users to work in partnership with service providers to create change.

The National Standards for Mental Health Services (Australian Health Ministers Advisory Committee, 1996) reflect the philosophies of both the democratic approach

and the consumerist approaches of participation. The Standards are guided by the principles contained in the *United Nations Principles on the Protection of People with Mental Illness* (1991) and the *First National Mental Health Report* (AHM, 1993). The former approach was evident in the introduction to the Standards where the following commitment to service users was made: "The Standards are … intended to reflect a strong value base related to human rights, dignity and empowerment" (NSMHS, AHMAC, 1996, p. 1). The latter approach is obvious by the portrayal of the quality improvement process as "a process, which measures performance, identifies opportunities for improvement in the delivery of care and services, and includes action and follow-up" (p. 53).

In the UK, Barnes and Bowl (2001) argued that the diminishing welfare state together with user participation, as per Giddens (1998) "third way", presents opportunities for users of services to shape key welfare state decisions. Although presented as a strategy to avoid the pitfalls of modernist policies based solely on either the community or the asylum, there has simultaneously been a re-emphasis on "protection" for the wider (mentally well) community with a hint at some type of incarceration if this is breached (Barnes & Bowl, 2001). Despite these undercurrents around security, the major debate in mental health has shifted from that of deinstitutionalisation Vs institutional care to debates about how and in relation to what, consumers and carers will be positioned to guide mental health services (Beresford and Croft, 1993).

The concept of recovery, which is directly related to forming partnerships with consumers and carers, and the participation of consumers and carers in service delivery, is a relatively new concept. Recovery emphasises the need for a comprehensive community based service system in which all sectors take responsibility for the mental health of their community and provide services and disability supports in a coordinated and collaborative manner. The importance of these partnerships has been highlighted in a range of strategic plans, including the *National Mental Health Plans* (AHM, 1998; 2003).

Concepts of partnership and participation

Foucault (1977b) argued that "the original voice of an author is but a vehicle that claims and extends a particular intersection of the thinking of that period. An author occupies a transdiscursive position" (p.131). Authors of the transdiscursive open up possibilities for various related discourses that stem from and branch out from their

work. The work of a transdiscursive author will undoubtedly be subjected to actions of 'rediscovery' or 'reactivation' (p. 146). In this sense, consumer participation is not a new concept. It developed from ideas of participatory democracy and the self-help movement. It has episodically re-emerged in Australia and other liberal democracies over the past 35 years and persisted as a philosophy of good practice in services for marginalised people (Phillips, 1998).

Concepts of partnership and participation are predominant constructions of contemporary policy. They recognise individual empowerment as an important aspect of a consumer participation strategy and recovery. Concepts of participation and partnership were therefore used in this study to unravel recent mental health policies and their claims of genuine participation for consumers diagnosed with schizophrenia and their carers.

Partnership is a relational, affective approach to participation. A basic premise for advocating participation and partnership is that consumer and carer contributions are valuable and critical to the successful development of a range of services that respond effectively to individual and community needs. An important assumption is that consumers have expertise regarding the intimate circumstances of their own lives and communities that is not necessarily available to professionals (Deakin Human Services Australia, 1999). In the opinion of Stone (1998), "partnership is about offering … [consumers and carers] the chance to completely develop a project, programme, service, group or innovative idea with as much control as they can cope with, without setting them up to fail" (p.86).

The notion of partnership is not without its critics amongst consumer groups. A Victorian report by the *Lemon Tree Learning Project* (Epstein & Shaw, 1997) documented consumers' mounting dissatisfaction with the term 'partnership' as their driving concept. This project offered a cogent analysis of the inherent tensions in the relationship between users and providers. In their words:

> …over the past twenty months we have come to realise that staff and consumers do not necessarily have the same agenda. Staff are [paid] workers and consumers are trying to get on with their lives that may or may not have much to do with the services they receive for their psychiatric stuff. Staff are (or should be) by definition, work-focused when they are at work. That is, they are meant to be there for consumers who are trying to recover. This does not make for easy partnership. The very unequal power relationships between the two groups, the history of paternalism; the 'reserve powers' which our society gives to professionals to withhold liberty, to forcibly inject and treat, all militate against the development of relationships which can truly be described as partnership (Epstein & Shaw, 1997, p. 5).

This conflict suggests that issues of deprivation of liberty and forced treatment of consumers with a serious mental illness are insurmountable barriers for any complete offer of partnership. Further, it reminds government that people with serious mental illness are capable of thinking critically and unwilling to tolerate further paternalistic policies with 'warm and fuzzy' overtones.

Skenridge and Lennie (1979) criticise participation in terms of its absolution of formal government for providing support to people in need. They cynically stated that notions of "participation" start with the problem of supporting people in need (resource intense) through to reframing this statement of need to a problem of decision-making, and finally presenting participation as an answer in place of increased resources.

These critiques of partnership and participation are important. The intent of using these terms in this study is to document the ways in which LIMHS is inclusive of consumers and carers and whether or not consumers and carers perceive that their needs are being met through their engagement with LIMHS. This research also unearths factors which constrain social workers from operationalising their own philosophical base of client centred, socially just practice including working in respectful partnerships with consumers and carers.

<div align="center">Implications for social work</div>

The significance of the change in the direction of mental health policy towards participation and partnership has important implications for social workers employed by mental health services in Australia. A major purpose of social work in the area of mental health is to promote principles of social justice (Bland, 1999). Social work has an extensive and notable history in mental health services and a strong background in case management (Aviram, 1997).

Bainbridge (1999) believed that it was the professional knowledge base, core values of social justice and holistic training that equipped social workers with skills required for working in mental health services. He reminded social workers of the need to promote consumer involvement in as many aspects of practice as possible. It could therefore, be assumed that social work would play a major role in implementing and guiding policies of partnership and participation with consumers and carers, in the workplace. If social workers are willing to grasp this opportunity to operationalise true

partnership with consumers and carers, this may go some way to prevent human and civil rights abuses of people with schizophrenia and those who care for them.

Social workers in mental health are located within contexts of social control. Their ability to resist less than socially just workplace practices should not be underestimated (Crimeen and Wilson, 1999). As Howe (1986) said, the way social work is organised and resourced is a strong determinant of how social workers perceive, assess and practise their work. An expectation of what is appropriate practice is built into an agency's policies and procedures and imbued through the attitudes of its workers. In relation to this latter, a study by Gawron (1998) found that the lack of consumer participation was blamed directly on the consumers of the service themselves. Consumers were perceived to be too ill, too stressed and lacking in appropriate skills to engage in matters of service delivery, which directly concern them. Gawron (1998) concluded that these attitudinal barriers are the greatest threat to successful and effective consumer participation. Yet it is policies like those of participation and partnership which can provide social workers room to manoeuvre increased political space for the voices of consumers and carers to be heard and to shift negative staff perceptions of those whom they serve. In addition, if these policies are a mechanism to further roll back resources to vulnerable groups, then it is even more important that social workers heed Webster (1995), who said that a "major imperative for social workers is to highlight the gaps between economic theory and reality, and to advocate for the promotion of social justice values in the policy making process" (p. 47).

Theoretical framework

This study draws on two major theoretical frameworks, both from Anthony Giddens. The first is that of structuration theory (Giddens, 1984) and the second is that of 'The Third Way' (Giddens, 1998). It is the second of these theories Giddens is best known for and which continues to have significant impact on welfare systems, in Britain (under Tony Blair), the USA (under Bill Clinton) and Germany (under Gerhardt Schroeder; Callinicos, 2001). 'The third way' is the natural theoretical home of participation and partnerships policies, imbued as it is with notions of the reinvigoration of democratic society. The theoretical perspective of this study draws particularly upon Jordan's (2000) analysis of the third way in guiding the implementation of social policy, and potentially social work, to analyse the data of this study in chapter 10 of this thesis. This allows for a theoretical framework of applied sociology with particular relevance to social work to guide the study at the outset, and

provides a critical lens to the theoretical framework of this study as iterated as a core aspect of the methodology (see chapter four; Kincheloe and McLaren, 1994). While it is somewhat unusual to draw on Giddens' earlier work in discussion of the third way in social policy implementation across the social welfare and health sectors (see for example Glendinning, Powell & Kirstein, 2002), it is the earlier work of structuration theory through which we understand the behaviourist basis of 'third way' politics in action, and through which we make sense of the background thinking of linking income support to personal responsibility and obligation; privatised packages of "care" rather than community resource provision; increased concern about "risk assessment and management" concomitant with increased surveillance of both consumers of services and those who serve them; and the moral dimension of third way politics and practices. Giddens (1984), in his work on 'structuration theory', therefore forces us to recognise *personal* agency as an intimate form of structure (that is, structures and persons are not placed in binary opposition to each other; one makes the other). These two theories of structuration and the third way, from the perspective of Bill Jordan, a world renowned social work theoretician, are discussed below. Two other theoretical frameworks are applied to the analysis of data (chapter ten) since they have particular application to people experiencing mentally illness and those who care for them, and for notions of partnership and participation. The first of these frameworks is that of Kemshall (2002) and the second that of Hudson and Hardy (2002). These guiding frameworks for analysis of participation and partnership are discussed below.

Structuration theory

In developing his theory of structuration, Giddens (1979; 1984) proposed agency and structure as key terms for consideration as an alternative to referring to the individual and society as though their separate identities were mutually exclusive. Giddens explained a departure from the concept of structure as a visible form and as a source of constraint on the initiative of the individual. Instead he perceived agency as a flow of the individual's actions that was connected to self-consciousness. He considered society a "complex of recurrent practices which form institutions" where "those practices depend upon the habits and forms of life which individuals adopt" (Giddens and Pierson, 1998, p. 77). An examination of structure and agency is crucial to understanding the importance of duality of structure in social theory (Giddens, 1987).

Structure

For Giddens, social systems comprise reproduced social practices, which have structural properties or 'rules and resources'. These rules and resources are actioned by individuals and exist in the time and space of practice by individuals and in their memory (Giddens, 1984). Thus, "structure is expressed in the things that individuals do in a regularised and institutional way" (Giddens, 1984; Giddens and Pierson, 1998). Giddens made the point, "structure has no existence independent of the knowledge agents have about what they do in their day-to-day activity" (Giddens, 1984, p.26). This implies that appropriate knowledgeability of an individual is a key element in structuration theory.

Individuals inherently engage the rules of social action and interaction as resources in their everyday practices (Giddens, 1993). These practices form the 'structural properties' of the organisations where the individuals are employed. The structural properties or rules and resources of organisations involve everyday recursive practices of individual members. Alternatively, the existence of organisations relies on the capacity of its members to continually reproduce these structural properties (Giddens, 1984). There is therefore, a perpetual process of structuration going on.

Rules

Rules of social practices "cannot be conceptualised apart from resources" and they "typically intersect with practices in the contextuality of situated encounters" Giddens, 1984, p.18). Rules often relate to specific instances of conduct, and have two inherent aspects; they help to form meaning, and they contribute to sanctioning modes of social conduct (Giddens, 1984). The main characteristics of the rules of social practices can be described as binary opposites, such as intensive/shallow, that is, those that are constantly invoked as opposed to those that are not always practiced. Discursive rules refer to those that can be articulated, versus implied rules which are those that are passively (tacitly) understood. There are informal and formalised rules, the latter operating in a legal sense. There are weakly and strongly sanctioned rules. Giddens pointed out that laws are the most strongly sanctioned types of social rules with "formally prescribed gradations of retribution" (Giddens, 1984, p.23). He also clarified that in the articulation of a rule, an interpretation is made which, in itself, can affect the application.

Within a mental health service there are rules that govern people's behaviours, which have both implicit and explicit components. Explicit rules include policies and protocols. When these are rigidly applied they are clearly explicit in that the actions

of staff conform to the "letter of the law". When these rules are applied more flexibly through the recurring actions of staff, they are also made explicit.

Rules and ontological security

For individuals to be able to perform their work to the best of their ability it is argued that they require 'ontological security'. Giddens (1984, 1998) proposed that rules help sustain ontological security. He defined ontological security as "confidence or trust that the natural and social worlds are as they appear to be, including the basic existential parameters of self and social identity" (Giddens, 1984, p.375). Turner (1991) further explained this concept:

> One of the driving but highly diffuse forces behind action is the desire to sustain ontological security or the sense of trust that comes from being able to reduce anxiety in social situations. Actors need to have this sense of trust (p.532).

Two phenomena of ontological security can be distinguished (Giddens, 1984). First is the comfort gained from routine practices. In general, any disruption to routine will be experienced as troubling. The second phenomenon is the routines that are adopted when in the presence of another, 'co-presence' (Giddens, 1984). Ontological security is, therefore, necessary for social workers to practice their profession at an optimal level. This is enhanced in a supportive work environment where social workers are able to apply themselves to their duties rather than worrying about their own ontological security.

Co-presence

Pertinent to the notion of co-presence, Giddens drew on the work of Goffman (1959, 1961, 1963, 1967, 1974), to explained that in face-to-face encounters individuals utilise tact to ensure that neither party loses face or threatens the other: "actors have a responsibility to protect other participants from blows to their self-esteem; they also have a right to expect that others will refrain from 'assaults' on their own self" (Giddens, 1993, p.15). Despite this Giddens viewed individuals in the workplace at risk of "double jeopardy" when they contravene social rules, thereby becoming vulnerable to social sanction while those rigidly complying with rules eventually becoming constrained by them and be less likely to engage spontaneous social interaction with other workers and less likely to engage creative autonomous practice (Giddens, 1993).

Similar to the concept of co-presence is the idea of "mutual knowledge" which is the knowledge incorporated through encounters with others (Giddens, 1993, p.91). Such

knowledge is practical in character, and although it may not be directly accessible to the consciousness of individuals, it allows them to continue the routines of their lives (Giddens, 1993).

Resources

"Resources are facilities that actors use to get things done" (Turner, 1991, p.523) Giddens defined two distinguishable types of resources; 'allocative resources' which refer to the capacity of generating command over objects, goods or materials and 'authoritative' resources.   Authoritative resources refer to "those that have transformative capacity generating command over persons or actors" (Giddens, 194, p.33). Authoritative resources can be mobilised to assist individuals to implement particular organisational policies, or may take the form of "time off" for staff education and training on strategies to operationalise policy at the local level.

Resources and the dialectic of control

All forms of dependence offer a resource whereby those who are subordinate can influence the activities of their superiors. This notion is the 'dialectic of control' (Giddens, 1984, p.16). Giddens stated, "in all social systems there is a dialectic of control, such that there is normally shifting balances of resources, altering the overall distribution of power" (1993, p.243).   Resources take multiple forms, including information, money, status and skills. In projects of the third way such as partnership building, the multiplicities of these resources are drawn upon to actualise democracy and the "moral" State.

Agents and agency

The term human agent and actor are interchangeable, as is action with agency (Giddens, 1984). Giddens believed that action can neither be discussed separately from the notion of the actor and their interaction with others and the environment, nor outside of time and space as ontological aspects of structure are constituted through social practices (Giddens, 1984, 1993). Actors are positioned in social systems through actual practice and through memory. Situated activities of individuals, reproduced across time and space, comprise the social systems in which structure is recursively produced (Giddens, 1984).

Giddens said that "agency refers to doing" (1984, p.10). He further elaborated that agency does not refer "to the intentions people have in doing things in the first place. Agency concerns events of which, an individual is the perpetrator, in the sense that the individual could, at any phase in a given sequence of conduct, have acted

differently" (Giddens, 1993, p.96). Gidden's (1987) stressed that to be a human agent is to be able to "act otherwise" and also to "know this to be the case" (p.220). He theorised that people feel a sense of freedom if they make a decision about their actions even when they are in oppressed situations (Giddens, 1987).

Another aspect of agency is the notion of 'unintended consequences'. In relation to this concept Giddens (1984) cautioned, "human knowledgeability is always bounded", and, "the flow of action continually produces consequences which are unintended by actors, and these unintended consequences may form unacknowledged conditions of action in a feedback fashion" (p.27). Giddens (1984) explained that the maintenance of system reproduction in human society can be regarded as involving the operation of causal loops, in which a range of unintended consequences of action feedback to reconstitute the initiating circumstances. He warned that, in many contexts of social life, processes of information filtering occur, whereby "strategically placed actors seek reflexively to regulate the overall conditions of system reproduction either to keep things as they are or to change them" (pp. 27-28).

A basic assumption Giddens (1984) made about individuals is that, "all human beings are knowledgeable agents" (p.281). He maintained that structure has no existence independent of the knowledge that individuals have about what they do in their day-to-day activity. Giddens (1984) described three aspects of consciousness. These are discursive consciousness, practical consciousness and unconscious motives. The first aspect, discursive consciousness is "what [people] are able to say, or to give verbal expression to, about social conditions, including especially the conditions of their own action; awareness which has a discursive form" (p.374). The second aspect practical consciousness is "what [people] know about social conditions, including especially the conditions of their own action, but cannot express discursively. The third aspect, 'unconscious motives', articulated by Turner as (1991) "the basic force behind much action is an unconscious set of processes to gain a 'sense of trust' in interaction with others…There are many pressures to act in certain ways that an actor does not perceive…much of what propels action lies below consciousness" (p.532).

Reflexive monitoring

Individuals are viewed as 'purposive agents' in that they have the capacity to articulate a reason and purpose for action (Giddens, 1993). An additional concept in relation to the purposive agent is the notion of 'reflexivity'. Reflexivity refers to the

ability of individuals to continuously monitor their actions (Giddens, 1993). Reflexive monitoring is dependent upon the competence of an individual to rationalise their action, which happens as a continuous flow of conduct. Giddens (1984; 1993) believed that individuals not only monitor their own actions and expect other individuals to reciprocate; they regularly monitor the social and physical aspects of the contexts in which they operate. In addition, Giddens (1993) indicated that in interactions with others, or co-presence, an evaluation of the competence of the other is made through the rationalisation of their actions within a variety of contexts.

Transformative capacity

Another aspect of agency proclaimed by Giddens (1993) is that agency is "logically tied to… power" (p.108). By this, Giddens (1984) meant, "power is the means of getting things done and, as such, directly implies human action" (p.283). Giddens (1984) termed this connection of action to power as the 'transformative capacity' of human action; "action logically involves power in the sense of transformative capacity" (p.15). Giddens (1993) qualified that transformative capacity is distinct from relations of power among individuals. Transformative power is the "capability of the actor to intervene in a series of events so as to alter the course; as such it is the 'can' which mediates between intentions or wants and the actual realisation of the outcomes sought after" (p.110). It is upon reaching the position of "I can" that individuals realise that they have a choice about taking a particular course of action and it is this realisation that enables them work from a position of power (or empowerment).

The Third Way

Just as Giddens (1984) set out to overcome the dualisms between notions of the individual and society, in structuration theory, so he sought to overcome the dualisms between socialism (with its concomitant notion of collectives and the communal and State provisioning of citizens), and neo-liberalism (with its concomitant notions of the free market and its focus on individualism) in theorising 'the third way'. Essentially, the 'third way' as a means for guiding the welfare/health sectors in service provision encompasses the following two major constructs (Jordan, 2002):

1. To make work pay, by increasing the means-testing of benefits while ensuring the compliance of consumers in employment, education or training;

2.   To strengthen responsibility and community. This construct is one which attempts to extrapolate the energies of small scale groups like families, clubs and voluntary organisations to wider society. Thus values like mutual obligation and responsibility are invoked as the means for reinvigorating society (and democracy) and overcoming selfishness and greed, increased criminality, family break-up, alcoholism, drug addiction (etc.). Under 'third way' politics, there is a tough stance taken by the State with regards to its dealing with criminality or deviance from the expectations of a liberal democratic society.

It is participation in work, education or training which leads to social inclusion, a major construct used directly by Giddens (1998):

> The new politics defines equality as inclusion and inequality as exclusion. Inclusion refers in its broadest sense to citizenship, to the civil and political rights that all members of society should have….It also refers to opportunities and to involvement in the public space (p.102 – 103).

Perhaps this notion of harnessing the energy of voluntary groups as a form of inclusion is best summed up by Vern Hughes, Director of the Centre for Civil Society in Australia. Hughes (2006) said:

> What is the biggest common-interest constituency in Australia? Trade unions? The green movement? Small business? The answer may surprise many of our political elite. Home based carers of people with a disability, chronic or mental illness and the frail aged number some 2.7 million people. Together with the people they care for (almost the same number again) they are the largest common-interest community in the country (p. 1).

Lest this group become a political force, as Hughes seemed to imply, third way politics seeks to use this energy to reinvigorate what Jordan (2002) calls the 'blood and guts' code of morality, inclusive of mutual obligation, family responsibility for its members with strong discipline (even to the point of coercion), for lack of compliance to this code. The State in third way politics, therefore, embraces the market as the primary site of citizen participation. The State imposes discipline on those who do not comply with this code, by withholding the goods of the State including income security measures, and by undertaking tasks of surveillance to ensure moral compliance.

In this process, Jordan (2002) argued, social workers have become more involved in 'evidence based' practices which are "legalistic, formal, procedural and arm's length…social workers were thus primarily involved in allocating services and exercising surveillance through systems of rationing and control" (p.8), rather than practices which are personal, intimate, caring and 'messy'. Jordan (2002) goes on to say:

> At the same time, the government has also set up a number of new agencies with a strong deterrence and enforcement ethos – such as the Home Office service for asylum seekers – and put more funding into others with similar cultures and functions, such as the Benefits Agency Benefits Fraud Investigation Service. This is part of the transformation of the welfare state into a tougher, more demanding and more punitive set of institutions, with new labour attempts to justify in terms of 'fairness' (p.8).

Despite the demise of Mark Latham, the strongest advocate of third way politics in Australia (Latham, 1998), this trend towards 'third way' politics is strongly mirrored in the Australian context in the proliferation of job network agencies, and in Australia's treatment of, and public discourse about, asylum seekers and Aboriginal persons as engaged through the Howard years (1996 – 2007).

Social work, argued Jordan (2002) has become marginalised in this process in Britain through the public's association of social work with public sector advocacy (over the market) and the advocacy of vulnerable service users in meeting their needs through 'rule-bending' and 'banditry' (p.19) during the Thatcher-Major period. In place of social workers, the state appoints what Jordan (2002) called 'enforcement counsellors'. These people may not have formal qualifications or may come from outside the discipline of social work, or may even be people with social work qualifications whose client (and master) is now the State, whose job is to strictly implement government policy. They may even be groups operating from outside of the nation state, but who are contracted by the state to undertake this work. At the same time as these 'enforcement counsellors' are being employed, so are 'street workers, support workers and project workers' (Jordan, 2002, p.37), many of whom also lack formal qualification and of whom Jordan (2002) said:

> …. these more 'hands on' workers, who get alongside service users, understand their subjective experiences, advocate for them, and help them organise to represent and meet their needs, are filling a vacuum left by the profession's bureaucratisation. It is also as if they are supplying the missing element of 'love' in the Third Way's unbalanced version of its policy implementation (p.38).

A primary construct of third way is the role of government in helping the populous manage risk, where risk is largely seen as arising from the action of individuals including anti-social individuals. Thus the damaging consequences of delinquent behaviour, criminal activity, domestic violence child abuse and neglectful parenting is focused upon with penalties invoked (usually through the withdrawal of State resources and/or imprisonment) for those perpetuating this behaviour and causing risk to persons and to society. Dangerous or "at risk" individuals then become the focus of state intervention. This has strong implications for practice. Jordan (2002) said:

On the one hand, there is the proliferation of guidance from the Department of Health on every aspect of social care, steering practice towards specific interventions and outcomes. Much of this concerns the assessment process – the requirement to identify risk factors (and particularly dangerousness), and indicators of priority need. This in turn gives rise to systems of resource allocation, review and monitoring in which service users are kept under constant surveillance, and interventions can be adapted and recast to keep control of risky or fragile situations (p.64).

It is this aspect of third way (of Giddens, 1998) which is particularly pertinent to mentally ill persons and those who care for them. This theme is the basis of Kemshall's (2002) work. Rather than the redistribution of wealth as the focus of welfare provision, the redistribution of risk becomes paramount. Giddens (1998) pointed to the fact that risk is an ongoing element of social and political life. He believed that the old welfare state stifled the entrepreneurship of its population by safeguarding it from the risks of capitalism (such as disparate rates of wealth and poverty between groups of people; market forces leading to recession or depression with resultant patches of unemployment etc.) and that engaging risk, as part of the human condition, is the responsibility of individuals not the State. In this sense, risk taking behaviour can lead to positive consequences (such as entrepreneurship which leads to active engagement of the individual in the economy) or negative consequences such as deviancy or criminality. In either case, the responsibility for these consequences remains with the individual. The state serves as a location of education about potential risks and responses, but through reflexivity, the individual is expected to arrive at moral decisions with regard to risk which enables them to engage actively with the state and the market in the requirements of both (to be a responsible, self providing citizen and a worker within the market; Giddens, 1998). The withdrawal of welfare benefits to an individual or a family, from the state, therefore, allows the individual to experience and respond to risks. This, Giddens perceived (1998) leads one to active engagement with the State rather than remaining a passive welfare recipient, which is seen as morally irresponsible and the result of poor individual choices in the face of risk. The state is responsible for not only supplying information about risk and responsible choices in its 'successful' negotiation, but also for providing opportunities at times of risk for increased participation of individuals in the market and therefore society, through opportunities for education and re/training ('investing in human capital', Giddens, 1998).

As Kemshall (2002) pointed out, the level at which responsibility for the management of risk is assumed, remains the level of responsibility for blame when risk is managed 'irresponsibly'. This latter aspect has led to government authorities responsible for ameliorating particular social issues (such as child abuse and neglect and mental health), to err on the side of caution – of safety, rather than potentially negative risk.

This has resulted in formalised systems for assessing and managing risks. Kemshall (2002) said:

> Individuals and organisations charged with getting risk right are required to defend these decisions, often from litigation, and formalised assessment methods are used to replace the vagaries of professional judgement … audit, formalised assessment and bureaucratic risk management systems have become a key response to the uncertainty of risk (pp. 9 – 10).

Kemshall (2002) further argued that 'risk is replacing need as the key organising principle in health and the personal social services' (p.22) and that these aspects are particularly so, in the case of mental illness where the move of mentally ill persons from the asylum to the community in the mid-twentieth century, has led to an increased focus on diagnosing 'dangerousness' of the mentally ill person to the general population. Thus Kemshall (2002) said:

> Resource-intensive multi-disciplinary assessments are reserved for those individuals suffering from severe social dysfunction, whose needs are likely to be highly volatile, or who represent a significant risk…This has focused attention (and services) upon a small residual group of 'high risk' individuals who are deemed to present a danger to the public. Provision has been skewed towards the identification, assessment, registration and surveillance of this group… (p. 92)

In addition, Kemshall (2002) later said:

> …while community care and risk taking have emphasised client needs and rights, in reality, mental health risks have been increasingly negatively defined and community care has become focused on how to increase compliance with community treatments and surveillance (p. 93).

Not only were mentally ill service users increasingly monitored for compliance, so too, service providers were increasingly regulated and made accountable, after all, it was their failures which led to the mayhem caused by 'dangerous' mentally ill persons and which were subsequently relayed to the British public throughout the 1990s in various newspaper accounts. Media responses heightened the community's perception of the dangerousness of mentally ill persons without recognition that these make up the minority of persons suffering mental illness. Numerous public inquiries into criminal cases involving mentally ill persons moved "the mental health agenda from care to management and from treatment and rehabilitation to control and surveillance" (Kemshall, p.98). Some of the controlling aspects of government responses in 1990s Britain, to mentally ill persons, were, the use of formalised and expert risk assessments upon user discharge from hospital; communication of previously confidential user information with other agencies without the users consent; compulsory supervision and monitoring ('assertive outreach') of some users upon discharge on the grounds of risk; compel a user deemed 'at risk' to self or others to live at a specified address; to attend medical treatment, education or

training; and to permit mental health professionals entry into their homes (Kemshall, 2002). Failure to comply with these conditions could lead to compulsory admission to a secure mental health facility. The primary guiding principle is the safety (including the psychological safety) of the non-mentally ill community. The social inclusion of some, under these policies, is therefore assured at the expense of the inclusion of 'others'. The Royal College of Psychiatrists estimated that it would be necessary to detain 50 people to prevent between 5 and 10 others committing a serious violent offence. In a risk society it would appear that the public is prepared to accept this discrimination, and human rights abuse of mentally ill people, if it assures their own safety (Kemshall, 2002). Jordan (2002) criticised 'the third way' for ignoring these dimensions of citizenship.

A final aspect of 'third way' politics guiding the theorisation of this research is that of the 'social contract', the notion that there are no rights without responsibilities (Giddens, 1998). These responsibilities are, to seek work or training; to take up opportunities for independence; to give support, financial or otherwise to one's children and family members, to save for retirement and to refrain from defrauding the tax payer (Kemshall, 2002). It is the third of these responsibilities which most impacts notions of partnership and participation, the engagement of family in the enterprise of care (and control). Since a mentally ill family member is seen as receiving services of the State, the family is expected to reciprocate through their participation with the State in this enterprise. This is seen as a core aspect of the revitalisation of democracy; tapping into and harnessing the energy of these 'third sector' or voluntary care providers. Fundamental qualities needed to do this, include 'network generated norms of trust, cooperation, reciprocity and mutuality' (Jordan, 2002, p.159). Jordan (2002) believed that there was little in the rhetoric of the third way which demonstrated this and argued vociferously that these are qualities of social work. Jordan (2002) further argued that it is this key element of the third way (engagement of the voluntary sector, including families) which indicates its need of social work. He said:

> Social work practice has always worked in the space between law and policy on the one hand, and family, neighbourhood, and community on the other….its established role is that of mediating between dissident, disaffected or 'maladjusted' individuals and the mainstream, between people with special needs and those agencies that provide for more generalised or universal needs, and between minorities, the disadvantaged and the unorganised, and the majority's organisations (p.77).

Further on this theme, Jordan said:

> …. The kinds of problems human –service professionals address are complex ongoing messes, the elements of which cannot be easily separated and subjected to scientific assessment and testing. Understanding in such situations develops out of a dialogue

> between the professional and the service user… Practice knowledge is therefore derived from 'reflection-in-action', from an interactive process in which the professional brings to bear experience, judgement and intuition in a creative response to the specifics of the situation and the person (p. 78).

It is with this complexity of the engagement of persons, in partnership that the final part of this section of the thesis is engaged – that of articulating partnerships as a key platform of third way politics. Clarke and Glendinning (2002) perceived the public service as moving from a bureaucratic hierarchy (in the old welfare state), through to a managerialist management style, where market principles applied to the management of service provision, to the newer model of third way service provision which engages networks of governance. They said:

> contemporary governments …can only achieve their objectives through indirect means, by surrendering the power of direct control and bringing other social actors and organisations into networks of mutual interdependence, which can shape, refashion and deliver policies more effectively (p. 34).

An important social actor in this sense, and in relation to mentally ill service users, is that of the family or carer. Partnership is not optional, but is mandated under third way politics. Yet, horizontal governance in mental health is difficult to achieve, both across professional groups, and at the level of inter-organisational or carer/family partnerships. Thus in relation to multi-professional partnerships in health, Clarke and Glendinning (2002) said there was tension:

> if there are long standing professional inequalities between medicine and social work (and accompanying concerns about the medicalisation of the social domain) ….(p.40).

And further, these tensions remain in 'partnerships', when:

> There are suspicions that priorities are driven by narrow clinical, rather than wider social priorities, or if pooled budgets are being used disproportionately to fund medical rather than social services (p.40).

In relation to partnerships between large bureaucracies and local communities, Clarke and Glendinning (2002) said:

> The impression is of top-down management with few opportunities to 'active citizenship' in the setting of priorities or the allocation and expenditure of (very substantial) resources (p. 43).

Hudson et al (cited in Clarke and Glendinning, 2002) found that in partnerships between service providers and service users, users were most likely to have been consulted when very detailed arrangements of the partnership had already been drawn up, especially when this involved patients. In this case, Clarke and Glendinning (2002) surmised that:

> ……partnerships may become sites in which contending interests are negotiated and accommodated; but only some interests may be well enough organised or articulated to be included in this process (p. 40).

They suggested that the autonomy of partners is circumscribed by central direction and control over resources. They further added that governments do not engage partnerships which threaten this control – they therefore recruit subordinate partners and that much partnership is therefore tokenistic and oppressive to community and voluntary groups (see also Craig and Taylor, 2002). Perhaps with this in mind, Clarke and Glendinning cited Joseph (2000) as saying that:

> 'Third Way' partnerships (can be considered) rather more as externally managed systems, whose internal dynamics co-exist, potentially uncomfortably, with powerful external direction and intervention (p. 43).

Finally, in order to provide a theoretical basis for the analysis of the partnership between LIMHS and its service users and carers, the work of Hudson and Hardy (2002) was interrogated for what it offered in terms of determining 'good' partnership qualities. They suggested that partnership building between diverse sectors is engaged to address 'wicked issues' – those that span portfolios or responsibilities rather than those which can be contained within a specific field of responsibility. Hudson and Hardy (2002) provided 6 principles which should be activated in the pursuit of a workable partnership. These principles are outlined below:

1. **Acknowledgement of the need for a partnership** – this principle encompasses an acknowledgement of a shared history; a measure of the recognition of a need to work together; identifying barriers of working together; appreciating interdependencies; appreciating specific domains of each partner in the shared enterprise;

2. **Clarity and realism of purpose** – the development of a shared vision; development of specific aims and objectives of the joint enterprise and an acknowledgement of the collaborative capacity of each partner including tangible resources like money, but also skills, expertise, status and autonomy;

3. **Commitment and ownership** – "an organisational commitment to partnership working is more likely to be sustained when there is individual commitment to the venture from the most senior levels of the respective organisations. Without this, it is possible that the efforts of partnership enthusiasts holding middle and lower level positions will become marginalised and perceived as unrelated to the 'real' core business of each partner" (p.56). Further, commitment needs to be consistent and activated through egalitarian means;

4. **Development and maintenance of trust** – the more trust between partners then the more likelihood of a successful partnership. Similarly, this will be maintained through practices which demonstrate the equivalent status of each partner, including agenda setting and a sharing of responsibilities. In this regard, Hudson and Hardy (2002, p. 58) cite the Barnsley MBC, 2001, thus: "respect and accept other people's contribution even if you disagree; listen, you may learn something; be patient, recognise and accept differences in people's ability to communicate; use clear, simple English; make sure that everyone has the support they need in order to contribute fully; explain processes clearly; recognise and record minority views". As part of this principle, Hudson and Hardy (2002) acknowledge the need to have the right people in place rather than those who are solely organisationally or professionally self interested;

5. **Establish clear, robust partnership arrangements** – ensure a clear division of responsibility; recognise and share conflicts arising from dual accountability; ensure that the size and complexity of the partnership meets the task at hand; and stay time-limited and task focused;

6. **Monitor, review and share organisational learnings from this engagement** – assess the performance of the group, provide feedback and share the learnings the organisation takes from this forum.

Location of the researcher

To fully grasp the interface between mental health social workers, their organisations, and the clients they serve, it has helped being a social worker myself. From 1993, I have had an ongoing interest in mental health, with a particular focus on families who have a member diagnosed with schizophrenia. Initial interest stemmed from my work as a sole social work practitioner in a hospital located in a small rural community called Brandon. In this position I experienced the common disadvantages of working in a rural area, such as a lack of professional support, peer supervision and accessing a locum when attending conferences, or when taking annual leave. More positively, the position had much to offer in the way of autonomy. It allowed for creativity, and freedom to assess, define and privilege the area of greatest need. It also accommodated a flexible implementation of rules due to the diversity of duties involved and the inability of management to understand what social workers do. This made it difficult for them to make me accountable to them, and consequently I could largely direct my own practice and have it guided by those I served.

The lack of services for people with a mental illness was immediately obvious, particularly for families with a member diagnosed with schizophrenia. I was able to provide a limited follow-up and crisis response service between the weekly visits by Lantana Integrated Mental Health Service (LIMHS). I also initiated a support group for carers, which provided the opportunity for radical collaborative practice whereby clients were encouraged to link their personal lives with their socio-political positioning and experience. During this period, aspects of my practice were discussed with colleagues employed by LIMHS. It became increasingly clear that while I could engage in participatory practice, this was not so for other social workers within the mental health arena. This was due in part to the constraints on practice arising from managerialism in a climate of economic rationalism, a model of service provision that favours economic efficiency over concerns for social justice (Rees, 1991). It was also due to the social workers' ambivalence towards principles of social justice in the face of managerialist demands.

To undertake this study, I left Brandon and moved closer to the university in Lantana. I selected LIMHS as the location for my research due to my insider knowledge of the organisation and that it was the local mental health service. I also commenced casual locum work, which progressively became more intensive, and towards the end of this research, I worked on a fulltime basis. This opportunity enabled me to experience the constraints and obstacles in professional practice that my colleagues had raised in conversations over the years and as participants of this research. More importantly, I was able to observe the organisation at a structural, discursive, operational level and note its impact on staff and consumers and carers.

The duties expected of me in Lantana were far removed from the duties of professional assessment, intervention and analysis that I was able to perform in my previous position. The new duties of tasks or competencies included applications for the administration of finances by the Public Trustee of Queensland, enforcing treatment, supervising the ingestion of medication, regulation (enacting involuntary status) and drug screening. This experience provided me with particular insights and intimate knowledge about social work and the constraints on social justice and consumer and carer participation.

Perhaps the most important factor that I can reveal about myself that may assist the reader to understand my subjectivities in this research are explained by acknowledging that mental illness is present in my family. This circumstance has offered insider knowledge of the various ways a mental illness can affect the person with the condition and the impact that caring for a person with a mental illness has on

family life. Conversely, my family situation and my work in mental health services, has convinced me that a supportive family environment, enhanced by compassionate, holistic professional intervention can result in an optimal outcome for all involved.

My decision to bring my voice into this research was informed by my family and professional experience with mental illness, my identification with radical social work practice and my privileged position as participant observer of the LIMHS over the last 12 years. While I have a good understanding of the organisation, and the current models of social work service delivery, my commitment lies with the consumers and carers. It was this group, I perceived, who had a right to be heard and this research sought to articulate this.

The Research Context

Figure 1.1 Research Design

Research Paradigm   �   **CASE STUDY**

Theoretical Paradigm   �   **Critical**

Methodology   �   Participatory (Consumers & Carers)   Ethnographic (Management, Social Workers & CDW)

Research Questions & Data Needs   �   **Views and Ideas**

Research Techniques   ➤   Semi-structured interviews & focus discussions   Archival research & semi-structured interviews

Analysis   ➤   **Thematic**

The Model
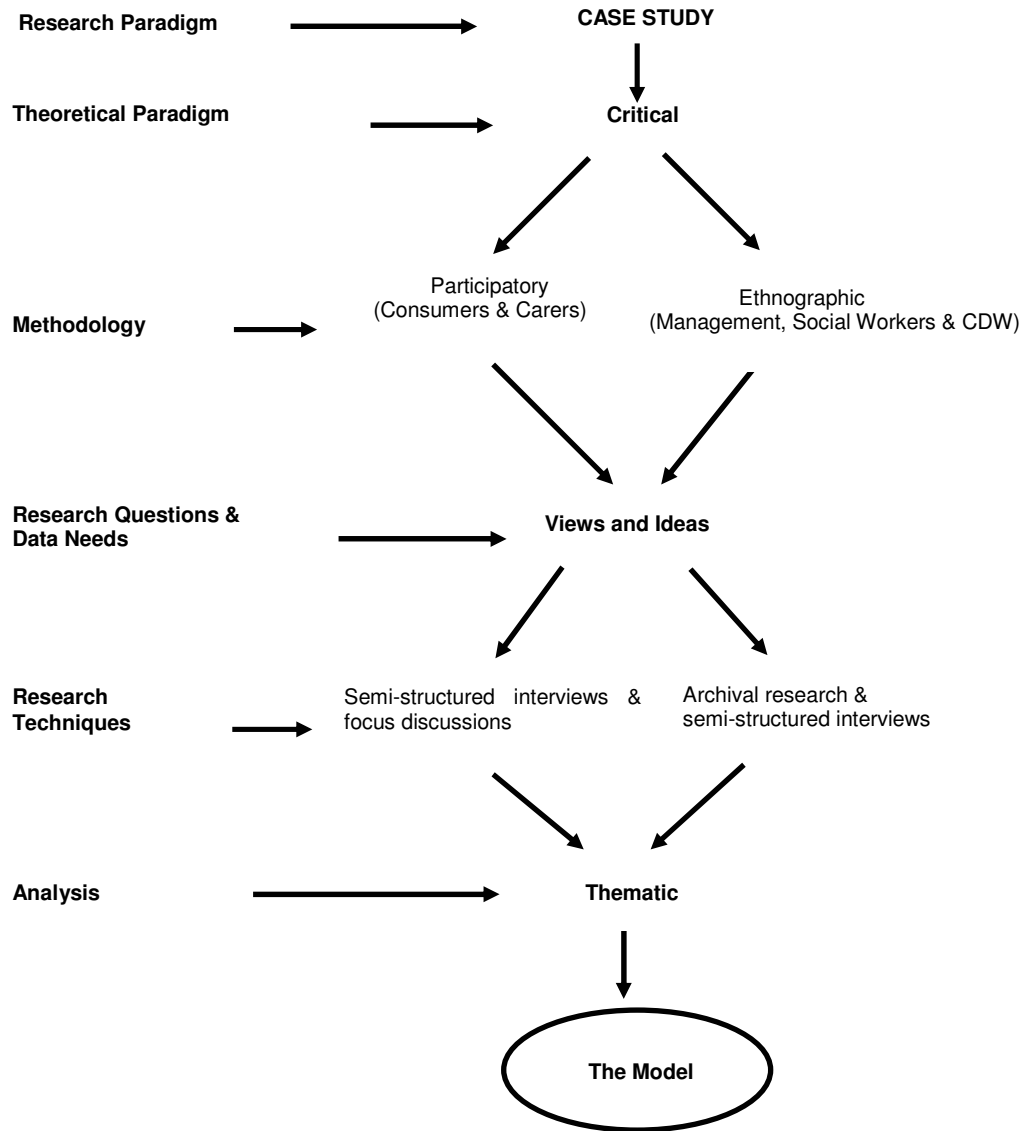
Figure 1.1 depicts the design of this research. To enable the case study, views from five discrete areas of LIMHS on the participation of consumers and carers and on each other were selected. The five groups covered were: (1) management, (2) the community development worker, (3) social workers, (4) consumers, and (5) carers. These groups were then collapsed into three areas to enable a review of the relevant literature pertaining to policy, social work and consumers and carers. These three areas, in turn informed my three sub-research questions. Finally, the groups were further reduced to form two methodolological streams deemed most appropriate for the investigation.

The two-streamed methodological approach used in this case study was drawn from critical ethnography and participatory research methods (Lincoln & Guba, 1994; Rodriguez, 1996) Critical ethnography has the potential to free research participants from oppression by increasing their personal awareness of injustice, inequality, and ideological distortion (Giddens, 1990). I examined the perspectives of management, the clinical director and the social workers employed at LIMHS, and the community development officer, funded by Queensland Health to enhance mental health services in the area. The views and ideas offered by these respondents in relation to consumer and carer participation and social work including social justice, were elicited by semi-structured interviews focusing on the organisation (LIMHS), current work practices and policies advocating the participation of consumers and carers in service delivery, planning and evaluation, particularly Standard 3 (see Appendix One).

The methodology of this study deviated from "pure" participatory research given my insider status in this organisation. Fuller and Petch (1995) argued that the practitioner-researcher is well placed to develop a participatory style of research that engages with both colleagues and service users, which in many respects is a better model than can be achieved by an external researcher. This insider knowledge, informed my ideas regarding the research inquiry and the development of data collection instruments and processes. The semi-structured nature of the questionnaires from which interviews were conducted, however, allowed participants to introduce material about consumer and carer participation into the data collection processes. Hall (1996) argued that there is no blueprint for participatory research methods. This means that the principle for participatory research "is that both issues and ways of working should flow from those involved and their context" (p. 4).

The in-depth interviews with the management, the social workers and the community development worker were analysed through four major themes, these were, participation, social work, social justice and social work post-graduate education. The findings of these interviews were used to design vignettes (see chapter four) that were used as a basis for educative sessions for consumers and carers about the research, its major aim and questions and their participation in the research. The idea for this technique was both part of the expectation of Standard 3, that consumers and carers be engaged in preparatory and educative processes to enable them to participate in the enterprise of mental health, including research, and also borrowed from popular education (Beder, 1996) especially the pedagogy of Paulo Freire. Reason (1994) reflected on the variety of research techniques utilised in

participatory research but recognised the predominance of those which focus engaging people in articulating, analysing, and making sense their individual and collective realities. The vignettes used in the preparatory sessions with consumers and carers were designed to encourage broad discussion around mental health policies and practices of participation, social work, education for MHPs (in the case of consumers of carers, some of whom did not know the discipline of their MHP) and social justice.

These four themes enabled the collation of all data sets (see chapters 5 – 9) in the presentation of multiple ideological, practical or preferred realities (Stringer, 1996) of consumers, carers, management, the community development worker, the service development coordinator and social workers. This approach to knowledge unearths multiple claims to truth which invite critical reflection (Falzon, 1998) including reflection about those claims of powerful stakeholders which perpetuate dominant ways of service delivery whether or not these are supported through newer policy directions.

The aim of this multi-phased case study research was to develop a participatory model of service delivery for the social workers at the Lantana Integrated Mental Health Service. By providing a forum for both streams of research participants to articulate their experiences of participation policies, social work and social justice services in the mental health endeavour, a proposed social work model of mental health service delivery was developed (see chapter eleven). The intent of the development of this model was not to prescribe new ways of being for social workers, but to give space to the subjugated voices of people with schizophrenia and their carers including their wisdom about helpful practices in the shared enterprise of mental health service delivery (see chapters eight and nine).

It is hoped that this model enables social workers, within the current political climate and in the current structural organisation of LIMHS, to hold on to their core values of social justice and client centred practice in order to promote genuine participation and partnership for people with schizophrenia and their carers. This research contributes to current literature on consumer and carer participation and social work practice in mental health.

This study was conceptualised as a case study, focusing on a bounded system (Stake, 1994) of one mental health service (LIMHS). This case study allowed for the explication of the location and practices of social work vis a vis other disciplines operating from this organisation; allowed for data collection about the experiences of a group of consumers and carers who each had experiences of the same organisation; and allowed an analysis of the opportunities and constraints within a single system of service delivery, in taking up policy directives of consumer and carer participation, to emerge. A useful way to conceptualise the organisation in terms of its manifest purpose is as a multi-level service clinic, offering crisis assessment, case management and mobile intensive services, to enable independent living in the community as the ultimate clinical outcome.

Lantana with a population of approximately 120,000 people is a mental health service centre for a network of health service districts in North Queensland, Australia. The geographic network encompasses Lantana, 200 kilometres of coastal belt, and a vast remote region which includes islands and hinterland. LIMHS provides comprehensive mental health services to this area. LIMHS also offers clinical outreach and satellite services to other districts in the network. LIMHS does not have psychiatric rehabilitation services.

Clinical teams

Social workers in this study were engaged in the following multidisciplinary teams:

- the Crisis Assessment Treatment Team provides assessment, referral, crisis intervention, psychiatric emergency response and, critical extended hours care. The team also promotes awareness of mental health issues for the population of the Lantana District. The Crisis Assessment Treatment Team is the single entry point into LIMHS and facilitates admission into the in-patient unit;

- the Mobile Intensive Treatment Team (MITT) provides long-term intensive case management and assertive outreach to a small number (25) of vulnerable people with a serious mental illness who lived in the community with complex needs. The programme is designed to provide a range of treatment and support services to clients and their families through highly mobile modalities. The target population includes adults between the ages of

sixteen and sixty-four who have had frequent admissions to an acute psychiatric facility over the past few years. MITTs services are also extended to people who exhibit the potential for multiple admission in the future for such reasons as non-compliance with treatment;

- the Child and Youth Team offers children and young people [Indigenous and non-Indigenous] specialist assessment and treatment programmes. Typically the children have severe emotional disturbance or are at identifiable risk of developing a severe emotional disturbance. The service is staffed by a multidisciplinary team of MHPs;

- the Adult Teams provide a community based flexible service to the southern and northern suburbs of Lantana. The two teams aim to meet the specialist acute and continuing care needs of people with serious mental health disorders. They employ an eclectic approach to mental health problems utilising a bio-psycho-social framework;

- the Indigenous Mental Health Programme employs Indigenous workers to provide a community based service to meet the needs of Indigenous people with mental health problems and disorders. They employ a holistic approach to mental health problems using a psychosocial framework. They work from a multidisciplinary team using an Indigenous case management model;

- the Day-centre Programme is run from the main centre of the LIMHS. It was part of MITT. It had both outdoor and indoor recreational areas. Consumers typically involve themselves with group activities of their choice. Lunch is provided everyday for one dollar. A small bus picks consumers up from home and drops them off in the afternoon. A nurse is employed to coordinate the day-centre programme. The role is to protect consumers from abusive intrusion, recognise relapse for early intervention and to ensure the day-to-day activities are running smoothly. There are also volunteers involved who are skilled in creative arts. Social workers from MITT have input at all levels and involve consumers in activities, such as bush-walking, swimming and assisting consumers to take turns cooking the lunch. To gain access to the day-centre programme consumers require a current case manager and adhered to compliance with medication. The day-centre programme operates as a panopticon (Foucault, 1987), it allows the coordinator [designated psychiatric nursing position] to observe through a glass window, the behaviours of each consumer at any given time. If this staff member deems

the behaviours inappropriate, individual case managers are immediately contacted. This constant gaze controls consumers and affects not only what they do but how they view themselves (Bentham, 1995).

Thesis layout

Following this chapter, the second and third chapters provide reviews of available literature in relation to social work and mental health, and literature focusing on consumers and carers living with schizophrenia. Chapter four describes the aims and design of the case study and details the ethnographic and participatory research methods employed. Chapters five, six, seven, eight and nine present the data sets gathered from semi-structured interviews and/or focus group discussions with management, the community development worker, social workers and consumers and carers of LIMHS. Chapter ten is a data analysis chapter and brings the data of these five diverse group together, to answer the three research questions relating to the constraints and opportunities for participation and partnership at LIMHS; how social work is structured into or out of LIMHS and how social workers engage their mental health practice; and finally, whether or not consumers and carers perceive their needs to be met through LIMHS service delivery. Chapter eleven is a presentation of a potential model of social work service delivery for LIMHS.

Conclusion

This chapter introduced the overall aim and research question guiding this single ethnographic case study design. It introduced literature to elucidate the context of consumers and carers living with schizophrenia. The chapter introduced the theoretical frameworks of this research as primarily belonging to Giddens' (1984) structuration theory and politics of a third way (1998). The chapter located the researcher and presented a layout of the thesis. The next chapter continues to explore literature and major themes within the current area of to social work in mental health.

CHAPTER TWO

Social work in mental health services

> The domain of social work in mental health is that of the social context and social consequences of mental illness. The purpose of practice is to restore individual, family, and community well-being, to promote the development of each individual's power and control over their lives, and to promote principles of social justice. Social work practice occurs at the interface between the individual and the environment: social work activity begins with the individual, and extends to the contexts of family, social networks, community, and the broader society (AASW, 1999, p. 21).

The history of the Australian social work profession had its roots in charitable and benevolent organisations and hospital almoners (Kennedy, 1982). Following the psychodynamic, psychosocial and psychobiological progression of the analysis and treatment of psychiatric issues over the past seventy years, social work has evolved into a significant discipline in the overall care (and control) of psychiatric patients in hospitals or in community/family care. Social work has become an important discipline at all stages of diagnostic assessment, family therapy, rehabilitation and as a service broker between the client and support agencies (Pargiter, 1991).

The mental health field is a major employer of social workers in Australia. Very few positions are for new graduates. A survey conducted in Victoria during 1997 of social workers employed in mental health services found that the number of entry-level positions in clinical services had declined over the last ten years from 61 to 14. This may lead to a lack of opportunities for social workers to gain mental health experience in base grade positions (Association of Mental Health Social Workers, 1997).

Australian social workers initially acquire their knowledge of mental health service delivery by undertaking a mental health subject in their undergraduate training, and possibly choosing a mental health field education placement. Working in the mental health field, attending in-service training and undertaking self-initiated postgraduate studies further develops this expertise (Harries, 1999). There are no paid training posts for social workers in mental health facilities, as there are in psychiatry (Carter, 1999; Harries, 1999). In Queensland only 3 of the 9 established universities offer a discrete course (subject) in mental health (Harrison, 1999). This means that most social workers who go on to pursue a career in mental health, generalise their social work studies to this field of practice and learn "on the job".

Case management and the multidisciplinary team

Social work built its professionalism on the casework method (Richmond, 1917). Casework as a method engages processes of assessment, intervention, follow up and evaluation with referral and service brokerage as intimate parts of service delivery. Casework, however, with its focus on the individual or family, can be at odds with the larger mission of social work to promote social justice when it polarises the political position of vulnerable groups from assessment, intervention and evaluation processes. Social workers, through their Code of Ethics (AASW, 1999) are ethically bound to practices of social justice. It is the understanding of the real socio-political material context of people's lives which is the hallmark of social work practice and which distinguishes it from others in the helping profession.

Since 1995, Queensland Health policy directs the appointment of staff be made under specific professional discipline titles and not as generic mental health professionals. Despite this, LIMHS makes professional appointments (except those of psychiatry) under the "Mental Health Professional" (MHP) category. Mental health positions which used to be the domain of particular disciplines (nursing, psychology, social work, occupational therapy etc.) are open to applications from persons holding a myriad of professional qualifications. Members of disparate disciplines therefore compete for appointment, as if they have identical skills and knowledge.

A clause in the *Queensland Health Mental Health Services Certified Agreement* (1998) allows this to happen. While this clause stresses that all staff should have access to, and receive professional supervision from, a discipline senior of their own profession, it acknowledges a view about the interchangeability of diverse professional groups. This process is one of genericism, where professionals are appointed to generic mental health roles. This process ignores the specific skills and contributions to service delivery of specific professional disciplines and can lead to marginalisation of some disciplines over others and to a merging of knowledges, skills and values, concomitant with a loss of discipline specific knowledge, skills and values. Trademarks, such as social justice and person-in-environment focus of social work and trademarks of other professional groups can be lost to the service organisation.

Thus Globerman, MacKenzie Davies and Walsh (1996) documented concerns about the impact of hospital restructuring on social work. They perceived that role changes would be imposed on social workers from outside of the profession; social workers

would lose control over decisions about the social work role; and other disciplines would lack of understanding of social work roles as understood and performed by social workers themselves.

Treating disciplines as one homogenous group is a problem for social work. It can lead to the extinction of the skills, knowledge and values unique to the social work profession, leaving social workers vulnerable to co-option within the more powerful medical model. Further, it has the potential to marginalise social workers within mental health teams, or effectively silence the voice of social work by privileging disciplines for whom generic vacancies are more beneficial (Callum, 1999). The constraints on social workers resisting this practice is exemplified in Queensland Health memorandums that call for employees to apply for voluntary retirement on the basis that their "current knowledge and values are not matched, or critical to current, or future strategic outcomes" (M. Byrnes, personal communication, June 21, 2002).

Another feature of genericism is that particular frameworks of practice become endorsed. Thus LIMHS has adopted a clinical case management model. Not only at LIMHS, however, but in all human services in Australia, case management has become the prevailing approach to service delivery (McDonald, 1999). A contemporary view of case management in mental health was defined by Kanter (1989) as:

> a modality of mental health practice that, in coordination with the traditional psychiatric focus on biological and social functioning, address the overall maintenance of the mentally ill person's physical and social environment with the goals of facilitating his or her physical survival, personal growth, community participation and recovery from or adaption to mental illness (p. 361).

Kanter's definition, case management can be understood as a web that pulls together essential services for consumers into one local system with major objectives of "efficiency, effectiveness, accountability, accessibility, comprehensiveness and continuity" (Pyke, Clarke & Walters, 1991, p. 23). Social work is the profession with the most active claim to ownership of, and traditions consistent with, case management (Moxley, 1997; Raiff & Shore, 1993). Informed by an holistic framework, case management is pertinent to all phases of care and critical in the management phase (Jacobs et al., 1989). A case manager bears the major responsibility for ensuring that the clinical and functional needs unique to each consumer are met within the mental health system. Case managers are accountable for constructing the management plan that defines a suitable response to the presenting problem (Solomon, 1992).

Basically, there are two models of case management used by the clinical teams at LIMHS. Solomon (1992) described them as the Expanded Broker Model and the Full Support Model. The Full Support Model requires the case manager, with a small case-load [six people], to provide all the essential services without relying on referral or brokering the consumer to existing resources in the community. This is the model used by the Mobile Intensive Treatment Team (MITT) in Lantana. All of the other teams in Lantana work from the Expanded Broker Model. This model enables the case manager to service more consumers [25 people] and relies on some motivation and insight on the part of the consumer, and the use of existing psychiatric and generic support agencies.

Social workers engaging with the Full Support Model, such as those employed on Mobile Intensive Treatment Teams often undertake roles that conflict with their professional ethical code. This discord was explained in the context of mental health, with particular regard to regulated treatment, by Thornicroft (2000). Thornicroft (2000) urged MHPs to adopt a critical view of their practice and to focus their attention as much on the conditions of control in the background, as on the illuminated community treatment team in the foreground. He questioned the ethical basis of assertive community treatment including the intrusiveness of the state in seeking out and treating non-compliant patients on behalf of the broader community. Farmer and Bentley (2002) suggested that these dilemmas are presented in current mental health reform by simultaneously interpreting intervention as a service to patients and as a public-risk control strategy. This discourse has been taken up by social workers.

Despite *The National Standards for Mental Services* (1996) which uphold the right of consumers and carers to human dignity, many social workers consider home visits for forced treatment acceptable practice, providing this is in the 'best interests' of the consumer *or* the community. Foucault (1977) discussed the way in which psychiatric patients are subjected to an institutionally endorsed gaze that monitors their every move. More recently, authorised mental health practitioners, such as social workers, stand in for psychiatrists in performing this monitoring role.

Recent literature on the social work role within the mental health domain, has documented the roles, values and competencies required of social workers in Australia (see Bland, 2001). Clearly this is helpful for social workers. Such documents would also be helpful to other MHPs who undertake the same casework roles as social workers. Regardless of which discipline is assigned to a particular

consumer, they are expected to address all the problems affecting that person. This includes their social problems and issues of social justice. It cannot be denied that disciplines, other than social work, are also caring and humane, displaying a sense of social justice in their dealings with their clients (Gilbert, 2003). Nonetheless the particular mission of social work in regard to social justice is compromised when social workers are obliged to develop skills in roles for which they have no professional training and which may have outcomes of social control and containment rather than social justice and social care. A particular example of social workers being made responsible for medication facilitation exemplifies this dilemma. This dilemma is heightened when roles of medical intervention become more prevalent than other roles. For example, a study released by SANE Australia (2003) found that two thirds of consumers were denied counselling in mental health services. This may indicate that medical interventions are superseding other professional interventions or possibilities for practice.

Nonetheless, Farmer and Bentley (2002) remind us that the 'new' social work role of facilitating medication "enhances the probability that desired medication will help to alleviate bothersome symptoms and, most importantly, enhance the quality of a consumer's life" (p. 228). These benefits to consumers cannot be denied, however, located within this practice and role, under the direction of the psychiatrist, social workers coerce and supervise consumers who refuse to take their medication, with the threat of regulation for continued non-compliance. The dilemma "for social workers is to hold contradictory beliefs about clients while satisfying themselves that they are not being inconsistent" (Margolin, 1997, p. 35). This suggests that social workers are increasingly forced to live by two mutually exclusive mandates. That is, to use and not to use social justice principles and to exercise and not to exercise power, or in Orwell's (1949) terms, "to be mindful of absolute truth while telling carefully constructed lies" (p. 33) even to themselves.

Coglan and Cheers (2002) unequivocally reminded social workers that they are not authorised to undertake roles that involved medication, and urged them to focus on what they were licensed to do. In their opinion, social workers should focus on efficient and creative ways of supporting the community through establishing sound working relationships, assisting with their social circumstances and advocating on their behalf. This includes helping other team members who are not social workers, to identify useful resources and assist them to form sound intervention strategies by sharing professional insights gained through skilled social analysis.

Twenty-five years ago, Engel (1977) proposed the idea of a bio-psycho-social model to replace the biomedical model in mental health services. He argued that the biomedical model was inadequate when dealing with social problems and disadvantage surrounding mental illness and "a bio-psycho-social model provides a blueprint for research, a framework for teaching and a design for action in the real world of healthcare" (p. 134). Despite this attempt to change the theoretical paradigm underpinning service delivery, the social role remains ambiguous and the medical dominance found within mental health care persists as the overarching framework for assessment, intervention and analysis. Psychiatrists have a controlling stake in the decision-making, record keeping and governance of everyday patient care, even though much face-to-face contact is carried out by generic 'others' (Berg, 1996, Berg & Bowker, 1997). Despite Samson (1995) perceiving a decline in the medical dominance of psychiatry, this line of influence remains strong in mental health in Australia.

Under the legislative frameworks typical of most modern democratic societies, psychiatric practices tread a fine line between benefiting and harming the exercise of human rights (Breggin, 1993). This is largely because the cultural objectives of psychiatry and human rights are to some extent, opposed to one another. The basic principle of human rights is to create a 'firewall' on the degree of social authority and social isolation that is imposed on individuals. The speciality of psychiatry however, is to identify, label and modify deviant individuals so they can be 'properly fitted' into the social fabric. These fundamental differences sometimes threatened to turn psychiatry and human rights into antitheses.

Psychiatry has little trouble in establishing its potential benefit to the exercise of human rights when 'deviant' individuals acquiesce to a diagnosis of mental illness and treatment. An explicit article of human rights law for psychiatry is *Article Twelve of the International Covenant on Economic, Social and Cultural Rights* (1966). Specifically, it concerns the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. The human rights sentiment expressed in Article Twelve is the 'right to treatment'. This is often promoted by psychiatrists as being the most important human right in regard to psychiatry. Yet this ethic is invoked outside of a wider human rights perspective with competing demands. The propensity of professional groups to privilege particular ethics or rights, led Foucault (2000) to suggest that the real function of ethics and rights is to mask the exercise of power and control.

Multidisciplinary teams ought to be able to balance multiple analytic and practice possibilities. Yet this potential can be lost through structures of management which seek to rationalise the delivery of care, which may privilege some disciplines over others and which may keep some professions at more of less arms distance from then than other professions (Hatchuel, 1999; McKinley & Taylor, 1998). Management in the context of community mental health services is not entirely about the cogent tasks of resource allocation or task planning, it is also about developing identities that are self-governing and self-tasking in the team and in the field, in ways which are expected by the organisation. Furthermore, managers of services share common backgrounds, experiences and qualifications with members of their workforce that in theory equip them to anticipate and control subordinate professionals (Adams, 1998). The development of discipline specific identities in these conditions becomes problematic and leads to ambiguous disciplinary identity (Rose, 1992). While there could be some argument that generic practices should lead to increased team morale since "we all do the same thing", this has not proved to be the case, with Ovretveit (1993) describing mental health services as rife with inter-professional conflict, ambiguity, unfocused aims and ineffective leadership (Ovretveit, 1993).

Regardless of this divide between management and practitioners and between psychiatry and other professions, social workers tend to overemphasise their professional autonomy and to under-theorise the depth to which management and governmental technologies of the self, penetrate everyday practice (Rose, 1989). This study aimed to document the ways in which social work is structured into or out of LIMHS, and the ways in which social workers both regulate themselves in compliance with less than participatory practices with consumers and carers, and how social workers defy these technologies of the self, to remain true to social work and social justice, inclusive of participatory practices with consumers and carers.

Continuous improvement

The policy technologies of mental health reform are not merely a conduit for technical and structural change of organisations, they act as a technology of the self since "reform does not just change what we do. It also changes who we are; our social identity" (Bernstein, 1996, p. 73). That is, mental health reform brings about change in our subjective existence and our relations with one another (Rose, 1989), as we transform from social worker, occupational therapist, psychologist and psychiatric nurse to mental health professional. Social workers interact with each other and the consumers and carers as MHPs rather than social workers.

The scope and complexity of the mental health reform agenda are extensive. The reforms are presented as giving managers and organisations greater freedom in operational decisions and removing unnecessary constraints in financial and human resource management. Du Gay (1996) referred to this new form of governance as controlled de-control. He believed the state provides a new general mode of less visible regulation, but a much more subtle, self-regulating modus operandi. Rose (1996) described this type of regulation as an "improvised mix of physical, textual and moral elements that made it possible to govern in a neo liberal climate" (p. 58). Within all this, social workers are represented and encouraged to think about themselves as individuals who analyse themselves, improve their productivity and live an existence of control. This suggests that the value of individual social workers replaces collective social work identity. Social justice as a backdrop to communal (group) living is thus problematic.

A significant aspect of clinical governance is the reliance on making social workers themselves responsible for developing their skills for accessing evidence, ensuring that practice is 'evidence based', and being responsible for their own professional development and for the implementation of quality standards. Clinical standards have been developed to introduce the seminal 'best practice' to assist social workers to understand their responsibilities (Queensland Health, 2002). New entrepreneurial, professional selves are encouraged by these initiatives, and backed by the *National Standards for Mental Health Services* (Australian Health Ministers Advisory Committee, 1996) and the *Second National Mental Health Plan* (AHM, 1998).

The concept of the social worker as an autonomous practitioner, responsible for their own education and professional development is central to a number of initiatives, such as continuous improvement (Piper, 2000). Important for the mental health service is the clinical governance that takes its cue from the 'Quality Improvement Process'. This was introduced as a framework that measures performance and identifies opportunities for improvement in the delivery of services. This process monitors the generic service to ensure consistency of generically defined and imposed 'quality' of care and services.

A barrage of propaganda is relentlessly hitting the social workers' desks reminding them that they are now working in an environment in which excellence in clinical care will flourish. Information sheets and memos update social workers on the methods that might facilitate their clinical governance more effectively. For example, one such document reads: "improving the quality of mental health services is a people process.

Today's mental health professional is trained to be a thinker in a learning organisation, to analyse complex situations and to think constantly about how to simultaneously improve their own performance and that of the service", and "the mental health professional is becoming more reliant on information. An individual without information cannot take responsibility; and an individual who is given information cannot help but take responsibility" (QHEPS, 2002, p. 1).

Performative mental health services

In an era of the performative mental health service, what professionals do is under constant review through consumer and worker database information, performance appraisal and review mechanisms, case review, file audit and written reports. It is not only the possibility of the continuous gaze that is the issue, as in the panopticon (Bentham, 1995), it is the doubt and instability of being judged in diverse ways, by different means, through different agents and the requirement that social workers reach a standard of excellence, at moments of review, appraisal and audit. The flow of changing demands, expectations and indicators make social workers continually accountable for "any element within an open environment at any given instant" (Deleuze, 1992, p. 7). It is these "ethical and governmental techniques and practices, that are the means by which the competencies, conduct, statuses and duties of individuals are problematised and worked on" (Dean, 1995, p. 565). Workers however, experience guilt, uncertainty, instability and a new subjectivity. This presents a particular set of practices through which we act upon one another and ourselves in order to make us particular kinds of beings (Rose, 1992).

Within mental health services the process of transparency involves a philosophical shift in the nature of the relationship between workers and their work commitments. Particular roles, such as advocating for social justice, no longer have value or meaning and professional judgment is subordinated to the requirements of performativity, marketing and commercial decision making (Khan & Dominelli, 2000). The freedom for social workers to follow their Code of Ethics (AASW, 1999) based in a shared moral language is curtailed. This dynamic plays its part in what Sennett (1998) called the 'corrosion of character' and what Power (1994) termed a 'regress of mistrust'. The policy technologies of market, management and performativity leave no space for an autonomous or collective ethical self. These technologies have potentially profound consequences for the nature of social work practice. They "are not simply instruments, but a frame in which questions of who we are, or what we would like to become emerge" (Dean, 1995, p. 581).

In February 1997, the Mental Health Branch of the formerly named Commonwealth Department of Health and Child Safety commissioned research into the attitudes of MHPs towards people with mental illness and their carers. This major study, entitled the *Attitudes of Mental Health Professionals Project* (Mugford & Walters, 1998) involved consumers, carers, MHPs and psychiatrists coming together to examine these attitudes. The project concluded that consumers and carers felt more strongly than MHPs that they were given insufficient choice and participation in the care they received, that MHPs depended on pharmacology too much for treating consumers, and that it was difficult to talk to MHPs about problems. The project noted that the underlying problem was often referred to as the 'attitudes' held by MHPs.

The overwhelming view of the workshop participants in this study was that they experienced more stigma and prejudice from MHPs than from any other part of society. MHPs were considered to have deficient communication skills, be paternalistic in their attitudes to consumers and carers and refused to recognise that consumers and carers had a legitimate right to be involved in all aspects of care. MHPs were also considered not to have kept up with recent changes in mental health reform. Conversely, an Australian study (Tooth, Kalyanasundaram, Glover & Momenzadah, 2003) found that the negative attitudes held by MHPs are a major contributing factor motivating consumers towards their own recovery. The negative attitudes of MHPs therefore act as a paradox in propelling people towards wellness.

The Mugford & Walters (1998) report identified psychiatrists as the group within mental health services who exhibit the most distance between themselves and consumers. Psychiatrists have the lowest identification with consumer perspectives and values, and generate the lowest consumer and carer satisfaction with treatment. The report detailed the difficulties experienced by the facilitators of this research when attempting to engage psychiatrists in a series of plenary workshops. The complexities ranged from psychiatrists' reluctance to engage with process, decreasing attendance at workshops and their inability to share a sense of common vulnerability with other disciplines and with consumers and carers. The facilitators' concern about the psychiatrists' behaviour, led to the conclusion that psychiatrists need to acknowledge they have different and complementary (rather than superior) areas of expertise and knowledge, as well as areas of inexperience and ignorance. The authors believed that psychiatrists should improve their skills in working

cooperatively and democratically with fellow professionals, and with consumer and carer groups.

Another conclusion reached by consumers and carers in the above report, in reference to psychiatric training, was the need for psychiatrists to have further importance placed on their understanding of ethical and legal responsibilities to both consumers and carers, and the community as a whole. The present psychiatric curriculum appears to support the training of psychiatrists as 'monomodal gurus' and fails to teach psychiatrists their limitations on legal powers and skills (Mugford & Walters, 1998). These findings have profound implications for consumers and carers and for social workers in mental health services. Social workers attempting to protect the rights of consumers and carers are forced to confront this arrogant psychiatric ideology. Failure of social work case managers to present consumers and carers with fair processes and outcomes may result in the social workers themselves being blamed for oppressive psychiatric decisions.

According to Ellis (2003), a consumer author and mental health social worker, the divide between consumers and psychiatrists is due to a class barrier. She believed that psychiatrists in Australia, through their education at top private schools, inexperience of poverty or disadvantage and their high income and material wealth, produces a huge gap between their lived experience and those of consumers within mental health services. She advised psychiatrists who want to work collaboratively with consumers, to recognise class structure and its impacts on consumers. Failure to do this will see consumers continue to have their treatment compromised by disempowering practices that are the product of social class differences.

In an address to MHPs during the first initial workshop of the Education and Training Partnerships in Mental Health (Deakin Human Services Australia, 1999) Michael Wooldridge, the then Minister for Health and Family Services, stated that the onus is on all participants to create a new work-force culture that recognises consumer and carer contributions as its highest priority. Dr. Harvey Whiteford, the then Director of the Mental Health Branch in the Department of Health and Family Services, said the culture of consumer participation is to permeate mental health services. His message was clear; mental health services have been unresponsive to consumer and carer interests and needs, based on their disturbing encounters as recipients of mental health service delivery. He reassured MHPs that government policy was now explicitly designed to make sure that mental health services did not return to or maintain old practices of consumer and carer exclusion. The interests of consumers

and carers must be first and foremost and a new direction, motivated by evidence of effective intervention and quality outcomes for consumers and carers, was to be the 'order of the day'.

The objective set for social workers at the end of the Deakin Human Services project (1999) was that the social work profession set core entry level competency standards for new social workers going into mental health practice. Fundamentally, the competency standards would position the involvement of consumers and carers as its first priority and would ensure that the central attitudes and values of social workers were underpinned by a broad national consultation that involved an analysis of the different models and locations of mental health service delivery. The preferred model arising from the consultative process required the support of social work educators and the full endorsement of the AASW.

The AASW was also obliged to develop secondary level competency standards for specialist social work areas to assist existing social workers to maintain and increase their skills in providing services for people with a mental illness and their carers through adoption of the competencies and postgraduate curriculum modelled on that developed by the Royal Australian and New Zealand College of Psychiatrists. While this decision was endorsed by consumers and carers and the social workers involved in the workshops, it imposed an individual psychiatric ideology that rejected other viewpoints and approaches to the care of people experiencing mental ill health (Mugford & Walters, 1998).

Despite this latter directive, and under the direction of Dr. Robert Bland, the final report of *The Development of Competency Standards for Mental Health Social Workers* (AASW, 1999) reminds social workers of the importance of partnership and mutuality:

> social workers recognise the importance of working in respectful partnerships with consumers and family carers. These respectful partnerships are marked by efforts to ensure consumer and carer participation and choice in decision-making and self-determination (empowerment), as well as mutuality in assessment and action planning. Partnership and mutuality are values that extend to working with social work colleagues (p. 52).

The Competency Standards capture the specific practice domain of social work in mental health services. First, they offer social workers a definition of the overall purpose of social work in mental health services. Secondly, they describe the five fields of social work practice. They consist of one 'primary field', which is working with individuals, groups, families and communities and four 'secondary fields' involving management, research, policy and professional practice. Thirdly, each field is

described in terms of elements and finally, the required level of performance criteria is documented for each element.

If such standards are obligatory, social workers must have the power and will to enforce them. Farrant (1991) analysed the ways in which professional interests, particularly medical ones, attempt to retain control over community health and health promotion activities, to the exclusion of local community movements which represent different interpretations of health needs and solutions to health problems. Farrant (1991) argued that ideas of participation can be easily accommodated to existing power structures, so long as they remain rhetoric on the lips of well entrenched professionals, who are not themselves likely to demystify their own knowledge or to concede control of the health agenda to community groups.

This proved to be so in an Australian study by Wadsworth and Epstein (1998), who tried to encourage communication between consumers and MHPs in an acute mental health service in Victoria. Accordingly, they attempted to unearth the rationale preventing consumer empowerment arising from their involvement with MHPs. The study exposed the behaviour exhibited by MHPs when responding to consumers empathically. Most of the dialogue was dominated by MHPs' own views regarding their work and dissatisfaction. This behaviour erects emotional defences, which in turn, are built into organisational roles and habits that control consumers rather than enable participation.

Consumers and carers participating in the *Learning Together: Education and Training Partnerships in Mental Health* (Deakin Human Services Australia, 1999) workshops had some understanding of the different disciplines that work under the generic case management model. However, many were unaware of the particular discipline of their case manager. Nevertheless, through consumer and carer workshop processes held in Victoria and Queensland, consumers and carers identified the qualities, knowledge, attitudes and activities of social workers, and compared these qualities with other MHPs. Interventions identified as the most helpful transpired when a consumer was admitted to hospital, and during the initial onset of the mental illness. The most unhelpful experiences for this group were when social workers offered inappropriate community care. Specifically, these were social workers being too restrictive in their expectations of the consumers' abilities and lack of contact. Towards the end of the workshops, consumers and carers clearly identified the elements involved in good social work practice. They required social workers to have a good knowledge of psychiatric disorders and the treatment and

prognosis of the specific disorder. This included expertise with explaining the prescribed medication and the possible side effects. They also expected social workers to have a good working knowledge of mental health legislation and the ability to assist carers through the process of involuntary admissions of their family member. Another important factor for social workers was their ability to access appropriate community resources, including special benefits and accommodation.

Consumers and carers in the above study viewed social workers as the bridge between them, the treating psychiatrist and multidisciplinary team. Carers specifically expected social workers to have the ability to approach psychiatrists to gain relevant information on how best to support their relatives. They acknowledged the need for confidentiality, but reminded social workers of their holistic duty to care for all family members. The overarching theme of the consumer and carer consultations was their expectation for mental health social workers to treat them with dignity and to listen to their issues. Specifically, it was noted that returning phone calls was extremely important as was maintaining a non-judgemental attitude. Social workers who demonstrated warmth and empathy, who were both assertive and firm, and who were able to help consumers and carers identify and appropriately address their individual issues were appreciated. Consumers and carers concluded the Deakin Human Services (1999) workshop, by assuring social workers that they were valued, and social workers themselves need to appreciate their own value and the work they carry out.

From expert to facilitator

According to Rees (1991), the basic objective of empowerment is social justice. The AASW (1999) considers social justice for social workers to be:

> concerned with issues of stigma and discrimination, of political freedoms and civil rights, of promoting access to necessary treatment and support services, and of promoting consumer and carers' rights to participation and choice in mental health services. It is concerned with making all human services more accessible and responsive to the specific needs and wishes of people with mental illness, and their family carers (p. 22).

Sophie Freud (1999) argued that social workers need to recognise the interface between ethical and clinical practice, suggesting that at times 'so called' abnormal behaviour (including abnormal organisational behaviour) may be needed to achieve ends of social justice. She emphasised that "in times of moral crisis, often, abnormal behaviour came closer to the ideal of humanistic values" (p. 337). It is common practice for social workers, prepared to speak up and advocate in the face of antipathy, to be labelled a 'loose canon', or ostracised by their colleagues. This

suggests that unless social workers recognise the moral aspects of their work by positioning ethical principles as its highest purpose, and insist on the analysis and interface between societal arrangements and mental health, social justice will remain an elusive and rhetorical goal of mental health service providers. Empowerment has become a practice framework under which social workers agitate for social justice

Renaud (1996) defined empowerment as the relocation of power and decision-making to those most disadvantaged in the community. Empowerment has become a central theme of the policies for participation and partnership in mental health service delivery. Central to this discourse is a claim that participation and partnership processes are a response to increased demands from consumers and carers for an increase in control over their own health. However, there is a lack of evidence for this relationship (Little, 1989). Rather, this rhetoric positions power as consumers and carers and government 'working together'. Subsequently, social workers, and consumers and carers assume 'new' roles that reflect the empowerment discourse. Both groups are presented as empowered decision-makers, with government taking on the role of facilitator and coordinator, rather than a centralised and powerful planner (Campbell, 1990; Giddens, 1998). The intent of this dynamic is to encourage consumers and carers to take control of their own situations, including their own problems.

Despite the rhetoric of power being devolved to local levels, activities perceived by MHPs as participation may not result in empowerment or power sharing. For example, carers and consumers are invited by social workers to participate in their treatment plans, and involuntary consumers to attend the six monthly reviews of their Involuntary Treatment Order by the Queensland Mental Health Review Tribunal. They then become complicit in measures of government intervention in their lives that have already been decided by the state, social work case managers and the treating psychiatrist. This type of participation may reconcile consumers and carers to powerlessness. In these ways, social workers can use the notions of enabling and empowerment, as a facade that disguises control.

A diagnosis of schizophrenia is disempowering, with consumers believing that care and treatment reduces them to an even more powerless state (Barker 2000). For social workers, the concept of empowerment creates a major dilemma. Parsloe (1996) argued that the very idea of a social worker empowering a consumer contradicts any notion of equality. This was supported by a consumer participant attending a workshop held by Barr and Cochran (1992) who declared that the word

'empowerment' and the word 'professional' must not be conflated, as the two are in absolute contradiction.

Empowerment however, is a crucial aspect of attempts at meaningful participation or partnership (Stacey & Hills, 2001). It is however, premised on an act of agency by consumers, to step into and speak from a position of power. According to Pinches and Dunstone (1997) this opportunity of having a say over their treatment and service development is denied to consumers, when their credibility is questioned due to their diagnosis, their mental ill health. Behaviours which deny credibility in this way are paternalistic, rather than practices of empowerment.

Dunst, Hamby and Trivette (1996) saw an empowerment model of practice being built on the strengths of people rather than a model of correcting weaknesses. Saleeby (1992) is arguably the most well known author in the area of strengths based practice. Saleeby's (1992) approach views the people with whom social workers engage as equals, as persons, as opposed to definitions of consumers fundamentally resting upon an imposed psychiatric classification. Strengths based practice rests in a poststructuralist perspective, that demands a shift from professional work as the application of the power of knowledge, to professional work as a partnership.

<p align="center">Recovery and hope for a future</p>

Correlated with the concepts of participation and partnership is the notion of recovery. Buckland (2005) believed that recovery is:

> more about the journey than the destination. It is a process that involves an overall upward trend but is not linear or planned. It involves growth and setbacks, and periods of slow and rapid change. It is a process that is often lengthy and complex and does not necessarily mean symptom elimination or individuals returning to a pre-illness state (p. 9).

An Australian study (Tooth et al., 2003) of fifty-seven consumers who identified themselves as "in recovery", found that the most frequently reported factors of recovery included consumers determination to get better; the discovery of their own way to manage the illness; the recognition of need to help themselves and having friends who accepted them. The *Third National Mental Health Plan* (AHM, 2003) defined recovery as a:

> deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and, or roles…Recovery is both a process and an outcome and is essential for promoting hope, wellbeing, and a valued sense of self-determination for people with mental illness. A recovery orientation emphasises the development of new meaning and purpose for

consumers and the ability to pursue personal goals. Mental health service providers should operate within a framework that supports recovery (p. 11).

Hope is an important element on the journey from rehabilitation to recovery for people with schizophrenia. Clearly hope must come from within consumers and carers themselves, however, social workers can play a crucial role by instilling hope through developing an appropriate therapeutic alliance. Jacobsen and Curtis (2000) viewed this alliance as demonstrating limitless belief that things do not have to remain the same and that change can and does happen. It focuses on strengths, the future and celebrates small gains rather than demanding "quick fixes". Social workers can encourage hope by expanding the sphere of possibility, colouring life perceptions and sustaining consumers during periods of relapse.

Hatfield and Lefley (1993) discovered that hope was a common theme within reflective statements made by consumers. They also decried the lack of literature describing specific techniques and strategies for MHPs and carers to use when attempting to encourage hope more effectively. However, by the mid to late 1990s this literature began to emerge (Corrigan et al., 1999; Darlington & Bland, 1999; Onken et al., 2002; Spaniol, 2001) with the documentation of personal stories and anecdotal evidence from consumers in recovery (Deegan, 1996; Meagher, 1995; O'Hagan, 1999).

An Australian study by Darlington and Bland (1999) focused on different approaches for assisting seriously mentally ill people maintain hope. The most valuable approaches identified by the participants concerned MHP's ability to listen to them, to identify the consumers' strengths and to acknowledge small gains past and present. This study also unearthed the need for MHPs to demonstrate genuineness and have a good working knowledge of the consumers' specific illness. Most importantly, consumers highlighted the obligation for MHPs to cling to hope during periods that the consumer cannot.

Likewise, a Canadian study undertaken by Kirkpatrick, Landeen, Woodside and Byrne (2001) found that participants valued MHPs attempts to encourage, understand and support them. This was particularly important on the occasions that the consumer relapsed and their families withdrew. These authors recommended that MHPs in their interactions with consumers, speak openly, realistically and strategically about hope. Most importantly MHPs need to actively listen to consumers' experiences.

Philosopher Mark Kingwell (1999) observed that hope's 'true country' was the imagination. Social work is a discipline and a practice where the imagination has a role equal to that of the empiricism of the social sciences. By immersing ourselves in the humanities, and especially literature, we gain a much greater appreciation for the inner lives and experiences of others and are able to begin to imagine the value of their lives. We can glimpse the "other" as fully human and understand more fully irony, pathos, diversity and ambiguity (Kingwell, 1999). This suggests that the humanities can enlighten our moral lives.

Advocating active involvement

It is nonsense to assume that all participation is uniform and that consumers experience it in a similar way. There is an array of approaches to participation. One of these is Sherry Arnstein's (1969) "Ladder of Citizen Participation". Croft and Beresford (1992) used this model to argue that most current initiatives concerning groups facing particular disadvantage and marginalisation fall into the first two categories: manipulation and therapy.

Table 2.1 Ladder of participation: consumers and carers

Nonparticipation **Low**	(1) Manipulation & (2) Therapy	Manipulation and Therapy, are both non- participative. The aim is to use consumers and carers to further the government agenda. The proposed plan is best and the job of participation is to achieve public support by public relations. Therapy is to heal or teach consumers and carers.
Degrees of Tokenism	(3) Informing	Unplanned associations with consumers and carers that social workers note in the course of their work and bring to staff meetings or management
	(4) Consultation	Attitude surveys or a suggestion box in the foyer of the mental health service. Policy and planning meetings, and public enquiries.
	(5) Placation	For example, co-option of consumer advisory groups. It allows consumers and carers to recommend or plan infinitely but retains for management the privilege to determine the validity or viability of the advice.
Degrees of Citizen Power	(6) Partnership	Power is in fact redistributed through compromise between consumers, carers and management. Planning and decision-making tasks are shared e.g., through co-operative committees.
	(7) Delegated Power	Consumers and carers holding a clear majority of places on committees with delegated powers to make decisions. Consumers and carers now have the power to assure accountability of the Mental Health Service to them.
High	(8) Citizen Control	A consumer-managed project or service, where the staff is directly accountable to a consumer management committee who oversee all key activities. There are no intermediaries between it and the source of funds.

Adapted from: Arnstein's (1969) Ladder of Citizen Participation

Draper (1997) believed that obtaining feedback from consumers was useful but only part of an overall successful consumer participation strategy. Draper reported that many of the methods used to obtain consumer feedback, such as consumer satisfaction surveys, treat consumers as passive recipients of service and "reinforced traditional, professional and authority relationships" (p. 75). Despite best intentions, such approaches fail to recognise the value and importance of actively involving consumers as partners in decision-making and are clearly at odds with the growing

expectation that individuals and community take more responsibility for their health and that health is a shared responsibility.

Education, training and development

Findings from an Australian study by Ziguras, Henley, Conron and Crawford (1999) demonstrate the decline in opportunities for mental health social workers to attend training sessions and conferences. Rural social workers said that the pressures of work did not allow them to network with other rural staff and that isolation was a major issue. The most frequently raised concern of social workers in this study, was the diminishing emphasis on discipline specific roles and skills. Respondents felt that managers did not recognise the value of discipline-specific training, or the need for discipline specific supervision, or the discipline specific work they engaged. Respondents desired the nurturing of a professional identity. They suggested that increased liaison with university schools of social work was a way to improve access to quality social work training. They also called for mental health issues to receive greater prominence in undergraduate and postgraduate social work courses.

The *Learning Together Report* recommended "the relationships between consumers and service providers and carers and services providers, should be the primary focus of practice and research in mental health (Deakin Human Services Australia, 1999, p. 1). The framework promoted by the Report was informed by three approaches: "treat consumers and carers with respect and dignity … recognise the rights of consumers and carers … [and help them], take responsibility for their own [MHPs'] attitudes and behaviours" (pp. 64-5).

Conclusion

The literature reviewed in this chapter has serious implications for the future of social workers in mental health services and, in turn, the consumers and carers they serve. This is particularly so for those who genuinely attempt to uphold the principles of social justice. Notions of genericism and the multidisciplinary team camouflage the roles necessary to enable the social work mandate of ensuring social justice. Social workers are increasingly coerced into undertaking roles that contradict these notions. They are becoming facilitators of medication and forced treatment.

Resistance to co-option is difficult through constraints imposed on social workers from outside and inside the organisation. Psychiatrists continue to claim a controlling

stake in the decision-making and domination of social workers and consumers and carers, even though most of the work undertaken is by the case manager [often a social worker] (Berg, 1996; Berg & Bowker, 1997). This is regardless of the fact that the case manager is responsible and accountable for consumer and carer outcomes. The perceived inability of social work case managers to use their professional ethics and competencies as a basis for challenging psychiatry serves to support the status quo.

Managerialism demotes the social justice mission, and reduces the professional judgment of social workers to a secondary requirement in favour of performativity. Attempts by social workers to resist these neo-liberal aspects are countered as part of a larger process of ethical retooling in mental health services. This is replacing both consumer and carer judgment, with a commercial style of thinking. Consumers and carers however, do not value the new technological aspects of the entrepreneurial social worker. They require a focus on more respectful, personal services.

While this chapter has focused on eliciting the tensions confronting the field of mental health *per se* outside of the lived experience of consumers and carers, (e.g. this chapter has focused on the move towards generic versus discipline specific appointments and roles; practices of control and coercion versus practices of care; best interests of the client versus community safety; psychiatric definitions and interventions versus models of practice based in human rights; full support models of practice versus more traditional case management models; codes of practice and practice standards versus the right to practice from one's own professional code of ethics) the next chapter presents a more clinical appraisal of schizophrenia and delves into the lives of those diagnosed with schizophrenia and those who care for them. If there is a perceived disquiet between this and the next chapter, then this may be reflective of the real uneasiness between people who live with schizophrenia and those who care for them, and those who purport to serve them.

CHAPTER THREE
Living with schizophrenia

In this chapter a foundation is laid for understanding the dynamics of psychiatry and consumer and carer participation. The question of power and empowerment and how consumers and carers living with schizophrenia perceive it, is paramount to this study. The recognition of power and who holds it, or who is perceived to hold it, is also important in determining who has the mandate to make strategic decisions about policy, which ultimately affects the lives of consumers and carers. Therefore, the ideology that governs mental health services was critically examined to highlight current inequalities, which determine the degree to which consumer participation has developed in mental health services.

Schizophrenia defined

Psychiatry has the power to define schizophrenia, and prescribe its treatment (Boyle, 2002; Thomas & Cahill, 2004). The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; 4th Edition; APA, 1994) defines schizophrenia as "a constellation of signs and symptoms which may include delusions, hallucinations, disorganised speech or behaviour, a flattening in emotions and a restriction in thought, speech and goal-directed behaviour" (pp. 274-75).

The diagnosis and causality of schizophrenia has been a source of considerable controversy. Originally defined in 1896 by Kraepelin, as dementia praecox (as cited in Rosenhan & Seligman, 1989), the word schizophrenia as a diagnostic label was introduced by Swiss psychiatrist Eugen Bleuler in 1911, to describe the ways in which different brain functions appeared to split off from each other. Wilkie (1987) elucidated Bleuler's description by explaining that a person with schizophrenia could have disordered thoughts and perception while processing general information normally.

While this is a common understanding of the term schizophrenia, and one that has been utilised over many years, the Burdekin Report (1993) revealed increasing opposition to the use of the word schizophrenia. The major contention is that the English translation of the word actually means 'split (schizo)-mind (phrenia)', suggesting the person had several personality types (Burdekin, 1993; Jackson, 2001; Rosenhan & Seligman, 1989). People with schizophrenia and their advocates do not protest the principle of the *Diagnostic and Statistical Manual's* psychiatric diagnosis

itself. Foucault (1988) believed this lack of protest exemplifies that "truth becomes a sort of power, precisely because it is accepted as self-evident" (p. 107).

Notwithstanding the power of psychiatry, there are other discourses that provide the impetus for a reconsideration of a DSM-IV type diagnosis. Sass (1992) proposed that the psychiatric diagnosis of schizophrenia is central to discussions on the nature of mental disorder:

> The history of modern psychiatry is, in fact practically synonymous with the history of schizophrenia, the quintessential form of madness in our time. The attention lavished on this condition seems not, however, to have fathomed its mysteries, and to this day we remain largely ignorant of the causes, the underlying psychological structure, and even the precise diagnostic boundaries of this most strange and important of mental illnesses (p. 13).

Sass's (1992) proposal that schizophrenia remains a mystery to psychiatry, was supported by senior psychiatrist Ernest Hunter (2006), during a recent coronial inquest into the death by suicide of a female consumer of LIMHS, when he conceded that psychiatry did not have access to the inner mind of the individual. He went on to state that the outer world of a person may appear to be resolving, however, there was no way that one can guarantee the internal part of an individual's mind was as stable as their external presentation. This acknowledgment by Hunter on the limitations of psychiatry surprised his peers while simultaneously offering comfort to families living with schizophrenia and experiencing guilt for failing to notice signs that the person for whom they care was suicidal.

To refer to someone as a schizophrenic, as though they have changed into the illness, is demeaning and invalidates them. Those who become objects of psychiatry fall short of standards defined as 'normal' because they are 'mad'. Persons so objectified are caught up in mental health centres, trapped in poverty, on disability allowances, anaesthetised by anti-psychotic drugs and shamed in public (Danaher et al., 2000).

Despite these concerns about the use of the term schizophrenia this term is used in this research since it clearly denotes that group of mental health consumers and their families most caught up in mental health systems. Government departments actively promoting more generic terms such as 'people with mental health issues' (Cameron, 1995) camouflage the extreme disadvantage and stigmatisation faced by people suffering this severe form of mental illness. Schizophrenia is not just a mental health issue, it is the most debilitating of the psychiatric disorders (Byrne & Carroll, 1991) and people with this disorder were described by Burdekin (1993), as the most marginalised of all mental health sufferers. Further, generic labelling of mental

illness can be used as a gate-keeping mechanism which hinders people access to mental health services (Swan & Raphael, 1995).

Incidence and prevalence of schizophrenia

No epidemiological studies focus specifically on schizophrenia in Australia, however a study into people living with psychotic illness in Australia during 1997-98 found the prevalence of psychotic disorders in the adult population in urban areas to be in the range of 4 to 7 per 1,000. Schizophrenia and schizo-affective disorders account for over 60 per cent of these psychotic disorders (Jablensky et al., 1999). There is variability however, in the reported prevalence of schizophrenia because different studies use different methods of ascertainment (e.g., rural vs. urban, community vs. clinical) and different definitions of schizophrenia (narrow vs. broad, criterion based vs. clinical).

In Australia and New Zealand estimates have ranged from 0.2 per cent to 2.0 per cent of the population suffering schizophrenia (see e.g., the NZ Christchurch Epidemiological Study, Hornblow, Bushnell, Wells, Joyce, Oakley-Brown, 1990; and The Epidemiological Catchment Area (ECA) Study: Implications for Australia, Rey, 1992). An epidemiological study of the Riverland in South Australia (Clayer, McFarlane, Czechowicz & Wright, 1991) shows prevalence of schizophrenia of 1 per cent over a lifetime. This 1 per cent prevalence data, suggests that nearly 120,000 Australians are diagnosed annually with schizophrenia (Henderson, 1992). This prevalence level was utilised in the development of the *National Mental Health Strategy* in 1995.

The onset of schizophrenia usually occurs in early adulthood (Jablensky et al., 1999; McGorry, 1992; Rey, 1992). The affected person withdraws from others, becomes depressed or anxious and develops phobias or obsessions (National Mental Health Strategy, 1995). Young people are therefore incapacitated and dependent at an age when they would normally be adapting to independence, with the corollary that families are needed most at a time when they should be withdrawing from the intimate care of their offspring. When service providers are unaware of this 'schizophrenic' dynamic, they expect parents and families to increasing withdraw from their adolescent or young adult offspring. When this does not happen, parents, more usually the mother can be labelled as "overprotective". 'Normal' developmental psychology is applied to 'abnormal' psychological events.

In Australia, schizophrenia inflicts losses comparable to cancer and greater than heart disease, but is lifelong and recurrent. It is an isolating illness; 31 per cent of sufferers live alone, 59 per cent have an impaired ability to socialise and 35 per cent have no frequent close contact with relatives. Employment creates a meaningful social role and enhances the probability of a better outcome for psychiatric illness, but most (72%) of sufferers are unemployed. The lack of opportunity for employment limits rehabilitation (Jablensky et al., 1999).

Common theoretical explanations for the cause of schizophrenia

Investigative studies indicate that a number of different factors contribute to the onset of schizophrenia. Tensions are inherent between these different paradigmatic understandings of schizophrenia. Each of these definitional paradigms is presented below.

Genetic Factors	A predisposition to schizophrenia can run in families. In the general population, only 1 per cent of people develop schizophrenia. If one parent suffers from schizophrenia, the children have a 10 per cent chance of developing the condition (National Mental Health Strategy, 1995). In some cases, therefore, it appears that genetics play a role in the development of the illness. It is important to note that even when two people are genetically the same (identical twins), it is quite possible that only one of them will develop schizophrenia. We may conclude from this that genetic inheritance is not the only factor involved (Rosenhan & Seligman, 1989).
Biochemical Factors	Biochemical substances in the brain are involved in this condition, especially raised levels of a neurotransmitter called dopamine. One likely cause of this chemical imbalance is the person's genetic predisposition to the illness. However, the additional dopamine required to cause the psychotic symptoms may result from environmental influences (Rosenhan & Seligman, 1989).
Family Relationships	Family theorists argue that families somehow cause one or more members to become schizophrenic. Faulty parenting, traumatic emotional events in childhood, failure in parent-child bonding and disturbed family relationships have all been blamed for causing schizophrenia. No evidence supports the suggestion that family relationships cause the illness. Subsequently, these theories have been discarded. However, some people with schizophrenia are sensitive to any family tension that, for them, may be associated with relapses (Jacobs, Crichton & Visotina, 1989).
Environmental Factors	Stressful incidents often precede the onset of schizophrenia in vulnerable people. People with schizophrenia often become anxious, irritable and unable to concentrate before any acute symptoms are evident. This can cause relationships to deteriorate, possibly leading to divorce or unemployment. Often these factors are blamed for precipitating the illness when, in fact, the illness itself has caused the crisis. It is not therefore always clear whether stress is a precipitant, or a result, of illness (Carey & Leggatt, 1985).
Social Constructionist	Schizophrenia is a socially constructed phenomenon lacking scientific status. Power imbalances in society create a sense of anomie for those members who do not benefit from the economic, social and political constructs of a given society. This dispossession of place can result for some members in disassociation from the original self. This gives rise to delusional beliefs of the position of oneself in relation to existing social structures to avoid the pain of one's real socio-economic

and political position. Similarly, hallucinations can be understood as a means for dominant society to discount traumatic events which may have actually been perpetrated upon the bodies or minds of those so diagnosed. From a social constructionist viewpoint, the way to assist those currently diagnosed, is to help them understand the social and political forces that shape and provide meaning to their experiences, and help them reclaim their own constructions of self (Boyle, 2002).

The view taken in this study is not mutually exclusive. It is accepted that multiple factors (as outlined above) contribute to the development of schizophrenia in the individual. A person with a high genetic predisposition to schizophrenia, going through the normal stresses of adolescence, may experience a schizophrenic episode, which may then lead to a diagnosis of 'schizophrenia'. Others who have a moderate genetic predisposition may develop the illness following significant or traumatic environmental circumstances (Boyle, 2002).

<div align="center">Consumer and carer participation</div>

Consumer participation can be considered at different levels. At the micro level, it means being actively engaged in clinical service planning and treatment decisions. At a macro level it involves contributing to decisions about the way services operate, including planning and reform processes. Lloyd and King (2003) provided several reasons justifying consumer and carer participation in mental health services. First, consumers and carers need participation in mental health services and vice versa as this system lacks competition or consumer choice, as would be available to consumers in other business transactions. Consumers and carers cannot move their patronage to that of a competitor. In other words, all monopoly providers carry a particular burden of consultation to offset the license to be unresponsive. Secondly, consumers and carers often have a protracted involvement when they become involved in mental health services. Therefore, the quality and nature of the services they receive may have a disproportionate influence on their overall quality of life. Third and finally, mental illness is often disempowering and can destabilise confidence and personal autonomy. Mental health services can cast a consumer's identity as helpless, dependent and with little to offer, or it can provide an enabling environment through which the consumer can re-contact or develop competencies for and confidence in decision-making and social engagement. It is this enabling environment that policies of partnership and participation attempt to mobilise (Giddens, 1998).

This new direction is a far cry from older notions of schizophrenia, when the prognosis was limited to a view of schizophrenia as an incurable, chronic condition,

requiring daily compliance with psychotropic medication to enable any quality of life. This view offered little more than a marginal, dependant existence for people diagnosed with schizophrenia (Deegan, 1996; Schmook, 1994). An attitudinal shift from this view has come about through two major sources. First was the growth in the consumer movement which vigorously campaigned for the recognition of consumer rights. The second source was the expansion of knowledge in both clinical and rehabilitation areas. that has reshaped to some degree the way in which the long-term prognosis for consumers is defined (Anthony, 1993). It is clear from the literature that whenever changes to the mental health service system occur and new policies are developed recipients of those services, including consumer and carers, should be involved at all levels of planning, implementation and evaluation (Burdekin, 1993). The devolution of institutional care to the community has directly conferred power on consumers and carers to take more responsibility for their own care and treatment. Rather than delegating direct authority to take this responsibility, consumers and carers become directly involved as partners with mental health service providers. This is directly in line with neo-liberal philosophy and the "third way" of energising and invigorating community in co-partnership with state enterprises (Craig & Mayo, 1995; Dickerson, 1995; Giddens, 1998; Helfinger & Nixon, 1998).

It has been suggested that mental health service providers and clinicians must be sensitive to a number of issues that consumers face, including stigma, disenfranchisement and social circumstances if participation and inclusion of consumers and carers in service provision is to become a reality (Lloyd & King, 2003; Moore, 1996). Nothing obviates this socio-political understanding of the real life contexts of consumers than the issue of women with children. Several studies have focused on the reluctance of women with children to disclose mental illness for fear of losing custody of their children (Cogan, 1998; Hearle, Plant, Jenner, Barkla & McGrath, 1999). Once children are placed into care, it is difficult to get them back. Stretched resources make it difficult for family support workers to provide adequate visiting time with their children for these mothers. A study undertaken by Wragg (1995) into the assumptions held by workers and the community about mothers with serious mental illness, found that negative attitudes prevail. Some of these attitudes are that "children are irrevocably harmed by remaining in the care of parents who might be psychotic … they are incapable of caring for their children and that parents with a psychotic illness have no right to have children" (p. 1).

In another study (Byrne, Hearle, Plant, Barkla, Jenner, & McGrath, 2000) that focused on specific services for mothers with a serious mental illness, 77 service providers from a range of government and non-government agencies offered their views on the problems facing these parents, interventions required to address the problems and constraints to service delivery. The researchers found that current services were scarce; parent-based interventions were more helpful than those targeting children; and the lack of liaison between agencies and the lack of coordinated service provision were viewed as the major obstacles to effective service delivery. These results indicate the need for multiple agencies to be drawn into case management and participatory politics.

One of the issues that challenge mental health service providers seeking partnerships of participation with consumers is that few people voluntarily seek treatment for their mental disorder (Gosden, 2002). Several reasons have been put forward for why people might not voluntarily submit for psychiatric treatment. Torrey (1997) alleged that consumers' refusal to seek treatment stems from significantly impaired insight into their condition. According to Torrey (1997), a former US government psychiatrist, as many as 40 per cent of people formerly institutionalised, denied they were sick, and would not take medication unless it was enforced. *The Queensland Mental Health Act*, 2000 adopted a strategy [Community Treatment Order] for involuntary outpatient compliance, which makes patients' hospital release conditional upon compliance with both medical appointments and ingestion of medication. This is an attempt to guarantee people experiencing mental ill health will get treatment to prevent relapse and minimise the potential for violence. This resistance to volunteering for psychiatric intervention gave rise to an ongoing campaign by psychiatrists and relatives of the mentally ill, to amend mental health legislation in order to make it easier to impose involuntary treatment. Gosden (2002) believed that these campaigns strongly influenced the changes in the new *Acts*, particularly the expansion of criteria for involuntary treatment.

Consumer advisory groups

Chapter one described the shift away from provider-led services to user-centred services (Croft & Beresford, 1992) where participation by service users is the focus of policy makers attention. The modern consumer movement began in the United States during the sixties and then quickly spread around the world (Crawford, 1998). In Crawford's opinion, the consumer movement in that country was in part responsible for making government agencies more accountable and reactive to a

range of issues that were affecting ordinary people. Whilst ensuring that consumers and carers receive appropriate responses to their claims for service, consumer groups are also concerned with consumers being in control of their own destiny. This refers to both control in decision making about treatment plans, and control over everything to do with them and their life (McLean, 1995). In the international context mental health has been recognised as a critical public health issue (Desjarlais, Eisenberg, Good & Kleinman, 1995). Consumer movements around the world serve to strengthen and unify groups of individuals who challenge the ideology of services, and the way that services are developed and delivered (Carling, 1995). Nevertheless, consumer groups have largely developed independently of mental health services.

According to an Australian study (Spink, 2000), it is through the modern self-help movement that consumers "have had a significant effect on the development of advocacy for consumer and carer rights" (p. 7). Although some consumers are focused on improving their own mental health through self-help initiatives, others are determined to focus on alleviating the associated consequences that forced treatment and institutionalisation has had on their lives and that of their families. Likewise, McLean (1995) contended that through mutual support and self-help, consumers experience elevated self-validation and self-esteem that promotes their recovery:

> Consumers share feelings of disenfranchisement and powerlessness resulting from their perceived abuse by service providers and their experience of human rights violations in being institutionalised through involuntary commitment and forced treatment. Thus, they declare consumer empowerment as their fundamental goal. Empowerment is evoked as a means to correct those violations and the pervasive debilitating consequences of their encounters with the mental health system. Thus, empowerment came to mean self-determination and control over their entire lives, not just their treatment. Consumer alternatives, by engaging people as producers of their own activities (e.g. social change, self-help, advocacy, information exchange nor running a business), conceptually reject reliance on professionals. Instead they endorse the principles of self-determination and control as a means to their empowerment (p. 1053).

In Australia, service user participation has been incorporated into Australian Mental Health Policy under the *Statement of Rights and Responsibilities* (AHMAC, 1991). The National Community Advisory Group (NCAG), funded by the Commonwealth Government, was established in 1992 as a means by which consumers and carers could scrutinise the implementation of the *National Mental Health Strategy* and provide advice to the Federal Minister for Health and Child Safety regarding reform of mental health service provision in Australia. It has been a slow process for state and territory mental health services to establish their individual consumer advisory groups, whose key role is to provide advice to the NCAG. By 1994, however, the Mental Health Advisory Committee of Australia (AMHAC) agreed that all consumer

and carer groups should be represented on all peak national, state and territory bodies central to and influential in the consumer and carer movement. The Commonwealth Department of Aged Care (2000) believed these "initiatives have rippled through to the service delivery field such that these groups now have many more avenues to make their views heard … and have been an important element in increasing opportunities for consumer and carer input" (p. 118).

Many of these advisory groups have formal approval and direct reporting powers at Ministerial level (AAMHAC, 2000). The groups are crucial to the facilitation of consumer and carer involvement in legislative changes and major service transformation across Australia. At a direct service level, however, consumers and carer participation in policy and planning is not occurring in inclusive, methodical and effective ways. The expectation of the NSMHS (AHMAC, 1996) that consumers and carers be involved on a quality assured basis in planning and other decisions of local mental health services, appear not to have happened. This situation could be partially explained by the inability of national and state Consumer Advisory Groups (CAGs) to function autonomously from commonwealth and state governments (Behan, Killick & Whiteford, 1994; Forbes & Sashidharan 1997; Kopolow, 1981; Solomon, 1992).

According to Plant (1994), CAGs act as a conduit for government to influence and control the aspirations and advocacy mechanisms of consumers and carers. When an advisory group is appointed to report at a ministerial level, it is co-opted to the government agenda and subjected to a stretched and strictly controlled budget. Consequently, the group is unable to initiate an apposite stance, thereby reducing its effectiveness to advise, or represent consumers and carers. A consumer advisory group initiated or supported by government is left vulnerable to the power of dominant mental health ideology, thereby diluting the opportunity of remaining an independent voice. This is not to say that the consumer group formed in line with the regulations of the *National Mental Health Strategy* is not of value. What is problematic is that most Australian CAGs are funded by their local Mental Health Service and therefore under the direct control and supervision of mental health officials. This situation makes it difficult for them to be critical. Bishop (2002) in the book *Becoming an Ally* referred to this dynamic as tokenism whereby:

> A dominant group sometimes promotes a few members of an oppressed group to high positions and then uses them to claim there are no barriers preventing any members of that group from reaching a position with power and status. The people promoted are tokens, and the process is called tokenism. Tokens can also be used as a buffer between the dominant and oppressed groups. It is harder for the oppressed group to name the oppression and

make demands when members of their own group are representing the dominant group (p. 165).

Attempts by consumers to set up advisory groups may be thwarted by mental health service management. For example, the CAG for the Sunshine Coast in southern Queensland closed down during 2004. The former chairperson considered the approach towards the engagement of the CAG as a key factor in the group's demise. Areas of concern included a lack of training provided to CAG members; the service's disregard for CAG's protocols and procedures for requesting consumer or carer representation; the lack of formal replies offered to requests or inquiries put forward by the CAG; and the lack of consultation around the service's operational plan. According to the former chairperson, effective consumer and carer participation requires real rather than token commitment from the management of mental health services (Gledhill, 2004).

LIMHS sponsored the local Lantana Consumer Advisory Group (LCAG). The involvement of LCAG with the consumers at the day-centre programme is minimal. Although this group claims to represent all consumers and the chairperson sits on the executive committee for this purpose, there is a general feeling from the day-centre programme consumers that they are not being adequately represented as no consultation takes place between them and the chairperson. In a recent article in the Queensland Alliance (2006) the local chairperson of the LCAG stated, "CAGs exist primarily to assist mental health services through the accreditation process" (p. 15). However, the consumers in Lantana believe that the LCAG's role is to consult with them and advocate, lobby, educate and raise community awareness about mental health.

Emerging Australian literature that attempts to expose the disquiet surfacing amongst consumer ranks regarding consumers who capitulate to the government plan, has been documented by Meagher (2002), an author and consumer activist. Meagher voiced what she considers to be, the 'unspoken reality', whereby the consumer movement has members not involved with the overall good of consumer groups. Particular consumers are selfish, dishonest and lack integrity. The reasons offered are threefold. First, power plays that are detrimental to the future of consumer groups were evidenced. Particular consumers nominate for crucial roles, fail to provide feedback and refuse to consider peer perspectives when these are contrary to their own position. They also align themselves with 'important' associates, while using their peers as a means to an end. This situation is perceived as detrimental to the integrity of genuine consumer organisations. Secondly, the concern that consumer

voices are silenced, then replaced with "politically correct" versions. Finally, Meagher (2002) described the diversion of 'tricking' funders, by falsifying the expenditure of CAG grant monies. Consequently, a favoured few gained financial assistance. Meagher suggested that money represents power and the abuse of that power disempowers others. She went on to say that 'shooting the messenger' by exposing unethical practices, dishonesty and unsatisfactory performance, has become a commonplace way of ensuring the whistleblower is silenced and disgraced.

Gosden (2001) believed that consumer advisory groups present government with an opportunity to fill positions with people who are 'eager consumers', that is, voluntary patients. He believed that voluntary patients were not concerned with important issues such as psychiatric coercion. Consequently, the voices of involuntary patients are silenced, preventing their inclusion in crucial advisory outlets, such as the mass media, public forums, public inquiries and political lobbying. Alternatively, in an attempt to counteract this situation, Gosden (2001) pointed out that involuntary patients are now using alternative outlets to lobby, such as the internet. The voice of the involuntary patient has the same right to be heard, as that of the voluntary patient. It is worth noting that all of the literature cited in Gosden's (2001) research, had taken place without input from involuntary patients. In an attempt to correct this situation, involuntary consumers were included as participants of this research.

Psychiatry has been analysed as a powerful, oppressive and paternalistic discipline (Boyle, 2002; Breggin, 1993). According to Brown (1985), a consequence of deinstitutionalisation and the relocation of people with mental ill health to community care, has been a corresponding upsurge in the number of mental health critics. These consumer led groups, confront the power base that psychiatrists and other mental health workers assume. Forbes and Sashidharan (1997) argued that consumer involvement requires a commitment to, "presenting and opposing current mental health service ideologies in an effort to politicise the debate" (p. 496). The authors' argued that, "the strength of the user position ... is its opposition to present services and their underlying ideologies" (p. 496). Psychiatrists, other mental health professionals and those involved in policy-making contribute to a mental health philosophy that encourages service users to define their reality in terms of the dominant paradigm (Brown, Kordas & Reeves, 1994). The anti-psychiatry movement that questions very foundation of traditional, medically oriented psychiatry has eased in recent years (Hopton, 2006; Tilbury, 2002). However, it appears the consumer rights movement has picked up this baton.

The medical model

Taylor (1995), drawing on research conducted in the United Kingdom, pointed to the inherent contradictions within the government's community care policies based on the principles of 'normalisation' (Wolfensberger, 1972). These principles recommend that people experiencing mental ill health are to be valued first as persons with the same rights as anyone else in the community. At the same time government policy requires MHPs to identify 'high risk' consumers, those who experience loss of accommodation or a supportive relationship. Surveillance of people with schizophrenia is thus undertaken in this way or through police involvement. In a study focusing on mothers of offspring with schizophrenia, Flanagan (1998) found that people with schizophrenia are zealously over policed in terms of their drug use. During random raids of the family home, only small amounts of marijuana, if any, were found on these people. A conclusion can therefore be drawn that drug use is used as a reason for policing people experiencing mental ill health.

The medical model of health perpetuates power differentials that exist between service providers and service users (Banton, Clifford, Frosh, Lousada & Rosenthall, 1985; Brown et al., 1993; Raphael & Martinek, 1994). Diagnosing and pathologising consumers reduces them to an illness, the treatment of which relies upon an educated, well-trained professional. The relationship between consumer and MHP becomes one of object and expert. Psychiatrists and MHPs monitor and report consumers who fail to comply with prescribed oral and intravenous medication. This removes the rights of people with schizophrenia to refuse treatment. Most often the response in these cases is a home visit, by an MHP, for 'forced' treatment (Daniel, 1990; Mulvaney, 1994). Many people with schizophrenia avoid taking medication, some out of paranoia, some out of forgetfulness, and others because they fear the Parkinsonian twitching or stiffness that accompanies chronic usage. In a study undertaken by Tooth et al. (2003) consumers reported feeling stupefied, numb and slowed down; most wanting to sleep or lie down.

The emancipatory ideals of consumer consultation and participation contradict the norms of the medical model in mental health services. The common use of coercive psychiatric practices and treatment methods has profoundly disempowering impacts on consumers and carers. The ideology of the medical model particularly that of psychiatry does not accommodate a sharing of knowledge and power. It does not equate with partnership between service providers and service users. It does, however, provide tokenistic 'partnership' through the provision of information to

consumers and carers about decisions that have been made by psychiatrists about the consumer (Bastian, 1994; Drake, 1992; Forbes & Sashidharan, 1997; Pinches & Dunstone, 1997). A report by Seymour (2004) depicted LIMHS as operating a medically oriented model of care with a custodial approach.

Pinches and Dunstone (1997) viewed the medical model as a major barrier to consumer and carer participation. They argued that many consumers consider the historic and ongoing domination of the medical model in mental health services as narrow and disempowering. Consumers in their study were concerned that individual and social factors tend to be paid lip service, while medication is the main treatment method. This was perceived as detrimental to the opportunity for exploring alternative treatments. The consumers were also concerned about the way the dominant medical model and institutional culture have skewed attitudes and behaviours of some MHPs towards consumers and carers. Consumers have been denied credibility on input about their treatment, or service development and planning, being presumed 'too sick' to be listened to (Gawron, 1998; Pinches & Dunstone, 1997). Attempts to help consumers therefore tend towards paternalism rather than genuine empowerment.

Similarly, Ellis (2003) highlighted the boom in the pharmacological industry that is mainly due to the increased usage of pharmacology in contemporary mental health services. She told us of the concern within the consumer movement of society's preference for medication rather than socio-material interventions when dealing with symptoms of mental illness. The general consumer experience was that as soon as any deterioration is noted, medication levels are increased prior to considering social or material causes of deterioration.

Often consumers will be viewed as having co-morbid conditions, involving an Axis I diagnosis (schizophrenia) and an Axis II diagnosis (a personality disorder), if they are perceived as deviant. This 'so-called' characterologic diagnosis (DSM-IV, 1994) may be defined as immutable and untreatable, or poorly treatable and indicating a poor prognosis. A personality disorder often manifests as non-compliance with medication, a forensic patient, or someone displaying anti-social tendencies. These identified defects are deemed treatable by psychotherapy if the consumer is capable of honesty and at least partial insight (Gosden, 2001).

Psychotherapy deals with thoughts, emotions, and behaviour, but not with the brain itself. Psychotherapy does not deal with the biology of the brain, but with the activity

of the mind and the social behaviour of the individual. It is obvious that in psychotherapy mental illness does not mean brain disease. If brain disease were the case, the person would be a medical patient, not a mental patient. Dr. Thomas Szasz (1978) harshly referred to the 'psychiatric impostor' [who] "supports a common, culturally shared desire to equate and confuse brain and mind, nerves and nervousness' (p. 7). In addition, the medical model supports the idea that a person with a social or mental problem is ill. With much sympathy, it labels people mentally ill, and categorises mental health problems under the key term mental illness. Szasz explained it this way, "if we now classify certain forms of personal conduct as illness, it is because most people believe that the best way to deal with them is by responding to them as if they are medical diseases" (pp. 183).

The assumption that medical illness and mental illness are alike was dealt with by Szasz (1974) in his book *The Myth of Mental Illness*. He stated that it was:

> customary to define psychiatry as a medical specialty concerned with the study, diagnosis, and treatment of mental illnesses. This is a worthless and misleading definition. Mental illness is a myth…I have argued that, today, the notion of a person 'having a mental illness' is scientifically crippling. It provides professional assent to a popular rationalisation, namely, that problems in living, experienced and expressed in terms of so-called psychiatric symptoms, are basically similar to bodily diseases (p. 262).

Psychotherapy is a very contentious word. Social workers are more likely to understand this form of therapy by the names of different models of counselling, or the term, Family Therapy (Howe, 1986). However, many MHPs use the term psychotherapy in an elitist fashion and in turn, misuse the medical model to support psychotherapy.

Putting the last first

The *Consumer Focus Collaboration Document* (2001) provides evidence of consumer participation in health. It highlights the importance of ensuring consumers and carers are involved at the 'coalface' of service delivery. This document used the results from the *National Survey of Mental Health Services* (1998) to claim that the involvement of consumers and carers in mental health service development is increasing. Quoting figures from the *Australian Health Care Agreements Annual Performance Report 1999*, the National survey revealed that between 1997 and 1998, 74 per cent of mental health service organisations in Australia had 'some type' of formal mechanism in place for consumer participation. This figure has steadily increased from a baseline of 53 per cent between 1993 and 1994. The authors concluded that 90 per cent of mental health organisations 'informed' consumers and

carers about what to expect from their mental health service. Informing people what to expect is not participation in the sense of the third way (Giddens, 1998). For an official government document to proclaim this finding in the context of success and evidence of participatory modalities is of concern.

The Commonwealth Department of Health and Aged Care (2001) also recognised that "consumer and carer participation and partnership in the design and delivery of mental health services helps ensure more responsive providers, better quality care and more empowerment for consumers" (p.80). Nevertheless, increased client input, which might lead to responsive services, is reliant upon the sharing of power and authority within mental health services (Brown et al., 1994; Croft & Beresford, 1992, 1994; Koplow, 1981; Weir & Casey, 1996). Historically, mental health consumers have been passive recipients of services. Increasing service user participation involves a reassessment of the traditional power balance between service providers and service users. According to Croft and Beresford (1994), this generates, "opposition and resistance ... It arouses fear and hostility among some power holders" (p. 64). The majority of service providers do not accept the need for a shift in their power base and the rise of advocacy for people once totally dependent on professionals for their treatment and care (AHMAC, 1997; Brown et al., 1993; Solomon, 1992; Weir & Casey, 1996).

Consumers' participating in their own treatment and care, as not feasible, has been rationalised in numerous ways. Consumers are viewed as unreliable due to spasmodic episodes of illness, or their acuity distorted because of their specific diagnosis (Bastian, 1994; Brown, et al., 1993; Pinches & Dunstone, 1997). These beliefs reinforce the view that people with schizophrenia are ineffectual at whatever they may attempt. Alternatively, a wealth of literature exploring ways of dealing with these problems or deficits has been documented by consumers and consumer groups and in some cases requires the support of service providers (Bastian, 1994; Berger, Carter, Casey & Litchfield, 1996; Epstien & Shaw, 1997). This contribution to current literature suggests that blaming the victim has run its course.

A number of authors refer to the 'culture' of mental health services as disabling for consumer participation (Bastian 1994; Kopolow 1981; Solomon, 1992). Cultural constraints to consumer participation are often less obvious than those that are political or economic as they comprise:

> a range of taken for granted, usually non-contestable values, beliefs, rules, practices and norms which seem to remain largely unidentified, or at least unarticulated, but which

contribute to the production and reproduction of established relationships of power and advantage (Solomon, 1992, p. 175).

Traditionally, the culture of mental health services has been to maintain the status quo. Engaging consumers in decision-making, concerning their own treatment and care, or the running of the service remains notional and idealistic. When power-holders in mental health services fail to actively encourage consumer participation, they deny consumers the opportunity of attaining meaningful and influential positions. This reinforces a reality where it is "the norm for professionals to exercise power and for consumers to be passive recipients of benefaction" (Luke, 1974, p. 62).

According to Lloyd and King (2003), resolving MHPs resistance to participatory policies is particularly problematic and has to be addressed from multiple fronts. The authors recommended that team leaders build collaboration and partnership considerations into both MHPs' core clinical accountability and performance and appraisal processes. They also recommended that MHPs established working parties to focus on specific aspects of consumer and carer participation and institute programmes that involve both consumers and MHPs working together to offer MHPs an opportunity to view consumers' contributions first hand. On a more structural level, Lloyd and King (2003) encouraged MHPs to form strong links with the non-government sector as a powerful ally when applying pressure on the mental health service in a bid to increase consumer and carer participation. Finally, staff education about new models of service delivery must involve consumers and carers in order that MHPs gain greater appreciation of the lived experience of consumers in an educative rather than a treatment setting.

Staff recruitment

In Queensland, CAGs requesting involvement in the selection of staff is largely disregarded (Gledhill, 2004). The AMHCA (McGrath, 2000) believed this to be one of the most contentious issues for mental health service providers, regardless of consumer and carer participation in staff selection processes being identified as core a Standard of practice by the Australian Health Ministers Advisory Committee and as stipulated in the NSMHS (AHMAC, 1996, Standard 3.2). Where involvement of consumers and carers on selection panels has occurred, this has not been at the level of professional or management positions. Consumers and carers are therefore engaged at lesser than influential levels of participation. Further, the AMHAC (McGrath, 2000) suggested public sector standards that requiring a minimum level of participation for consumers and carers on recruitment panels do not extend to non-

government or private service providers which also weaken the influence of consumers and carers across the mental health service spectrum.

The Australian Mental Health Advisory Council (McGrath, 2000) believed that opposition by MHPs to consumers and carers on selection panels for fear of "personal preferences" or on the grounds of "personal (rather than professional) information" could be challenged, as the AMHAC demands that consumers undertaken training in appointment procedures set down by the Equal Employment Opportunity Commission. This requirement is not compulsory for other members of the panel. Clearly, anyone on a recruitment panel may be biased and mechanisms are in place to counter this. Further, the suggestion that consumers and carers are less capable of taking a professional approach than the other panel members is discriminatory.

Consumer day-centre programmes

Employment of consumers of mental health services in the workforce has traditionally posed a problem for society. Over 80% of people in Australia suffering a mental illness are unemployed (Hughes, 2005). Large mental health institutions therefore often have facilities for providing occupational and industrial therapies to consumers. Activities range from repetitive assembly and the construction of wooden toys and furniture to working in metal shops. Employment in horticultural settings is also available. Consumers are offered a graded series of jobs, which commence from least to more challenging levels. Consumers who live nearby these facilities are able to commute to these facilities everyday (Leff & Trieman, 1998). A community model that provides consumers with some of the supportive elements of the institutions is the Clubhouse Model (Glickman, 1993). This is an attempt to offer consumers, living in the community, meaningful paid work in a supportive environment.

Mark Glickman (1993), the first coordinator of Fountain House in New York pioneered the innovative Clubhouse model. Members of Fountain House have educated other interested stakeholders at an international level to set up similar centres. Glickman considered that people working with mental health consumers in relation to community, including work engagement:

> must allow people to pace themselves, because it is beyond our ability to say what someone can or cannot do. I can understand the temptation of well meaning people to attempt to mandate participation … participation is based upon the success of opportunities and relationships for consumers and carers and is not effected by artificially imposed guidelines (p. 1).

Yet, Warner and Mandiberg (2003) found that employment helps to both reduce the alienation of people with schizophrenia and aids their recovery. The Clubhouse model enables consumers to enter the workforce in a manner and speed best suited to their needs. The programme operates from a 'clubhouse' where club members are people with a disabling psychiatric illness. Club members have access to employment, living skills and accommodation programmes. Employment schemes are varied but usually involve in-house work programmes to learn new skills and redevelop skills lost by hospitalisation, and to rebuild confidence. The model guarantees employers an agreed standard of employment each day. This involves a trained 'backup person' to fill the role when a particular person is unable to work (Jackson, 2001). Multiple people are therefore trained and available to fulfil a particular position.

The clubhouse model involves assistance with housing, clinical, legal, financial and personal issues. It provides assistance for people to discontinue employment and access disability payments without being penalised at either end of this continuum. It ensures that the inability of club members to continue working at particular times is not seen as a failure of the individual, but an indication that rehabilitation and support may be needed at these times in place of a work requirement. It is recognised that the process of regaining confidence and building skills requires patience and support (Jackson, 2001).

Loneliness, the lack of social contact, relationship connections, meaningful activities and daily structure are common experiences for consumers with schizophrenia living in the community. The development of day-programmes and drop-in centres are aimed at addressing these issues. In New South Wales, the Australian Capital Territory and Victoria, there are two main government approaches to day-centre programmes. The first approach is the living skills centres which take an educational approach teaching consumers skills of cooking, shopping, budgeting and personal development. The second approach focuses on activities, social support and drop-in centres (Seymour, 2004). Although the day-centre programme in Lantana offers some educational elements, the latter approach more closely resembles the current situation in Lantana (Seymour, 2004). Seymour criticised the day-centre programme of Lantana in terms of its engagement of consumers in activities not resembling those everyday activities engaged by other members of the community. Further, Seymour (2004) felt that the LIMHS day-centre programme failed to provide opportunities for "normal" social contact and community interaction. He felt that this

led to over-dependence by consumers on staff and was generally a stigmatising environment for LIMHS consumers.

Knowledge and training

One of the major factors for consumers of mental health services becoming well is that they are not wholly reliant upon a professional 'other' (Bastian, 1994; Berger et al., 1997; Dixon, Krauss & Lehman, 1994; Koplow, 1981). Consumers became more self-sufficient as they gain insight and knowledge about their illness. Saul (1995) suggested that, "to know, was to instinctively understand the relationship between what you know and what you do" (p. 5). This knowledge provides the basis from which consumers can voice their concerns and challenge service providers regarding their own treatment and care. Consumers writing in the area of participation point to an increase in self-confidence and self-esteem as they bridge the gap in knowledge between themselves and service providers (Bastian, 1994; Berger et al., 1997).

One of the greatest impediments to effective participation is the lack of knowledge that many consumers have regarding choices in their treatment, medication and care; and limited skills and training (Croft & Beresford, 1992; Weir & Casey, 1996). In the opinion of Clarke (1994), an author and consumer:

> education is something that is often interrupted by mental illness yet consumers are expected to be able to understand complex concepts … a knowledge of whatever rights you have is necessary to notice breaches and it seems that only a small percentage of consumers are aware of even basic human rights, let alone any specific rights relating to services. Even consumers with a good education do not necessarily understand the jargon of another field (p. 1).

Other important ingredients to increasing consumer participation include personal development, skill development, practical support and support from service providers (Croft & Beresford, 1992; NCAG, 1997).

The NSMHS (AHMAC, 1996) emphasised the need to maximise consumer involvement through the introduction of effective policies and procedures, and the provision of training and support for consumers. Recent literature has clearly demonstrated that consumers themselves are demanding a greater role in all aspects of mental health service provision (see National Consumer Advisory Group, 1995). In Australia, the *Lemon Tree Learning Project* (Epstein & Shaw, 1997) and a *Toolkit for Mental Health Consumer Participation* (Nolan, 1997) are useful guides to establishing and maintaining significant consumer involvement. While consumer groups demonstrate a desire to participate in planning, literature indicates that such

involvement requires knowledge and skills that consumers may not already possess (Campbell 1990; Chamberlin 1988). Despite efforts to promote consumer participation, little has been published on the training of consumers for the new roles they are asked to undertake.

It is now recognised that former patients of mental health services have unique and valuable insights for mental health services (Epstein & Wadsworth, 1994; Felton et. al., 1995; McGill & Patterson, 1990; Segal et al., 1993). Moxley (1997) considered the expansion of consumer roles in psychiatric rehabilitation services to include that of outreach to consumers. In order for this role to be realised, mental health service providers need to recognise that past consumers offer special expertise complementary to that of professionals, and legitimise these credentials.

Meehan and Blum (1994) also recognised that past consumers offer expertise not otherwise available to mental health services, including the sharing of concrete and practical skills of managing life with a mental illness. They also offer positive role models for consumers in hospital. Sherman and Porter's (1991) research demonstrated that the employment of former consumers in formal and paid casework aide roles helps their own mental health prognosis in the long term. Other consumer support programmes highlight the value of peer involvement as counsellors, consultants and transitional aides for consumers in both hospital and community settings (Barry & Schaecken, 1995; Felton et al., 1995; McGill & Patterson, 1990). Engagement of past and present consumers with each other therefore is beneficial to the service organisation, consumers presently suffering mental illness, and former mental health care consumers.

Despite these documented benefits of consumer and carer engagement in mental health, there is little available literature presenting consumer and carer experiences and perspectives on their participation in an evolving mental health service system. This study which intimately involved consumers and carers therefore contributes to building this literature.

Conclusion

This chapter elucidated the policy and literary contributions to mental health consumer participation. Participation has been highlighted as beneficial to both consumers and mental health service providers. A number of barriers to participation have been identified. The culture of the mental health service is one that perpetuates false beliefs and myths about consumers and service providers. Existing power

differentials are a product of these myths and false beliefs and hinder meaningful participation by consumers within the service.

This chapter grappled with some of the tensions within the field of mental health, presented in the previous chapter, from the perspective of those who live with schizophrenia and those who care for them, and they do so in a way which bode ill for the development of models of participation and partnership built upon true equality. Consumers and carers therefore perceive a mental health system which privileges the voice of psychiatry over their own; which engages practices of coercion and control over practices of care; which privileges the 'safety' of the community over their own human rights; which demands openness and honesty from them while operating in a system seeped in secrecy (confidentiality); and which privileges the economic 'bottom line' over their needs and interests.

Having surveyed literature and research concerning the context of consumers and carers living with schizophrenia, the following chapter introduces the manner in which the study was conducted. It presents specific information on the methodological rationale and scope of the thesis. It also offers explicit information concerning the research techniques, planning and processes of data collection.

CHAPTER FOUR
Research Design and Methodology

> I am not a researcher but I am many things. One of the myriad factors that has made me who and what I am is that I am a consumer of psychiatric services. I make the point because it is vital that the individuality of people with consumer and carer experiences is always respected. Assumptions are made about the needs and wishes of consumers and carers participating as if we are a class, not a number of individuals with perhaps some common experiences. Consumers, ex-consumers and carers are surely the best resource available to any research regarding the psychiatric system. We may not always see the problems, but most of us feel the effects at some point. Any valid research is likely to impact on our lives, so research into any issues within the system should have consumer and carer input into the design (Clarke, 1994, pp. 1-3).

In chapters one, two and three the socio-political contexts of mental health services including the particular positioning of consumers, carers and social work was explicated. This chapter presents the research design and methodology through which this research was conducted. The ethnographic, participatory design reported in this study is qualitative, flexible and based on the experiences, views and opinions of participants elicited through:

(i)   educative sessions for participant consumers ,

(ii)   in-depth focused group interviews (Krueger, 1994; Morgan, 1991; Stewart & Shamdasani, 1990), and

(iii)   individual interviews (Erlandsen et al., 1993; Sarantokos, 1993) using a semi-structured interview schedule (Minichiello et al., 1997; Patton, 1990; Rubin & Babbie, 1997).

The data collection of participants' experiences was facilitated by these techniques due to their non-intrusive, didactic nature appropriate to the collection of data around potentially sensitive issues (Erlandsen et al., 1993). This approach constituted the primary method of detailed data collection from participants, as discussed later in this chapter.

Research paradigm

This study used qualitative, case study research methodology (Denzin & Lincoln, 2000). A case study is an intensive description and analysis of a single unit (Yin, 1988) or bounded system (Stake, 1994) employed to gain an in-depth understanding of a situation and its meaning for those involved in the case at hand. Case studies are therefore particularistic, descriptive and heuristic (Stake, 2000). This thesis focuses on an Integrated Mental Health Service called Lantana (LIMHS), as the unit

of case study and analysis. Discourses of mental health practice were documented from the perspectives of management (the manager and the services development coordinator); the community development worker; social workers; and consumers and the carers employed by or interfacing intimately with this single service provider. These research participants provided 'thick descriptions' (Denzin & Lincoln, 2000; Geertz, 1973; Stake, 2000; Yin, 1988) of their perceptions of: (i) policies of participation and partnerships of consumers and carers in one mental health unit, Lantana; (ii) the positioning and practice of social work at LIMHS; and (iii) whether or not LIMHS was meeting the needs of consumers and carers from a consumer and carer perspective.

Data collected in the form of these "thick descriptions" were used to meet the overarching aim of this study which was to develop a model of social work service delivery which could accommodate new policy directives of consumer partnership and participation and meet consumer and carer needs.

Stake (2000) described the use of case study methodology as follows:

> The case is of secondary interest, it plays a supportive role and it facilitates our understanding of something else. The case is still looked at in-depth, its contexts scrutinised, its ordinary activities detailed, but all because it helps the researcher to pursue the external interest (p.437).

Similarly Yin (1988) viewed the case study as a focus for investigating a contemporary phenomenon within a real life context. Using Lantana as a case study provided the means for this research to articulate the opportunities and constraints of one mental health service to engage partnerships and participation with consumers and carers of mental health services as per *Standard 3 of the NHMHS* (1996), and the place of social work in this endeavour.

Case study research demands ethnographic engagement. As defined by Altheide (1998), "[qualitative research] is carried out in ways that are sensitive to the nature of human and cultural social contexts, and is commonly guided by the ethic to remain loyal to the phenomena under study" (p. 290). Qualitative methodology has been discussed by numerous authors (Beanland, Schneider, Lobiondo-Wood, & Haber 1999; Cresswell, 1998; Guba & Lincoln, 1989; Lackey & Gates, 1997) as an increasingly acceptable research approach and as a way of identifying and unravelling political assumptions embedded in our social institutions (Marshall & Rossman, 1995). Ethnographic case study research enables the researcher to view similarities and differences between people engaged with and experiencing similar

phenomenon. It engages the researcher in setting aside their own preconceptions to explore a setting from the perspective of its intimates (Walker, 1985). This is the hallmark of undertaking an ethnographic case study research.

Ethnographic case study research is part of a much larger qualitative research paradigm. Qualitative research:

(i)   is concerned with the meanings people attach to things in their lives;

(ii)   is inductive;

(iii)   studies settings and people holistically;

(iv)   is concerned with how people think and act in their everyday lives;

(v)   is undertaken by researchers who consider that all perspectives are worthy of study;

(vi)   is undertaken by researchers who emphasise the meaningfulness of their research;

(vii)   is undertaken by researchers who consider there is something to be learned in all settings and groups;

(viii) is a craft rather than a science.

> (From Taylor and Bogdan, 1998, pp.7–10).

LIMHS not only provided the case study for this research, but provided a naturalistic setting from which the research was conducted (Lincoln & Guba, 1985, 1989). The naturalistic setting of research engagement was enhanced since the majority of participants were known to each other and carers' interviews were held in their own home. All participants in this study were either employed by, or receiving services from the same mental health service, or caring for a person receiving such services.

The critical research paradigm

The qualitative research methodology employed in this study borrowed from the critical paradigm of Kincheloe and McLaren (1994) in the following ways:

(a)   unravelled aspects of domination that occur in the practices of Lantana; articulated the social construction of consumers and carers within one mental health service;

(b)   utilised the theories of Foucault and Giddens to postulate that social workers and other mental health service professionals can "determine their own existence" (Kincheloe & McLaren, 1994, p.139) in their relationship to consumers and carers;

(c)   aspired to the critical empowerment rather than subjugation (Kincheloe and McLaren, 1994, p.139) of mental health consumers and carers;

(d)   took the form of "social or cultural criticism" (McKincheloe and McLaren, 1994, p.139) by examining the ways in which mental health discourse is implicated in relations of power;

(e)   participants in the study could begin to perceive mental health as a site within larger economies of power and privilege from which they, as mental health consumers and carers, were largely discounted;

(f)   allowed for exploration of alternative ways of being (see chapter 11);

(g)   focused on the current workplace and mental health practice of one service provider, Lantana and was therefore based in a practice site rather than remaining in the domain of theory.

Participatory research

Participatory research has the potential to empower historically marginalised groups. It locates knowledge within the social, political and material history of the knower and regards this as a vantage point from which to see, and acknowledge verifiable claims made by these groups. Since participatory research serves as a tool of social, political and economic liberation, it must assist in clearly identifying what needs to be changed and what processes help or hinder that change. In order to position a project in the lived concerns and experiences of people historically marginalised, participatory researchers self-consciously work with the community to produce knowledge. They work "from the perspective of researchers while at the same time maintain(ing) a sense of connectedness" (Rodriguez, 1996, p. 425).

Research about, rather than with consumer and carer participation has been more prevalent than participatory research with consumers and carers (Ellis, 1993). In more recent times however, research on policy and practice in Australia has seen a major epistemological change (Mugford & Walters, 1998), whereby consumers and carers have been transformed from passive respondents or objects of research, to active participants in the research endeavour (Buckland, 2005).

Engaging in dialogue with consumers and carers reveals the social subjectivities of consumers and carers with whom social workers engage. A dialogue embedded within critical theory shapes the nature of the working partnership, and leads to politicised working relationships. This type of engagement enables social workers to forge partnerships with consumers and carers that have the potential to liberate (Freire, 1996) and empower (Rees, 1991) marginalised groups and to focus their

research activity on high risk environments (Labonte, 1992) rather than focus on individuals and groups themselves outside of the environments in which they live.

Social work, with its emphasis on social justice, shares this person –in-environment focus. Gorman (1993) considered social workers to be in a privileged, enabling position when interacting with those who are marginalised through the structures of society. Participatory research enables voices of the marginalised to be documented and has an overall goal of contributing to the betterment of their lives. This study used the discourse of consumers and carers to develop a model of social work service delivery, which potentially enables active, coordinated, respectful consumer and carer participation at LIMHS.

Locating the researcher

I considered myself as interfacing the insider/outsider researcher status in this study. James Banks (1998) stated that insider researchers sanction a given community's knowledges and perspectives by sharing common cultural intuitiveness. Outsider researchers have a different cultural frame of reference to the group under study and are not perceived by members of the group under study, as having an insiders' point of view. My claim to insider researcher status is accrued through my work as a mental health social worker and part of the mental health system and from the more intimate perspective of experiencing life with a member of my family who has a mental illness. It is a combination of these professional and personal contexts, which led to me advocating for and advancing the views of consumers and carers in my work and my research (Kincheloe and McLaren, 1994). Nonetheless, it would be arrogant of me to assume that this nominal membership of the group *per se* assures that my viewpoint reflects that of the consumer and carer group under study. Indeed, it was my demonstrated acceptance of the group, time spent with the group as well as my personal insider knowledge which locates me as an insider.

Ethical considerations

People are more likely to tell their story when the researcher creates a climate of trust and rapport, where confidentiality is guaranteed, and where the researcher can hear and understand the participants' personal experience (Smith & Noble-Spruell, 1988). Melton and Gray (1988) considered that a non-hierarchical approach to research ensures that people can voice their concerns and express them in such a way that the demonstrated regard of the researcher is not jeopardised. It was these

conditions of mutuality, confidentiality and unconditional positive regard, which directed the process of this research.

To ensure that the design and the methodology complied with the ethical guidelines for research with human participants, the following considerations outlined by the Australian Association of Social Workers (AASW, 1999) were addressed:

> The social worker engaged in research will consider carefully the possible consequences for individuals and society before participating in, or engaging in proposed research or evaluation, and also before publishing research results (AASW, 1999, p. 20).

To these ends, possible consequences of participating in this critical research were discussed with the participants at the first educative session and at the time of interview. Some of these possible consequences included a sense of guilt at not being able to care for their family member as well as other participants might appear to be doing, and the potential to lose faith in a mental health system that is designed to help consumers and carers and upon which they rely.

Positive consequences of joining the study included the potential that participants might discover the power they have in relation to this system through policies of partnership and participation, and to begin assuming greater control of their lives in relation to this system. By participating in educative sessions and focus group interviews, consumers and carers might build friendships and support systems extending beyond those they had at the outset of the research. Finally, participants may experience a sense of belonging, of community with others in recognising that they are not lone sufferers with mental illness.

A letter of introduction (see appendices six, seven, eight and nine) informed potential participants as to the nature of the study and outlined their rights. A consent form (see appendices two, three, four and five) was agreed to and signed by all participants before data collection commenced. There was no penalty, reward or coercion to participate in this research and participants were informed that they could withdraw their consent to participate at any time. All participants were given a choice about whether or not to participate in the research as a whole and in specific discussions or activities and signed a consent form.

> The social worker engaged in research will "ensure that informed consent to participation has been obtained from either the potential participants or their representatives ... [and] that the consent must be voluntary without inferred disadvantage for refusal to cooperate (AASW, 1999, p. 20)".

The letter of introduction explained that participants retained the right to halt discussions whenever they chose. Rules of confidentiality, mutual respect and boundary setting were established in the first educative session or interview. Furthermore, participants were offered debriefing after each interview and provided phone numbers of individual counsellors if they required independent assistance during or after the interview/session. This arrangement was put into place before data collection commenced.

> The social worker engaged in research must "strive to protect research participants from unwarranted physical or mental discomfort, distress, harm, danger or deprivation (AASW, 1999, p. 20).

Since I had worked with this target group over many years, my confidence of working in a sensitive, respectful manner, which would minimise potential distress amongst participants, was reinforced.

All participants received assurance that pseudonyms would be used in the research thesis. Additional identifying information was disguised to the satisfaction of the participants, or totally removed of unique identifying information after it had been transcribed. Employee participants of LIMHS were asked to choose between identifying their organisation and location, or to use pseudonyms. While there was no objection from management and the social workers in identifying LIMHS in the thesis, this was later de-identified. Lantana is a pseudonym for the mental health service under scrutiny in this research.

The NHMRC (2002) reminded researchers not to deceive research participants by concealing the true nature of the research. Therefore, participants had the purpose of the research outlined to them personally by me to ensure they were clear as to the nature of the study. This was also outlined in the introductory letter issued to all the participants.

Ethics approval from the James Cook University of North Queensland for research involving human participants was granted before any type of preliminary explorative work was undertaken, and prior to any data collection commencing. This included adherence to the guidelines of the NHMRC for research on human participants. The approval number for this research was H985. Furthermore, the raw data generated from the responses of all participants was stored in a lockable filing cabinet and will be kept there for a period of at least five years from completion of this research.

Participants

Management

The manager, the clinical director (psychiatrist) and the service development coordinator were males working in their fields for between 25 and 35 years. They were colleagues with prior knowledge of both my research and my intentions of including them as participants. Formal contact involved a phone call to each of them explaining the aims of this research. All three of these participants agreed to an interview within 10 days of my phone contact. A consent form (see appendix two) was signed by each participant prior to interview.

Community development worker

Similar to management, the community development worker was a colleague with knowledge of my study. This worker was a female working in the field for five years. She agreed to an interview after a telephone conversation to her office. This interview occurred three days later after signing the consent form (see appendix three).

Social workers

The manager of LIMHS was contacted by letter requesting consent for me to approach the twelve social workers employed in the organisation to ask for their involvement as participants in the research. The manager responded by letter within one week, approving my request and giving permission for me to interview the social workers during work hours. I contacted the social workers by phone and all 12 accepted my request for interviews. This high rate of acceptance may have been due to their long-term relationship with me as a colleague and friend. The social workers consisted of two males and 10 females practising from five to 30 years respectively. A letter of introduction (see appendix eight) was mailed to each of the social workers the following day. The letter outlined the purpose of the study and methods of the research, and how to contact me if they required further information. A consent form (see appendix four) was presented to the social workers to sign before their interview. Consequently, the total population of social workers employed by LIMHS were participants in this study.

Consumers and carers

Fourteen consumers and fourteen carers were recruited from a press release focusing on my study. I had requested consumers and carers to contact me if they

were interested in becoming involved in my research. The first 14 consumers and 14 carers that made contact (12 carers and 14 consumers by telephone and two carers by e-mail) were mailed a letter of introduction (see appendix nine) outlining the purpose of the study and methods of the research, and how to contact me if they required further information. A consent form (see appendix five) was enclosed for the consumers and carers to sign and return to me before interview. Fourteen carers and 12 consumers returned the consent forms. It was then necessary for me to find another two consumers willing to be involved. I decided to recruit two Indigenous consumers as I had two Indigenous carers involved. I recruited the Indigenous consumers from LIMHS day-centre programme. After agreeing to involvement, they signed the consent forms. The consumer participants included six males and eight females who had experienced schizophrenia from eight to 35 years respectively. The carer participants included one male and 13 females who had undertaken this role for between 10 and 30 years. One carer and one consumer participant were members of my PhD confirmation seminar panel and offered input into the design of the study.

Research techniques

To maximise the chance of successfully addressing the research questions, an ethnographic, participatory approach, incorporating qualitative data collection, was undertaken. The data collection techniques utilised were educative sessions using vignettes and focused and individual in-depth semi-structured schedules (see appendices 10 – 14).

Educative Sessions

Studies focusing on consumer and carer participation demonstrate a lack of input from consumers and carers (Beresford, 2001; Ellis, 1993). Freire (1996) argued that knowledge for liberation must come from the people themselves rather than be imposed by outsiders. He further argued that the dominant class in society has an interest in maintaining its dominance, so its knowledge will tend towards maintaining existing social relations, even when shrouded within the language of justice and equality.

Paulo Freire's educational philosophy as described in his book *Pedagogy of the Oppressed* was set within a larger framework of radical social change viewed as a necessary corollary to critical reflection. Freire (1996) stated that education was never neutral as it either oppressed or liberated. The oppressor's interests lie in changing the consciousness of the oppressed, not the situation which oppressed

them, while liberating education involves the action and reflection of men and women upon their world in order to transform it.

Another key concept in Freire's work that had importance for this research was conscientisation. This is a process of problem analysis, self-awareness and self-reflection by which consumers and carers can achieve a deepening awareness of the socio-political reality that shapes their lives and their capacity to transform it. Finally, Freire identified dialogue, which, in the context of this study, referred to the interaction between the researcher and consumers and carers. This process required humility, faith in humankind, hope, love, commitment and critical thinking. Freire (1996) stated that this cultural synthesis involves actors who come from one world to another, not to teach or transmit, but rather to learn with people.

Ife (1997) writing about Freire's work, explained his development of literacy programmes to help people define their experiences and articulate their needs. These were related to a political analysis of oppressive structures that affected their lives and that defined their life chances. This followed with programmes of action. This process involved linking the personal to the political and vice versa. Freire in his classic text 'Pedagogy of the Oppressed' (1996, p.33) stated that:

> functionally, oppression is domesticating. To no longer be prey to its force one must emerge from it and turn upon it. This can be done only by the means of praxis: reflection and action upon the world in order to transform it. To achieve this goal the oppressed must confront reality critically, while simultaneously objectifying and acting upon that reality because it is not a true perception but a subject perception cast upon by the oppressor.

Accordingly, the methodology in this study used vignettes as an educative technique before holding group and individual in-depth interviews with consumer and carer participants. Hill (1997) defined vignettes as "short scenarios in written form intended to bring forth responses to typical scenarios" (p. 177), and Rahman (1996) considered them a useful technique to broaden the focus from personal experiences to more abstract issues. They are particularly useful therefore, when highly sensitive topics are under discussion. In the opinion of Wilkinson (1998), vignettes can be used with participants both individually or within a group.

Semi-structured in-depth interviews

Broad question areas based on literature and Standard 3 of the NMHS were developed before undertaking the research reported in this thesis. Guba and Lincoln (1989) contended that naturalistic studies are virtually impossible to design in any definitive way before a study is undertaken. However, my experience with people

who have schizophrenia informed my decision to formulate broad question areas to guide the interview. This was also necessary to enable me to design vignettes for use in educative sessions with the consumers and carers. Alston and Bowles (1998) said that "semi-structured interviews vary enormously in the degree of structure and amount of initiative which is given to the interviewer" (p. 118).

According to Rubin and Babbie (1989), a semi-structured interview is defined as one in which the interviewer has a general plan but not a specific set of questions that must be asked in specific words in a particular order. Sarantakos (1993) described this type of interview schedule as typically containing many open-ended questions with the opportunity for controlled non-directive probing. Bearing these characteristics and limitations in mind, the interview schedule used in this study consisted primarily of a general plan of question areas (see appendices ten, eleven, twelve, thirteen and fourteen), designed to obtain in-depth accounts of participants' experiences of delivering and receiving mental health services.

Focus group interviews

It is widely acknowledged that group interviews as a data collection technique, occur within a natural environment where participants both influence others and are influenced by them. Group interviews produce data and insights that would not be obtained through individual interviews alone (Bryman, 1988; Grinnell, 1988; Krueger, 1994; Stewart & Shamdasani, 1990; Morgan, 1991). Marshall and Rossman (1995) believed that a person's attitudes and beliefs are not formed in isolation. It is necessary for them to listen to and understand the opinions of others in order to form their own views. Individual interviews do not allow for social, participatory reflection of a topic and participants may feel unprepared to respond. Morgan (1991) considered group interviews to offer a concentrated insight into participants' thinking on a topic and "uncover… why participants think as they do" (p. 25).

The educative sessions based on vignettes informed participants about participation and partnership policies. Educative sessions assisted with preparation for the group interviews. Questions not covered sufficiently in one interview were pursued at the next session. Immersion within the group, in the opinion of Fetterman (1989), would assist the researcher to internalise the "basic beliefs, fears hopes and expectations of the people under study" (p. 45). It also helped the researcher to clarify an understanding of observations and to gain direct insight into the participant's feelings on the issue (Morgan, 1991). The facilitation of in-depth group interviews uncovered

consumers' constructions of their experiences of mental health service provision at LIMHS, and carers' experiences of service provision when caring for their family member suffering a mental illness (Krueger, 1994).

Interview Processes

The interviews reported in this study were facilitated between September and December, 2000. They were held in four phases. The first phase entailed capturing the views of the social work participants, management and the community development worker. The second phase involved consumers and carers in educative sessions based on vignettes. The third phase followed with in-depth group interviews. The fourth phase was necessary due to three carers and four consumers missing the group interviews. Individual semi-structured in-depth interviews were conducted with these participants following the same process as phase three.

Phase One: Semi-structured Interviews

Social workers

Initially semi-structured interviews were undertaken to discover the 12 social workers' constructions of their experience of working with people who experienced schizophrenia in their lives. The interviews also included questions relating to issues surrounding the participation of consumers and carers. These interviews were held during working hours and conducted in social workers' offices at their request. The interviews lasted for one and a half hours. The social workers were aged between 25 and 50 and consisted of two males and ten females. Three of the female social workers were Indigenous Australians. All of the workers were my long-term colleagues and one of them was my team leader. Three of the social workers held senior positions (PO4 team leaders).

Management

In-depth interviews were held with management to discover their perspectives on both issues pertinent to the social workers in the organisation, and the participation of consumers and carers in context of Standard Three of the NSMHS (AHMAC, 1996). Management consisted of the manager, the clinical director and the service development coordinator. The one hour interviews were facilitated in each individual's office at their request.

Community development worker

The community development worker undertook the in-depth interview and requested it be held in her office. The interview lasted for one hour and the question areas related to her views on the LIMHS, social workers and consumer and carer participation.

All of the above participants were given the opportunity to read their interview transcription. The social workers, the community development worker and the service development coordinator took advantage of this offer. No changes were required. One of the social workers asked me if I could change her into a 'nicer person' after reading her transcript! After failing to hear from the manager and the clinical director, I sent a copy of the interviews to their office; with a letter stating that if no changes were required, to shred the copies. I never heard back from them. Ultimately no changes were requested.

Phase Two: Educative Sessions

The importance of process as well as outcome in participatory research informed my decision to use a data collection technique that encouraged open communication and collectivism with the consumers and carers. The responses of the interviews held in Phase One were analysed thematically and used as a basis for compiling vignettes (see below) for the educative sessions with the consumers and carers. Standard 3 of the NSMHS (AHMAC, 1996) was also used for this purpose. The vignettes were used to introduce the diverse ideas and views elicited from the interviews with management, the community development officer and social workers. To reduce potential bias, I did not want to speak from the first person and own any particular view. In addition, I was mindful to respect the confidentiality of the Phase One participants, by speaking only in general terms.

Consumers

One educative session was held for six male and four female consumers. This session lasted for two hours and the venue was my own residence in central Lantana. The consumers agreed by telephone and face-to-face contact, that this would be the most convenient location. I picked up four consumers by car and drove them to the location. I had previously met seven of the consumer respondents in a professional capacity and most of them were acquainted with each other. The consumers were aged between 24 and 35. I supplied refreshments throughout the

afternoon and several consumers contributed finger food. The atmosphere was very relaxed.

After discussing and agreeing to issues surrounding confidentiality, I outlined proceedings and responded to several questions about how the educative sessions would progress. I assured the consumers that they could decide how to proceed. I passed around the six vignettes for the group to familiarise themselves with the topics. The group decided to discuss the contents of the vignettes in an unstructured fashion. I believed this decision was based on some of the consumers feeling they needed to hear other opinions before offering their own. I then read out the first of the following six vignettes:

1.   Since the institutions have closed there are reports that some consumers are living on the streets with no support services. However, some live with their families, though this is often a lot of work, expensive and disruptive for families. The latest policies are asking people with mental illness and their families to participate in all aspects of service delivery and health ministers are saying that people who work in mental health services will not return to the abusive practices of the past. These policies have intensified over the past ten years. What do you think about these policies and concerns?

2.   Some people who work in mental health services are pleased with the new policies and see them as a good thing. Others are unsure, seeing them as a lot of work and somehow 'interfering in their patch'. What do you think?

3.   Consumer interest groups in the area of mental health in Australia are becoming more active. Consumers and carers are speaking at conferences, undertaking research and writing papers and books. The government has funded many of these projects. Many of you would have seen the media campaigns that attempt to break down stigma and encourage people experiencing mental ill health into the job market, or back into previous places of employment. What are your opinions on these changes?

4.   Management in mental health services complain that there is no money coming from government to fund the new policies they speak and write about. What do you think this means?

5.   Some consumers and carers have good experiences with mental health staff and others do not. What do you think the problem is?

6.   Training is recognised as an essential part of introducing better ways for consumers and carers and mental health staff to work together. What training does each group need for all to benefit?

Each participant had an opportunity to respond to the vignettes and to present their individual views. This strategy was repeated with the remaining 5 vignettes until I was convinced that everyone had understood the issues and the different ways they could be viewed. I was mindful not to represent any particular stance as my personal preference. I responded to questions from the group in a neutral fashion seeking more elicitation from them or answering questions factually where this was desired and appropriate (especially for questions around clarification of policy directions within mental health). The consumers were very involved in actively leading and discussing the topics under study.

Before the conclusion of this educative session, we discussed and agreed to hold the first of two group interviews on the following week at the same venue. Everyone appeared to be excited about the research and happy to be involved. I debriefed all participants after this session which served as a check that nobody left the venue with unresolved issues or discomfort. I then returned 4 of the consumers to their place of residence.

Carers

One educative session for carers lasted for approximately 2 hours and was held on the back verandah of a house in central Lantana that belonged to one of the carer participants. All participants agreed to the arrangements of time and venue by telephone. Ten female carers and 1 male carer attended and most of them knew each other. Two were Indigenous Australians. I was also acquainted with several carers, however, this was not in a professional capacity. Refreshments were available throughout the session, mainly provided by the carers themselves.

An outline of the evening's proceedings and issues of confidentiality were agreed to by all. I commenced by reading the first of 6 vignettes and then passed these around. Various participants read out the remaining 5 vignettes. In between each vignette, we discussed the scenario and the carers asked a lot of questions about mental health policy, the situation for carers with adult offspring and the attitudes of MHPs to participation policies. Many of the questions reflected a high level of each participant's understanding of their situation within a mental health context. I responded by offering multiple views on the same topic. I was careful not to portray any particular view as 'truth'. I spoke and summarised participants' views in general terms, giving equal emphasis to each viewpoint.

At the end of this session we agreed that I would listen and learn from them over the next two sessions. It was important for me to impress upon the carer participants that their knowledge and opinions were central to the research. Before we departed, we agreed to meet at the same venue in two weeks.

Phase Three: In-depth Focus Group Interviews

Consumers

Ten consumers arrived for the first group interview. The interview lasted for 3 hours and was audio taped with permission from the participants. The interview got off to a slow start as several participants appeared shy. This surprised me, as they had not behaved in this manner when participating in the educative session. I stopped the interview and explained that individuals could respond to the question areas when they felt comfortable in doing so and not in any particular order. I then asked them to say their names before they responded so that I could identify them when transcribing the interviews. This strategy worked better and the interview proceeded. On several occasions, their passionate views and detailed descriptions of their experiences troubled me. I was aware of many of the issues raised, but had not realised they were so prevalent. Alternatively, the ideas that participants offered as solutions to the problems they experienced with service providers were inspiring. Overall, I found the interview a difficult and exhausting process. The participants often talked over each other and it was necessary to remind them to let others have their say without interruption.

The second group interview lasted for two and a half hours. The process did not present the problems evidenced during the previous interview. Participants appeared to enjoy listening to each other and constantly affirmed individual experiences. This

dynamic has been written about by several authors (Bryman, 1988; Grinnell, 1988; Krueger, 1994; Stewart & Shamdasani, 1990; Morgan, 1991) who wrote about the benefits of using focus groups as a technique for eliciting information. On this occasion, consumer participants did not speak over each other to the same extent as previously. Although many of the responses were stories of oppression, others related to experiences that were more positive. After the interview, I promised everyone I would get back to them with the opportunity to check their transcript and make changes if necessary.

Carers

The first in-depth focus group interview for the carers went for one and a half hours and was audio taped with their permission. All the carers turned up and appeared to be enjoying themselves. They refused my offer for them to take turns asking the questions. However, they did agree to take turns when offering views. I was relieved, due to mild concern that the participants who remained quiet last fortnight would do so again. We covered three quarters of the questions during this session and I was pleased that everyone participated. I was surprised by the intensity of some of the responses and spent time afterwards ensuring that everyone had settled, providing participants the option of discussing issues outside of this group context.

We agreed to wait for three weeks before meeting again. This was due to one of the participants going to Brisbane for a week. When I left I had mixed emotions. I knew that the data was rich, however, I was saddened by some of the experiences that people were sharing yet I knew many of these related experiences through my association with LIMHS.

The final session was rather festive. We attended the same venue with plenty of snacks and cool drinks. We completed the rest of the questions in less than an hour, and then spent another two hours debriefing and sharing all kinds of stories that were not necessarily related to the research. I reminded the carers that they had granted me permission to transcribe the audiotapes and assured everyone that I would return their interview personally for them to read and make changes if necessary. I also reminded people to phone me if they had concerns. On the way home I thought about the carers' description of their needs. I felt their requests for resources to meet their needs were modest, not much to ask for, and things quite reasonable to expect from their MHPs.

Phase Four: In-depth Individual Interviews

Consumers and carers

Unfortunately, three carers and four consumers were unable to attend the focus groups due to economic constraints. The *Consumer Focus Collaboration* (2000a) recognises that paying consumers to participate in research and evaluation through focused groups is an important component of consumer participation, especially as the research contributes to health services delivering quality services. There is evidence that paying people to become part of the research process increases participation rates (*Consumer Focus Collaboration*, 2000a; O'Neal, 1999; Thompson, 2001). Payment could recognise knowledge, skills and experience and equalise power relationships. It also assists to counter exploitation of marginalised groups and indicates that the researcher values their time and contribution whilst also enabling the participation of people who cannot afford to participate (Thompson, 2001).

I fully support the view that consumers and carers be paid for their involvement in research projects. However, the consumers and carers in this study were not paid. I could neither afford to pay them, nor did I wish to be seen as "rewarding" them for participation in this research as per NH&MRC and James Cook University ethical guidelines. I did, however, ensure that the four consumers and three carers who could not afford petrol, or did not have a vehicle, got the opportunity to have their voice heard. I travelled to the outlying coastal areas and Tablelands and interviewed each of these participants in their home on two occasions. They received the same vignettes, educative session and question areas as the participants who attended the group interviews. Their stories were therefore collected through individual interviews rather than the focus group participation.

Consumers and carers were interested in the research and anticipated the final outcome. The unstructured nature of the focus groups and individual interviews permitted consumer and carer disclosures to be ventilated in a supportive, confidential environment. Exchanging intimate knowledge throughout the 3 sessions, cultivated a very close supportive relationship amongst the participants and between the participants and myself.

The research participants were invited to my PhD pre-completion seminar and several consumers and carers took up this invitation. The seminar was also attended by three social work case study participants. They were invited to contribute feedback before the final write-up of the research. All of the participants were invited

to attend a Microsoft PowerPoint presentation of the research findings and recommendations once the study was marked and bound.

Limitations of the research

Qualitative methodology was utilised in order to explore and document the experiences of consumers and carers living with schizophrenia in their lives. Data collected were collated around the themes of participation, the place of social work at LIMHS including themes of social justice and post-graduate education of social workers and/or MHPs, and the meeting of client needs at LIMHS. That consumer and carer respondents eagerly shared the complexity of their lives with schizophrenia, reflects the need for more inquiry into areas that are of concern and importance to them.

It is acknowledged that analysis of qualitative data can be subject to the interpretive bias of the researcher. Although this is a risk, the advantage of qualitative data is that it gathers complex and rich understandings of participants' perspectives which itself protects against research bias. That participants are engaged in processes of correcting the researcher's interpretation or summary of data throughout interviews, and receive transcripts of what they have said in order to clarify accuracy, also protects data from corruption through research bias (Strauss & Corbin, 1990). In addition, because of my intimate knowledge of mental health impacts on persons and their families, as well as pre-existing professional relationships with many of the participants of this study, I was vigilant in taking a meta-position in relation to data, examining and re-examining how it challenged and enlightened my own views of the experiences of living with mental health, and service providers responses to consumers and carers. This intensive meta-positioning of my own views and affective responses in relation to data, was the focus of many research supervision sessions.

This research was restricted to consumers and carers living with schizophrenia rather than people with other mental health conditions. It was also limited to non Indigenous and Indigenous Australians and does not include people from other culturally and linguistic diverse backgrounds.

There may have been disadvantage, or difference, in the data of the three carers and four consumers who engaged in individual interviews rather than focus group interviews. This process may have denied these participants the experience of being

influenced by others and producing data and insights that are not possible through the closed nature of individual interviews (Bryman, 1988; Grinnell, 1988; Krueger, 1994; Stewart & Shamdasani, 1990; Marshall & Rossman, 1995; Morgan, 1991). While participant's stories contained unique and even contradictory views, a marked difference in discussion topics and focus was not apparent in the reading of transcripts across research participants, regardless of the research process engaged.

Data analysis and presentation

Thematic analysis

Initially the qualitative data from the individual and focus group interviews were transcribed from audiotapes (Spradley, 1979) to a Microsoft Office Word 2003 programme. After this transcription phase, audiotapes were stored in a safe place where they will remain for the following five years, as per National Health and Medical Research Council and the James Cook University guidelines. Data were then thematically classified in terms of their response, or "fit", to the large research questions (see p. 5). Thus data were collated according to themes of participation; social work including social justice and post graduate education of social workers; and the extent to which consumers and carers felt that LIMHS was meeting their needs. In the data presentation chapters (see chapter 5 – 9), data from management, the clinical director, the community development worker and social workers, were classified strictly to these themes, whereas in the data analysis of consumers and carers (see chapter 10), data from consumers and carers about social justice is presented under the theme of service provision rather than social work. This provided consumers and carers a discrete and privileged space to share their views about LIMHS meeting their needs. Thematic classification in these ways allowed for "bringing together components or fragments of ideas, or experiences, which are often meaningless when viewed alone" (Leininger, 1985, p. 60). Data is presented cleanly in chapters 5 – 9 outside of analysis by the researcher except under thematic headings, and outside of its link to literature. This allows for both participants and readers of this study to view data unambiguously. This allows the reader to develop their own (hopefully empathic) understanding of "where the person is coming from (Marshall & Rossman, 1995).

Once the themes were organised, and presented in chapters 5 – 9, data were interrogated through the literature presented in chapters 1 – 3. This is presented in chapter 10. This organisation allowed for a focus of the research around the three

research questions and allowed this study to be linked with other studies in the same/similar field while also allowing for the presentation of unique data (see chapters 10 and 12). The process of triangulation of data facilitated these processes. The process of triangulation (Denzin, 1989) involved the cross-checking of data from a number of sources (Lincoln & Guba, 1989). Interviews on the same topic were held with social workers, management, the community development worker and consumers and carers. Whilst the views and opinions they expressed reflected their past and current views on mental health services and about each other, it was important to compare the themes arising from this data with other data sources available such as field research already conducted (Flanagan, 1998; Gawron, 1998; Wadsworth & Epstein, 1998) and through government policy. The data provided by consumers and carers provided an invaluable opportunity to compare their collective experiences with those of management and employees of the mental health service. Whilst opinions differed within and between each group of participants, there was potential to substantiate claims and concerns both positive and negative that were common and had an impact across all groups.

Finally, the results of chapters 5 - 9 were examined to draw out aspects that contributed to a new model or vision of social work service delivery for consumers and carers living with schizophrenia (see chapter 11).

Generalisability and transferability

As this research utilised qualitative, case study methodology to achieve an in-depth understanding of the experiences of consumers and carers living with schizophrenia and interacting with LIMHS, generalisation of this topic to other contexts was not an intent of the study. It is recognised, however, that some generalisation may occur, especially where the findings of this study correlate with the findings of other studies cited (see chapter 11).

An alternative concept to the construct of generalisability is Lincoln and Guba's (1985) notion of transferability. Transferability can apply in varying degrees to most types of research. Unlike generalisability, transferability does not involve broad "truth" claims. The readers of research apply transferability by making associations with elements of a given study and their own experience. For example, the provision of thick descriptive data in the form of detailed information presented in this thesis enhances the possibility of social workers from LIMHS, and other mental health organisations, to selectively apply the findings from this study, including the model of social work presented in chapter 11, to their own organisations. It was this intent

which guided the study rather than for it to make 'grand' claims of generalisability across contexts.

Conclusion

A qualitative methodology was used to investigate the views, ideas and experiences of social workers, management and consumers and carers involved with Lantana Integrated Mental Health Service. The use of qualitative methodology was justified as ethically congruent with the participatory focus of this research since data collected through in-depth group and individual interviews necessitates research processes of partnership and participation.

The following five chapters present data from the individual and focused group interviews conducted with management, the community development worker, social workers and consumers and carers of LIMHS. This data is presented under headings reflecting the three research questions:

1.   what is the policy environment of the mental health service, Lantana, which either invites or constrains participation and partnership building between this mental health service and consumers and carers?

2.   how is social work structured into and/or out of Lantana mental health service and how do social workers provide a social work service?

3.   to what extent do people diagnosed with schizophrenia and their carers, perceive mental health services in Lantana to be involving them in meeting their needs?

CHAPTER FIVE
Data Set 1: Management responses

This is the first of five data chapters. It presents the responses of the Lantana Integrated Mental Health Service's (LIMHS) managerial team, to four major areas of focus: participation of consumers and carers; social work as a specific discipline within the mental health structure of LIMHS; social justice; and post-graduate education (see Appendices Ten & Eleven). The management perspective was based on the views of the manager, the clinical director and the service development coordinator of LIMHS. The interview with the service development coordinator covered the same focal areas (as above) to the manager and the clinical director, but did not include questions relating to clinical issues since they are not areas of his job responsibility. Each position has its own philosophical base and area of professional responsibility, which is mirrored in the 'language', and worldview of participants. This is made evident by the positioning, in this chapter, of all management responses to each of the discrete focal areas, followed by a preliminary analysis of the responses of the manager, clinical director and service development coordinator as these compare and contrast with each other. A fuller data analysis is presented in relation to literature and theoretical orientation of this study, in chapter 10, which brings all the voices to the table in order that data is fully triangulated in relation to all participants. This allows for a presentation of unique knowledge gained through this study in relation to that which has been presented in chapters one to three of this thesis, to emerge. This present chapter concludes with a discussion comparing and contrasting responses of each member of the management team across the four focal areas.

Background and introduction to management participants

The **manager** is the single point of accountability for the LIMHS. The manager is directly responsible to the Lantana District Health Service's manager for the coordination and the monitoring of mental health services. The manager's professional background is commerce and social work.

The **clinical director** is a psychiatrist with training in psychotherapy and has responsibility for all clinical programmes and standards. The clinical director reports to the medical superintendent of the Lantana Base Hospital.

The **service development coordinator** reports to the manager and is responsible for the development and implementation of models and policies of service delivery,

including those of partnership and participation for consumers and carers. The service development coordinator's professional background is administration with supervisory responsibility to all administration staff.

Participation

As previously discussed, Standard 3 of the NSMHS (AHMAC, 1996) is the guiding policy document for the inclusion and participation of consumers and carers of mental health services in Australia. Management were asked individually for their understanding of Standard 3 of the NSMHS (AHMAC, 1996). The manager said:

> The NSMHS were intended to go right across the board, involving consumers from one part of the service right through. Ideally, Standard 3 states that consumers and carers should be involved in the planning and the management of mental health services. You will have consumers represented on the executive or on the board of management. At the same time, it should reinforce the way we go about case management in mental health, but I presume that individual practitioners' operations are reflecting the need to involve consumers. For example, on an individual basis, consumers are to be involved in developing their treatment plans, and signing them. On a broader basis, consumers are to be involved in working parties developing new programmes. The way I see it, consumers should be involved. Standard 3 then leads to ethics, as it is linked to the other standards about respect and dignity.

The manager responded to Standard 3 from two perspectives. One was a broad, principled perspective of what Standard 3 should involve – participation should be across the board; should involve consumers in planning and management; should have consumers on the board of management; and should be engaged in working parties developing new programmes. The other perspective on participation, however, is one of practicality – participation should reinforce what LIMHS already does; is the responsibility of individual practitioners engaging consumers in their treatment plans. These are quite distinct perspectives and the manager does not clarify which position he would prioritise.

He did, however, clarify his perspective later in the interview, prioritising a "practical", narrower form of participation:

> some people would say 'Well, where do you draw the line in terms of level of involvement.' Some people would argue that they [consumers and carers] should be on interview panels for recruiting staff. Ideologically and philosophically, I have no trouble with that. Practically, I think, 'What does that actually mean?' We have not done that here [consumers or/and carers on interview panels]. Participation is encouraged firstly on an individual basis, through day-to-day clinical practice. They [MHPs] should be suggesting issues like involving consumers and carers in developing their treatment plans etcetera. This means participating in reviews of treatment and management. If consumers are unhappy with the service, there is a complaints procedure where an ability to complain is encouraged, in the sense that it is made easy as a process. There is no stigmatisation for complainants' etcetera. Therefore, consumers are involved in complaints.

Whereas the original statement by the manager included a broad engagement of consumers in management and planning and developing programmes, in this second response, he presented a reactive role (complaining) for consumers in terms of participation which is in juxtaposition to the active, broad perspective of participation.

The manager also pointed out that consumers and carers are:

> involved to a lesser extent in training groups, like rehabilitation services and things like that. A few consumers have been involved. There is consumer involvement in terms of funding of the consumer advisory group (CAG). We provided about ten thousand dollars this financial year for them. So that is 'well hey, here are some resources to develop your CAG a lot more.' What this will mean in terms of what they will do and how that will change our service is too early to tell. So we encourage consumer participation in that we are willing to help in any way we can. Consumers are also invited to most meetings. We are going to re-establish a mental health advisory group under a new name early next month and consumers will be invited to attend. That will be a broad planning forum for mental health services. I thought we would call it Mental Health Quarterly Forum, or something like that.

This third response of the manager further demonstrates his prioritizing of a passive stance of consumers engaging programmes already provided by LIMHS (like rehabilitation) and being invited to meetings rather than the first response which indicated that they would be actively involved in planning and managing.

The **service development coordinator** did not acknowledge the wide scope of participation possibilities in which consumers and carers could be involved, but appeared to have a narrow, reactive response (providing feedback) at the outset. He minimally mentioned engagement in planning. He stated:

> at a minimal level, opportunities are to be provided for consumers and carers to become more involved in the service, provide feedback on how the service is operating, and have some input into the planning process of new services or enhancement of existing services. We have been able to implement the standards to some extent, though not to the extent that I had hoped for. I guess the main problem is that we are not funded to cater for consumer and carer participation, and until that stage is reached, what we do is minimal. We do provide some funding to the CAG but that is only a nominal amount. There have been some workshops that we involved consumers and carers in over the last twelve months.

Later, the **service development coordinator** suggested that funding is needed for support and training of consumers. He said:

> (I am) very much in favour of them being involved. I guess the only issue is that we really need to provide support and training for consumers so that they can participate actively. The benefits are that, because they are able to participate, they can give their views and that is obviously going to ensure that services are better than would commonly be the case. MHPs have some understanding of issues for consumers and carers, but obviously their own [consumers and carers] perspective will provide a better insight.

The **service development coordinator** implies that consumers' and carers' views will be acted upon when they are shared with LIMHS.

Unlike the manager and the service development coordinator, the **clinical director** was unable to identify Standard 3 specifically. He believed that:

> The eleven standards are directed towards providing good mental health care in a respectful, dignified fashion and culturally appropriate manner for patients, which is basically what they are about.

This view is less descriptive of participation opportunities and possibilities for consumers of mental health services, but directs us to the "manners" of engagement with consumers of mental health services, which the clinical director intimates is the core message of all 11 standards of the NSMHS (AHMAC, 1996). When reminded specifically of participation as a policy direction for mental health services, **the clinical director** stated that he was:

> very much in favour of consumers participating, but it can't be just carte blanche. For example, someone who is a paranoid schizophrenic and actively paranoid will have an extraordinarily distorted perception of themselves in relation to the world. They will not be able to contribute to mental health planning in a constructive manner. On the other hand, those people who have experienced treatments and who have reasonably well-integrated personalities may be able to contribute a tremendous amount to the service, in terms of their own experience as consumers.

In his opinion, consumer and carer participation was encouraged at LIMHS:

> For a long time now, there has been an effort to have a consumer and carer group, and to have people participating in the programme to some degree. There have been difficulties with that, not so much now, but in the past. A few people who were involved, unfortunately, had the kinds of personalities that I am talking about [disordered] and were not able to contribute much in the way of constructive participation. They offered a wealth of criticism, which we took on board, but could not really contribute much more than that. I support it [participation]. When I go to meetings and that sort of thing, I simply support it. I support it verbally, I support it in writing, and any way I can. Certainly when I've seen patients personally who have had comments and criticisms to make, I encourage them to participate.

The clinical director held a narrow view of participation which centres around the diagnosis of the consumer and focuses on consumers' critiques of the service (reactive). This response indicates participation as something we pay lip service to – "I support it verbally, in writing" (etc) rather than something that is actively engaged as core practice.

In each of the responses above, management focused on particular aspects of participation and these appeared to be linked to their roles. Each of these aspects potentially limits the participation of carers and consumers in particular ways. Thus, the manager limited participation to individual engagement in treatment plans and grievance procedures (complaints). The service development coordinator limited participation to "some meetings", CAG and consumer and carer feedback (reactive). The service development coordinator inferred that participation is limited due to consumers and carers not having support and skills needed to participate actively

and therefore they need training. The clinical director limited participation via the "wellness" of the consumer

Despite these lenses of limitation, the service development coordinator believed that consumer and carer participation was encouraged within the LIMHS and offered the following as examples:

> a couple of workshops that are facilitated at the day-programme. Certainly mental health week activities have been a key area that we have encouraged consumers to be involved in. We have been successful in getting funding for a mental health consumer and carer organisation. I guess with a lot of that sort of work, we are really trying to encourage the non-government organisations in town to take on some of the role and have been reasonably successful in the past three or four years getting them to do it. There is still a fair bit of scope for improvement. Given what we had several years ago, it is a much better situation now.

The service development coordinator went on to describe his personal contribution to participation:

> There are two major things that I have done in the last twelve months. Firstly, we had a conference earlier this year and part of that process was to look at what issues there were for people with mental illness and those who care. That is, non-clinical issues, such as housing, employment and support. We were trying to get some sort of priority from the community, of issues we need to work on within LIMHS, so that we could attract funding. Prior to that process, we encouraged a large number of consumers to participate around workshops, where we went through some of the 'language' that would be used at the conference. We went through issues to do with public speaking and addressing an audience of multidisciplinary professionals, non-government organisations and consumers and carers, so that they could participate on a more equal basis with everybody else. I think that was successful. Secondly, we have mental health week coming up, with the main focus on the consumers' entry [float] in the reef festival. Last year I did a fair bit of the organising because it was the first time that we thought about doing it. It was fairly successful, so this year I have left it to them [consumers] to do most of the organising. They had to work out what cost was involved and what they wanted to do and there has been some funding obviously from us, but it [the float] is their concept this year. I have also been involved in the Mental Health Help Group, though I have tried to stay in the background so that the group can evolve itself. It is mainly consumers and carers who have nurtured the group and got it off the ground.

While the manager focused on participation as a form of engagement with consumers and carers in what LIMHS is already providing, the service development coordinator presented a much larger view of participation as embracing whole-of-life aspects such as housing, employment and support, which therefore needs a whole-of-community response. This contrasts sharply with the clinical director's focus of participation as inherently to do with mental health diagnosis. The service development coordinator further said:

> Hopefully down the track I will be able to step back from that role and it can be taken over to a non-medical perspective. I am quite happy to give input, but I will try not to be the driving force. If it falls over, it falls over; I can't be there to prop them up. Obviously with mental health services we deal a lot with other government departments and we are finding them becoming more amenable to discussing issues to do with clients who have a mental illness. They acknowledge that we have a degree of expertise in this area and we are looking at ways we can work together on particular projects. Certainly, we have had a lot of co-

operation from disability services, education, the police and the commonwealth department of health, as well as Centrelink [social security].

The next section is presented in relation to the second aim of eliciting data about social work.

Social work

The Competency Standards (AASW, 1999) for Social Workers were released in 1999, as a guide for social work practice in mental health services. The manager, the clinical director and the service development coordinator had not heard of these competencies, despite social workers being the second largest group of clinicians employed at the LIMHS (second to psychiatric nurses). Perhaps this was due to the release of the *National Practice Standards for the Mental Health Workforce* in August of 2001. While this document was heralded as complementing discipline specific competency standards, it may have served to supplant them. Another explanation could be the lack of senior discipline representation at management level. Nonetheless each member of management ascribed particular roles to social work.

The manager identified case management as the predominant model of practice that social workers engage. He also referred to their broad generic training. He stated:

> like all clinicians they (social workers) work from a clinical case management model. There is a whole range of different approaches but the basic description is clinical case management model. On top of that, each discipline has its own area of expertise, or might have a particular approach to dealing with their clients. I do not know if I can answer this. It is easy in terms of psychologists; they can obviously do psychometric testing because that is part of their training. Nursing staff in case management positions are obviously able to deliver parenteral medication where other staff cannot. Occupational therapists undertake living skills assessments. For social workers it is different because you can't say there are certain things that only they can do, whereas in other professions there might be certain things that no other professional can do.

The manager initially found it difficult to articulate the social work role since he looks for unique, qualifying tasks that other professions "can't" do. He therefore disqualifies the roles that social workers do as part of their professional role, because these roles are not outside of what other professionals "could" do (their capabilities). Later, though, he recognises that the predominating framework of case management is a unique social work contribution to the delivery of mental health services. Thus, he said:

> Social work was the first profession to develop the case management model. So in a sense, the whole way we operate in mental health is now based on a social work principle of holistic care, coordination of services, etcetera. You could say that I don't see it as unique; it should be across the board.

The clinical director commented on the model of service delivery he believed social workers should use at LIMHS:

> What we encourage is the biopsychosocial model that they [social workers] need to be able to integrate, not only those humanistic aspects of working with people but also the medical aspects of their treatment. This is becoming increasingly sophisticated. This is a very important aspect because, in the past, the degree of sophistication of psychiatric treatment for major mental illness was not very high, and sometimes rather clumsy. The degree to which that is changing, and it is changing quite rapidly, does require social workers in mental health services to have an understanding of the medical dimension, and an ability to constructively have their input, and sometimes their criticism. Certainly not to the degree where in some instances people say to psychotic patients who don't want to take their medication 'oh, that's all right' in an attempt to empower them and then find them relapsing over and over again. This is the position taken from a lack of education, or a lack of understanding of the importance of all the aspects in a care plan. At the top are equal medical and human model in parallel. You cannot diagnose and treat without seeing the person's character and life. Freud said 'where there is symptom there is character,' and if you miss out the human part of it, then your chance of making a mistake and of having a less than optimal treatment is much higher. I put them both [human and medical] at the same level.

The manager focused on the social work role in terms of a generic casework framework whereas the clinical director focused on social workers integrating both the biopsychosocial and medical models of practice. He further acknowledged the empowerment approach of social work even though he appears somewhat exasperated with this and argues for a more "balanced" approach:

> I think social workers come from a training background where they are encouraged to empower people and work with those who are disadvantaged, not from a biological medical model. It has its place in the system [empowerment]. There is always the struggle between medical, biological psychiatry, which is an explanatory type of model, and an understanding kind of model, which is the more human model. There have been times in psychiatry when the pendulum has swung too far in the biological direction. During the seventies that was the big sway and push, and I think that social workers can reinforce the humanistic model of looking at the whole person, not just as a mechanical entity that has something wrong with it. However, that needs to be balanced against an educated background. It is all very well to try to empower someone, but if that someone is suffering from a rather malignant psychotic illness, they do not have the requisite executive functions to be able to take on board what that social worker is saying, and use it in a constructive fashion. It is a question of balance and understanding.

The clinical director however, could see the unique contribution of social work to mental health services. He said:

> social work roles are obviously the things that have to do with issues of societal functions and bureaucracies, and navigation through that kind of stuff. Social workers are much better equipped, through aspects of their framework, to handle those issues and facilitate people navigating through them. That is a highly important issue, particularly for people who are psychologically impaired. I think that is an area where social workers can, with a greater degree of sensitivity and pragmatism help people. The doctor, who has no idea of the vicissitudes of Centrelink, says 'oh well, send this person to Centrelink'. Suddenly this poor, unfortunate person is confronted with a bewildering array of bureaucracy. I only have to look at some of the bits of paper I have to fill in. I find them complicated enough, never mind suffering from a mental illness and hearing voices, that sort of stuff. That is a vitally important area, particularly when you are dealing with people who are seriously impaired. If they start to flounder, their anxiety levels go up, and then you have got someone who begins to crumble or relapse. So it is, you know, a vitally important area, and just as important as the medical aspects of treatment.

Similar to the manager, the clinical director valued the approach taken by social workers. Their expertise and ability to 'cut red tape' maximised the potential for consumers to come through the income support process without further deterioration in their mental state. Often social workers refer to this process as 'practical assistance'. The clinical director's validation and portrayal of this role as 'just as important as the medical aspects of treatment' sends a message to social workers that reinforces this role as a crucial component to consumer wellness and critical to forming a successful therapeutic alliance with them.

Performance and evaluation of social work at LIMHS

In the opinion of **the manager**, social workers were:

> the same as others. Performance, Planning and Review (PPR) is in place. We have not been very prescriptive about how the process is to work. Generally, there is an agreed format as to how they [MHPs] are to do PPR; the team leader facilitates it. Ideally, it would involve the team leader plus a senior from each MHPs specific discipline. We have not said 'It has to be like that,' but I would see it as a joint process. It does not have to be the director of social work; it could be peer involvement. I think most of the staff have chosen a peer from the same discipline.

Performance Planning and Review (PPR) at LIMHS, as portrayed by the manager, centres on the team leader. After that it was depicted as an egalitarian process.

Clinical care is the responsibility of the clinical director (psychiatrist). He described the way he evaluated social workers' practice:

> I regularly meet with some of our team in clinical supervision to look at detailed aspects of their treatment of patients and ongoing counselling, and discuss the cases with them. These are people who have expressed a wish to do this. Above and beyond that, we have case reviews and that sort of thing, to look at what's happening in a worker's interactions with patients. I have just drafted a letter to one of our social workers about a patient I saw, and how the patient will be counselled. It will also provide some ongoing supervision, if that worker is willing to participate. It can also lead to optimal outcome for that particular patient. That treatment is not medical treatment. The medical aspect of this patient's treatment is only a small part.

The manager saw performance and evaluation in terms of the very formal, summative process of PPR, whereas the clinical director saw evaluation in normative, supervisory terms where he again reiterates a holistic approach incorporating more than medical aspects. Despite this the clinical director appears prescriptive about the process of treatment in his supervision of social workers. This matter of leadership of social workers is the focus of the next section.

When asked for views on the need for a senior social worker to provide direction and leadership for social workers at LIMHS, **the manager** appeared to be ambivalent,

alluding to funding constraints preventing the engagement of discipline seniors. He responded:

> That is a difficult question to ask me, the manager. The combination of clinical needs, professional development needs and budgetary needs, go through my mind, also numbers games and implications. Most people would argue that we should have discipline seniors in all disciplines in mental health, and that should encourage professional development. Appropriate research and pilot studies on that issue are going on now. On the one hand, the answer is yes. On the other hand, it depends on a commitment from the government of the day to provide more funding; it is not just a matter of finding the funding from elsewhere.

The **clinical director** was much less ambivalent than the manager about the need for a senior social worker. He said:

> I think that would be a good idea. A senior social worker with a wealth of experience in mental health would be an enormous asset and certainly that person would then be able to provide the kind of clinical supervision, and professional supervision that would be optimal.

Social justice

Social Workers are guided by principles of Social Justice. This framework is sanctioned at both national (AASW Code of Ethics, 1999) and international levels (IFSW, 1994). Whether or not the current nature of mental health service delivery impedes a social justice focus is expanded in the next section.

The manager was asked whether he thought there were constraints to social workers incorporating social justice principles in their practice. The manager said:

> there shouldn't be. Mental health is one area where people can get treatment against their will and be locked up against their will. In one sense, it is a real flashing light area for civil liberties and social justice. On the other hand, the *Queensland Mental Health Act 2000* passed legislation to protect vulnerable people, like people with serious mental illness. In theory, there aren't barriers to social justice, because that is the principle that mental health services work from, the least restrictive care under a legislative framework designed to protect people's rights. There are also the National Standards to protect people's rights.

The manager went on to describe the backlash against psychiatry as essentially being about human and civil rights abuses which has not, however, stemmed the influence of psychiatry and psychiatrists in mental health services:

> In practice, psychiatry in mental health services has not had a very good track record, so it is not hard to come up with instances where people's fundamental civil liberties, never mind social justice, were trampled on. It is all very well to ask, how does it [abuse of rights] happen, but it is still happening. We have had a Royal Commission in Queensland and New South Wales etcetera. Therefore, it is a puzzle about how it can happen given all the protection. In a sense, strong forces are at work; you have powerful players in mental health services, you have people with strong opinions. It is a medical model to a certain extent. The system trusts psychiatrists a hell of a lot, and we have seen them go off the rails a few times. Poor leadership has obviously influenced services; psychiatrists have had a strong influence on service delivery.

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Initially the manager thought there were no constraints to social justice given protective legislation to safeguard people's civil rights. In this second response, however, the manager is puzzled about civil liberties abuses and lays this at the feet of psychiatry.

By contrast, **the clinical director** (psychiatrist) seemed to minimise the human and civil rights issues of mental health consumers by prioritising the diagnosis over these rights. He seemed to have difficulty with a social work approach which advocates for rights even in the face of diagnostic vulnerability. He sought "balance" in social workers' approach to service delivery. Clearly, this "balance" is skewed towards a psycho-medical view:

> Sometimes there are differences of opinion. More often than not, they come out of a relative misunderstanding based on the lack of knowledge about the nature of the person's illness. It is all very well to advocate for a person who has bipolar disorder and is manic, firing away their assets at a rate of many thousands of dollars a week. Then someone [worker] cries hell when they [the consumer] are put under the Public Trustee, saying, 'this is not fair, it is unjust towards them'. I question those kinds of differences. There needs to be a balance which comes out of knowledge and understanding of the nature of the beast someone is working with.

The **service development coordinator** integrated both the views of the clinical director and the manager, by 'hoping' that MHPs were implementing social justice perspectives but at the same time articulated the complexities of balancing human and civil rights within a system which sometimes necessarily constrains these. He was a lot more humble about the "science" of psychiatry (the diagnosis) than the clinical director and recognised the subjectivity involved when resolving the dilemma of ensuring the human and civil rights of consumers within a system which at times needs to "regulate" these consumers. He said:

> In principle no, there are no barriers. We have a statement of consumer rights and responsibilities that I am looking at on the wall at the moment. This statement sets out a lot of those principles stating basically that consumers, carers, advocates, and service providers in the community are aware of the consumers' and carers' rights and responsibilities. Hopefully they [MHPs] are exercising them. I believe that many people with mental illness are in the position of being totally disempowered, particularly if they have been regulated. It is a very difficult situation when you are dealing with people who on the one hand are questioning why things are happening, and on the other hand are having great difficulty understanding what is going on. It requires a fair degree of subjectivity. It is a difficult one to answer; there is certainly room for complaint about how the service functions. Providing we can reach, in most cases, a reasonable solution, I think that's basically all we can do. It is very subjective what happens to some people.

Having discussed the philosophical framework of social justice as guiding social work practice, management were then asked to discuss what they thought social workers should receive in their training as mental health practitioners. This is the focus of the next section.

Postgraduate social work training

Education of mental health staff is recognised as a major contributor to the success of involving consumers and carers in all aspects of mental health service delivery (Bainbridge, 1994; Bland, 1999; 2001). **The manager** considered it beneficial for social workers to undertake postgraduate studies in mental health. He said:

> it depends, when you say postgraduate, is it a Masters in social work, or people doing postgraduate diplomas in mobile intensive treatment teams, or something like that? Obviously, the nature of the course is important. As the manager of mental health services, I would be very interested in staff doing postgraduate diplomas in mental health. Social workers could go straight from an undergraduate course, to a postgraduate diploma. It is very helpful for us if social workers have a good background in mental health, how the social worker fits in, and what everyone else does. That would happen automatically, and be of great benefit in terms of new graduates coming into the workforce without much experience: if they had that broader academic training and some incorporation of practice elements, where they might get some hands on skills during the course.

Having discussed the type of education needed (post-graduate); **the manager** then went on to discuss the course content for this education for social workers. He said:

> What would be an advantage for us is specific training in areas like psychotherapy. There are a whole range of skills in psychotherapy that mental health professionals can acquire, including social workers. It is a useful skill that fits into the system. At a meeting last week we were discussing setting up new programmes. One of the issues was 'what will we do with people with personality disorders?' One is the psychotherapy approach. We have to make a decision whether we want to resource it. It is quite resource intensive. Secondly, you need to have skilled staff to do psychotherapy. You might look at a particular need and say this is what we would like to do, but you may not have skilled staff. Obviously, the more skilful your staff is, the broader the range of programmes from a psychotherapeutic perspective you can offer. Therefore, you would always be happy if people were developing particular skills. Then you have to decide, what is their level of expertise? For example, to be a real psychotherapist, does that mean you have to do two years study and undergo analysis yourself? Does it mean honing up your counselling skills in a psychotherapeutic approach? We have to be clear on who is an expert and who is not, and what our standards are.

In regards to the education and training needs of social workers, **the clinical director** highlighted the inherent conflict when combining case management and therapy. He stated:

> fundamentally, if they are working in mental health, they are functioning as case managers. Case managers effectively function as therapists, counsellors. They may do more than that; they may be facilitators, networkers and that kind of thing, which in some ways introduces complications into the role of the therapists. In this town, unless one has private insurance, the case-manger effectively becomes the person's therapist. That job is very difficult; it does seem to contaminate the therapeutic role at times, or has the potential to, when you are in the role of a case manager and have to set limits on people. That tends to cloud the therapy role. It doesn't make it impossible but it does require a greater degree of skill, sophistication and training.

The clinical director was more confident that case managers are engaging in psychotherapy than was the manager. Nonetheless, both raised the issue of

expertise and "sophistication", with some implication that social workers do not already have this.

The clinical director provides us with some understanding of why postgraduate study, as previously preferred by the manager, is important in both practical terms (geography and economic) and professional terms. He stated:

> I would like to see postgraduate training in psychotherapy. I am talking about referring people with personality difficulties. The Axis 1 mental disorders [seriously mentally ill] are our target, things like schizophrenia. The complicated personality difficulties and relationship problems that evolve out of those [schizophrenia or bipolar disorder] require much more skill to prevent a tremendous rate of morbidity in the community. Here [Australia] doctors under Medicare are covered [for claiming a rebate for services] and sometimes psychologists under private health insurance, but social work therapists no. I think this is the direction social workers need to go. There are vast numbers of people who need help and treatment. We get people coming from humanist backgrounds and then they gradually evolve new skills and training. We need to have that at universities here. The nearest we have available is the University of Queensland, offering courses in psychotherapy. Being 1700 kms away makes it difficult.

The interview with the service development coordinator did not canvass his views on aspects of social workers employed at LIMHS or education and training needs for social workers since these are not areas of his responsibility.

Conclusion

This chapter presented data from the management team about participation of consumers and carers at LIMHS; social work; social justice; and post-graduate education for social workers. The manager went from a broad, principled understanding of possibilities of participation of consumers and carers at LIMHS. He could philosophically see that Standard 3 demands that consumers and carers participate at all levels of the organisation including governance; service design; treatment interventions; programme participation and grievance processes. The manager however appeared to favour a minimal approach to participation which focused on clients being reactive and passive participants of a service which was already operational. In this sense he saw LIMHS as fixed and static rather than an organisation which is organic and dynamic. While the manager went from a broad focus to a narrow focus, the social development coordinator went from a narrow perspective of having consumers and carers involved in treatment plans; grievance procedures; workshops, mental health week activities and being represented at training opportunities, to a wider embrace of participation as a whole-of-community response embracing issues such as housing and employment. The clinical director was much narrower in his understanding of participation, seeing this limited by the

diagnosis and wellness of the consumer and only in terms of their own life experience.

Both the manager and the service development coordinator expressed initial difficulty in articulating a unique professional role for social work. When engaged further, both could see unique and valuable contributions of social work, including the contribution social work has made to the dominant method of service deliver, case management and in terms of helping clients negotiate bureaucracies.   The clinical director recognised the focus of social work on empowerment and advocacy frameworks for their practice. The manager was ambivalent about LIMHS engaging a senior social worker while the clinical director, who had initially presented a strong supervisory role "over" the practice of social work strongly supported the notion of a senior social worker.

The manager initially felt that social justice was safeguarded through protective legislation. He acknowledged the civil rights abuses of consumers of mental health services, however, and while being puzzled about this, eventually laid responsibility at the level of societal sanction of psychiatry. As he had previously done in discussions about participation and social work, the clinical director prioritised a focus on diagnosis and "wellness" over social justice issues like human rights and civil liberties. The service development coordinator acknowledged the difficulties of operationalising social justice in a mental health context which can regulate consumers. He did, see that the responsibility for ensuring consumer social justice lay with MHPs.

The next chapter focuses on the responses of the community development worker to questions about participation, social work, social justice and education for social workers.

CHAPTER SIX
Data Set 2: Community Development Worker's Responses

This chapter is a presentation of the community development worker's views of participation, social work, social justice and social work education as these relate to consumer and carer participation at LIMHS. The community development worker is employed by a non-government organisation called the Mental Health Network and accountable to a management committee. The funding provider (state and commonwealth governments) defines her duties. This is a sole practitioner position and the incumbent's professional background is community welfare. The importance of including the community development worker in this study is due to her collaboration with all staff at LIMHS and with the local consumer advisory group. She thus has a unique overview of the system. The rationale for reporting the findings of her interview after that of the manager, the clinical director and the service development coordinator is to enable her views to be compared and contrasted with those of that group.

Participation

The community development worker readily identified the policy which directs her practice in consumer participation as Standard 3 of NMHS (AMHS, 1996). She particularly pointed to the margin of manoeuvre workers have to develop this policy with consumers to ensure localised implementation. She said:

> Standard 3 refers to consumer and carer participation in mental health services. It is a very open-ended policy and that is good because it is open to interpretation. Working through the standards, we [respondent and consumer advisory group] developed our own policies for participation with our local mental health service.

The community development worker was asked directly about consumers and carers participation in planning and policy development at LIMHS. She replied:

> obviously they aren't, and where they are, it is tokenistic. I think it would be wonderful, but we certainly have a lot of education to do before we can get to that stage. We can't just plonk someone into it and say 'here you go, you are in the policy development party, go for it' because that is incredibly tokenistic, and incredibly silly.

Like the service development coordinator, the community development worker saw participation by consumers and carers limited by lack of training.

As to whether consumer participation is encouraged at LIMHS, the community development worker stated:

> to be quite frank, it is not. The service development coordinator might be the only person who has some sort of understanding of it. However, he's not inclined to think that when the

people are trapped, to look at the training and education side for the consumers. There are a couple of workers and one of them is a social worker, who certainly does have a good grasp of consumer participation, but in general I would have to say no, there isn't any really. I am very hopeful that the culture is beginning to change.

The community development worker intimates that it is up to individual MHPs themselves to become au fait with participation policies and to implement them in their practice. This meshes somewhat with the views of the manager and the service development coordinator who "hoped" or assumed that MHPs were engaging participatory practices, rather than perhaps ensuring that MHPs do engage policies and practices and policies of participation.

The community development worker thought that social workers viewed the preparation of consumers and carers for participation in service delivery, planning and evaluation at LIMHS as her responsibility. She pointed out, however:

it is not actually my job, it is the LIMHS's job to do that. It is everybody's job really, but specifically the LIMHS. However, I do it because I can see that the LIMHS is not ready to take it on board yet. I have been able to see that for some time. Consumers and carers currently have a non-professional role, a very low-key unrecognised role of being hospital visitors, specifically the psychiatric inpatient unit. The consumer advisory group goes and visits clients and provides basic support. The carers, to date, have assisted with a programme that was developed and initiated by a social worker. It provides education to carers when they are coming into the system. Carers were asked to assist with communication at the end of the programme; to talk to the new carers. To my knowledge, they have absolutely no other role in the LIMHS.

The community development worker had a broad understanding of the responsibility for participation as a whole-of-organisation. This contrasts with the view of management who saw this as the responsibility of individual MHPs.

The community development worker was somewhat ambivalent about whether or not management listens to her ideas and the ideas of CAG about consumer and carer participation. She said:

the manager and the service development coordinator are open to listening to me and to my ideas, though it is very difficult. When we [participant and the consumer advisory group] approach them, we would hope to sit down and talk in an open and honest forum, rather than them being suspicious and not getting around the table and sorting things out. We did try to do it, however, there was a social worker present who has, as a case manager, treated some of the people in the consumer advisory group poorly, and throughout the meeting he was quite insensitive. I don't know whether it was because of his involvement with some of the individual members of the consumer advisory group, in terms of being their case manager. He certainly put a spin on everything and it was very noticeable to me. There is no honesty there, just doubt, fear and mistrust. It was shameful.

The assertion that the manager and service development coordinator were difficult to engage in attempts at involving them in discussions regarding reform, demonstrates unwillingness on their part to embrace performative, participatory practice. This

statement of the community development worker was in direct contrast to the view of service development coordinator who stated that when consumers and carers shared their views, these would be acted upon.

In the opinion of the community development worker, consumers and carers can engage with some specific roles within LIMHS. She believed that:

> one of their [consumers and carers] most important roles is to be on interview panels. They need to be trained to be on interview panels and they need to be well at the time. Obviously, it would be ludicrous to consider otherwise. They need to be doing everything from policy development through to evaluation and quality assurance. They need to be involved in everything that is going on, all the way through. They also need to be involved in advocacy and education. I would like to see them [LIMHS] consult with consumers and carers as equals, not as lowlifes. I would also like to see the process of education of consumers and carers commence. They need to be respected and this would require a change in culture.

Whereas the clinical director saw participation and partnership secondary to the diagnosis and wellness of the consumer, the community development worker saw that it as the responsibility of LIMHS to break through these barriers to participation, through engaging training and development to take significant roles at LIMHS. She therefore did not limit the roles of consumers and carers as did the clinical director, the manager and the service development coordinator.

The following section presents data about the community worker's views of social work and their service delivery model.

Social work

The community development worker identified that social work has competency standards *(Competency Standards for Mental Health Social Workers,* AASW, 1999) from which social workers should practice, however, she recognised the dilemma for social workers of implementing these without strong leadership which acts as a guarantor of these practices. She said:

> Locally the social workers don't have a strong leader or leadership, or anyone to give them professional supervision and steer them in the right direction.

The community development worker inferred the need for social workers to gather leadership around their policies and practice.

The community development worker believed that the model of service delivery used by social workers at LIMHS was:

> the mental illness theory of mental health. They work very much from the model 'we know best' it is very heavily medicalised. They certainly don't work from a promotion and prevention perspective when they are so called 'treating' people. You just have to look at

the hierarchical structure and the medical model being so dominant, it filters its way right down through the whole system. One of the tensions certainly is that the service providers know that the consumers and carers are not necessarily happy with the service they provide. I really don't know how, as a social worker, you could gain any job satisfaction having to work daily in a role such as that.

The community development worker saw social workers at LIMHS working from a dominant medicalised model which stifles multiple professional and personal ways of being as articulated in the following:

There are lots and lots of power plays and absolutely no honesty. An outsider walking into the service (LIMHS) feels that it is quite ill. This is due to some of the social workers in the service being forced against their will to work in the medical model, or get out. One of the other tensions is that if a person wants to work in the area of mental health because it is their passion, there are few choices regarding where you can go to get work, so therefore some of them just stay, hoping it will get better. There are many tensions. One of the main ones is this awful closed shop, where 'we will run it this way and no other way'. There is absolutely nothing holistic. I think it is making people quite sick. It makes my role increasingly difficult. The defensiveness and resistance make it uncomfortable. It is quite a simple concept really and everyone can feel it. Other organisations also have their problems. However, when you walk into them there is a completely different atmosphere. It is friendly and accepting, and people don't ignore you, it is a completely different concept.

Social justice

Despite this sense of constraint on practice options, the community development worker positioned herself differently from other employees:

I work from the community development perspective. I am controlled from the top down, but my role is fairly autonomous. I am not allowed to do things like upset Ministers and stuff; however, I can still say a lot more than public servants. I certainly practice at a community development level, in that I don't go where I am not needed. Social justice principles are also very high on my list. I have hope and I see hope. I see many people fly when given the opportunity. I see people actually achieve wellness and recover. On the other hand, the most frustrating thing about my role is the politics and its effects on people's daily lives. When you think things are going really well, some sort of game, a political party game, frustrates you.

The community development worker practiced social justice by prioritising consumers and carers training needs and opportunities over her own within the training options provided through LIMHS. Thus she:

work(s) very hard at trying to get consumers to go to conferences. They don't work therefore they don't have the money. I was doing my Masters in community mental health. It really expanded my horizons. It has given me the big picture behind the scenes, the history and looking through the eyes of different professions, and their theoretical backgrounds.

Social work education

When asked about social education for mental health practice, the community development worker felt that :

there is a great need for them [social workers] to cover the areas of promotion and prevention. Mental health is not a separate entity. There is a need to look at it from a holistic

point of view and to start looking at it when people are young and include their parents. They need to take the bull by the horns and take it right throughout a person's life. They have to look at parenting skills. Social workers need to take a holistic view of how a person maintains mental health within the family, the community and the school-yard. There is a need to start educating people, rather than putting mental health into a square box on its own. If social workers look at a person from the mental illness theory, and say 'that person has schizophrenia and once we ameliorate the voices then we are going to deem that person to be well and OK in the community', then who is looking at that person's life? This is where social workers have a huge role. The person may be illiterate, or between two cultures, or may have a broken heart, be suffering from hopelessness and despair, have no friends, or perhaps come from a dysfunctional family. They have no way of disseminating information about the world around them. One of the areas where social workers are so important, and where so much has to be done, is to look at the person holistically. I cannot see any benefits to social workers looking at and incorporating the medical model in their training.

Unlike the clinical director and the manager, who focused on social workers being educated in psychotherapy and medical aspects, the community development worker took a diametrically opposite position. She felt that social workers should privilege their own knowledge in approaching mental health service provision from a holistic, developmental perspective and that this training should not incorporate more of the medical model.

Conclusion

The community development worker differed markedly from management in her views. She felt that participation and partnership at LIMHS was tokenistic and best or non-existent, yet she pointed out that open ended policies can be applied to a local context as she has done through her engagement with CAG. She did not think that that participation should be limited through filters of diagnosis or activity type; rather that LIMHS should be enabling consumer and carer participation particularly through education, training and participation at conferences. She felt that a lack of social worker leadership contributed to the disregard of social workers implementing their own standards of mental health service delivery. She perceived LIMHS to be a medically driven, closed system. Unlike the clinical director and the manager, she felt that social work education should not centre on models already imposed through the medical framework of practice; rather they should privilege a holistic understanding of mental health and a holistic practice framework.

The next chapter is a presentation of the views of social workers about consumer and carer participation and their roles and practices at LIMHS.

CHAPTER SEVEN
DATA SET 3: Social Workers' Responses

This chapter is a presentation of the views of the 12 social workers employed by LIMHS in five clinical teams, about their practices of participation and partnership with consumers and carers; social work; social justice; social work education for mental health practice. The five teams have different clientele across adults, children and youth, and Indigenous people.

Participation

Social work participants were asked to describe their understanding of Standard 3 of the NSMHS (AHMAC, 1996). This Standard (see appendix one) clearly delineates the obligation MHPs have towards consumer and carer participation and offers examples of how the standard can be operationalised. Six participants (half of the social work participants) had knowledge of Standard 3, albeit to different degrees:

> Consumers and carers are supposed to be included. **Natalie**

And:

> It is all about consumer participation in service delivery. **Rowena**

And similarly:
> Participation in planning, implementing and evaluating mental health services and ensuring consumers and carers are involved from start to finish. **Camilla**

Another participant revealed a more comprehensive understanding of Standard 3:
> It is a partnership with consumers in regards to ensuring a quality service appropriate to their needs. It is integral that we have consumers involved in all aspects of service delivery. Also, in terms of consultation with management for service direction and service priorities and all that sort of stuff, we could do a lot more on it. **Carol**

Carol's response conveys an acceptance of Standard 3. It also suggests a willingness to progress the policy within the mental health service and assist consumers and carers to undertake their new roles.

By contrast, Joyce and Maria raised concerns about increased participation of consumers and carers. They said:
> It involves consumers running the service. However, something that I do not understand is that consumers are not involved in the running of any other service. For example, the business next door [real estate] or across the street [hardware]. **Joyce**

Joyce potentially limited participation by invoking usual business practice. She was confused about whether or not mental health is a business, like any other business.

Although Maria agreed with the policies of partnership and participation, issues concerning her personal information and security disturbed her:

> It is about allowing the consumers to have some participation in the way the service is operating. I think it is a good idea, because while we are professionals and we have all this theory on mental illness behind us, most of us do not have that experience [mental illness] so the consumers have a better idea of their needs. However, it depends on how far you go with participation, what does it mean? I was talking to a nurse and she said that they have consumers on interview panels for nurses applying for a job. In some ways that is good because the consumers have an idea of the people who are coming through. Myself, I feel a bit strange having consumers who might have information about me. That has always been a concern of mine; I have a problem with consumers having knowledge that they should not have. **Maria**

Maria could embrace some aspects of participation; the idea, the principle of participation but inferred that it should be limited to the consumers and carers defining their needs and in terms of information to which they privy.

Social work participants of this study were asked about the roles undertaken by consumers and carers within the organisation and the ways in which participation is encouraged at LIMHS.

One participant believed that:

> Lip service is paid to it. **Thomas**

Neither did Wendy see much encouragement of consumer and carer participation throughout the organisation nonetheless; she saw that the new carer self-help group lobbying for resources for LIMHS:

> It is probably not encouraged quite as much as it could be but I am not terribly familiar with it. I assume the community development worker encourages participation. I guess the biggest push is the new mental health help group. It is consumer and carer driven. They have been doing a lot of lobbying, particularly for new psycho-geriatric beds in Lantana, rather than people going down south. **Wendy**

Wendy confirmed the community development worker's perception that social workers perceive that ensuring consumer and carer participation is her job rather than them perceiving this as the role of all employees of LIMHS.

Another participant stated:

> They don't have any roles here. We are starting to have a consultative type process through the consumer advisory group, but that needs to be broadened and enhanced. Recently management has given the service development coordinator more time to work with the

community development worker to give consumers more of a say. I have seen things moving a bit more. The service development coordinator has been spending more time working on issues, but it is moving slowly. Obviously, he has seen it as a priority and has been able to spend more time on it. It is a step in the right direction, but it seems to be concentrated more on one person [the service development coordinator] rather than a service wide approach. **Carol**

Carol agreed with Thomas and Wendy that there are no roles for consumers and carers at LIMHS. She agreed with the community development worker, that the service development coordinator, as part of management, was the person directed to work on consumer and carer participation within the organisation, with the community development worker. Like the community development worker, though, Carol saw that participation must be a service wide approach.

Joyce viewed participation as something that happens in the day-centre programme, rather than on the executive:

They [consumers] are actually service recipients rather than participants. They receive a service and they are consulted about that service. I don't know that they feed back into the service to any great extent. It happens at the level of the day-centre programme. It needs to take place at management level. Consumers and carers need to be involved in the mental health executive. When we set up the team leaders meetings, information into what should be happening with consumer participation was one of the things written in. We decided that it should take place at the mental health executive. There is not a culture of consumer participation in the executive; we have not set up a way that consumers can participate safely. For example, if I went to a meeting of the board of directors of a finance company, I would need to know what the briefing was and get some training. I do not think that aspect is adequately addressed for the consumers. **Joyce**

Joyce saw that participation at present is limited to their activity in the day care centre, nonetheless she though participation was the responsibility of management – that is, not part of her role.

Rowena saw CAG as the site of participation for consumers and carers, with case manager encouragement :

They are represented on the consumer advisory group. Here in Lantana, the day-programme has high consumer input. I think consumers have to be encouraged by their case managers to participate. **Rowena**

Another participant described consumer participation as carrying out unpaid domestic duties without the opportunity to aspire to complex tasks:

We have certain consumers responsible for tasks in the day programme. That is encouraged. People have what they see as their jobs [unpaid domestic duties such as washing dishes and making lunch]. Previously, we did not have that and now people are taking responsibility. In the day programme there are meetings going on. The push is for them to take control of that area themselves. Maybe they will move away from the building and be independent. Certainly, they are not taking a much higher role like being on interview panels. It is a new concept. Whilst many consumers are saying they would like to do it; change is quite scary for them. It needs introducing slowly. **Maria**

Maria seemed to view participation as limited to the mundane activities of the day-centre programme. She saw participation as being limited by consumers themselves (being scared, being committed to particular low level tasks "their jobs")

Lucy felt that staff are limited in their participation in decision making implying that if "higher" level people within the organisation do not share in participation what is the likelihood that this would happen at the "lower" level of consumers and carers:

> I despair of any participation for us, never mind consumers and carers. I am divorced from any decision-making. The consumer advisory group represents the consumers on the mental health advisory group. They are consulted and have input into ideas, but who has the final say. Is it real consultation and input? **Lucy**

The difficulty of challenging entrenched authoritarian attitudes especially for the medical domain was described as a barrier to consumer and carer participation at LIMHS:

> There is a gradual swing towards more consumer input, but to get consumer input you have to challenge a lot of deeply ingrained attitudes and opinions. People from medical backgrounds like psychiatrists and nurses that have been around for years, this is a new concept for them. **Sian**

Natalie agreed that consumers were involved in participation through the day care programme and suggested that other roles particularly at the level of executive are contentious:

> I don't think that they have any consumers on the executive. They are just involved in the day-centre programme. When you are talking about involving consumers in decision-making that is a very different space, our programme is not for that. We have the executive and I heard some discussion of whether they should be included and why, and if they are not, why? I know that people have contention about it. They are things that I cannot discuss. **Natalie**

Camilla, like Rowena, thought that participation of consumers and carers is engaged through CAG. She implies that people participate in CAG when they are well, and she further highlighted some of the activities engaged:

> The consumer advisory group (CAG) works in with the service development coordinator. They are involved with mental health week. We are also looking at reimbursing CAG for their work on accreditation. Obviously, sometimes the consumers are not well, they are not able to cope with it [participation], or have the understanding. Currently, we have a couple of consumers who understand, they are well, and able to meet with other people that are not looking down on them. There is no actual consumer training that happens in a systematic way across mental health. **Camilla**

Another participant described the inclusion of parents (carers) at monthly meetings and that these serve as a support mechanism around the diagnosis:

> I am not aware of any roles they have within the service such as being on planning committees. Quite a few kids are diagnosed with ADD and we have a monthly meeting

facilitated by a staff member. Any parents who want to come along can raise any concerns or issues. It is also a cooperative kind of support mechanism. **Conrad**

Social work participants described what they were doing to support consumer and carer participation:

My experience has been in my individual work, ensuring clinical treatment plans are a collaborative approach and negotiated with consumers, as well as involving the families as much as possible. I've also undertaken group work with the relatives and families that are educational and supportive, and linked to consumer networks. Other than that, I've only had an occasional discussion with the community development worker about these things. That is the limitation of my experience, offering to be of assistance, finding time to do it, then having nothing opened up for me to be involved in. **Carol**

Clearly Carol perceived the Community Development Worker to be responsible for participation policy implementation. Carol limited participation around diagnosis, treatment plans and support around this diagnosis.

Rowena accepted that consumers and carers should participate in the delivery of services. She appeared unsure about how this could actually occur and appeared to lay responsibility for participation at the feet of consumers.

It is essential that consumers and carers participate, they are the ones directly affected by service delivery. We must have representation from them. I do speak to my consumers of possibilities of being involved if they wish to do so. **Rowena**

In the following response, Conrad seemed to limit participation to carers being involved in the treatment of their child. He implies that he develops treatment plans to which parents agree. They then implement this plan:

I think it is important, so consumers have some ownership of it. Wherever possible I get the whole family involved as I am only seeing a young person or child for one hour a week or fortnight, whereas the parents are with them all the time. If the parents are involved in the service delivery, and they agree with the service strategies I am discussing, they can help implement them at home, which is infinitely more beneficial than anything I could do in one hour a week. **Conrad**

Maria had very similar views to Conrad. She said:

It is quite important for them to be involved, however, I cannot look at consumer participation at the moment. We do encourage our consumers to give ideas on where they want to go and what they want to do with their day. It is essential because we spend so much time with consumers. We need to be sure they want to do the things we plan. **Maria**

Maria, at best limited participation to consumers having some input into the activities they engaged when the consumer and case manager spend time together, but Maria also implies at the end of her response, that consumers will do what "we plan".

Joyce and Camilla had previous experience of the consequences for individuals and organisations when standards are non-existent or unmet:

I think participation keeps a check on the service. There have been many abuses in the past, and probably still are. I observed the kinds of abuse that can take place in a mental health setting when you are working with a marginalised group. Participation also implies that you have to budget and that you have a way of not disabling consumers or putting them on the spot. For example, when you use them in things like interview panels, or the running of the day-centre programme, consumers need training. The input itself is valid, because what consumers say is how the service needs to operate. It is a great theoretical and practical idea. I do nothing, you have to understand that I am a case-worker not a manager, and as far as consumers go, they are self-determining. Part of my brief is empowerment; therefore, I listen to [consumers' and carers'] comments on the running of the service, and then feed them back to the team. I do not have a direct social policy function. Indirectly, I would listen to their concerns and feed them back up the line. **Joyce**

Like Rowena, Joyce at some level understood the importance of participation as an accountability measure for consumers and carers yet, she admits to doing nothing in these terms (accountability), but she does listen and pass consumer comments back to the team. She does not tell us how she follows this up or whether she feeds team responses back to the consumer. There is little in this response to indicate participation as a two-way process.

Camilla said:

I am all for it. My background is in Disability Services and I was involved in the changes to the *Queensland Disability Act*. It is based on participation and I was a reviewer. If they [non-government disability agencies] failed to meet the standards, they were defunded. In terms of my background, it is second nature. However, I have also been involved in the problems that occurred with those changes and so I do have an attitude that we have to go slowly. We do not want to set consumers up to fail. I support individuals on my case-load to have a say in their consumer group meeting. I also see my role as being aware if they are paranoid and saying negative things about doctors before they attend the General Practitioners meetings. I work through those issues with them, before the meeting. See that is what I mean about setting people up to fail. You have to be careful not to say 'Yeah, get out there and say your stuff.'   **Camilla**

Similar to Joyce and Carol, Camilla made a strong statement about the importance of participation and then followed this up with a limitation to *consumer* meetings. She further appeared to see participation as helping consumers articulate things in ways acceptable to doctors. She therefore tries to protect the more powerful group (doctors) from possible "negative things" without telling us how she does, or might simultaneously protect the rights, interests and feelings of consumers.

Wendy appeared to consider participation as the responsibility of consumers themselves:

Consumer participation is warranted, as long as they [consumers and carers] have a good understanding of what the concept is. However, I am not undertaking anything at all. It is not my job. **Wendy**

Similar to Wendy, Tilly suggested that it is up to the consumer and carer to put themselves forward to participate at LIMHS. She said:

> I am very happy for consumers and carers to participate. Presently I have no consumers who want to be involved. I have asked one or two consumers, but they showed no interest whatsoever in doing it. They have not continued with the recreation group. It is a matter of not having interested consumers. I have not been able to do it because we got a second worker recently and she is still on contract. Things like consumer and carer groups, or a recreational group are not on offer. **Tilly**

Lucy appeared to see participation as an additional task to what she already does. She said:

> Great, but until our caseload comes down we cannot be expected to do anything about it. **Lucy**

Whereas other social workers saw that participation was not their job, Lucy positions participation as a very low priority and separates participation from her "caseload" work.

Two participants mentioned the inherent difficulties involved with translating policy into practice:

> They should be included; the service is for them. Too often, however, organisational policies are written but when we start to put them into practice they get lost, they do not make sense, or it is too difficult. **Natalie**

Natalie provided an implied that policies are written outside an intimate connection with practice. This might go some way to explaining the number of social workers who proclaim a strong positive view on participation, whilst not actually implementing participation in their own practice.

And:

> I believe that consumers should have a lot more input into the types of services provided for them. I think that some of the conflicts that come up are due to us working for a large government bureaucracy. It binds us to working within the guidelines of what the government wants and often that is in conflict with what the consumers want. Consumers should have a lot more input into the services provided; government policy makers should stop thinking so much and start listening. In the Indigenous mental health programme, we check ourselves with consumers. When I attend clinical reviews with the other Indigenous staff, we challenge each other on "how did so and so feel about that". If there is a conference on, I look for ways of encouraging our Indigenous consumers to tell their story; it is part of healing for them. A consumer who has an infamous reputation who I have worked with previously, has a lot of prejudice directed at him. When I heard about a mental health conference, I arranged funding and he told his story and it was amazing. He came back on a real high. I could have gone to the conference, but it is about turning it around and considering the consumer first. **Sian**

Like the community development worker, Sian prioritised consumers' attendance at conferences over her own. While she saw this as helpful to the client's healing she

also intimates that it is one way government and other professionals can hear directly from consumers. She further stated the importance of the consumer's voice in clinical review meetings through a process of always asking about what the consumer thought about whatever was being discussed at the review. This seems to imply that before things go to the clinical review meeting they are discussed with the consumer.

Consumer participation for Thomas is to involve himself with the consumers in the day-centre programme:

> I go and speak to the consumers every week, I know most of them, and get on well with them. I go down to the day-centre programme; I acted as Santa Claus for them at Christmas and made myself known. I've taken part in meetings. **Thomas**

Thomas saw participation as focusing on himself. He gave no indication of how consumers perceive him or how they respond to him in the various activities he described. He did not share how his participation increases or decreases the consumers own participation in these events or activities.

Roles which could be engaged by consumers and carers

Social work participants offered ideas on the roles consumers and carers could engage within LIMHS if presented with the opportunity. Carol's views included active engagement around treatment plans and within the economy of the organisation:

> You would want them to be involved in every aspect of the treatment plan and involve them in regular family meetings. They could advise staff on their needs and take a more active role in the organisation. There needs to be a plan developed for affirmative action to bring consumers and carers into the service to work in paid positions. **Carol**

In addition to individual consultation by the service development coordinator, Joyce wanted to see consumer forums formalised:

> There could be a forum for them to comment on the service. I see the service development coordinator in the day-centre programme talking to consumers. They could do more with consumer participation and empowerment. **Joyce**

Joyce wanted more consumer participation and empowerment, but did not tell us what this might mean in active, concrete terms.

Thomas provided an example of a mental health service's attempt at participation. He said:

> I've thought about this a lot. I think the problem with Lantana is it is a small city. What happens in Sydney is not applicable here. I've been on committees' where unstable patients were discussing the possibility of being involved in a recruitment process. The community development officer recommended that some patients be on an interview committee. The

community development worker jumped up outraged, because I said, "those consumers are not appropriate, they are unstable". She has put the process back years; it showed poor judgement on her part. **Thomas**

Thomas perceived that his judgement of who is stable and who is not, and who is appropriate for inclusion in recruitment processes, is better than the judgement of the community development worker. Because his judgement is better in his terms, then he blamed the community development worker for putting the participation process "back years" by including "unstable patients" in this discussion. He echoed the sentiments of the clinical director (psychiatrist) about the wellness of clients determining participation. He also referred to consumers as "patients", which further demonstrates his embrace of the medical model. An implication made in this discourse is that until all employees of LIMHS agree on who is well enough, stable enough to participate, then participation should not proceed, or at least until everyone agrees with Thomas about who is stable enough to participate that is, staff must individually, be personally convinced about the stability of particular consumers before participation can ensue, rather than trusting each other's judgements. This is particularly important since many social workers saw the community development worker as having the role of ensuring consumer participation, yet, in this example she was not trusted in her practices around this. Further, there seems little regard in this story about Thomas's respect of consumer's views about their participation.

Camilla conceived a wide range of committee roles for consumers:

> They could be involved in strategic planning. We could also get them involved in our internal mental health promotion committee and our quality assurance committee that meet once a month. **Camilla**

Camilla did not explain what committee roles and responsibilities consumers might assume.

Conrad said:

> They could be more politically active, whereby they take on a watchdog role and report anything they are dissatisfied with to management. **Conrad**

Rather than taking a proactive stance in relation to LIMHS, Conrad, like the manager, saw consumers taking on a reactive role – the right to complain/respond.

Other social workers had difficulty articulating specific roles which could be undertaken by consumers of LIMHS. They said:

> I am not sure about what they want. They need to talk to us and tell us what we can put in place for them. That is if we can. **Maria**

> They can be more involved with the service by giving us an idea what they want. You know, have forums. **Natalie**

> It would be good if the consumers gave us feedback on how the service is for them. In addition, carers need to share with other carers, to learn of others' experiences and share their own. **Tilly**

These social workers saw it as the responsibility of consumers to ensure that participation at LIMHS occurred. This is in direct contrast to Conrad's reactive position – here consumers were expected to of and by themselves, initiate, guide and engage in participation.

Four participants could not think of any roles that could be undertaken by consumers and carers at LIMHS. They declined to respond to this question.

<div align="center">Social Work</div>

Social work participants were asked their views about the *Competency Standards for Mental Health Social Workers* (AASW, 1999). This was important since it is these national standards which direct social work practice in mental health settings. The *Competency Standards for Mental Health Social Workers* (AASW, 1999) were released in 1999. One third of social work participants of this study (4) had heard of them. Those who were aware of these standards viewed them as similar to the existing Code of Ethics (AASW, 1999). They were disappointed that nothing new was offered:

> I received a copy and distributed copies to the various social workers. They do not say anything different from our ethics. It is the first time I have seen them written as standards. There is the issue where the AASW are pushing for ongoing professional development. It is moving towards registration, where social workers are a registered body like other allied health professionals. We are at the level where social workers are looking at them and I'm afraid social workers getting together and looking at their professional development doesn't occur because there is no designated senior, or anyone looking out for discipline specific professional development issues. Interested social workers would say, "look, do you want to talk about how to implement this", but only two people would show up. It needs to be structured into work requirement and professional development, but the nature of mental health services with case- management, is the flattening out into generic positions. It is a lower priority for the service, management are not pushing it. It reflects not having a senior social worker in the discipline. **Carol**

Carol highlighted the difficulty of implementing even professional standards without the leadership of a senior social worker, just as the community development worker, the manager and the clinical director perceived other generic mental health policies as weakened without strong discipline leadership. Yet it is this lack of discipline

specific leadership which has allowed the genericism of mental health service delivery, through case management, to flourish.

Another social worker, Joyce, was at best ambivalent that case management and social work practice are different. She said:

> They have outlined a method for working in mental health. I have the competency standards here and I have read them. It is social work ethics, theory and knowledge put into practice, you know, empathy and respect, and that is straight out social work. Other social workers that I distributed them to think it is what we are doing anyway, however, it is good to have them. I did not look at them from the point of view of how case management differs from social work in the service. If I wanted to treat people by the competency standards, I would have carte blanche to do it. The things that I do as a case manager are wider than my brief as a social worker, like delivering medication and filling dosettes (medication boxes that define daily doses) for starters. My brief as a social worker is to educate myself about the roles I undertake. I am educating myself about drug therapy and that is something I never dreamed I would do, but the job is a case manager, not a social worker. **Joyce**

At one level Joyce saw social work practice imbued with characteristics of empathy and respect but she appeared to see herself more as a caseworker than social worker. She did not see that the implementation of the AASW competency standards could/would be curtailed in any way by LIMHS.

According to Sian, there were cultural differences when interpreting the Competency Standards:

> The Competency Standards provide guidelines and indicators for social workers to operate within the workplace. They are similar to our Code of Ethics and there are a few constraints on interpretation by people from different cultural backgrounds. In particular, social workers from different cultural backgrounds like myself; I am Aboriginal. The process that I would use as an Aboriginal, to ensure that the service we provide to our Indigenous consumers meet those standards, is very different to the process that non-Indigenous social workers would use to provide the same service to non-Indigenous consumers. That causes conflict in the workplace and I have said to people "it is not one or the other, it is just that we use a different process to achieve the same outcome". **Sian**

Sian, like the community development worker understood that policies, including the Competency Standards, are open to local, including cultural application and of themselves do not lead to a "one-size-fits-all". She also, however, like the community development worker implied that LIMHS can be constraining of this flexibility by seeking a totalising understanding of the standards.

Social work at LIMHS

Social Work participants were asked what they believed was the unique social work role and contribution to LIMHS. The most scathing critique came from Thomas:

> I am a case manager. There is no social work collective here. Everyone just accepts the situation that we don't get to work as social workers. I am disgusted at the lack of insight

> with most of the social workers here. They play neurotic games, they don't play structural games, and they don't engage in process, they engage in neurotic dependency needs. It is embarrassing to watch; I disassociate myself from them. **Thomas**

Just as Thomas previously judged the community development worker and his team leader negatively, here he does the same thing to his social work colleagues. He judges them in psychiatric terms ("neurotic") without telling us how he does things differently. In fact, he intimated that he accepts the situation since this is what "everyone" does.

Camilla both highlighted her role as a case manager and specified how this relates to social work:

> I don't have a specific social work role. I am a case manager. I have a good knowledge of resources. Case management is what we learn in social work from day one, and so it is about working with others". **Camilla**

Like Thomas, Camilla felt that there was little social work cohesion, though she seemed to lament this and inferred that getting together would be helpful to her in maintaining her professional values and knowledge:

> I feel isolated from other social workers. I am not sure if I am losing some of my knowledge base or my values because we are not getting together. The last time we all got together as social workers was a year ago. I don't know if there is anything else I can do. **Camilla**

There appears to be a disjuncture between occupational self-identification and the formal organisational representation of discipline specific roles at LIMHS. In pursuing this during the interview, Maria expressed tension in terms of role confusion:

> I am a social worker, but we all do the same job case management, and have the same issues. The only difference would be the giving of injections. **Maria**

Wendy expressed difficulty in defining her social work role; nonetheless, she could see that social workers were holistic in their practice:

> I really don't know. Probably to look at each consumer in a more holistic way. **Wendy**

The following five social work participants undertook a case management role, however, they also recognised unique social work contributions:

> We [social workers] look at things from a consumer's point of view and establish empathy. This is not written into other professions as it is in social work. The rest of the team consult the social workers regarding what to do about empowerment. We articulate a consumer perspective of what is happening, rather than a medical perspective, or a treatment perspective. What is that consumer good at, or thinks is helpful? Putting the consumer at the front of what is happening is what social workers are good at. We are also good at family work. **Joyce**

Where previously Joyce was ambivalent about consumers participating in executive function of the organisation since this was not expected of other businesses, here she sounded clear, strong and assertive about placing the consumer at the forefront of her practice and recognised this as a core social work function.

Like Camilla, Carol would like to see more of a social work professional identity at LIMHS. Where Joyce recognised empathy, family work and putting the consumer at the forefront of our practice, Carol saw that social workers contribute through their knowledge of community resources:

> Officially, I am a generic case manager and undertake similar work to my other colleagues on the team. However, my other colleagues pick my brains about resources in the community. When they bring up issues for case review, or at the morning meetings, I offer social work input such as, have you thought about this or that, or such and such may be of assistance. We need to have some professional identity. People just see themselves as case managers, not as social workers. **Carol**

Conrad recognised approach to a case, understanding of law and practices of social justice as core, unique, social work contributions to LIMHS:

> I take the opportunity to show how a social worker would approach a case. I have a better understanding of law; family systems and can certainly bring social justice to the fore and give the others a different perspective on a particular situation. **Conrad**

Like Wendy, Natalie saw the holistic perspective of social work as a unique contribution to mental health at LIMHS and further provided evidence of empowering clients through family participation and working with clients so that they understand the jargon of LIMHS. She said:

> Just providing that holistic perspective on things. Even just trying to tone down the medical jargon. Encouraging family meetings and discharge planning that includes all the parties and family members who care for these people when they go home. It may sound simple, but it is not. **Natalie**

Rowena and Lucy expanded on this holistic social work perspective:

> A social worker has a broader understanding of all the influences on the consumers' illness, not just specifically psychological or environmental. When individual matters come up concerning case management, the social worker is able to glean those broader aspects. **Rowena**

> Social workers have a lot more expertise on how a person fits into their family and relationships. **Lucy**

In the following account, a social work participant linked the traditional roles of social work to the reality of working in the medical model, where the social role is hidden, located as it is under more generic nomenclature (MHPs) :

> Social work takes a wider view of everything that contributes to people's mental health, and then addresses those issues. However, there is very little on the assessment form for people's social issues to be included. Another difference is that I don't always refer out. If

something comes up about relationships, or family issues, I am happy to establish a working relationship to address these issues. I see it as contributing to the consumer's mental health. The danger is that in a medicalised setting this isn't valued. When I am in case review and have gone into some detail about what I am doing with consumers, I get a negative response to refer out, refer out. **Tilly**

Like social workers cited above, Tilly showed a clear understanding of social work and its strength in working with mental health consumers, but she illustrated the difficulty of maintaining social work practices and processes at LIMHS.

Another social worker recognised the unique roles of other disciplines as well as her unique contribution to this rich multi-disciplinary tapestry of mental health:

The uniqueness that social work brings to mental health services is that we are trained to look at all aspects of the consumers' life and not just one aspect. Psychologists will always talk about psychometric testing. Doctors and nurses are medication oriented. Social workers come from the social model of the person in their environment. **Sian**

Social Work participants were asked for their opinion on the predominant model of service delivery at LIMHS. Two participants highlighted the difficulties encountered when the social and medical models clashed:

It is a medical model influence but there are aspects of the psychosocial model. It depends on the personalities you have working here at any one time and how much power they have. The medical model is the antithesis of the psychosocial model, and when you have two people with opposed views, it is likely to cause tension. What makes it comfortable is when people are willing to acknowledge where they are coming from and willing to work towards neutral compromise in treatment. What is uncomfortable is when people are very rigid and not about to acknowledge where other professionals are coming from. If they are willing to acknowledge the differences then it can be worked through. **Rowena**

And:

It is a medical model establishment and that certainly has its own inherent limitations as far as decision-making goes. It is trickle down rather than bottom up. We are able to do individual therapy with families, so long as we stick within the reasonably broad framework of the mental health model. This offers an opportunity to incorporate our personal practice model and is good for job satisfaction. Most people when they apply for the job are aware of the boundaries. In applying for the job, they are agreeing with the criteria. There is conflict when a member of the team prescribes medication and you are unsure of the side effects. It may be detrimental to the consumer or worse than the initial complaint, or it may be addictive. If you have a pragmatic and autocratic medical officer who says "no this is the only way", there can be conflict. You have to agree to disagree. If you have a medical officer who is willing to be cooperative and discuss the situation with you, it can be a good experience for all. **Conrad**

A social work participant further described working within the confines of the medical model:

It is a medical model. It starts with your position description. Sometimes you just sit there and you can't even tell the difference between the disciplines; they don't talk like social workers or psychologists, it is very medically oriented. I feel very uncomfortable with this. I am caught in situations where I get annoyed; the medical model speaks about people in a very dehumanising way. When they do speak about people, it is, what is their name, diagnosis and what medication are they on? What are their symptoms and are they

improving or not? There is nothing about, are they married? Do they have a supportive wife or husband, do they have children and how are they coping? It is none of that stuff and I find that frustrating. Natalie

Natalie highlighted the limitations placed on social workers in bringing their unique holistic understanding of consumers to the consulting table.

Tilly explained how she was coerced into working from the medical model:

A diagnosis is necessary therefore; it is medical model to that extent. It is an issue at times to get the GPs to work with us. If you join a mental health service rather than doing social work in a more generalised setting, you can expect that medical dominance would be a strong aspect of the work. We are co-opted. We would also, as social workers, look to address problems of the 'worried well.' That has been a problem for me as I have been dictated to, to some extent. When someone comes up for case review and the diagnosis is anxiety attack or panic attack, I have to advocate for the person and explain why I am seeing that person. It is an issue that I have to conform with. **Tilly**

Not only do social workers experience difficulties of bringing their unique contributions into LIMHS, they also have difficulty working at a level of prevention or early intervention.

The restrictions that social workers encounter when working in a medical model environment were described further by three participants:

Mental health is very medically oriented and that is why a lot of change needs to happen. You have people in charge who are medically focused. I had never been involved in the medical model, but felt it would be useful for me to be involved. You really notice it when someone is sent to the psychiatric ward. There are differences of opinion and things are put in place in the ward without collaboration with the case manager. Medication gets changed, things happen within a couple of days, then the consumer is sent back out and you may not know where they are until a few days later. That's when the medical model really takes over. Decisions are made between the doctors and nurses on the ward and there is no room for discussion, or to look at their social needs. It is about getting this person out of the ward. It is bums in beds not about the long-term needs of the person. They can be well in the community for months, and then admitted to hospital and discharged abruptly, and then everything that you have done is overturned. **Camilla**

And similarly:

Within the eight months I was away, the place turned entirely medical model. I have seen social workers publicly vilified by the clinical director. We have been coerced into it. We all rolled over, no one stood up to be counted. **Thomas**

Thomas noted the pace at which a dominant culture can take over. Thomas stated that social workers were coerced into a medical model, but as seen in earlier quotations, Thomas is deeply seeped in medical terms and privileges medical definitions of stability over consumers' rights to participate. Thomas indicates some punitive, public action (vilification) when social workers do not conform and it is

possibly this that makes Thomas identify so strongly with the medical model – it is much more personally safe than other options:

Carol bore Thomas out by saying:

> We work from the medical model. Most of the team leaders are nurses. If you choose to work by your professional social work knowledge and value base, there is no support, and the consequences are then borne by you. You feel ostracised because social workers are a minority on the team. The others [team members] don't take you seriously and you are not supported. It is very stressful. There is a need for back-up, support from other team members. It is as if there is no respect for professionalism, like your hitting your head against the wall. **Carol**

Sian attempted to resist co-option by challenging her peers:

> We work from an Indigenous model that is guided by the NSMHS. We incorporate the Indigenous mental health policy statements into our service. It is a very subtle process. I think that sometimes it is the social worker's value system that will allow a thing to either happen or not. I remark at meetings 'is that person a nurse?' I am told 'no, they are from occupational therapy or social work'. What they were saying was so medically oriented, so treatment focused. They open their mouth and comment on the medication and pharmacology. I have seen some tensions in situations like that. I challenge them as to who they are and the profession they come from. I see that this person is trained in a very different profession and basically they have no backbone to stand up for the profession they are trained in. They are easily pushed into the medical model. I get uncomfortable when I see a social worker talking like a nurse or a doctor. **Sian**

Sian provided clear examples of ways in which social workers could invite more diverse views into mental health, by helping people to talk from their differing professional bases and challenging the right of other professions to assume the jargon (etc.) of professions in which they have not been trained.

Whereas Sian was uncomfortable with professionals speaking outside of their own domains of expertise, Wendy, Maria and Joyce appear to have capitulated to the medical model. They justified this in the following transcripts:

> We work from a biopsychosocial model. See I have this debate with social workers a lot. This service doesn't come from a strictly medical model. There is always a lot of division in the service because there are factions and some that push that [medical model accusation] and some who don't. There is a lack of resources and a big push within the western world to use more medications. At one time in psychiatry there was a big push on psychotherapy and that sort of thing. Now there is a much bigger push for biochemical solutions through pharmacology. Obviously there is a slightly different slant in this service as the clinical director is a psychotherapist, so he pushes psychotherapy with a combination of pharmacology, as pharmacology has improved so much. There is such a lack of resources to treat people on a long drawn out process of psychotherapy and we just don't have trained clinicians to do that. We don't have the resources because psychotherapy is such a drain on the service and there is a big push towards medication. It has also become increasingly clear that people don't want to deal with it [their mental health problem] long-term, they want a quick fix and that is going on within the community as a whole, people want quick fixes. In that way yes, social workers are coerced because that is what people want. People are also much happier to see the doctor. They don't want to see a social worker; they want to see a doctor. **Wendy**

And:

> Sometimes people say the medical model is this or that, as if it is no good for us to work with. However, the medical model has value and is a very important part of what we do. As a case manager, we see the medical side as essential. Often we have to get in there and say that a particular consumer's medication needs to be increased. The mental health service claims to work from the biopsychosocial model but it is medical model really. We have to cover many medical issues. I have been working in mental health services since leaving university. It is not important what you do as long as you get results. **Maria**

And similarly:

> Consumers are managed in the medical model first, like when they are acute. I find some good things about the medical model. It stopped society blaming mental illness on families. It was given a disease entity and that was helpful. I boned up on the medical model last year because it's something we all flip around without knowing exactly what it means. There are a lot of good things about the medical model. It is the dominant model. Who is paid the most, so who is the more powerful? This is the structure we have to work in, if we want to stay working in a medical arena. I think ethical issues about how you do your work arise in every agency. Here, at times people may be coerced. For example, I can go into their home with a key because they are a restricted consumer. Drug therapy happens in the context of other therapies such as counselling and support. However, unless you get the chemicals right you are going to have a much harder job. The drugs themselves are improving, from the point of view of the side effects. Due to better medication, it is now much easier for people who have mental health problems and this helps to rationalise the treatment. **Joyce**

Wendy, Maria and Joyce articulated strong support for a medical focus in mental health, for reasons of efficiency; takes the blame away from families through a focus on disease; and allows access to consumers with or without their consent. Maria took an "ends justifies the means" approach which is somewhat at odds with new consumer rights policies, focused as they are on process. Maria went so far as to tell the psychiatrist when medication should be increased despite having no training in this area. She gave no indication that she is rebuffed when she did this.

Social work evaluation

Social Work participants were asked how the organisation evaluates their clinical practice. Wendy stated that she did not have her practice evaluated. The most common strategies for appraisal of the remaining participants were Performance, Planning and Review (PPR) and case reviews:

> I do PPR and case reviews. These reviews are on what we do and how we do it. We have the CESA database [a funding strategy] and that reveals to management how many people we have seen, and what our interventions were. **Sian**

> We have meetings with our team leader and it is quite effective in evaluating how you are working. We have weekly case reviews and undertake PPR. **Carol**

> Through supervision, case reviews and PPR. **Camilla**

I do case reviews and PPR. **Thomas**

Thomas is involved in evaluation but does not indicate whether or not, as a team leader, his own work is evaluated.

We do PPR. That has been going for two or three years. Maria

Tilly said:

We do PPR. There is no discipline specific evaluation to find out how we are performing as social workers. Also, if there were an issue with one of my consumers, I would have to put it to the team. I find that aspect of teamwork difficult. I regard myself as being a professional person and I would be inclined not to check if it was OK by everyone. **Tilly**

Tilly acknowledged that there is no discipline specific evaluation. Perhaps for this reason she resented having to explain her work (presumably her social work) to other team members.

In addition to PPR, two participants were included in random audits:

We are evaluated by PPR and random audits on our files and case notes. Our administrative requirements are randomly audited. Four months ago, they also did a random survey of files and sent off letters to consumers to see if they were happy with the service. It was anonymous who the service providers were. Apparently, there was a good response, but I do not know what the results were. **Conrad**

And:

Evaluation happens through PPR and random audits, though they have not happened for a while. We are currently doing an annual report and are all contributing to that. So we are forced to think about what we have done with training, quality improvement and what direction we are heading. We are forced to think about what we have done in the last twelve months. **Joyce**

Conrad indicated that random auditing and surveying consumers' views happens without the knowledge or participation of the direct service provider.

One participant mentioned the CESA data base as a source of evaluation:

PPR and the statistics we enter on CESA to see how quickly we can move people out to their GP in the community. **Natalie**

Another participant stated that LIMHS was preparing to evaluate the NSMHS (AHMAC, 1996):

….there is a lot of evaluation of outcome measures being put into place due to the National Standards for Mental Health Services. **Rowena**

Professional supervision

Five of the twelve social work participants received professional supervision, and the process was undertaken with medical staff:

> I get supervision from the clinical director. **Wendy**

> I get supervision every week from a clinical nurse. **Joyce**

> I get supervision from the child psychiatrist and an elderly gentleman who is a retired psychiatric nurse. His discipline is irrelevant; it is his knowledge base and philosophical understanding that I gel with. **Conrad**

> I get supervision fortnightly. I am open to supervision from psychiatrists and nurses. **Rowena**

> It hasn't been happening. I have been supervised twice in eighteen months. The supervisor is from nursing. **Tilly**

All social workers receiving professional supervision do so through medical personnel. Seven social workers are not receiving professional supervision at all.

Social justice

Social justice principles are the cornerstone of the social work profession (AASW, 1999; IFSW, 1994). Therefore, it was important to discover what the participants perceived as major constraints, or obstacles that hindered their attempts to achieve social justice within the context of implementing consumer and carer participation.

Wendy indicated that social justice is a whole of sector concern. She said:

> As far as social justice goes the constraint is that there is a lack of both trained case managers and resources in the community to refer people to. It is extremely frustrating. **Wendy**

Carol thought that workload prevented workers prioritising consumer participation despite this disadvantaging them:

> Direct workload ends up disadvantaging consumers and carers. I have been attempting to do more community development type work and the consumer work would be a priority to some of the other stuff that has to be done. When you try to take it on, to do it properly, you have to take time out from your caseload, or not have as high a caseload as other case managers who are not involved. I still think that it should be part of all social workers' practice. They should have a certain amount of time for clinical work plus a certain amount of time for consumer stuff. It should not just be "hey, you two can be the people doing that work." There is also social injustice to do with management and staff attitudes and that is all I want to say on this topic. **Carol**

Clearly Carol polarised clinical work from either social justice practices or participation. She appears to find difficulty in operationalising a social justice framework in her practice despite the AASW Code of Ethics and said that it is the attitudes of staff and management which hinder this social justice framework.

And similarly:

> Overwork and a lack of time. Management do not understand what social justice is, and they are disinterested. Issues surrounding hospital versus community, playing the politics of what happens in the community, management's philosophy, the government's agenda and funding issues. At the end of the day, services are designed for the good of the greater community, and so that often means mental health consumers miss out. That is a constraint. The trick is to keep pushing for it. **Camilla**

Camilla intimated that where decisions are to be made about either the "good of the greater community" or the good of mental health consumers then the former will win out.

Joyce shared Camilla's opinion about the attitude of the many prevailing over the interests of others. She related this directly to worker's attitudes, suggesting that workers do not prioritise professional values or views when these are in contrast to those of the wider community:

> You do see a lot of social injustice going on, you just have to see the way people are treated when they come in here. Workers attitudes, workers are just like anyone else, we take on whatever anyone else takes on in the community. **Joyce**

Sian seemed to illustrate this when she said:

> The Indigenous mental health team is up against personal opinions of other mental health workers. I hear comments from mental health staff that are derogatory and demeaning to consumers. This is to the point where I think, 'did I really just hear what they said'. Some of the comments are so bad that it doesn't give much hope for social justice to ever happen. **Sian**

Lucy provided a direct example of this anti-social justice attitude. She said:

> Medical, certainly not social justice, is the current culture. Like on a ward round when the psychiatrist said, 'I don't want any of this silly empowerment stuff.' **Lucy**

Institutionalised attitudes were described in the following transcripts:

> The major constraint is the team leader. She is incompetent and that prohibits social workers from taking action in terms of social justice. For example, she says things like 'he [consumer] is going to end up in [local prison], I'll second that, and it will do him good' I kid you not. Why do they play patriarchal games, why do they ingratiate themselves? **Thomas**

Thomas judged his team leader in a negative way, just as he previously judged the community development worker as having "poor judgement". He saw this as

preventing social workers from taking action in terms of social justice. He intimated that the incompetence/poor judgement of those around him impacts his ability to act with competence in terms of socially just practice.

The majority of social work participants in this chapter and of the community development worker in chapter six articulated a culture of offensive attitudes towards consumers and carers by MHPs and management and perceive this as the main constraint to social justice.

Allied Health, which includes social workers, appears under-represented on the executive committee:

> Social work fits into allied health and being a mental health system that is so medically oriented, it is difficult to get involved at the level of implementing policies. Myself, as a social worker, can go over to the day-centre programme and help with things like the float for the reef festival, do day-to-day activities with them, have lunch with them. When you start talking about the executive level it gets difficult, there is only one allied health representative on the executive to represent all of allied health. **Natalie**

Lack of access to the executive by social work staff limits opportunities to get consumer and carer issues on the agenda. Previously in this section, Wendy stated that she can communicate directly with management, however, Natalie did not have this perception. Participating at the level of the day-centre programme was the limit of her involvement.

Two participants described ambivalence towards consumer participation due to disinterest and a perceived need to survive organisational stress:

> Maybe a blinkered way of looking at things. Social workers say "well this is the way we do it in Lantana" and tend not to take the broader perspective. **Lucy**

And:

> I am not very involved in that area and unaware of what is happening. I just do my job as that is the kind of person I am. I do what I have to. I have a family at home and I have to ensure burnout does not occur; that is a problem when working in mental health services. **Maria**

Several social workers including Lucy and Maria found it difficult to uphold the moral features of their work and the need to locate ethical principles as its highest function (Freud, 1999) in the face of a culture that does not do this.

Conrad highlighted the situation whereby the expectation was that social workers undertake case management, whilst a member of management represented the organisation at grass roots community meetings:

> We are not involved in that area. We have to do a lot of the stuff that the service development coordinator is doing. This person has a bigger say and participates in things like accommodation and other types of social services than social workers at present. **Conrad**

The genericism of MHPs when not fully understood by social workers can produce uncertainty and role confusion. It is fair to assume that under managerialism it is 'safer' options to have a member of management represent the organisation at community meetings. Particular practices of social work, such as advocating for social justice are therefore diminished.

Postgraduate Social Work Education

Although none of the participants had postgraduate qualifications, they cited some diverse areas for possible future postgraduate studies. Four participants had an interest in gaining skills that would assist their clinical social work practice. Ultimately, they were keen to gain mental health managerial qualifications:

> I would find it useful to have units in research skills, management skills, supervisory skills, community development focusing on increasing partnership outcomes and strategies to increase change, and mental health policy focusing on conceptual work and forward planning. **Carol**

And:

> New directions in the management of mental health and new methodologies, new ideas on consumer participation. **Joyce**

And:

> I want to do something on depression and dual diagnosis. Something to really skill me up to use in my day-to-day work. Like why are mental health consumers being sexually abused, there seems to be so much sexual abuse in their background. Down the track I would like to do a Masters in Health Administration. **Camilla**

And similarly:

> A postgraduate course would be helpful if it included managing and developing mental health services in a cross-cultural context. **Sian**

An upgrade in micro skills was high on Tilly's agenda:

> Practice oriented skills and counselling skills. I have a real interest in using the self in my work. **Tilly**

Four out of the five respondents wanted training in management and one so that she could find new methodologies and ideas on consumer participation. Joyce was the only participant who felt she would benefit from further training in the area of consumer participation. Only one, Tilly, wanted counselling post graduate education

and one of the Indigenous social work respondents wanted training in cross-cultural mental health.

Conrad wished to pursue studies that offered an alternative discourse for explaining and understanding schizophrenia:

> University could not offer me anything. I have enrolled in a global correspondence school to study humans as energy, and who and what we really are. It is not an academic institution. Psychiatry has no understanding, they can't explain schizophrenia. **Conrad**

Like Joyce, Conrad was seeking different or multiple understanding of psychiatric phenomena.

Four participants had no interest in pursuing postgraduate studies in the area of social work. They considered psychotherapy an important skill for their future direction with practice in mental health services:

> An update on clinical practice, maybe psychotherapy, not necessarily social work. **Wendy**

> I am not interested in doing any postgraduate study in social work. I am interested in doing something on psychotherapy. **Rowena**

> It is important for me to look at postgraduate studies in psychotherapy. That is the direction for mental health services. **Lucy**

> Because I came into mental health straight from university. I would like to learn more about working with delusional people. Also new ways of doing psychotherapy. **Maria**

Natalie had no interest in postgraduate social work study, nor psychotherapy, rather she had an interest in pursuing psychiatric diagnostics:

> We really have to get into that medical model stuff unfortunately. The DSM-IV type diagnosis is very important for social workers employed in mental health. **Natalie**

Conclusion

This chapter presented the views of 12 social workers in the areas of participation and partnership, social work, social justice and social work post graduate education. The discourse of social workers aligned most closely with that of the community development worker and contrasted markedly with that of the psychiatrist. This chapter demonstrated diverse views about participation and social work practice and education from within the social work group itself. The following chapter examines the views and ideas of the 14 voluntary and involuntary consumer case study participants regarding a broad range of issues important to consumer participation

and their experience with mental health services. It also explores what happens to consumers when MHPs, including social workers, exert power over them.

CHAPTER EIGHT
Data Set 4: The Consumers' View

This chapter provides a presentation of the views expressed during in-depth, semi-structured focused discussions and interviews with 14 LIMHS consumers on issues relating to participation, social work, social justice and social work education. While management, the community development workers and social workers were asked directly about social justice, in this chapter, social justice is engaged through hearing from consumers themselves about mental health practices which they have found helpful and unhelpful, and provides space for them to share their vision of an ideal mental health service. Prior to engaging consumers in responding to semi-structured focused discussions on participation, consumers attended educational sessions where the use of vignettes (see chapter four) offered at least a basic discussion of the participation policies of LIMHS. The voices of all consumers in this chapter were from people who had, at one time or another, experienced both voluntary and involuntary admission for their disorder of schizophrenia.

Participation

At the time of the interviews for this case study, consumer participation in mental health services had been an agenda item for over a decade (AHMAC, 1991, 1992, 1996). Consumer participants in this study understood participation in mental health services in a variety of ways. Two consumers interpreted participation as consultation and involvement in decision-making within the context of their treatment:

> It means I am consulted about every aspect of my treatment. **Roland**

And:

> Participation means I am consulted about the decisions made by the psychiatrist about my treatment and my mental state. **Rose**

While Roland perceived participation as his involvement in all discussions about his treatment, Rose thought participation was being consulted about the decisions made by the psychiatrist, implying that participation does not include Rose in decision making about the treatment she receives from LIMHS nor about her mental state.

John provided a more illustrative example than Rose, in articulating the power psychiatrists have in relation to the schizophrenia suffered by people whose agency

is ignored in its diagnosis, treatment and evaluation. He suggested that participation is about getting consumer views about schizophrenia:

> What it means to me is a chance to get the schizophrenic side of schizophrenia out into the open. There is a textbook diagnosis, made by sane people who have never had a touch of anything. They don't have the foggiest idea about what is going on in a person's head, but they claim to know. They prescribe medications, which are just trial and error. They won't admit it, but it is trial and error. If you appear better, they have done something right, if worse, they have done something wrong. The consumer perspective on schizophrenia is essential due to its complexity. The manifestations of schizophrenia are very diverse. **John**

John alluded to the arrogance of psychiatry, "*If you appear better, they have done something right, if you are worse, they have done something wrong*". This statement is important in a study on participation, since it encapsulates a very low level of participation of the client in being able to impact the course of their illness/wellness.

This is illustrated starkly, by Vera and Lara, who said:

> I cannot participate in my own life because all the decision-making is done for me. I have a case manager handling my life. I am under the Public Trust and they handle my money. I have a person employed to take me shopping and monitor what I buy. A nurse arrives every fortnight from mental health services to give me my injection. This is whether I want one or not. This is my life. Vera

And:

> I was not aware of consumer participation. I have never felt listened to. In fact, I feel that my life is totally out of my control. **Lara**

Roger and Mia indicated that participation in matters to do with their schizophrenia is perceived in isolation from their overall participation in community/family life. They both demonstrated a preference for participation in other matters:

> Before I had schizophrenia, I completed a degree in horticulture. I am still able to operate and think clearly, when I am well. I am aware of the policies that mandate participation. The question I ask myself is 'why would I want to participate?' I would prefer to be working towards another cause. I am interested in the environment and what is happening to our planet. I also happen to have schizophrenia. I don't want it to consume any more of my life than it already has. **Roger**

This appears to encapsulate the views of four other consumers:

> No I haven't been asked to participate.   I try to stay away from all services. I have friends and a social life like other people. I don't want any roles. It is enough that my case manager visits several times a week. **May**

And:

> I prefer to hangout with my friends. I am not interested in what they do at the centre. My friends don't behave like I am different to them and I don't feel different from them, except I take medication or sometimes get tired. **Mia**

And:

> I have recently been discharged from hospital. I am just interested in trying to survive and feel over-medicated and sleep nearly all day. They [MHPs] take me shopping once a week, but I would rather socialise with my cousins and some neighbours that I have befriended. **Paul**

And:

> Consumer participation is for the people who want to be involved. I do not attend the service very often. My case manager is also Indigenous and I mainly see her several times a week at home. I have other friends who I visit during the day. **Mia**

May perceived types of participation as developmental. She said:

> I think participation means continually being reviewed as we change and grow older. We are like other people and change as we age. We become interested in different activities, become resigned to our condition and find other ways to survive schizophrenia. **May**

Two participants were not aware of consumer participation:

> At the moment all I do is get my blood test, collect my pills and then I am out the door. **Sally**

And:

> I have not heard of this. **Paul**

Mary had a much broader understanding of participation than other consumers. She said:

> People with schizophrenia need to have input into every part of their treatment. This includes planning and the development of policy. Involving consumers with interviewing new staff needs to be the 'norm'. It is necessary for us to be able to hear the attitudes, ideas and perspectives of new workers. This happens when non-Indigenous people apply for jobs in Indigenous agencies, an Indigenous person is on the panel, why not us? **Mary**

Mary's interpretation on the participation of consumers closely aligns with official government mental health policies. She makes strong statements about the need for consumers to be represented on interview panels. The NSMHS (AHMAC, 1996) described involvement in treatment plans, planning and policy development, and sitting on interview panels, as some of the ways people with mental illness could participate in mental health services. Mary's view is shared by the community development worker, but not by social workers and management.

Participatory activities in which consumers are engaged

The day-centre programme at LIMHS was described as a venue of great importance for four participants:

> It's going to the day-centre programme at mental health and being involved in the outings. **Isobel**

And:

> It means sitting around at the day-centre programme with a group of people who are consumers and talking about the problems they have with their minds and what they plan to do about it. **Ray**

And similarly:

> I go to the day-centre programme every day. The bus picks me up in the morning and drops me off in the afternoon. From the day-centre programme I participate in activities or go to the gym. This is how I participate. **Jim**

Vera also considered the day-centre programme important for consumer participation:

> Participation is when I go to the day-centre programme and talk to the other people with schizophrenia. **Vera**

While Vera had previously expressed no control over her life, she recognised the day-centre programme as "participation". She went on to express a strong emotional response to the day-centre programme and its activities. She demonstrated an active involvement in this. This statement is in direct contrast to Vera's sense of lack of power and control when it comes to other matters in her life, which are assumed by mental health professionals, as previously presented (above):

> At the day-centre programme we are asked what kind of activities we want to do. It is really good. We go on bush walks, swimming, yoga and walk the dogs from the pound. We also learn how to use the computer, cook and undertake lessons on sewing, crafts and T-shirt printing. Every week we have a picnic or barbeque at different locations. We can buy lunch for one dollar at the day-centre programme. I regularly attend all these activities. **Vera**

Another three consumers were participating at the level of involvement with their treatment plan:

> I get consulted about my treatment plans and asked if I agree with it. I haven't been asked about participating in any other way so far. **Rose**

And:

> Yes, my case manager always explains my treatment to me. I don't know anything about interview panels or policies. **Roland**

And similarly:

> I am asked about my treatment and reviewed every month. My mother sometimes attends the reviews. **Jim**

A quarter of the participants were involved in their treatment plans, at the level of agreeing to a plan already established or being consulted about their treatment.

John involved himself with the Division of Rural Practice GPs. He appeared to have adopted the language of this group:

> I have been involved with the development of policy in the general practice side of things [private rural GPs' consultations], nothing from the mental health service side of things. The division of rural practice is an innovative, pioneering area. The system has no control over this forum and they are making good inroads in the area of mental health. **John**

John indicated involvement in policy and with an organisation separate from LIMHS.

Mary did not consider her contribution valued:

> I contribute to consumer newsletters. However, I am regarded as a trouble-maker. I am quite vocal on the rights of consumers. I have read all the reports and literature that has come out in recent times. I don't think that mental health services appreciate you having insight into current thought on policies for people with schizophrenia. They would rather I remain ignorant. **Mary**

Mary involved herself with promoting consumer rights, but perceived herself as a trouble maker.

Two participants stated that they had not been invited to participate even at the level of their own treatment:

> There have never been any discharge or treatment plans that I am aware of. **Sally**

And similarly:

> No I haven't been invited to participate in anything. I have never seen a treatment plan. I would like to be involved in my treatment. **Isobel**

Ideas for consumer roles

Of the fourteen consumer participants, nobody was offered or had assumed any type of role within LIMHS. However, nine participants had ideas on what roles they could undertake if asked.

Most consumers were interested in furthering their involvement with the day-centre programme and furthering the notion of the Clubhouse Model of consumer run services:

> I have often thought that we should be running the day-centre programme ourselves. A major problem is that most of us cannot drive. This is mainly due to our medicated state. I got really excited about the Clubhouse Model. The LCAG received funding to go down south to explore this model. When they returned, they did not tell us what happened. After we complained the service development coordinator intervened, then we were advised that this model sees us running our own service. It also involves support into paid employment. This has me very excited. **Roland**

Mia seems to agree with this idea of self-management. She said:

> Several years ago, I tried the day-centre programme, but I didn't like that the staff were always walking through, or using it as a venue to catch up with the consumers they look after. The staff should not use the centre in this way. We need a place away from the mental health services **Mia**

This problematises Thomas' view that he was engaging participation by walking through the day-centre programme and talking with consumers and presents the idea of the day-centre programme as needing a physically separate space to

LIMHS

Some consumers prefer more involvement at the LIMHS day-centre programme:

> We need to be involved in more activities at the day-centre programme. I think that we could do more with creating our own activities. A few people that I know are involved with the LCAG. They told me they had received funding from the mental health services. Subsequently, they are able to forge ahead with attempting to set up their service. It is the Clubhouse Model. They appear to be motivated towards this. **Jim**

And:

> I think I could participate in most things. I could take more responsibility for what happens at the day-centre programme. I could also give my opinion on what planning needs to take place. They have funded the LCAG. The LCAG encourages consumers to participate in the festivals with floats and stuff. They told us about the Clubhouse Model. I am not really clear on what it is, but we would be running our own service. Quite a few of us are interested in this. **Rose**

And:

> I could work at the day-centre programme centre and teach living skills on how to budget and shop. If we used the Clubhouse Model I could run courses for consumers on looking after their personal hygiene and raising their self-esteem. **Sally**

Mary thought that consumer advocacy and decision making powers were important:

> There are roles I could undertake. I am educated and keep up with current affairs. I would be a useful advocate for people with schizophrenia. I am able to take the middle ground between consumers and service providers. If they would allow me the opportunity to participate on decision-making committees, I could prove to them that I am not full of hot air. It is time that someone took a stance. All the inquiries and services have done little to change the real circumstances of the mentally ill. They are still lonely, suicidal, living in poverty and having lip service paid to their needs. **Mary**

Lara added:

> Sometimes I think I could be an advocate for mothers with schizophrenia. I have a lot of anger at the way I am treated. Family Services (now the Department of Child Safety) has taken all of my children. **Lara**

Therapeutic activities:

> I am sure that I could be helpful in providing people with schizophrenia a therapeutic alternative to their day-centre programme. I would be able to show them how to understand and work with nature. **Roger**

A consumer had secretarial skills to contribute:

> I could type. I am a very good touch typist. I would like to do some voluntary typing. I have just become the secretary of a self-help group and I prepare the minutes for them. **Isobel**

Community consultant/researcher:

> I would really like to make myself available to get in touch with the community and see what their thoughts are on mental illness and the people who have mental illnesses. Discover what they perceive as the major problems that impact on the community regarding mental illness, and their ideas on addressing these problems. I could then offer this information to the mental health service. **Ray**

Previous MHP participants thought that participation was limited by the diagnosis and wellness or stability of the consumer. The following participants agree with this view that they cannot participate when unwell. However, when they were well, which they viewed as the majority of the time, they considered they were capable of participation:

> When I am unwell I cannot do anything rational. That is not too often, thank goodness. Much of the time I am able to participate as well as the next person. **Roland**

And:

> When I don't feel well I can't do anything but stay at home. When I feel well, there are many things I can participate in. I often have a lot of energy. **Vera**

And:

> I agree that I do become unwell, but most of the time I am well and can do the things that others do. **May**

And:

> Of course consumers cannot participate when they are unwell. It is an awful illness to have. They can participate when they are well. Not everyone is unwell at the same time. **Mary**

And:

> My mother makes me stay at home when I am sick. I haven't been sick for the last two years. I can do everything when I am well. **Jim**

And:

> During the times when I am unwell it is really difficult to be involved in a social activity. I don't really know where I am. It is difficult for me to get a grasp on how things are for me at that time. However, it is also true that I am not always unwell. I have been well for over a year this time. **Ray**

And:

> Unless we are in hospital, we can usually participate at some level. If we are just unwell and not hospitalised, it is good for us to be doing something meaningful. It helps us to get better and feel worthwhile. **Rose**

Consumers also had ideas on how LIMHS could deal with periods of instability or ill health. They said:

> Sometimes I am unwell. They just need to work more with us when we are well, then let someone else take over during our relatively short periods of illness. **Lara**

And:

> If someone is unwell and cannot participate, other people can stand in for them until they recover enough to take over. **Mia**

Isobel described the possibility of increasing participation through developmental steps. She provided an example:

> When I first got ill I was seen by an occupational therapist. She said "I'll get you going on a pom-pom". After that I did more complex things. Next time I went to hospital, they had bought a loom. They asked me if I would like to learn to use it. I am now really good on the loom. I think that no matter how sick you are there are still some things you can participate in. **Isobel**

Creating the right environment:

> I believe that if you create the right environment consumers would be able to participate. As Socrates said "everyone has the answer to everything, if they haven't given the right answer it is because they haven't been asked the right question". **John**

Roger and Sally were cynical about MHPs who limit participation by invoking the "unwell" label. Roger said:

> I think this is bullshit. It is a way for them to stop consumers becoming empowered in their own illness. Consumers need to be able to take charge when they are well. This offers them an incentive to stay well. **Roger**

Sally said:

> I think that is a cop out. **Sally**

Only one participant felt he was too unwell to participate in a meaningful way. He said:

> In my case, I would say they are right. **Paul**

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Consumer concerns about participation

A participant expressed cynicism with the concept of consumers sitting on selection panels that employed new staff:

> I am involved in my treatment plans. I know that it is stated that we can be on interview panels for the employment of MHPs. I have no experience with their disciplines and don't consider that I would be of any use. I am not interested in tokenism. **Roger**

Roger's view meshes with those of management in chapter five and with those of the social workers in chapter seven. Just as Roger previously problematised mandated participation since it could reduce participation in other (community, interest) activities outside of a specific focus on schizophrenia, he also raises the likelihood of tokenism when consumers are asked for input outside their areas of expertise. Clearly consumers had a wider view of participation than MHPs and more positive views about their capacities to engage participatory roles.

Social work

Of the fourteen consumer participants, five were unaware of their case manager's professional background and another had a nurse as case manager. The remaining eight participants currently have social work case managers, or did so in the recent past. They were asked directly about social workers.

Consumers said:

> Social workers are the ones who think like us. I can relate to them and find they have a good sense of humour. When I have worked with a social worker, I have felt the least mentally ill. Social workers don't concentrate on your mental illness. They are more likely to ask you about other things in your life. Sometimes they even confide in you about the things in their life that are difficult. This makes me feel like a real person. It helps me to sort out things that I thought were symptoms of my illness. I feel good after those interactions. **Mary**

And:

> Social workers are usually interested in other things than your mental illness. They will ask you about what you are doing in your life as regards to your leisure time and community activities. I find them good to be around. One of the social workers I was involved with set me up with a community group that was interested in the environment. I have become quite involved with this group. **Roger**

And similarly:

> Social workers seem to understand your situation better and are willing to listen. I can usually tell when my case manager is a social worker. They present themselves in a different way. It is as if you have known them for some time. They are more inclined to listen to your story over and over without getting tired of it all. At times I need to tell my story again to make sense of my situation. They often help me to do that. **May**

And:

> My current case manager is a social worker. She is very kind to me. She has tried a few times to contact my husband and find out what is happening with my sons. It has been very difficult for her. I appreciate that she has tried. She tries to get me interested in other things to take my mind off this problem. However, I can't help but worry if they are being looked after, and if they miss me. I have found all the social workers I have been involved with to have my interests at heart. I don't think I would have survived without them. **Vera**

And:

> The social workers that have worked with me have been very caring and helpful. They have tried to advocate for me on many occasions. It still gets back to the fact that they have no real power to change my situation. I have schizophrenia and most people don't understand I am also a warm and loving person. It is too difficult for them; they just see a schizophrenic and refuse to look any further. The social workers are always caring. They have tried to get the Department of Child Safety to recognise my human rights. They often console me when everything blows up in my face. They also try to get me increased access to my babies. **Lara**

These consumers positively relate to social workers who demonstrate kindness, caring, helpfulness; an understanding of what clients are saying; an understanding of clients as a "whole" person not just in terms of diagnosis; have a good sense of humour; self disclose in ways which are helpful to the client; lift the spirits of those they are working with; have a focus broader than the mental illness. This focus may include leisure activities, and wide community (not only welfare/health focused) knowledge and referral; sector knowledge and advocacy for the clients rights and interests across bureaucracies.

Further, social workers demonstrate skills in persistence and lack of negative value judgement in the ongoing engagement of their role:

> My case manager is a social worker. I have a good relationship with her. She has been able to talk me through some bad times and has been helpful to my family when they have been worried about me. She shrugs off the hard times I've given her when unwell. It is like nothing has happened. I appreciate being given another chance and her understanding that I couldn't help myself. **Roland**

Rose appreciated her social work case manager's willingness to visit out of normal working hours:

> I have had social workers and found them kind and supportive. Once a social worker came to visit me out-of-hours. She had been very busy all day. I didn't think she would come, but she did. **Rose**

One consumer had a negative experience with a social worker. She declined to discuss the issue:

> Not very good. I don't want to talk about it. **Sally**

Consumers' opinions of their social work case managers was much higher than the opinions and attitudes regarding consumers described by some of the social work participants in chapter seven.

Social justice

Participants were asked to respond to what they regarded as the most positive aspects of their involvement with the LIMHS. Five consumers considered the day-centre programme as the most positive feature:

> Everyone is treated the same. There is no racism. The other consumers and staff at the day-centre programme are nice people. **Jim**

And:

> It is my life. It is where I meet my friends [day-centre programme] and get understanding. It is where I get hope that things will be all right in the future. I was in an institution, now I am out. I need to be around people like me to survive. The service is supportive of us. They always ask what we want to do. They go out of their way to do what we want. Like when we went ice-skating. **Roland**

And:

> The day-centre programme is a good place for us to gather. We get to talk to each other and activities get arranged there. If anything is happening, it is at the day-centre programme where you hear about it. We get to decide what we want to do ourselves. **Rose**

And:

> It has helped me not to be so lonely. I meet other people at the day-centre programme who have the same concerns as me. It somehow makes me feel better. **Vera**

And similarly:

> I have gone to their [day-centre programme] and spoken about the self-help group. All the consumers know me and I feel good with them. **Isobel**

Undoubtedly the day-centre programme plays a central role in the lives of many consumers involved with this study.

Two participants had contrasting experiences of general practitioners in the community:

> Mental health services help you without a hidden agenda. Private GPs are prone to self-interest. They have prescribed drugs for me that I should not have been taking. They also try to get you to attend them too often. Mental health services never over prescribe. I know this from personal experience as well as the experiences of many of my friends. **Mary**

And:

> I have not been involved with them for some time [mental health services]. I attend my GP, he writes my prescriptions and monitors my mental health. I have found this satisfactory. It

has resulted in me feeling more 'normal' than when I was under the mental health services. **Roger**

A further four participants appreciated the care offered to them by MHPs in the community and when in hospital:

They care about what happens to me [MHPs]. They have helped to sort out some of the problems I have created when I am unwell. This has been helpful to me and to my family. **Paul**

And:

MHPs never award blame to me when I have had a relapse. They look after me in hospital and then help me back into the community again. Sometimes they have had to go around the cycle with me several times. They don't seem to mind and are always kind. **May**

And:

I was impressed by the way they made me feel included in hospital. They do the best they can. I had no problems with them. **Ray**

And similarly:

As I have already mentioned, it is the MHPs who understand what it means to have schizophrenia. They don't believe in the myths that surround the illness. Even though I am forced to get treatment, they encourage me to keep going when I don't feel it is possible. **Lara**

Sally presented evidence of a psychiatrist taking a carer's perspective into account. She said:

They decreased my tablets after my carer complained about me sleeping all day. **Sally**

Consumer participants were then asked about the most negative aspects of their involvement with LIMHS. These could be seen as indicators of lack of social justice concerns and practices.

A consumer's lack of understanding about what is being said:

I don't always feel comfortable when voicing my opinion. When we get consulted about change, I don't always understand what is being said. By the time I do get a grasp, they have moved on to something else. Some consumers are good at picking up things quickly. I didn't receive much of an education. **Rose**

Treatment plans that include interventions with which the consumer cannot comply:

Their attitude makes me feel that I can never be a well person. The psychiatrist and nurse wrote up an agreement that they said was a legal document. I had to take my pills at 12noon, 2pm and 4pm etc. I wasn't able to because I was bombed out. They were saying it was a legal contract and I would be regulated if I didn't comply with the set times. I ripped it up in front of them because it was ludicrous for me to comply with times when the medication [Clozaril] rendered me almost unconscious. **Sally**

Perceived collusion between government bureaucracies:

> My case manager is very good. She understands my situation very well. However, the psychiatrist contacts Child Safety and together they over-ride any decisions that we make. The powerlessness of MHPs to get the police or Child Safety to understand our unique situations. I don't think that my case manager has the power to be able to support me. When I comply with my medication, and am promised that I can keep or see my children, it doesn't happen. The psychiatrist and Child Safety are too powerful. **Lara**

Emotional distance between psychiatrist and consumer and perceived arbitrary nature of treatment decisions made outside of a real material context:

> The psychiatrist's attitudes are the only hindrance. It is the perpetrator victim scenario. I have never seen a psychiatrist being a victim of a consumer. It is always the other way around. There is much that needs to be changed. Mental illness is a problem within a person and the only way to deal with that problem is if another person helps you with the problem. When you are faced with a non-person, someone who shuts up their emotions and keeps professional distance, 'you can't get involved with nut cases, keep them at arms length', that is bullshit, you get nowhere. I reckon that 90 per cent of a psychiatric condition is psychological because you have the power to calm yourself down when you realise the situation is a calm one. I spent years living in fear of the system; surrounded by people I didn't know, and they would not let me know them. Psychiatrists make arbitrary decisions. A psychiatrist asked me how my house was going. I hadn't done anything to the house, so she said I was unwell. The facts were that I didn't have any money to do anything to the house, but that didn't come into it. So just because I hadn't done anything to the house, I had to have my medication increased. I once heard that a major symptom of being a psychopath is a lack of empathy. I consider that this episode was a major violation of my human rights. **John**

Single focus on diagnosis instead of broader issues:

> Management needs to let consumers participate. There is no patience, understanding or training given to consumers. They just consider it their job to make all the decisions. Sometimes they have consultation, which is them telling us what is going to happen. They think it is inefficient to spend time trying to take on the consumer perspective. They are always busy. Sometimes it would be good if they had more time to spend on the broader issues that affect us. They are aware of these things and often start to address them. I just think work pressures prevent them pushing things through, so they get sidelined. The abuse of our human rights is so great, it needs to have a whole team just working on them. **Mary**

Lack of coordinated, shared decision-making between government bureaucracies:

> I have self-harmed several times because my children were removed. My case manager cannot help me. I lost my marriage due to my illness and the effects it had on my husband. I cannot afford to see my children as they have gone to live in Adelaide with their father. What are we to work on? It is enough that I get through my day. There is not enough MHPs. If there were more, they could do a lot more work with other services in getting them to understand us better. Why should my children be removed to Adelaide? Other men would have to get the mothers' permission to take the children so far away. **May**

And:

> What I would like to do with my case manager is to find out how to go about accessing my two sons. She cannot help me. It has been four years since I have seen them. Whenever I try to get information on them, my husband moves them away. The worst part has been the realisation that the mental health service has not been able to make a difference with me accessing my children. This is the main source of my unhappiness. **Vera**

Failure to pay consumers' expenses for the work they perform:

> I was going to the psychiatric ward once a fortnight. They wanted me to do that, and they were paying my taxi fare. However, somebody in the mental health service stopped me having those fares. Even though the activities' nurse wanted me to keep going to help with the newly discharged patients' orientation. It is very important for patients at discharge to know they have a support group they can attend. We can't afford the petrol just being on the pension and we only have a rusty old van. **Isobel**

Staff busyness:

> They pick me up for a barbeque and sometimes we go to a movie, but they are too busy to do too much for us. **Paul**

And:

> MHPs do seem to be very busy in my opinion. Perhaps it needs consumers to do more. **Roger**

And similarly:

> The staff are very busy and when we attend outings the staff have to drive us. The bus is too small. **Jim**

Other negative aspects articulated by consumers centred on a lack of consumer training for participation in mental health service delivery. Consumers iterated several ways in which they could be prepared for participation in LIMHS. This section indicates that social justice policies like those of participation necessitate empowering consumers in their uptake.

Four participants believed that gaining communication skills would be beneficial:

> Communication skills. I could then be better equipped to understand what is happening with my illness and feel more confident about discussing my treatment. **Roland**

And:

> I would like to have the confidence to speak up. Like when I don't understand something at consultations, I wish I could ask them to repeat themselves in a way that I understand. **Rose**

Roland and Rose both wanted communication skills to assist them in participating in their treatment.

Ray wanted training in communications skills but did not offer a reason for this:

> Training in communication skills would benefit. **Ray**

Assertiveness training may have helped Jim to communicate with the psychiatrist:

> I need to learn how to deal with the psychiatrists. I know they are there to help me, but I feel that he makes fun of me. My case manager says that he is only trying to get more information, but I always come away feeling bad. **Jim**

Similarly Mary wanted communication skills for advocacy and for assertiveness in terms of her impact. She said:

> I need training in communication skills. I need to be able to use my knowledge to the advantage of consumers. To do this, I need to learn how to take up issues in such a manner that people will listen to me instead of dismissing me as subversive. **Mary**

Another participant identified her preference for psycho-pharmacological education:

> I need to receive ongoing education on my illness. I really don't know very much about the side-effects of my medication and how different medications affect me. **Sally**

Understanding how different government department's policies administer consumers' lives was viewed as essential by three participants:

> I think I could do with some training in law. It may make a difference to my situation when dealing with other departments. However, the reality is, I have schizophrenia and people are scared of us. **Vera**

And:

> I would be interested in learning about the *Queensland Mental Health Act*. I am not convinced that I get accurate information from my case manager. I think they just tell me what is easiest for them. **Isobel**

And similarly:

> I need to be aware of the legislation that regulates the way I am treated by different services. **Lara**

Consumer participants were asked to describe their vision of an ideal mental health service. Most participants responded to this in itemised ways, that is, they desired particular things like debriefing after critical incidents such as friends dying; supportive group homes; additional staff:

> It could be better if there were more staff. We need experienced staff to encourage us to continue. Some of my friends have suicided and we all feel bad at the day-centre programme. It would be good to have staff to explain why these things keep happening. Maybe it would be better if there were some supportive group homes for people to stay in while they are vulnerable, or if they are so unwell they can't make a go of it in the community. I feel frightened when people I know kill themselves. **Rose**

Three participants were convinced the mental health service would improve if they employed additional staff. The staff could then address broader issues that concern people with schizophrenia. Some of these issues include alternatives for vulnerable people and addressing violations of human rights.   Thus:

They should also have people looking into our rights. These people would have the power to ensure our rights are enacted. If we are entitled by law to have access to our children, then this needs to happen. It is not fair that because we have schizophrenia we are disregarded, as if we are not human. **Vera**

And:

More staff employed to follow through with addressing human rights issues. **Mary**

And similarly:

To be there when I need them, not to say they are too busy. They need to have more staff to protect our human right abuses. **Sally**

John and Jim would like to see the professional distancing by psychiatrists reversed:

I would like to see psychiatrists involved at the same level as the consumers who are in the funny farm [secure facility]. See them mingling to get the socialisation aspects of the patients. I would like to see some more hands on work by the psychiatrists rather than having them sitting in their crystal palaces making decisions at random, as they seem to do now. **John**

And:

My case manager and the staff at the day-centre programme are great; they really know us. On the few occasions that I have attended the psychiatrist he has made me feel ashamed. He often tells me that I can do more for myself. I do the best I can. The psychiatrist should come into the day-centre programme more often. **Jim**

Jim intimated that the psychiatrist should come to the place where he, the consumer feels known and not ashamed. It is unclear the purpose of this, either to decrease the social distance between the psychiatrist and the consumer and/or the psychiatrist and other parts of the mental health system as John intimates or perhaps Jim is referring to psychiatrists engaging with clients in a place not intimately controlled by the psychiatrist (not a "crystal palace" as John described above) or perhaps so that the psychiatrist can see and hear other alternatives to his dominant (lazy?) story of Jim.

Mainstreaming consumers back to their GP was considered less stigmatising for Roger. He articulated the need for mental health services in the initial diagnostic and pharmacological treatment stage but urged the more "normalised" role of the General Practitioner. Roger said:

Ideally, people with schizophrenia need to be treated in the initial stages by the mental health services. When they have been educated in their illness and stabilised on the right medication, their local GP should take over. Attending your local GP, as opposed to mental health services, seems more 'normal'. People do not know why you are in the waiting room. You are just the same as everyone else; visiting your doctor. When you attend mental health services, it is obvious why you are there. **Roger**

Clearly the most negative experiences for two consumers in this study stemmed from their interactions with two bureaucracies which did not seem to cooperate in the human/political/civil rights of shared consumers. In this section about an ideal mental health service, Lara requested maternal rights including the necessary resources for her to enact those rights. An ideal mental health system, in her view, would have the power to advocate for her rights across governmental portfolios. She said:

> I have had all my babies removed by Child Safety. I have never hurt or neglected any of my children. Sometimes I sleep too long due to the medication. My children sometimes got out of the garden onto the road. After the first child was removed, they just kept on taking my babies from the hospital when they are born. I don't get to bond with my baby. They have no grounds to do this. They just keep dragging up the old assessments and mainly saying that I have schizophrenia. If I have been compliant with medication for a long time before baby is born, they say I have a history of non-compliance. They advise me not to fight them. I know I can't fight them because my access hours are reduced. I get supervised access. The person who brings the baby often complains that I don't have a cot or pram. I don't have much money. The eight hundred dollars maternity allowance goes to the foster mother and the birth certificate to Child Safety. Sometimes my lack of baby things is used as an excuse not to bring my baby for access visits too often. It is like I have no feelings and don't deserve any rights. An ideal mental health service would have the power to address my rights. This includes advocating for mothers with schizophrenia. **Lara**

Several consumers suggested that LIMHS privilege "normalising" practices. They said:

> It would be good if the day-centre programme was away from mental health services. Maybe they will find a house that we could rent. If they don't, then I think things are okay as they are now. **Paul**

And:

> It would be a house with a lounge-room and an outside area to sit. It would have consumers and staff working to give us skills. **Isobel**

And:

> Ideally, services should leave you alone when you are well. This allows us to feel we are part of the community, rather than just a mental illness that needs to be constantly supervised. **May**

Two participants expressed enthusiasm for the day-centre programme becoming consumer-driven. This included payment for their work:

> Consumers would have input. They would be contributing a lot more to the running of the service and offered opportunities for paid work. **Ray**

And:

> If some of the staff at the day-centre programme were paid consumers, I think it would be better. **Roland**

Education for MHPs

Three participants wanted MHPs to have training in working on behalf of clients to advocate on their behalf across government and other government departments to ensure their political/civil rights:

> MHPs need to know how to get our message over to government. They need to publish their knowledge in professional journals and attend gatherings and talk on our behalf. This will eventually educate the people who remain ignorant of our plight. **Mary**

And:

> MHPs need to be aware of the legislation that guides all parts of a schizophrenic's life. They need to work hard at getting the government to recognise our unique situations. This may result in mothers with schizophrenia getting a better deal with other departments that intrude in our lives. MHPs should be involved in partnerships with the courts, police, Centrelink and Child Safety. **Lara**

And similarly:

> They [MHPs] need training in getting our human rights addressed. We need to have another inquiry like the Burdekin one. This time they need to look more closely at mothers needing to have contact with their children. **Vera**

Four participants desired that MHPs receive training in empathy, love, compassion and respect. They said:

> They [MHPs] would need to learn what it is like to belong to the most stigmatised group in the world. They would need to understand what it is like to get through their day while heavily medicated and to tolerate walking instead of driving. **Roland**

And:

> The psychology of understanding. How do you teach a person to be humane? They could recruit more empathetic people in the first place. **John**

And:

> They need to understand and show real love for consumers. Then they could try to give them some hope by encouraging them to do something. They need to learn to be more compassionate. **Isobel**

And similarly:

> I think that MHPs need to learn to respect the consumers. They could learn how to communicate respectfully. **Jim**

One participant described an event through which she clearly identified steps in dealing with a critical incident. She said:

> Training to change their attitude towards you when you are ill. Training in talking people through their psychotic episodes. Learn how to cope with people when they are violent because they have no idea how. I have gone in with my arm slashed, veins exposed and blood running everywhere. They closed all their doors and called the police. A bit of medical intervention would have been good. They said "you are going to jail, people like you belong

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in jail". They then said to my carer, who had brought me in for help "what is the matter with you, have you got masochistic tendencies, what are you doing this for [caring]? you have got a life ahead of you." They [MHPs] shouldn't be running away from these incidents. They need to learn to keep the person safe and everyone else around safe. **Sally**

Previously, Rose suggested that consumers get training in communication so they can understand what the MHP is telling them. She made a similar suggestion for MHPs. She said:

MHPs require training in the appropriate way to consult with people who have minimal literacy ability. They need to check that everyone understands in a non-threatening manner, one that doesn't make you feel foolish. **Rose**

The policy of mainstreaming was important to Roger. He believed that MHPs may be delaying the referral of stable consumers to their own general practitioner:

The MHPs need to know when it is time to refer you back to your general practitioner in the community. **Roger**

Conclusion

This chapter presented consumers views of participation and partnership, social work, social justice and postgraduate education for MHPs. Consumers demonstrated a clear grasp of participation as intended under Standard 3. Consumers envisaged much wider, roles for themselves than management, social workers and the community development worker envisaged for them. Consumers at times presented poignant stories of discrimination at the hands of a system which purports to serve them. Consumers wanted education of MHPs to be grounded in facilitative conditions of empathy, non-judgementalism and to the extent these were displayed by social workers, so consumers relayed their satisfaction with service provision. Consumers were most scathing of practices which did not engage these affective elements.

The following chapter examines the views and ideas of 14 carer participants regarding a broad range of issues crucial to carer participation and their experiences with mental health services through the person they care for. It also explores what happens to carers when MHPs, including social workers and psychiatrists, exert power over them.

CHAPTER NINE
Data Set 5: Carers' Views

DO YOU SEE ME?

Do you see me? I am not sure that you do
When I take the person I care for through those doors,
seeking help, before the next crisis.

Do you see me? I think I am the one you 'miss'.
You don't see my pain, my need for you to help

You don't look me in the eye, unless I shout or cry
You turn away from me

Do you see me?

Are my eyes tired, sad or wise
You don't know, because you don't see me
                        DO YOU?   (Gill Palmer, Carer, 2000)

This chapter is a presentation of the perspectives of 14 carers of people diagnosed with schizophrenia, on issues relating to the policies of partnership and participation; social work; social justice and education for MHPs within the Lantana Integrated Mental Health Service. Carers provide assistance for consumers who have, at different times, experienced admission to an inpatient unit as a voluntary or involuntary patient. Similar to the consumer participants in the previous chapter, the carers attended educational sessions prior to their interviews where the use of vignettes (see chapter four) offered them a basic discussion of mental health participation policies.

Participation

At the time of interview carer participation in mental health services had been on the national mental health agenda for over a decade (AHMAC, 1991, 1992, 1996). The carer participants reported in this study understood participation in mental health services in different ways. Two carers interpreted the process as consultation and involvement in all decision-making within the context of the cared-for's treatment:

> Carer participation means that I can talk to the case manager about issues of concern such as medication, education and maintenance. I should also be able to participate in the ongoing recovery process. Basically I should be able to participate whenever I have the cared-for person's permission, which I do. This is to help the person get through the psychotic stage when they are too unwell to be able to speak for themselves and they do not know what is going on. I can relate to being left out of the picture. A perfect example is the time I was shut out of an interview and two days later I had a telephone call from the case manager saying how well they thought the cared-for was. Unfortunately, the cared-for was delusional and the mental health service did not pick up they were delusional. **Paula**

And:

> Carer participation is being included in the whole process from hospitalisation to medication. As far as I am concerned it is just part of the package. A person who is ill needs someone to care for them. If someone takes on that role, it is all encompassing. It is being part of the decision-making process and being included at all levels. This does not happen here in Lantana. **Teresa**

Paula and Teresa both considered themselves entitled to participate throughout the entire process from onset of an acute episode to recovery. They were very clear on the importance and relevance of their input when the cared-for was going through an acute stage of schizophrenia.

Louise and Prue articulated not only a content side in consulting MHPs in relation the cared-for, but also expected affective components like respect and comfort to be engaged:

> Participation means that you are involved in everything that affects the cared-for. I should be able to attend all consultations and have my opinion respected. Participation also means that MHPs help me to feel comfortable and confident when I offer my contribution. **Louise**

And:

> When I go to the hospital or on an appointment with the cared-for, I expect to be listened to and my opinions respected. This is all I expect from the mental health services. **Prue**

Participation and education in the pharmacological choices and treatment plans of the cared-for were paramount for three carers:

> Carers should be involved in every single part of the treatment plan. They need to be informed about all decisions and educated on different medications and their side effects. **Ada**

And:

> It is when I am invited to be part of the treatment plans. It is important for me to be able to recognise the side-effects of the medication and know what to do. Sometimes I get frightened when (name of cared-for) stares into space. **Marion**

And similarly:

> Participation is being involved in my daughter's treatment. She puts on a lot of weight with the tablets and I want to know how to help her. **Fran**

Notification of the hospitalisation or arrest of the cared-for was a priority for three participants:

> Participation means that I am involved in every aspect of my daughter's treatment. I need to know when they [MHPs] think she is going to relapse. I also need to know when she has been taken into hospital. I know how scared she is in hospital and have to be there with her when decisions are being made. That is all I want to participate in. **Rena**

And:

> As a carer I expect to be advised when my son has been put into hospital or has become involved with the police. **Simone**

And similarly:

> I have understood more about participation in recent times. We now have an Indigenous case manager who understands our situation and works with the whole family. Participation means that the family is informed about all major decisions and interventions. This includes the occasions my son is hospitalised or arrested and taken away. **Gloria**

Three carers have lived through many changes in the direction of mental health policy. They were sceptical of the overall direction of policies on participation, preferring to have more fundamental needs met:

> I am aware of these policies, mainly through my son. In my role as the mother and carer of an adult son with schizophrenia, I have witnessed many different policies through the years. I am as suspicious of the participation policies, as I was appalled by past policies. To me, it sounds as if more and more responsibility is going to the carers and family. I don't wish to be negative, but at my age, with the changes I have already gone through, I don't see any improvement in my son's situation. **Thelma**

And:

> Carer participation for me would be that all mental health service staff understands the day-to-day experiences of carers. The difficulties we have with finances, grief, dealing with the law and other departments.

And:

> I have never felt welcome. The psychiatrist rarely returns any of my phone calls. For me, participation would be having the treatment plans explained fully and being offered some explanation of whether the new treatments offer any improvement in my daughter's condition. Regardless of policy changes, nothing has changed for me. **Annie**

Laura iterated the importance of participation being mutual, a two-way process. She said:

> Participation is something that should be shared. These policies say we can share with them, but are they going to share with us? From past experience, I think not. **Laura**

Tom was not interested in participating with the mental health service. He understood his primary role as meeting the immediate day-to-day needs of his wife:

> Carer participation means nothing to me. I am here to take care of the person who needs me (wife). **Tom**

Tom appeared to view further involvement with the service as adding to his burden.

Participatory activities of carers

Carer participants were asked to describe the participatory roles that they currently undertake in the mental health service. Tom described a situation that he perceived as crucial to his wife's interests:

> I always go with my wife whenever she attends the psychiatrist. They [MHPs] were going to give her shock treatment and did show us a video of what happens. She doesn't remember the video or getting the shock treatment, therefore I need to be present to look out for her interests. **Tom**

Tom implied that the consumer's interests may not have been "looked out for" without his engagement. Tom positions himself as a human rights observer in the way Mary had previously articulated a need for such roles.

Three carers had been invited to participate in the treatment plans of the cared-for:

> Lately I have been included in the treatment plans. I am not sure if this is happening across the board, or if it is an initiative of our current case manager. **Louise**

And:

> I have attended some of my daughter's consultations at LIMHS. The psychiatrist has relied on me to clarify some of the things that my daughter has told him. That is all I have been involved with. **Rena**

And similarly:

> I have been present at reviews and agreed with medication changes for my son. **Laura**

Four participants had attended the psycho-education sessions held at the LIMHS:

> Psycho-education courses are available. However, I know many carers who are not referred. I think it depends on the case manager allocated to the cared-for and how well you are coping in the caring role. **Ada**

And:

> Last year I completed a course on psycho-education. It was difficult for me to participate because the other carers were non-Indigenous and their issues were different than my own. **Annie**

And:

> I have been to the psycho-education course where I was taught how to cope with the cared-for's symptoms and about medication and the potential side effects. **Prue**

And similarly:

> I attended the six weeks of psycho-education and learned a lot about how to cope and medication. **Simone**

Paula voiced her annoyance at having to form her own self-help group:

> I have had to develop a carer's support group out of frustration from the lack of consultation or any sort of communication with the LIMHS. I didn't even know that LIMHS existed until three weeks after my son had come out of hospital. I was in despair. **Paula**

Paula expresses the emotional consequence for the lack of communication between the hospital and LIMHS.

A carer did not attend meetings with her partner; however, she sporadically destroyed the treatment plans:

> I don't involve myself with any roles within the service. However, I drive the cared-for to and from appointments. The nature of the illness presents difficulties with transport. I ensure attendance at blood tests and supervise medication. I do not attend any of the appointments or see the care plans. The cared-for has been asked to sign care plans a couple of times that were inappropriate and I have ripped them up. **Teresa**

Teresa did not provide a context for this statement. It is unclear, therefore, whether she refused to attend psychiatric reviews with the cared-for, or she was excluded. She provides real material support for this consumer, but implies that her lack of participation in developing the treatment plans, renders these useless (since she rips them up) working documents.

Three carers were convinced that the roles they currently undertake with the cared-for are more than enough for them to cope with:

> I haven't been asked. I think that the roles I have always undertaken are more than sufficient. Looking after my son's interests has consumed most of my life. I don't think that anyone could say I haven't done a good job. **Thelma**

And:

> Just the things that I have to do for my daughter everyday. It is like a fulltime job. They [mental health services] check on me occasionally. **Fran**

And:

> I have to look after three children and my mother at home. This is over and above supervising my daughter with schizophrenia. She is a good girl and does not give us much trouble. I don't have any time left to help the mental health services. I am sure that I am doing everything as it should be. **Marion**

The possibility of Gloria's involvement with the service is complicated by her son's cultural, social and medical needs:

> It is difficult for me to have a role as my son is often in (Aboriginal community) with relatives. He comes down to Lantana when he becomes unwell, or missing his sister and me. **Gloria**

The lack of adequate mental health services in Indigenous communities has been recognised by the Australian Mental Health Advisory Council (McGrath, 2000). Due to lack of remote mental health services, Gloria must remain living in Lantana to provide for her son when he becomes unwell.

Possible carers' roles

Carers were asked to describe what type of roles they could undertake at LIMHS. Fran and Tom were willing to extend themselves by offering their time to teach the consumers sewing and to drive them to activities at venues that were accepting of mentally ill participants:

> I am able to teach needlework and am willing to do so. **Fran**

And:

> I do not have any education, but I do have a bus license. Perhaps I could drive the bus for them to access activities in the community. **Tom**

The majority of carers considered that carer support by, and of, other carers would be helpful:

> I could relate the exact needs of a carer and what support they need. It would also be nice to be asked how I was coping. I do not get any debriefing after crises. I get no support. I had to self-educate on everything. **Paula**

And:

> Just to be with other mothers sometimes. I would get a lot out of hearing other women's accounts. I am sure there will be some like me and perhaps we could help each other, even if it is only listening. **Marion**

And:

> The most important thing that I could offer is to share my knowledge with other carers, and assure them that somehow you do get through the experience. **Thelma**

And similarly:

> I could share my experiences in a support group and hear other people's experiences on how they cope, especially financially. **Laura**

Likewise, an Indigenous carer wanted to meet other Indigenous carers:

> Sometimes I think about other Indigenous people that are in a similar situation as me. I believe that many Indigenous families are faced with the dilemma of living in Lantana for better treatment. If I had more confidence, I could share my stories with them. **Gloria**

Simone viewed a carers' support group as crucial to understanding the many losses experienced by carers of people with schizophrenia:

> I think there needs to be a support group for carers to be able to come to terms with their hidden grief. My grief over my son's illness is ongoing. It takes different shapes but it is always there. I also grieve over the removal of my grandson by his mother. It makes me incredibly sad that my family has disintegrated due to my other children not coming to the family home. Most of this grief is hidden from my son and is a journey I travel alone. This is a common but serious problem for carers. **Simone**

Each of the above respondents had a clear purpose for the support group they imagine. Simone poignantly highlighted the intensity of issues which could be engaged by a carer support group and the profound work in which they could be engaged. Louise intimated in her narrative below, how this agenda could be minimised to meet the more material needs of LIMHS. She said:

> Carers could provide support for other carers. There has been a carers' group but it disbanded. The major reason for this was that the LIMHS was putting too much pressure on them. They pushed them [carers' group] to become incorporated and apply for funding for a halfway house. This is not the role of a carers' group. It is for caring and sharing or whatever the carers feel comfortable being involved with. **Louise**

Louise highlighted the danger for carer self help groups to collapse when they are co-opted by mental health services for their own purposes. This response intimates the necessity for partnerships of participation to have shared goals.

Ada and Fran suggested that carers could be involved in committee work. They said:

> I have good skills in office administration. I can chair meetings. If we were to have a carers' working group set up to address the deficits in service delivery, I would be of great assistance. **Ada**

And:

> I would like to be on a committee that decides how the MHPs work with the consumers. I don't think they do enough to help the consumers overcome things like alcohol addiction. They get around the streets and do anything they want. When they were in an institution, they couldn't do these things. **Prue**

Prue particularly wanted to be involved in issues of dual diagnosis.

In Teresa's view, a fully integrated, collaborative approach between all mental health services would be a powerful force in improving the well-being of consumers:

> I honestly think that if there was cooperation between the hospital, the psychiatrist, LIMHS and carers, and they were genuine, the carers could be a very powerful group in improving the well being of the patients. Presently, carers are not included. **Teresa**

According to Fran and Marion, there are insufficient numbers of MHPs. Increasing the involvement of consumers is viewed as a solution to this situation:

> They are very busy. Maybe they need more workers or let some of the consumers take over the non-professional roles. **Fran**

And:

> I think they are too busy to get into these sorts of things [participation]. They are always dashing around. They need to have more staff or volunteers. **Marion**

Rena and Annie had no time to offer additional services to LIMHS outside of what they were already providing to the cared-for. They said:

> I have a large family and my mother is in bad health. It takes everything out of me to buy and cook the food, look after the children and attend to the health needs of my mother and daughter. I am already stretched. **Annie**

And:

> Why would I want to have a role within the service? I am already doing so much at home. I clean, buy clothes, pay rent and drive her everywhere. I am 58 and still work full-time to help my daughter get by. She gets her pension, but often spends it all in one day. I have no time to get involved with LIMHS. **Rena**

Social Work

Six participants did not know the professional background of the cared-for's case manager. The remaining eight participants described their experience of social work case management.

Three carers described incidences of inclusive social work practice:

> The social worker invited me to attend the day-centre programme and teach some of the women needlework. She has also intervened for me with Centrelink when I was too upset to chase up a mistake they had made with my daughter's payment. Nothing was too much trouble. **Fran**

And:

> The social worker was the one who got my daughter her flat. One thing that was outstanding is that she took me to see the flat, and ensured it was in close proximity to my home and to the day-centre programme. A few years ago, another social worker referred me to psycho-education and I benefited from my attendance. The same social worker was able to get us Legal Aid assistance. **Rena**

Prue appreciated a social workers' successful intervention when her son's jail sentence was converted to treatment for his schizophrenia:

> I rang her and told her that my son was in the lock-up for possession of marijuana. She picked me up from home and took me to the lock-up. I was present through the whole process. It certainly reduced my anxiety. He ended up being transferred to the psychiatric unit. **Prue**

Rena, Fran and Prue clearly highlighted the importance of whole-of-government-sector knowledge, process, and resource mobilisation skills of social workers to help carers meet the needs of the cared-for.

Laura, however highlighted that the manner in which social work practice is engaged is helpful:

> They are very busy. However, I have found them to be kind and polite. They have also come out to the house to tell me bad news about my son, instead of phoning. This was good because we could talk it through and come up with a solution together. **Laura**

Three other participants discussed social workers in relation to other Mental Health professionals and made their judgement of social workers comparative. Louise compared the approach of the psychiatrist and nurse with the practice style of a social worker:

> Previously we have been involved with a psychiatrist and a nurse. The experience with the psychiatrist was unsatisfactory. He was very directive and clinical and appeared to lack insight into how devastated we were at his diagnosis. I came away feeling guilty, like it was my fault that my son had schizophrenia. We were allocated a case manager with a nursing background. This person would tell me about the medication and fill my son's dosette. She would take my son outside and talk to him without inviting me. Then she would phone me to check if my son was taking his medication as prescribed. I was expected to monitor his mental state and his medication while being excluded from the discussion on his treatment. When the social worker took over as case manager, I was then included in the visits and plans. I was put in contact with other carers, received supportive counselling, and referred to psycho-education. This was the first time that I had received any assistance that recognised my experience and needs as a carer and a mother. **Louise**

And:

> When I attended the first session of psycho-education I started crying and the nurse facilitating the group did not respond and I was embarrassed. At the next session, there was a social work student sitting in for training purposes. Once again, I started crying then apologised to everyone. The social work student said to me "it is alright for you to cry, you are grieving the loss of the son you knew before he had schizophrenia". I had not recognised this before. Other people in the group then started talking about their grief. I will never forget the experience with that young social work student. **Gloria**

Two carers expressed dissatisfaction with the social worker case manager. They told a story about ringing a social worker case manager when their cared -for was demonstrating signs of relapse. The social worker:

> didn't want to know and refused to come to the house. Their perspective was that the person I care for has a carer (me), so I should be able to get on with it. Other than medication, there is no other support they offer me. **Paula.**

Paula's story indicates the shift from formal care of psychiatrically diagnosed persons to the intimate, residual care of the family (or carer) and intimated the burden of responsibility she bears.

Teresa believed the role of the social worker is to contact the family of consumers at the stage of intake assessment:

> I have never sighted one (a social worker). Why didn't the social worker access me when my son had his initial onset of schizophrenia? **Teresa**

Carer participants were asked about their positive and negative experiences of LIMHS. Their responses allowed for data collection around performative social justice. Four participants were unable to depict anything positive in their involvement with LIMHS. Therefore, this section describes the optimistic views of the 10 remaining carers. More critical, negative views comprise the following section.

The activities and groups held at the day-centre programme have been directly responsible for improving the mental health status of Rena and Simone's offspring:

> The best aspect is that they are beginning to involve the consumers in more activities through their day-centre programme. Some of these activities have given my daughter new skills. She also looks forward to going there. This is a step in the right direction. **Rena**

And:

> They provide a venue called the day-centre programme where my son gets to enjoy various activities. This has improved his mood. **Simone**

The positive outcome gained from attending the day-centre programme is pervasive throughout this study. The consumer participants in chapter eight found the day-centre programme the most positive feature of the LIMHS.

Four carers appreciated the services already on offer at the LIMHS. They compared their own experience with those of carers in more remote areas of Queensland:

> We are very lucky to have a service that takes care of us at all. I mean some people live on the streets in other parts of Australia and the world. I am grateful for what we have. **Fran**

And:

> That we have a team here in Lantana who offer a reasonable standard of service. **Laura**

And:

> If we lived further out, we would not have a service at all. I am happy with what they do. **Marion**

And similarly:

> Now that we have the services of an Indigenous case manager, our situation has improved. In (Indigenous community) there is no service to speak of. I appreciate the service we have. **Gloria**

Four carers described their satisfaction with the LIMHS:

Currently I feel much better about my involvement with LIMHS. The case manager includes me in the treatment plans and supports me with my concerns. This small shift has made a huge difference. **Louise**

And:

MHPs try to do the best they can under the circumstances. I have seen my son abusing them verbally. It was awful, but they just took it in their stride. I mean this is a very hard job. **Prue**

And:

The CATT team was very helpful. They came out to our place at 9pm and then I rang the hospital and a nurse came back again later. They usually don't offer that service, but they did for us and I appreciated it. **Tom**

And similarly:

Occasionally a MHP listens to me and assists with problems over my son's involvement with the legal system. **Thelma**

Positive work practices were described as MHPs' willingness to listen to carers and include them in the treatment plan of the person cared-for. Carers respect MHPs who exhibit tolerance and understanding of consumers' behaviour in an acute phase of their illness. Prue recognised that this work was difficult in complex situations and expressed her appreciation when MHPs respond in a professional manner. Carers also conveyed admiration for MHPs who were willing to respond to an out of hours' crisis and actively advocated for them over police matters and in the court system.

The responses of carers regarding the worst aspect of their involvement with the LIMHS centred on the insensitivity of psychiatrists. Three participants believed that constraints within the service that hindered MHPs and carers working in partnership were apparent from the first consultation:

It is at the point of entry to the LIMHS. The attitude of the psychiatrist makes you feel inadequate and guilty. This tends to make you think it will remain this way as you continue through the process. When the psychiatrist told us that my son had schizophrenia, I was devastated and left the building in shock. There was no discussion on what the future held, or on what we could do about the situation. I think that the psychiatrist could have been more caring in the way he conducted the interview, or referred us immediately to someone who could deal with the feelings and answer the questions that are a consequence of being given such bad news. **Louise**

And:

When I had my first family meeting with the psychiatrist and a nurse, the psychiatrist was obviously trying to rush us out. The nurse tried to get my daughter to speak, but the psychiatrist intervened and silenced her. He declared the meeting closed and hurried out. The nurse apologised for him, however I remain ashamed of that experience. I will not let a psychiatrist do that to me again. **Annie**

And similarly:

> There is a lack of communication between the psychiatrist and the carers. Our first meeting was over within a few minutes. They don't sit you down and tell you about the side effects or what could happen with particular medication. They just give you the medication and say come back in a fortnight. **Tom**

Prue described how she was silenced:

> The psychiatrist often insults me and I take it because I know there is nowhere else for us to go, as I cannot afford to go to a private psychiatrist. When I go to the mental health service with my son, the people that work their make me feel uncomfortable. They don't like me to ask questions, they tell me to be quiet and let my son speak. This is when I know my son is telling lies. **Prue**

Several of the carers in this study encountered negative attitudes of blame. They considered this affected them as mothers and carers and viewed this as a major barrier to working in partnership with MHPs:

> It is the attitude that it is them [MHPs] who have all the skills and we [carers] are the people who have caused the illness. This prevents us working together. The day that I went to see the psychiatrist about my daughter's increasingly immoral behaviour, he said it had nothing to do with her illness. He made me feel that it was something she had learned within the family, or that the family had failed to prevent the behaviour. I had read in several articles that it was part of the illness, and that is why I went to see him. He said that I should not take these articles as gospel, however, a psychiatrist wrote the articles. **Ada**

And:

> I have been told that the mother is to blame for schizophrenia. That it is hereditary. Okay, I agree, as my husband's father had it, but not my father. I hold a responsible position in the workforce and enjoy close friendships. I don't view myself as being in any way abnormal. MHPs have no right to make women feel bad about themselves. The psychiatrist has made me feel ashamed in the past and I am blamed for my son's disorder and will never forget how awful that was. I went to a social worker at Centacare [catholic welfare organisation] and we worked through my feelings. Since those counselling sessions, I have not allowed myself to feel ashamed, however, I will never forget what happened to me. The problem is that psychiatrists have preconceived ideas about carers, and that interferes with their intervention. **Thelma**

Simone was prepared to understand the psychiatrist's lack of empathy by comparing it with her own hidden, disenfranchised grief:

> I seriously think that the psychiatrists do have empathy, but they hide it. A professional, distant image is required to protect them from the harrowing reality of the work. This is much the same as I feel when I hide my grief from my son. The only difference is that they can go home and on holidays, where they are sheltered from this reality. Therefore, they should be prepared to give more of themselves when they are at work and receiving good wages. **Simone**

A culturally sensitive psychiatrist was compared to a culturally insensitive psychiatrist:

> The first time I met a psychiatrist was at (Aboriginal Community). He was a very nice man and spent a lot of time explaining my son's illness to the family. He was educated in Aboriginal culture and had written books about Indigenous mental health. When we moved

to Lantana to be closer to the mental health service, I was very upset when meeting the psychiatrist. He was very rude and spoke in a rough manner. **Gloria**

Gloria acknowledged that there are differences between psychiatrists and their approach to carers, which implies that psychiatry, like social work, is practiced in diverse ways.   Perhaps, she intimated, it is training in Aboriginal culture which provided this psychiatrist the skills to engage in a time rich manner.

Teresa indicated that she would like to be part of agreements between LIMHS and her son and that this would ensure that his wishes are attended to when he is unwell. She also made an important point about agreements being made when the cared for is "in the right mood and frame of mind":

> I feel there is an over emphasis on confidentiality, yet I do understand it, it is like tug-of-war. I can see the difficulty if there is friction between the carer and cared-for, and I respect that can be a big issue. However, you have to look at the whole picture and their [MHPs] attitude is self-defeating because you are there as the carer and they [consumer] are there as the unwell. They [consumer] are regulated and not well enough to make their own decisions; it is a bit of a catch twenty-two. I want to do an agreement with my son when he is in the right mood and frame of mind and if he is regulated again, I can make the decisions for him. To me it is like a little child that cannot look after itself, so someone has to make the unpleasant decisions. If you exclude the carer, the person who looks after them twenty-four hours a day, the person who does not just see them as a clinical object, then who will look after the emotional side and give them hope? **Teresa**

Paula pointed out that "confidentiality" as a guiding practice principle, means that she is excluded from information which might be helpful in her relationship with the cared-for:

> I get upset when I am refused information due to confidentiality. How are we going to sort things out if we don't all sit down as adults and discuss the situation within four walls? No one else is around to hear. I know the person much better than they will ever know them and that is the situation with most carers. If there is an agreement between the carer and the consumer that confidentiality is assured, I think we should be involved, or we will not get the best outcome for the cared-for. **Paula**

Laura and Rena discussed their lack of status in relation to the cared-for:

> I think that our roles are very different. They (MHPs) look after the clinical side and the carers do everything else. The problem is that carers would like to participate in the clinical side, but MHPs do not value the carer role. **Laura**

And:

> It is the impression you get when you talk to them [MHPs]. Although everyone who works in mental health services must be aware of the contribution made by carers of people with schizophrenia, they are rarely empathetic. It is like 'okay, you do all the hard work, but don't expect an invitation to participate in the medical side of things'. **Rena**

In order to help carers explicate their responses to questions about participation, social justice and social work, they were asked about the major concerns they have

for themselves. This provides a context from which to understand carer's perspectives on LIMHS and potentially provides direction for the ways in which carers can be supported in holistic and socially just ways.

Carer participants were asked to describe their major concerns in relation to their roles. The major concern of carers was who would care for their offspring if something happened to them. This was described in the following ways:

> If anything happened to me and I started not to cope, what would the consequences be on the person who I love and care for? There is no contact with the psychiatrist for me. When I have to go away, they [case manager] never follow through with what they say they will do. I would like to see them [CATT] respond; not for me to make a phone call and be told to ring Relationships Australia, or join a lesbian support group. **Paula**

And:

> I get very frightened when I think about what will happen to my son if I am not able to care for him anymore. My role involves so much more than a case manager could provide. Perhaps he would adapt to me not being around, but I really can't convince myself of that. **Louise**

And:

> The most worrying aspect of being a carer is the very real possibility that no one will take on the role of caring when I am old, or dead. I have no other children who could do this. Currently my son lives independently in a small flat. This place is always a mess, or he runs out of money for food. I am concerned that in the future he will have to live in filthy conditions and go without food. **Thelma**

And:

> What will happen to him after I am dead? Who would do what I do? Whilst I am here, he has someone who loves him. I know that he feels that love. When I die, he won't have that support and I don't think he will cope with that. **Marion**

And:

> It is very stressful for me to think what could happen to my mother and daughter if I became sick. I try very hard to keep myself well. **Annie**

And:

> Sometimes I worry about what will happen to her if I die first. We do have a son here in town and his wife says that they would take care of her but you are never sure of what the future holds. **Tom**

Participants' responsibility towards caring for their family members exists not only in the present but extends to the future to a time when they will be too frail or sick to continue performing previous caring roles.

The main concern for Rena and Laura was finding the finances to continue caring for their offspring indefinitely, or when an unanticipated event throws the budget into chaos:

> I get worried that I won't have enough money to take care of my daughter in the future. **Rena**

And:

> I am constantly trying to make ends meet financially. I am very good at budgeting but there are times when everything blows out. So far I have managed to keep on top of things. It is however, very stressful as I never know what my son is going to get up to next. **Laura**

The caring role often involves financial difficulties.

Some carers discussed as major concerns, issues to do with drug taking and drug compliance:

> It is getting my son to self-medicate. For him to realise that he does have to consistently stay on his medication. He has only been on it for a period of five months and has become very, very well. We hit a bit of a glitch recently because he now feels so well that he doesn't think he has to take any medication. This is very difficult for me. **Teresa**

And:

> My son often takes different drugs; things like marijuana and speed. On occasions he has become quite ill and aggressive and I get frightened of him. He has never hurt me, but I worry that he might kill me one day. He doesn't know what he is doing when he mixes different drugs with the ones he is prescribed. **Prue**

Three clients lamented the disintegration of the family and/or stigma expressed by family members of the cared-for:

> I have four children besides [name of daughter]. Two of them are married with children and one lives in Lantana. They don't come to visit the family home because of their sister's behaviour. I go to their house, or out to different social functions with them. I would like them to come and visit, bring the grandchildren with them and be with their sister sometimes. I miss that kind of family life. **Ada**

And:

> I have a grandson who lives with his mother in Mt. Isa. The mother has told me that she will never come near our family again and unfortunately her parents support her in this. My son doesn't seem to mind, but I often feel very sad that this has happened to us. **Simone**

And:

> My daughter has two children. One lives with their father and the other one is grown up and lives in Melbourne. This has caused me a lot of anxiety over the years. I haven't seen them for over twelve years. My son is married but I don't think they are going to have children. They are scared of their children getting schizophrenia. **Fran**

To offer her son optimal care, Gloria relocated from her community to Lantana:

> I moved to Lantana with my son and daughter to be close to the hospital and mental health services. My son returns to the community quite often and when he is there he lives with other family members. I have to stay in Lantana as I have a house here and my daughter attends school. My son goes to (Aboriginal community) and returns to Lantana when he wishes, or when he becomes unwell. He can just turn up. This all means that I have to stay in Lantana permanently, to be here when he comes down. I miss my family and community and am unable to visit often. **Gloria**

The lack of mental health services in Gloria's Aboriginal community leaves her no choice but move to Lantana with her two children. Her son however, misses his relatives and friends and frequently returns to visit them. This option is not available to Gloria; she has her daughter at school in Lantana and rent to pay. If she could access the services her son required in their community, she could remain and enjoy the support of the extended family. This situation is recognised by a social work participant in chapter seven who described the lack of services in Indigenous communities as a serious social injustice.

Access to a psychiatrist adds to the burden of caring for a wife with schizophrenia:

> Access to a psychiatrist when you need it. If you go to the hospital to get treatment you can sit there for four or five hours at outpatients. Tom

In order to provide a further context for understanding the perspectives of carers and to engage thinking about practices of social justice, carers were asked about the concerns they have for those for whom they care.

Two carers worried about the quality of life endured by their daughters. These mostly consist of issues relating to companionship, partnering and love:

> Some of my children who are younger than [name of daughter] have partners. I know that she is envious of them, though she tries not to show it. **Annie**

And:

> I would like her to have a relationship with a man who understands her and makes her happy. Not to have children, just companionship and love. My daughter has a lovely nature. **Rena**

Another four participants expressed sadness at their sons' loneliness:

> I often worry about him not having a real life. He appears to be lonely and doesn't have any friends. I see other men of his age with their wives and children and they look happy. My son must also see this and I feel his pain. **Louise**

And:

> I know that my son is very lonely. He has few friends and never had a girlfriend as far as I know. He sleeps a lot, or sits at the television. It is like he is already dead. Maybe it doesn't worry him as much as it worries me. I always compare him to myself at his age. I had a very full life when I was his age. **Marion**

And:

I am concerned about my son's lack of a sexual outlet. **Prue**

And similarly:

One of my greatest concerns about my son is that the illness is so socially isolating that it cuts him off from mainstream society. This is not only employment wise, I can come to terms with that, but socially, like not having a girlfriend. It is awful. **Teresa**

Non-compliance with prescribed medication, a common symptom of people with schizophrenia, was another of Teresa's ongoing concerns for her son:

Another concern I have for my son is the lack of insight he has regarding taking his medication. Even though intellectually he can understand he needs to take it and has no qualms about taking a vitamin pill, there is something blocking him about actually taking that pill that appears to be endemic to the illness. **Teresa**

Four carers described fears for their sons' longevity:

I worry that my son may eventually take his own life. Sometimes I feel that it is just a matter of time and there is nothing I can do to prevent it. **Prue**

And:

I am afraid that I will go around one day and he has suicided, or been murdered. He often brings transient, homeless people back to his house. **Thelma**

And:

I am frightened that my son will kill himself. It may be an accident from the antics he gets up to, however, he has attempted suicide three times in our house. This is a major source of fear for me. **Laura**

And:

I mainly worry about what will happen to my son if I get sick. There is no other family that would be willing to take care of him. I think he would suicide. **Simone**

And:

There has been a lot of publicity given to Indigenous people suiciding and my son has also got schizophrenia. The potential for him to suicide is high. This is another reason why it is important for him to have family in both Hopevale and Lantana. He needs to have constant support. **Gloria**

Gloria feared that her son is exposed to double jeopardy in relation to suicide due to race and diagnosis.

A daughter's suicidal attempts resulted with Fran feeling helpless:

When she is unwell she often threatens suicide. This is mostly when she gets depressed about not being able to visit her children. Several times she has attempted suicide and I feel

quite helpless to prevent this happening. That is what concerns me more than anything else. **Fran**

Tom expressed fear after his wife talked of suicide:

Once my wife talked about suicide and I worry about her getting up in the night and taking too many tablets. **Tom**

Concerns about the impact of the behaviours engaged by the consumer when they are unwell were of concern to Ada. She said:

My daughter is quite immoral. She is not able to have children, thank God. However, she has contracted sexually transmitted disease as a result of not using safe sex practices and being with men that she doesn't really know. She has also been beaten up by some of these men. **Ada**

Paula's concern for her daughter was about her ability to access ongoing quality services:

That she has the right to the best treatment. That is, medical, legal and case management. It is just a basic right. **Paula**

Carers were asked to share their descriptions of an ideal mental health service. This is what they said:

I am very passionate about a shared care idea. I am very keen on the right GP who is interested in the area of mental health, having a pivotal role. That is mainstreaming, where your GP refers you to a psychiatrist if necessary, then you return under his care. He doesn't lose sight of you as a person. The idea of shared care means you have a watchdog in your GP to watch the MHPs and psychiatrists. I would like to see MHPs and psychiatrists handpicked for the job and the government to show a bit more caring. You only have to look at the mental health unit here, you can't see out of the windows and only have a glass cage to walk up and down in. It all looks very clean but no one seems to have thought about what it is like to be locked in there for any length of time. It needs to be re-thought. **Teresa**

Paula suggested that there is nothing ideal in the service at present. She argued for extra mental health services and a more open style of participation between service providers, consumers and carers. She said:

Ideally, it would look nothing like it looks now. I would like to see consumer and carer participation implemented and extra services available for consumers, such as courses on self-esteem, life skills, and hope for recovery. For carers there could be training in place such as train the trainer, skills in critical response, education in processes of recovery and other alternatives in addition to expecting us to dole out medication. Certainly not this closed mental health service where they think they have all the answers. **Paula**

Louise, Simone, Thelma and Ada urged a more holistic service response shared between multiple health disciplines and involving consumers and carers:

I am all for a different approach by the psychiatrists. It would be better if there were another person at the interview when the psychiatrist tells you that your family member has schizophrenia. It is not just the medical side of things that are important; it is the fallout from the devastating news. If the psychiatrist is not able or willing to deal with this stuff, then another MHP should be present who will. **Louise**

And:

> It would be more democratic. The psychiatrist would not have so much power. He would share it with other MHPs and consumers and carers. That way the social side of a schizophrenic's life would receive more attention. **Simone**

And:

> In an ideal mental health service, the psychiatrist would have assistance to notice that schizophrenia affects the whole family. They would then be able to offer assistance with all of the issues surrounding schizophrenia, not just the medical aspects of the family member with the disorder. **Thelma**

Later in the interview, Thelma added to this by saying:

> MHPs need to spend time encouraging carers and consumers and talking to them about possibilities other than the current emphasis on medical intervention and medication. It needs moderating to include counselling. **Thelma**

And:

> An ideal service would be open not closed. Carers and consumers would be on decision-making committees and the day-centre programme delivered by consumers. A complete change of culture is required. **Ada**

And:

> Letting the consumers have more control over their programmes would be an improvement. **Fran**

And:

> The consumers are more than able to run the day-centre programme by themselves.
>
> **Marion**

And:

> The service would be better if the consumers were encouraged to take more responsibility with the day-to-day activities at their day-centre programme. **Gloria**

An ideal service would advocate on behalf of consumers:

> An ideal mental health service would advocate for consumers. When they were institutionalised they could not get into trouble. Okay, they are now in the community, but surely they can't be expected to behave like the average citizen. I mean that was why they were in institutions. A good service would assist more by intervening on behalf of consumers, unless it was a very serious incident. **Laura**

Prue believed that courtesy, empathy and compassion would be present in an ideal service and the family would be viewed as a resource:

> The staff would be polite and accept the family as an important resource for them to access. If they thought about what they would do, if their son or daughter had schizophrenia, I am sure they would have a lot more compassion. **Prue**

Carers were asked to offer opinions on the type of training that would best enable them to participate more fully in the mental health service they envisaged. A broader training in psycho-pharmacological and crisis education of all family members would assist Paula:

> Probably education on the disorder schizophrenia and on the medication, for all family members. Training to enable us to recognise early warning triggers and how to lower stress in the cared-for's environment for both the consumer and family. Also how to lower expectations when the person is unwell and to give us skills to take the fear and the scary stuff out of an episode. This would enable friends and family to stay involved rather than avoiding the cared-for. This can create a holistic support network instead of everyone running away when there is a crisis. **Paula**

Louise would like education in carer support:

> Training to speak to other carers when they are beginning the journey I have already travelled. This could be similar to the training received by the cancer support people. A friend had breast cancer, she was allocated a support worker who had survived breast cancer. It provided her with a person who understood her treatment, emotions and pain. It offered her hope for survival. **Louise**

Similarly, Simone wanted specific training in carer support:

> I would like to have some training in running groups. I certainly would like to contribute to a group on grief and loss. **Simone**

Ada saw an educational niche for consumers and carers in prevocational activities:

> The people employed at mental health services, should work solely in clinical positions. Consumers and carers can be trained to undertake all prevocational activities. There is no need to waste resources paying MHPs big salaries for undertaking these activities. **Ada**

Training in assertiveness skills may enable Prue and Annie to communicate better with the psychiatrist:

> I need to be more assertive. If I could challenge the psychiatrist without him getting angry and sending me out, it would be useful. **Prue**

And:

> I would like to have the guts to confront the psychiatrist's treatment of me. This would entail me becoming more confident. **Annie**

Gloria asked for training in dealing with non-Indignous service providers:

> Learning to be more confident when dealing with the non-Indigenous service providers to assist me to gain a better understanding of my son's illness and side-effects. We do have Indigenous mental health workers, however, the psychiatrists are always non-Indigenous. **Gloria**

Gloria pointed out that cross-cultural training needs to be extended to Aboriginal people in order that they have the skills to understand non-Indigenous people.

Gaining a broad Australian mental health perspective in relation to carers would be helpful to Laura and Fran:

> I would like to find out how carers in other parts of Australia manage their roles. **Laura**

And:

> Training in understanding how other mental health services involve their carers would give me a better idea on what could happen in Lantana. **Fran**

In contrast to others, one carer felt sufficiently equipped to deal with her situation:

> I don't want to participate in the service and I don't want any training. Life experience has trained me to deal with my situation in the best way I can. **Thelma**

Education for MHPs

Carer participants offered ideas on what type of training would enable MHPs to meet the requirements of their vision for a better service. Two participants highlighted the need for MHPs to learn from carers. Louise considered it would promote empathy in MHPs:

> MHPs could learn from carers. It is necessary they don't become insensitive in their work. Why would they not think to offer supportive mechanisms when people receive such a horrendous diagnosis? Carers could train MHPs in the carers' reality. This may help MHPs to remain sensitive to the experience and role of the carer. **Louise**

And:

> I think carers should train MHPs on our perspective, not for them to go home at the end of the day, close the door and collect their pay-packet. **Paula**

An Indigenous carer had different and additional needs:

> I would like the MHPs to be aware of the differences that exist for Indigenous carers. For example, we [participant and daughter] have to live a long way from our community to ensure my son has family to support him when he is in Lantana. This has been a big sacrifice for us, as we miss being away from our relatives. Furthermore, there are other problems that exist within the family in Hopevale, and I am unable to assist with these due to having relocated to Lantana. **Gloria**

Gloria required MHPs to gain specific knowledge on the unique experiences of Indigenous carers.

Simone intimated that MHPs need training to translate policy into practice:

> If the mental health service staff took an approach to their work that was in keeping with the current standards that we have discussed, the service would be significantly improved. **Simone**

Not only did carers want communication skills training for themselves, they also wanted this for MHPs so that the "atmosphere" in the service as a whole, and in relation to carers can be improved:

> Firstly, they [MHPs] need to learn a few basic communication skills. This is something I really feel strongly about. I went to the hospital to this GPs meeting last week and the atmosphere down there was foul. It is all disconnected. I don't think that anyone should be allowed to be a MHP without having a psychological test. Psychiatrists should also have to have psychological testing before they can practice. They are dealing with people's lives. **Teresa**

And:

> They need training in communication skills, especially listening. They need to work on their attitude towards carers. It feels like they consider us [carers] to be the enemy. **Tom**

And:

> They need to change their attitude towards the family and communicate in a more respectful manner. If they do this they would have learned a lot. **Prue**

Fran wanted MHPs to have training in involving carers:

> Perhaps learning how to involve the carers in programmes where MHPs could do with some help. **Fran**

Laura highlighted the need for MHPs to receive training that assists them to understand that people with schizophrenia did not necessarily view the world in the same way as people without schizophrenia:

> Just remembering that they are working with people [consumers] who don't necessarily put as much weight on rules and laws as the average person does. **Laura**

Conclusion

This chapter presented the responses of carers to major focal areas of participation, social work, social justice and post graduate education for MHPs. This data reveals a broad knowledge of participation policies and possibilities. Carers did not seek participation which would either take them away from or add to the care they were already providing to their offspring. Carers, like consumers, felt participation was constrained mainly through affective engagement which did not encompass respect, warmth (comfort), empathy and inclusion.

The following chapter brings the five data sets together and explores the similarities and differences between the various stakeholders' views in relation to participation, social work, social justice and education for social workers/MHPs. These views are analysed in relation to the literature presented in chapters one to three of this thesis.

CHAPTER TEN

Data analysis: all voices at the table

This study set out to achieve the aim of developing and articulating a model of social work service delivery at one mental health service, Lantana. The study had a specific focus on processes of participation and partnership between Lantana (LIMHS) and consumers diagnosed with schizophrenia and the people who care for them. To meet this end, three questions (see pp. 5–6) were interrogated through a literature review and through participation of management, the community development worker, social workers and consumers and carers of Lantana, in critical ethnographic case study research. Responses to these questions enabled this study to:

1. elicit the policy environment of Lantana which either invites or constrains participation and partnership building between Lantana and its consumers and carers;
2. document how social work is structured into and/or out of Lantana mental health service and how social workers provide a social work service; and
3. document the extent to which people diagnosed with schizophrenia and their carers perceive mental health services in Lantana to be involving them in meeting their needs through processes of partnership and participation.

This chapter synthesises literary, theoretical and research participants' responses to these three areas of interrogation, which also demarcate the organisation of this data analysis chapter. Section one concludes that participation and partnership building between the administrative, professional and consumer and carer sectors of LIMHS is fraught with constraints which mitigate against the operationalisation of government policies at LIMHS. This chapter further concludes that the articulation of mental health services through a third way politics (Giddens, 1998) and structuration theory (1984) poses LIMHS and the wider community several dilemmas primarily revolving around a focus on personal responsibility and risk taking versus community safety; and internal inconsistencies in these theories which on the one hand use the 'blood and guts' code to argue that those who are served must pay, but renege on this when the State is served by others than those in its formal employ (such as carers).

Section One: The policy environment of Lantana which either invites or constrains participation and partnership building between this mental health service and its consumers and carers

This study found that current state and federal mental health policies demand participation and partnership building between consumers and carers of mental health services and mental health professionals. Thus current policies (*Queensland Mental Health Act , 2000; The National Standards for Mental Health Services, 1996; The first, second and third National Mental Health Plans, 1992, 1998 and 2003; The Queensland Mental Health Plan,1998; and The Ten Year Mental Health Strategy for Queensland, 1996)* overtly and actively invite participation of consumers and carers in service delivery, planning and evaluation with mental health providers, but this invitation to participate (particularly at the level of performance) can and is actively or passively resisted by both mental health service providers and consumers and carers themselves. It is both the performative aspects and the directives of participation policies which either invite or constrain partnership building between service providers and consumers and carers of this service.

Participation is defined at a policy level as the engagement of consumers and carers, by mental health authorities and services, in the planning, service delivery, evaluation and accountability of mental health services. It encompasses notions of consumers and carers having as much control over services as possible (Stone, 1998). Standard 3 (AHMAC, 1996) further explicates participation as:

- maximising the roles of consumers and carers involvement at every level of mental health services;
- supporting a range of activities which maximise this participation, including advisory committees, consumer/carer networks, consumer/carer evaluations of the MHS, establishing and maintaining contact with consumer/carer groups, public meetings, consumer/carer participation on staff recruitment processes, consumer and carer participation in consumer and staff training and the provision of space and equipment for consumers and carers to use;
- assisting with training and support for consumers and carers and staff. This could include training in peer support, consulting, staff selection, computing skills and financial management;
- reimbursing consumers and carers for expenses and their time and expertise;
- having a written statement of roles and responsibilities and code of conduct for consumers and carers, which is written and reviewed by consumers and carers;

- supporting consumers and carers to independently and individually determine who will represent their views to the mental health service;
- monitoring performance of Standard 3 and using the data collected to improve performance as part of a quality improvement process.

Partnership, as an essential process of participation was defined in this study as "associating in a common endeavour, moving forward together, through the process of learning about each others' skills, knowledge, strengths and abilities in mutual growth" (Meagher, 1995, p.20). Participation therefore encompasses what consumers and carers and mental health service providers need to negotiate in order to conform to Standard 3, while partnership refers to relationship qualities embracing respect, mutuality, trust, reciprocity, and openness (Glendinning, Powell & Rummery, 2002; Jordan, 2002). In common social work parlance, participation typically involves task processes, while partnership is about maintenance or relationship functions. The following discussion of participation therefore encompasses both these task and maintenance (relationship) notions.

Table 10.1 below provides a summary of data provided by management, the community development worker, social workers and consumers and carers in relation to participation of consumers and carers at LIMHS.

Table 10.1: Policy and participation data summary

Respondents	Roles of Participation envisaged through Standard 3	Current roles of consumers and carers at LIMHS	Constraints of participation	Responsibility for participation
Manager	Across the board Planning and management Representation on the executive or board Development of new programmes	Can complain Attend rehab programmes Invited to most meetings Reinforce LIMHS practices	Funding	Individual MHPs
Service Development Coordinator	Planning new services	Can complain Reinforce practices already engaged – workshops at day-centre programme; mental health week activities.	Training and support needed for consumers and carers to participate	Whole-of-health/ welfare sector (not me in the long term)
Clinical Director	No response	Can make complaints	Diagnosis: consumers wellness and stability	No response
Community Development Worker	Interview panels Policy development Service evaluation Quality assurance Advocacy and education	Low key unprofessional roles	Participation is tokenistic; Essential partnership qualities are lacking at LIMHS; Suspicion of consumers and carers; Consumers and carers are poorly and insensitively treated; Consumers and carers are not skilled up to enable them to take up participatory roles.	Everyone
Social Workers	Service delivery planning, implementation and evaluation; Representation on the executive/board; In the treatment plan Advise staff of their needs Paid positions; Engage in consultation forums Engage in strategic planning; Engage in mental health promotion Engage in quality assurance	Implementing treatment plan designed by case manager; Have a say in what they do with their day; Watchdog role; Provide feedback; Monthly meetings for carers and consumers to raise issues; Involved in the treatment plan; Engaged in mental health education.	Lip service is paid; Consumers and carers have no roles; Consumers and carers take on unpaid lowly roles; Consumers and carers are used for the purposes of LIMHS rather than mutual goals; Consumers and carers have to agree with what MHPs provide; High caseloads.	Service development coordinator; Community Development Worker; CAG; Consumers; Not me.
Consumers	Input into every area of treatment; Policy planning and development; Running the day-centre programme; Creating more of our own activities; Teaching other	Involvement at the day-centre programme; Involved in treatment plans.	Consumers not consulted about their treatment; Consumers are absolved of responsibility – objects of psychiatry; Consumers are	Everyone

Respondents	Roles of Participation envisaged through Standard 3	Current roles of consumers and carers at LIMHS	Constraints of participation	Responsibility for participation
	consumers – hygiene; Being advocates for other consumers; Being negotiators and mediators between other consumers and services; Being part of decision making structures; Providing therapeutic alternatives to consumers; Engage in the administration of LIMHS; Engage community consultations about mental health.		powerless.	
Carers	Direct work with consumer they care for; Being on carer's group to address the deficits of LIMHS; Being on a committee that decides how MHPs work with consumers; Take over non-professional roles; Strive for genuine partnerships between the hospital, the psychiatrist, LIMHS and carers.	Carer can speak to the MHP; Carers may be invited to be part of the treatment plan; Consulted with the psychiatrist; Carer looks out for the interests of the consumer; May be present at reviews or treatment; Attend psycho-educational sessions; Supervise medication	Carers: Are shut out of interviews; Rarely have phone calls returned by the psychiatrist; Are not informed of the treatment or about the consumer; Are not consulted by LIMHS; Have no communication with LIMHS; Do not have input into treatment plans but are expected to implement them; Lack debriefing after critical incidents; Have their agenda co-opted by LIMHS; Indigenous persons do not have access to Indigenous MHPs.	Everyone

Discussion and Analysis: Participation and Partnership

Generally, this study supports that of Seymour (2004) which found little evidence of participation and partnership policies as outlined in *Queensland Mental Health Act, 2000; The National Standards for Mental Health Services, 1996; The first, second and third National Mental Health Plans, 1992, 1998 and 2003; The Queensland Mental Health Plan, 1998; and The Ten Year Mental Health Strategy for Queensland, 1996,* being engaged at LIMHS. This lack of compliance with mental health

participation reforms nationally was also noted by Mugford and Walters (1998) and disinterest in furthering these processes noted in numerous studies and inquiries (Burdekin Inquiry, 1993; Carter, 1991; Chelmsford Inquiry, 1988 – 1990; Deakin Human Services Australia, 1999; Inquiry into Ward 10b; McGrath, 2000). While the findings of this study are therefore not unusual in this regard, the following analysis of participation and partnership at LIMHS is largely a critical analysis of the constraints to participation, reflective of both the critical methodology of this study and also research participant discourse.

Data related to participation and partnership, demonstrate that all research participants except the clinical director had a wider view of participation and partnership than is currently engaged at LIMHS. The clinical director (psychiatrist) appeared unaware of Standard 3 and at best perceived participation as the invitation extended to consumers and carers to make complaints. Of all case study participants, it was consumers who most clearly articulated the roles they thought were envisaged of them through standard 3 and which they felt they could meet. The manager, the service development coordinator, the community development worker and social workers variously and mainly stated things like, participation means that consumers and carers should participate "across the board; in planning and management of services; having representation on the board or executive; in the development of new programmes; in policy development; in service development, planning, implementation and evaluation; in quality assurance; in advocacy and education; in engagement in consultative forums; in strategic planning; in mental health promotion".

While some consumers did talk in this broad way about their participation, they were generally more clear in articulating actual roles they could be involved in: "input into every area of treatment; running the day-centre programme; creating more of our own activities; teaching other consumers things like hygiene; being advocates for other consumers; being negotiators and mediators between other consumers and organisations; being part of decision making structures; providing therapeutic alternatives to other consumers; engage in the administration of LIMHS; engage community consultations about mental health". This discrepancy in the way service providers speak and the way consumers speak is important for participation. The descriptive language of consumers is much clearer in obviating what would be engaged – teaching; decision making; negotiation and brokerage; treatment input; running the day-centre programme; administration of LIMHS (etc.); and who would

be the focus of participation activities – other consumers; the wider community and who would engage particular activities.

The language of consumers, therefore, is more likely to lead to success in the participation enterprise, than the language of professionals, under Hudson and Hardy's (2002) framework of principles for partnership success since it is this language which indicates more "clarity and realism of purpose" (principle 2) than the esoteric language of "policy development" or "service delivery" (etcetera). This distinction between the language of service providers and service users also holds true to some degree with the language of carers, who, whilst focusing more clearly on their direct engagement with service consumers, said things like, "being on a carer's group to address the deficits of LIMHS; being on a committee that decides how MHPs work with consumers".

Despite all participants (except the clinical director) understanding Standard 3 to embrace wide forms of participation, all provided evidence to show the narrow roles currently undertaken by consumers and carers at LIMHS (attending rehabilitation; participating in the day-centre programme; participating in mental health week; making complaints; implementing the treatment plan). These narrow roles are largely passive or reactive, rather than roles which demonstrate a sharing of power and status. Thus they focus on the rights of any service user (to complain), and on services which could be expected of any mental health service provider (rehab and the day-centre programme), rather than demonstrating innovative shared practices between service providers and service users of LIMHS. In this way the roles engaged by participants appear driven by the agenda of the organisation rather than reflecting items which might more strongly indicate them as arising from consumer and carer perspectives. In this sense, they are minimal and tokenistic (Arnstein, 1969). One exception to this is the human rights observer role undertaken by a male carer (Tom) of his wife when she goes for treatment. While this role has been driven by the consumer himself, it speaks far louder in relation to the carer's lack of trust in LIMHS to ensure that these rights are upheld, than it does of participation. That carers are involved in providing clinical services (supervising the medication of a LIMHS consumer) is perhaps the epitome of an activity which subsumes the work of a carer into the work of the organisation since this places the carer in the role of overseer in practices of compliance, especially at times when a consumer may be rejecting of medication. In these cases, the carer is placed in a dilemma, by LIMHS over who they serve – the consumer or LIMHS. Placing carers in this ethical

dilemma does not seem participatory but controlling. This activity also displaces "risk" to the carer (Kemshall, 2002) and may place consumers and carers in a more difficult position to claim compensation in the case of mistreatment. This potentially adds to the financial burden of caring (see below).

Not only were service providers unclear about what specific roles were required of them under Standard 3, no professionals except the community development worker, saw that participatory policies can only work if they are engaged across all operational service levels and across all service programmes, consistently over time. Participation seemed to serve as a 'hot potato' with no-one taking responsibility for its engagement and monitoring. Thus the manger assumed individual MHPs were engaging participation with the consumers they serve; the service development coordinator saw it as a whole-of-sector responsibility (case management) from which he "hoped to withdraw"; social workers variously saw it as the responsibility of the service development coordinator; the community development worker; CAG; consumers themselves, but definitely "not me". This was in stark contrast to consumers, carers and the community development worker who saw participation as the responsibility of everyone. Clearly this aspect mitigates against successful partnership, since it contravenes Hudson and Hardy's (2002) third principle of ensuring "commitment and ownership", where "an organisational commitment to partnership working is more likely to be sustained when there is individual commitment to the venture from the most senior levels of the respective organisations. Without this, it is possible that the efforts of partnership enthusiasts holding middle and lower level positions will become marginalised and perceived as unrelated to the 'real' core business of each partner" (p.56). Clearly this bodes ill for participation at LIMHS since the clinical director, who is the psychiatrist, but knew nothing of Standard 3, was seen to wield enormous influence in the day to day work of consumer-LIMHS interaction (chapters 5–9). The manager and the service development coordinator also showed minimal attachment to either participation in its broad sense as articulated through policy, or as an organisation wide activity.

Neither did social workers see themselves responsible for engaging processes of partnership and participation. Perhaps this was explained in some part by social worker Lucy who said that social workers themselves did not participate at any level of the organisation or engage in any decision making. Thus they are not represented as a discipline in the management structure of the organisation and are simultaneously offered the sanction of the psychiatrist when they medicalise their

practices (overseeing medication and advising the psychiatrist when medication needs to be increased) and receiving his opprobrium when they do not.

The manager and the service development coordinator cited funding as another constraint to the implementation of participation policies, yet, only one item in Standard 3 refers directly to the provisioning of money in the participation enterprise. This is the fourth item where it is explicitly stated that consumers and carers are to be remunerated for their time and expertise. All other items, except the $10,000 set up fund for CAG, could be seen as demanding support in kind from LIMHS directly (such as training) and from consumers and carers themselves (such as training). The manager did not articulate which aspects of participation need funding and which he saw as additional to the 'normal' LIMHS budget (and therefore not essential, not 'core' business), neither did he indicate that he has produced a costing for the implementation of this Standard. The manager's discourse implies that participation is only a cost to the organisation without recognising that participation is likely to be more costly to consumers and carers than to mental health organisations. Numerous carers in this study undertook activities like taking the consumer to and from appointments at Lantana, supervising medication, attending psycho-educational sessions. Each of these activities involves them in either spending money (for example, on petrol) or being available to the consumer at times when they could be earning income elsewhere. This discourse neglects the fact that the 'community', more usually single families, have borne the brunt of cost shifting from the asylum to the 'community'. McGrath's (2000) study found that carers were contributing approximately 104 hours per week for a family member, and Pezzullo (2002) found that carers are bearing a third of the financial cost associated with schizophrenia. Without these carers it is evident that consumers would not be able to live in the community over time, and certainly without this carer contribution, the gloss of deinstitutionalised care as a humanitarian response to schizophrenia would be severely tarnished (Baines, et al, 1993; Goodwin, 1990; Scull, 1984).

Arguments that funding constraints stifle the implementation of participation policies are also spurious in their implication that the cost of consumer and carer participation outweighs the benefits. Research has shown that participation helps consumers recover their sense of self esteem and responsibility, helps the carers they serve, and benefits mental health organisations (Moxley and Mowbray, 1997; Sherman and Porter, 1991). When they are paid for their work, this also aids recovery and reduces isolation (Lloyd & King, 2003; Warner & Mandiberg, 2003). If the raison d'etre of mental health service provision is to help consumers recover their mental health,

then the participation enterprise is intimately bound up in this mission and should be seen as 'normal business'. While third way politics talks about the moral responsibility of service users to 'pay their way' (Giddens, 1998; as part of the 'blood-and-guts' code discussed by Jordan, 2002) it is much more silent about this code being applied in a reciprocal fashion. Instead the system (in this case mental health services, and the public in general who are shielded from people who are mentally ill when they are tended to by private carers), when confronted with Standard 3 and its directive that consumers and carers be paid for the services they render, cries poor and refuses to pay this bill (by invoking the 'moral' duty of families to support their members). Reciprocity as a pivotal ingredient to partnership building is sorely tested when professionals are paid for their engagement with consumers and carers, sometimes in the same enterprise (such as attending meetings, inputting psycho-educational sessions, running a carers' meeting) but consumers and carers are not similarly recompensed even though their insights and knowledge can prove invaluable and cannot be gained without their participation, as recognised by social worker participant Joyce (see also McGill & Patterson, 1990; Segal et al., 1993).

Funding was cited as a constraint to the implementation of participation policies, without explanation, as if this is an incontestable notion. This discursive practice (Giddens, 1984), contributes to the hegemony of neo-liberalism and signals the need for social workers to integrate study of economics with that of social work (Jordan, 2002; Wilderquist, 2002). A number of writers argue that consumers and carers must be engaged through their own budget line of management and accountability (Forbes & Sashidharan, 1997; Kopolow, 1981; Solomon, 1992), yet this is difficult as the State has hitherto funded both mental health services and CAGs, with the same line management. Conflicts of interest are most often resolved in favour of the professionally driven priorities.

There seemed an implicit view by professionals of LIMHS that participation helps consumers and carers but provides no direct benefit to themselves and that therefore, if consumers want participation then they should be responsible for implementing these policies. As well as negating the work that carers and consumers themselves undertake in processes of recovery and sufficiency, this discourse is one which demonstrates lack of understanding about the mutuality needed if participation policies are to be implemented. Contrary to the views of professionals, consumers and carers suggested several roles they either do undertake or could undertake and which would provide a direct benefit to the

administration, the clinical provision of services, other consumers and carers and the community at large. These roles included:

- being a partner in the design and implementation of the treatment plan, sharing information about the difficulties and possibilities for treatment as partners with the MHPs (including psychiatrist);

- being active at the day-centre programme – teaching, hygiene, sewing (Sally);

- running a carer's group to deal with issues of loss and grief; providing a human rights observer role and advocating for the rights of consumers (Mary and Tom);

- brokering services between organisations for other consumers and carers (Lara);

- opening possibilities for mental health consumers to engage in society outside of the welfare/health system (Roger);

- engaging in the administration of LIMHS by typing minutes (Isobel);

- providing a consumers perspective at decision-making meetings; engaging community consultations about mental health (Ray);

- being on groups that guide MHPs in their work with consumers; take over non-professional roles; and driving the bus for the day-centre programme (Tom).

The energy exhibited by consumers and carers in their responses to roles they could undertake in participation practices, is the positive energy third way politics tries to embrace. That the engagement of consumers and carers in these activities would help LIMHS, since there are real material and physical services being offered, appears to be either ignored or rejected by professional respondents in this study. Until this principle of mutuality is grasped, participation policies have little chance of success (Hudson and Hardy, 2002).

The potential roles for consumers and carers as elucidated by them, clearly articulates a different and more active agenda for consumers and carers, than that of management who had a much narrower focus of participation as reactive, engaging complaints procedures. While this latter was invoked as evidence of participation, a 2002 review of LIMHS noted the lack of consumer and carer complaints indicating that this form of participation was not engaged. This demonstrates management's ease with third way politics which ensures opportunity (for complaints and other things) without being simultaneously concerned about the outcomes (including uptake) of these opportunities (Jordan, 2002).

At another level, however, LIMHS does recognise the potential for consumer and carer energy to be harnessed for positive outcomes for the organisation, since carer Louise and social worker Wendy reported that a group set up by carers as a mutual

support group, was co-opted to lobby the government for increased psycho-geriatric hospital beds. This example is important to this study, since it demonstrates lack of recognition that all parties have needs and goals – service providers, service consumers, and carers which may be met through working together. As the example above shows, however, there is an assumption at LIMHS that the carer group belongs to them, outside of the carers (even though it had been set up by carers themselves), and that LIMHS can therefore decide the work it will undertake, without a discussion about what the carers group wants for themselves, and how the resources of LIMHS could be harnessed to help them meet their needs. Another example of this was that of a carers' group at LIMHS, which had formed for the express purpose of mutual support, but disbanded when management made attempts to co-opt this work to that of running a half-way house for consumers of mental health services. Clearly this was an enormous expectation of a group which already bears most of the labour of care in supporting mental health consumers (Twigg & Atkin, 1994).

This study indicates that the defensiveness of professionals to implementing participation policies is unwarranted. Consumers and carers are not asking for much. Carers especially did not indicate that they want to participate in ways which would expect more of them than they already offer the person for whom they care. Consumers like Roger, Mia, May and Paul indicated that they want less participation with LIMHS since their participation in the mental health sector does not lead to greater inclusion in society but further exclusion, due to stigma and myth surrounding mental illness. That consumers and carers do not want increased participation therefore contradicts government rhetoric that these policies have been driven by consumers and carers themselves (*First National Mental Health Report, 1993*; *National Standards for Mental Health Services*, 1996; Whiteford, 1999; Woolridge, 1999).

Consumers and carers in this study went from articulating broad views of participation in line with the criteria of Standard 3 (see above) to a desire for less participation in their lived experiences with LIMHS but participation with a more honed focus on their issues in living with schizophrenia. Thus consumers wanted to: be involved in the day-centre programme (including outings); be involved in their treatment plans (one quarter or research participants had been involved in their treatment plans); and have their treatment explained to them. Carers thought that participation should include them attending all consultations; having their opinions respected; that the MHPs help them feel comfortable and confident when offering

contributions; that they should be informed about all decisions made in regard to the cared for; and that they should be educated on medication and its side effects. Carers wanted to know about relapse and they want to be informed when the cared for is taken to hospital or is engaged with the law. They wanted MHPs to understand their day to day experiences and understand their concerns about finances and their ongoing grief. Carers particularly wanted a support group around grief. Consumers and carers were hardly putting forward a radical agenda; rather they were requesting things which could be perceived as normal professional practices. Furthermore, carers like Fran and Marion wanted to help in ways which would free MHPs from their current busyness, by taking on non-professional roles.

This study therefore contradicts the view of Forbes and Sashidharan (1997) that the strength of the consumer movement lies in its opposition to present services and underlying dogma, and that consumers and carers should see themselves as political tools for changing systems. Consumers and carers largely wanted to participate more equally in the services already provided. Ironically, LIMHS is prepared to use consumers and carers as political tools to get the things it needs to do its job, such as using the carer group to lobby for more psycho-geriatric hospital beds, or putting a public face to the service through participation in the Reef Festival. These could be seen as mundane tasks to consumers and carers if their needs in the ways outlined above are not also realised. Dunst and Trivette (1996) reminded us that the engagement of service consumers in mundane tasks does not lead to empowerment but the opposite.

These analyses indicate that LIMHS fails Hudson and Hardy's (2002) first principle of successful partnership and participation enterprises, that of acknowledging the need for a partnership which encompasses an acknowledgement of a shared history; recognition of the need to work together; appreciating interdependencies; appreciating specific domains of each partner in the shared enterprise.

Professional research participants focused on consumers themselves as constraining participation. They focused on consumers' diagnoses, wellness, stability (the clinical director, social workers Camilla and Thomas); the lack of consumer knowledge and skills about how to engage relationships of partnership and participation (the service development coordinator, social workers and the community development worker); that consumers don't want participation; that consumers fear change and participation should be introduced slowly (social workers Maria and Camilla). This gaze at the 'problematic other' obfuscates the constraints professionals themselves

bring to this enterprise. This study shows that management and social worker research participants did not understand participation as elucidated in government policy documents and practice standards, yet they projected this lack of knowledge about participation onto consumers and carers. Similarly, as discussed below and as presented in chapters 5 – 9, some MHPs (particularly the psychiatrist) do not operationalise qualities needed in the building of partnerships with consumers and carers, including those of respect, reciprocity, trust, cooperation and mutuality (Jordan, 2002).

While the psychiatrist posited the 'stability' of consumers as a principle constraint of participation, some consumers and carers noted the irritability of the psychiatrist and the apparently arbitrary treatment decisions made by him (consumer John). Consumers were cynical of the view that diagnosis or wellness would hinder their engagement in participation. They argued that they are more often well than unwell and that strategies of tasking multiple consumers in the same role would ensure that at least one consumer is able to undertake a particular role of participation on any given day. Another felt that engagement should be developmental, according to the stage/wellness of the consumer in relation to their diagnosis, and that the right (affective) environment should be provided in order for participation to be actualised at LIMHS. This latter response highlights the importance of partnership building.

Clearly these mutually negative views (of instability and even psychopathy) of each other indicate the need for joint education and training in processes and possibilities for partnering and engaging participation. While consumers and carers recognised the need for training in working with MHPs (especially the psychiatrist), and the need for training in government policies and as recognised in government policies (McGrath, 1996), MHPs did not recognise that they need similar training, let alone training by and with, consumers and carers as recommended through the work of Deakin Human Services (1999). Perhaps in an environment which increasingly prioritises risk assessment and management over need and service delivery (Jordan, 2002; Kemshall, 2002), professionals are unlikely to declare their need of training in government policy (especially policies that have been around for over a decade) in case this infers that they accept some blame for not engaging them. In this case consumers and carers become scapegoats for the inertia of government departments and carry not only more of the cost for participation than mental health service providers, but also more blame when policy implementation is engaged in less than expected ways.

While Clarke (1994) agreed with mental health service providers about consumers needing training in order to engage policy directives, he noted the irony of this focus given that mental health service providers (especially psychiatrists) expect consumers to understand complex psychiatric terminology and treatment regimes. The lack of consumer education therefore is recognised inconsistently and in ways which do not challenge current discourses and practices of service providers. Bastian (1994) and Berger et al. (1997) argued that MHPs (including psychiatrists) need to address educational limitations of consumers through inclusive processes of bridging the gap in what they know and what consumers and carers know. Rather than mystifying psychiatric knowledge, it should be demystified as part of professional practice. Clearly these authors shifted the emphasis on education back to professionals rather than leaving it at the feet of consumers and carers.

A constraint of participation cited by social workers Tilly, Lucy and Wendy is that participation is additional to the already large case load carried by MHPs, it is not in their job description and therefore workers are not obliged to engage these policies. This argument has similar aspects to that of the manager forwarding the case that participation is 'additional' to the funding of LIMHS rather than 'core' business. This discourse reveals a lack of understanding of policy directives in relation to participation and the responsibility of all employees to engage with consumers and carers of mental health services in particular ways. It also potentially supports Jordan's (2002) contention that under third way policies, like those of participation and partnership, social workers are increasingly working to a technical reading of their job descriptions rather than in professional social work ways which would accept the processes and values of partnership building with consumers and carers. These include respect, non-judgementalism; empathy; informed choice; active engagement in assessment and decision making; an holistic, person-in-environment (including social, political, material and spiritual aspects) focus, which demands an engagement in the 'messy' business of social work (AASW, 1999; Jordan, 2002). At one level, this data indicates that under third way politics of social provision, participation policies in organisations must be stated in ways which unambiguously name all employees and service consumers and carers, as having responsibility for participation policies. Yet this is a complex finding, since this command position could also be seen as more strongly binding workers to the underlying philosophy of participation which is that service users must be held responsible for their own troubles which have arisen as a result of their negative choices, and must pay and be seen to pay by wider society, for services provided through the public purse (Giddens, 1998). Rather, social workers who are MHPs need to seize the tensions

within third way politics and within participation policies (these are specifically outlined as they pertain to mental health consumers and carers, at the end of this chapter) as a means for using them to serve their clients in ways which are emancipatory and lead to their real empowerment. This finding is also complex, since many social workers in this study were seen by consumers and carers as engaging more participatory practices than many other mental health service providers at LIMHS (see following section of this chapter).

Carers focused participation more narrowly than Standard 3, to their engagement with the consumer. They therefore thought that participation was engaged when they: spoke with the case manager about medication, education, maintenance of the treatment regime and consumer recovery; were invited to be part of the treatment plan; when they consulted with the psychiatrist; when they look out for the interests and human rights of the consumer; when they are present at reviews and medical treatment; when they attend psycho-educational sessions where they learn to cope and they also learn about medications; when they do practical things like drive the consumer to and from their appointments with LIMHS; and when they supervise medication. Despite all of these tasks engaged by carers, management was unable to cite instances of carer participation, the community development worker insisted that nothing was happening and social workers resisted the concept of participation. Either the participation engaged by carers is literally ignored by professionals, or they cannot see the participation that is engaged, because of their narrow reading of what it actually comprises.

Not only was the participation of carers dismissed in this way, carers provided data about LIMHS obstructing them in these roles (of participation), by shutting them out of interviews; rarely having phone calls returned by a psychiatrist; not being provided information about the consumer and their treatment; not being consulted or having any communication with LIMHS; treatment plans being developed outside of consultation with the carers with whom the implementation of these plans often lies; lack of adequate Indigenous MHPs; lack of debriefing of carers after critical incidents including lack of support following a critical incident; and being co-opted into the agenda of LIMHS, rather than LIMHS considering carer objectives in service provision. Essential partnership qualities were thus found to be lacking at LIMHS. Carers Teresa and Paula were both concerned that were excluded from decision making due to MHPs indiscriminate use by MHPs of 'confidentiality'. Lloyd & Kind (2003) and Schodel (1994) believed that this is used in mental health settings to legitimise exclusion rather than to uphold an ethic of overall care of which

confidentiality is one principle. Seymour (2004) found similarly that LIMHS staff invoked confidentiality indiscriminately rather than from a position of a carefully considered and applied ethics in terms of the consumers' right to privacy and a carer's duty of care to the consumer, implying a consumer's right to knowledge about that care. This finding is also indicative of carers not being acknowledged as part of a 'pool' of care surrounding a consumer and therefore themselves being involved in determining outcomes of professional dilemmas.

Yet confidentiality is not the only professional ethic posing dilemmas for the practice of participation and partnership with consumers and carers. So to do those of 'professional boundary marking' and 'mutuality.' Mugford and Walters (1998) found that psychiatrists were the professionals with the most distance between themselves and those they serve. This was one of the largest obstacles to the engagement of consumers and carers in participation and partnership arrangements at LIMHS, according to consumers and carers.

Similarly mutuality as a cornerstone of partnership building poses a problem in the implementation of participation and partnership policies in mental health. It implies openness and sharing of all stakeholders in the focus and address of common concern issues. Perhaps the community development worker best exemplifies this constraint at LIMHS. She talked about wanting the manager and the service development coordinator to sit and talk with CAG in an open and honest forum. She said, "there is no honesty there, just doubt, fear and mistrust" by administration and the professionals at this meeting. She further said that LIMHS consults consumers and carers "not as equals, but as lowlifes". Yet she argued, this would "require a change in culture". To exemplify this further, carers Prue and Louise intimate that basic skills and attitudes of partnership are not demonstrated in their relationship with MHPs (including the psychiatrist). Thus their opinions are not respected and they feel uncomfortable even sharing their views with MHPs.

Another concern of mutuality was shared by social worker Maria who was concerned that if consumers and carers were to be on interview panels, then they would be privy to the personal information of LIMHS personnel (as they would be if they were on interview panels). The amount of information shared in an interview situation is much less (in both volume and intimacy) than the information MHPs expect consumers and carers to share about themselves. This irony is not lost on carer Laura, who said, "Participation is something that should be shared. These policies say we can share with them, but are they going to share with us? From past experience, I think not"

This issue of mutuality also presents a contradiction to a third way politics which expects organisations to engage consumers and carers in organisational planning, implementation and evaluation of services, yet at the same time seeks to manage risk. How does a mental health organisation meet both of these expectations, since an open sharing of themselves with consumers and carers would expose their weaknesses and dilemmas and therefore place them open to much more public scrutiny that that it already experiences? For this reason mental health organisations are likely to remain closed to this quality of mutuality.

The argument by some professionals that consumers are too unwell or unstable to engage in participation was seen as a "cop out" by consumers in this study, except Paul, who agreed that he was too unwell to participate. The others all argued that they are well most of the time and able to participate. They demonstrated insight about their wellness and their ill health and suggested that multiple consumers be skilled in the same task so that they could back-fill for each other when necessary.

The consumers in this study (and some carers) felt that the biggest constraint to their engagement in participation was their powerlessness in the face of psychiatry, both as this impacted them at an individual level, and also as a result of the power of psychiatry over their interactions with other bureaucracies. Consumers Lara, John and Vera, clearly articulated their lack of accountability for any action, since psychiatrists perceive indications of recovery as due to their interventions, and failure of recovery due to the intervention needing tweaking (increased medication). Public interactions are also monitored through the Public Trustee. As Vera says, someone comes to help her do her shopping, a nurse visits every fortnight to give her an injection, she feels powerless about any aspect of her life. This constrasts sharply with the primary philosophical assumption of third way politics, which is that people are agentic beings (Giddens, 1984). Since persons are capable of making choices, they must face the consequences of their choices, rather than this being the responsibility of the state and its service agents (Giddens, 1998). This study clearly demonstrates the weakness of third way politics in relation to persons who may be acting under the influence of conditions not of their own making (such as schizophrenia). Conversely, it also demonstrates the weakness of a third way politics to ensure that psychiatry and psychiatrists, engage with mental health consumers at some level of responsibility (that is, consumers should not be absolved of any responsibility (or choice), for indefinite periods of time). Thus a primary tension within third way politics is exposed. How does a third way politics

reinvigorate mentally ill persons to enterprisingly embrace challenge and self responsibility, while at the same time ensure the implementation of the blood and guts code which is tough on people who do not conform to the normal rules of society, and which itself holds a 'dangerous' view of mentally ill persons? The State engaging a third way politics errs on the side of caution (Kemshall, 2002) sanctioning powers of enforcement – witholding welfare benefits; utilising police and the sanctions of law; and utilising its coercive measures for mental health consumers, for example, by 'regulating' consumers under the *Queensland Mental Health Act, 2000*. Since a third way politics' spiritual home is with the behaviourists, it cannot account for persons who will not or cannot comply with the blood and guts code, for reasons outside of a behavioural analysis . Far from obtaining its own goal of active inclusion of these persons or groups in society, a third way State cuts them from the social contract, incarcerating them in prisons (Jordan, 2002), leaving them at the mercy of their families, who may or may not provide for them, or leaving them the passive recipients of mental health services (Kemshall, 2002). In these ways, consumers are viewed as dependent and they are expected to show this through compliance. Seymour's (2004) critique therefore of the day-centre programme making consumers 'over-dependent on staff' is confusing, since under the psychiatry practised at LIMHS, dependency is nurtured and expected. Clearly there are mixed messages being sent to consumers and carers about self responsibility, compliance and dependence. Perhaps this is a demonstration of the lack of coherence in the 'blood and guts code' which simultanously demands compliance/dependency and self responsibility (agency and independence) for persons with a mental illness.

All research participants except the clinical director (psychiatrist) provided more than philosophical evidence of psychiatry constraining participation. Some of the examples of how it does this are through:

- its focus on the biomedical rather than the socio-emotional condition of consumers and carers (Ellis, 2003). While the clinical director (psychiatrist) in this study talked about the importance of psychotherapy, consumers and carers gave little evidence of this occurring from the basis of a "talking therapy". Rather, the major focus of psychiatric intervention appears to be that of pharmacology. When consumers are not well, their medication is increased (even upon the recommendation of a social worker). When a consumer appears overly sleepy, in the case of Sally, a carer can recommend a review of the drug treatment and there is evidence that this will be attended to. When a consumer takes the medicine and then after a while feels better and thinks that they are 'cured', then they are placed on involuntary fortnightly injection treatments or oral anti-

psychotic medication which MHPs (even those not training in medical practice) can administer. Drug treatments have a number of physical and psychological (unintended) side effects. This is particularly pronounced in the case of illegal drug use. When consumers combine amphetamines and marijuana within anti-psychotic medication, this can lead to a psychotic episode. Engaging a prescribed course of medication without being provided an explanation of how it works and its potential side effects including its mix with non-prescription drugs, places mentally ill persons at higher risk for their illegal drug taking behaviour than for other persons.

- privileging of psychiatric definitions and 'solutions' to schizophrenia over other definitions and other possible interventions including those proffered through the lived experience of consumers and carers themselves. Psychiatry does this through a process of 'labelling', which presents mentally ill persons as being in a fixed, static, homogenous state. Once labelled, consumers are treated as if they are their diagnosis, thus the clinical director referred to 'someone who is a paranoid schizophrenic". They are therefore seen as being unreliable and lacking in credibility (Taylor, 1995). The person's life becomes comprehensible to the State only in terms of their label rather than through their lived experience including their real material life. John's story highlights this: "A psychiatrist asked how my house was going. I hadn't done anything to the house, so she said I was unwell. The facts were that I didn't have any money to do anything to the house, but that didn't come into it. So just because I hadn't done anything to the house, I had to have my medication increased". Regardless of what John's real material opportunities are, he is judged through the myopic lens of the psychiatric diagnosis which has been applied to him and over which he loses any right to articulate a contrary definition of self. Such is the strength of psychiatric discourse and the blood and guts code of society, that the psychiatric diagnosis (and therefore intervention) is elevated to truth status despite many interwoven factors impacting a person's 'messy' life, and an increased recognition of the subjectivity of psychiatry (by the manager in this study, and by psychiatrists themselves, see for example Hunter, 2006).

- its co-option of other MHPs to psychiatric knowledge and practices including a shift towards "medicalising" their own interventions, rather than staying true to their own complementary or distinctive practices (Coglan and Cheers, 2002). Thus social workers received the approval of the psychiatrist when they implement his intervention plans, oversee the medical requirements of consumers (Joyce) and inform him when consumers needed their medication

increased. They also receive his public opprobrium (Thomas) when they did not conform to these medical mores. Discursive engagement across professions in team meetings and between the psychiatric unit at Lantana Hospital and LIMHS occurs through medical discourse and rules. Thus social worker Tilly is told to refer to other organisations for other than medical needs of clients as if these 'other needs' are divorced from the consumers lived experience with schizophrenia; meetings are conducted through medicalised language and processes in ways which do not distinguish the input of multiple disciplines. There is no mention of consumers' social network or other social aspects (Natalie); at the psych unit, social workers (as MHPs) may not even be informed of planning for consumers even at the point of discharge – doctors and nurses make these decisions even though positive outcomes upon discharge rely on social aspects (Camilla). There are also formal processes which mitigate against multi-disciplinary input, such little space on the referral form for a social assessment (Tilly).

- its inability to account for class and race distinctions between the consumers and carers and MHPs which produce barriers to working together in relationships of partnership and participation, and its inability to account for class and race variables between consumers and carers in both mental health assessments and interventions. John's story above will suffice to exemplify class distinctions between consumers and psychiatrists who cannot account for poverty as minimising opportunities to participate in demands of bureaucracies. Gloria's story as an Indigenous carer exemplifies the difficulty in ensuring participation across 'race'. Swan and Raphael (1995) argued the need for Indigenous mental health workers to act as a conduit between non-Indigenous MHPs including psychiatrists and Indigenous peoples. An Indigenous view of mental health involves spiritual, social, emotional, cultural and physical well being and issues related to land and unique way of life. Their views of mental illness are inextricably linked to their experience of colonisation, history, racism and social factors. Removal of Indigenous consumers to the mental health unit or watch house has particular significance for Indigenous families. Many of these families are affected by the legacy of the stolen generations, violence, past policies, and the deaths of Indigenous people in custody. Many Indigenous people remain disturbed about these relatively recent past events and do not trust non-Indigenous people to deal with their family members in an impartial manner. For these reasons, the national *Aboriginal Health Strategy Working Party* (1989), the *Second* and *Third National Mental Health Plans* (1998; 2003), and Burdekin (1993), recommended the employment of Aboriginal mental health workers.

Where these workers are available, their work is considered invaluable by carers and consumers, yet Indigenous social workers in chapter 7 reported resistance from some MHPs to the delivery of unique services to Indigenous people. Annie's experience of attending a psycho-educational session was more confusing than enlightening, since it did not fit with her Aboriginal, holistic understanding of the aetiology of schizophrenia (Sailor, 1989), nor would this training account for the wide family engagement of Gloria's son with his Indigenous community which simultaneously denied Gloria this support since she had to remain in Lantana to ensure that her son received the treatment he needs, when he needs it, since this service is not available in their Aboriginal community;

- the potential and documented cases of human rights abuses under psychiatry. Despite Royal Commissions into this, the manager believed that strong forces and powerful players operate in the field of mental health. He considered it problematic that this system places so much trust in psychiatrists. Similarly, carers and social workers shared stories of at very least, disrespectful treatment of them by the psychiatrist at LIMHS, and which left them feeling powerless and vulnerable. The rules of co-presence, including the lack of shaming as articulated through Giddens (1984) structuration theory clearly did not apply to the psychiatrist either in his relationships with consumer and carers or in his relationships with social workers. These practices implicate psychiatry in the business of power and control rather than care and healing (Foucault, 1977). This is discussed more fully below.

In addition to the power of psychiatry as a factor constraining participation, so too is the power of bureaucracy which has its own momentum and needs which may not correlate in time or meaning to the needs of consumers and carers. Thus mental health services have difficulty in accommodating dual diagnoses of schizophrenia and alcoholism; schizophrenia and depression (etcetera) let alone accommodating schizophrenia with life traumas and trials like domestic violence, sexual assault and rape; housing issues and poverty. Mental health consumers can therefore fall between services, with sexual assault services, alcohol rehabilitation services (etc.) expecting mental health services to work across these portfolios, while mental health services position themselves as working with discrete psychiatric conditions and expect to refer to community organisations for these other problems of living.

The combination of both of these forms of power (psychiatry and bureaucracy) in relation to consumers and carers creates a 'David and Goliath' situation. This is recalled vividly in the story of consumer Lara who does not have access to the basic

human right of interfacing with her children. Lara clearly believed that the psychiatrist had overturned her negotiations with the Department of Child Safety to see her children. She felt powerless in her ability to influence this outcome and lives with the angst of being separated from them. The power of psychiatry and the law predominates in the lives of mental health consumers. For example, when consumers with the law, MHPs facilitate a report from the psychiatrist to the magistrate or if it is a serious offence then they are placed under an involuntary forensic order. If MHPs are aware of the hearing date then they present to court and explain the mental health status of the consumer to the magistrate. Typically the matter will be remanded until a psychiatric report is obtained. Thus the law (and therefore society) esteems psychiatric determinations over competing discourses of schizophrenia and other possibilities of intervention. Yet this power could also be used to advocate, in a spirit of partnership with consumers and carers, in the interests of the client. This is also provided for under the *Queensland Mental Health Act, 2000* but does not get rid of the dilemma of the interests of the consumer over the interests of wider society, which in a risk focused society are more likely to be skewed in favour of the wider society.

While Lara's story (above) evidences the relative powerlessness of consumers when bureaucracies actively use their power to stifle consumer desires/rights, a weak bond (of inaction) between bureaucracies can also stifle the opportunities of consumers to become responsible citizens, as demonstrated through the expectations the State holds of parents. Thus, Lara was not entitled to income security or maternity benefit as a mother, yet the rationale provided to her for not having access visits with her baby was that she had not supplied the material goods the State deemed necessary for the active engagement of parents with children. Legislation itself is therefore contradictory. While the *Mental Health Statement of Rights and Responsibilities* (AHMAC, 1991), recognises the rights of mental health consumers to access relatives and friends, income security legislation withholds the resources that would make this possible in compliance with expectations of bureaucracies like the Department of Child Safety. The consequences of the failure of bureaucracies to navigate these catch-22 situations, is borne by consumers.

Bureaucracies themselves may not be internally coordinated across programmes (Seymour, 2004) as evidenced by Paula who was not told about LIMHS upon her son's discharge from Lantana Hospital, despite both of these institutions coming under 'Queensland Health'. Without this coordination, consumers and carers are not in a position to participate in engaging services except as they are able to locate

them themselves. This finding indicates that while a third way State talks up its own responsibility for providing information in order for consumers to respond appropriately, consumers can be left ignorant of the range of 'responsible' choices they can make at times of dealing with psychotic episodes.

A further constraint to the enactment of participation policies is the longevity of employment of dominant service providers (Gilbert, 2003). The manager, service development coordinator and the clinical director had each served between 25 and 30 years in mental health services. Structuration theory would suggest that they are entrenched in particular modes of social conduct which they discursively produce and reproduce to assure their ontological safety (Giddens, 1984). Disruption of these discursive forms (and therefore structural forms) requires 'reflexive monitoring' (Giddens, 1984); the ability of persons to monitor their own actions in relation to a given study of work based expectations and practices. Clearly management (and other professional research respondents in this study) did not monitor themselves in this way. Rather, they focused on the consumers and carers as if they were the problem. This lack of performative engagement in participation with a focus on the self, suggests that the transformative capacity of LIMHS to change in ways which support participation is limited, especially in the light of mental health consumers having little choice to invoke the "I can" also necessary for this structural transformation (Giddens, 1984).

This section of data analysis has elucidated the policy environment of Lantana as constraining of participation and partnership with the consumers and carers it purports to serve. Constraints to participation and partnership were found to be those of:

- limited understanding of participation and partnership policies across the administrative and professional sectors of LIMHS;
- the lack of clear articulation of the participation and partnership goals of LIMHS;
- no personal responsibility accepted for participation and partnership policies across the administrative and professional sectors of LIMHS;
- funding constraint discourses which position participation and partnership possibilities as being additional to the normal budget of LIMHS, not part of 'core business' and a drain on its resources. These discourses ignore the contribution of carers to the mental health enterprise and present "funding constraints" as self-evident and incontestable;

- a narrow view of participation which constrains administration and professionals to either see their own engagement with these policies or that of consumers and carers;
- co-option of carers goals and needs to the agenda and established programmes and processes of LIMHS;
- a focus on consumers as themselves constraining participation outside of a simultaneous focus on the self as a site of constraint;
- demonstrably low partnership behaviours which do not include mutuality, sharing, openness or concerns for co-presence;
- the power of psychiatry at LIMHS;
- consumer and carer powerlessness in the face of psychiatry;
- consumer and carer powerlessness in the face of the combined influence of bureaucracy and psychiatry;
- lack of internal coordination at LIMHS;
- longevity of the employment of mental health management at LIMHS.

This section of data analysis also highlighted several dilemmas for a State applying both a third way politics (Giddens, 1998), and structuration theory (Giddens, 1984) to mental health service delivery. These dilemmas are posed as questions:

- How does a third way politics resolve the conflict between an expectation that all citizens will comply with the blood and guts code of morality when some of these citizens may be driven by forces (like schizophrenia, or drug treatments) which abdicate their responsibility or ability to comply with this code?
- How does a third way politics, imbued as it is with notions of personal responsibility, including risk taking, ensure that agents of the State extend this expectation to those with mental illness, or those experiencing a psychiatric episode? Put more specifically with regard to this study: How is the discourse of agency, under a third way politics, mediated within a powerful institution like mental health, which operates from a discourse of compliance?
- How does the behavioural basis of a third way politics resolve the diverse abilities of persons to respond to either the withdrawal or application of stimulus (withdrawal of benefits and/or service or the provision of opportunity) in ways which lead to conformity with the 'blood and guts code' (to either be in work, education or training)?
- How does a third way politics resolve the tension between partnership qualities of openness and mutuality between 'officers of the State' and those they serve, when the engagement of these qualities could lead to public exposure of 'weakness' or 'less than best practice' within State bureaucracies?

- How does a third way politics with its rhetoric of voluntarism and personal risk deal with legislation within the State which compels those with mental illness to behave in particular ways and to comply with intrusive measures?
- How does a third way politics ensure its internal moral consistency of a 'paying your own way' discourse when persons (carers) not directly employed by the State, are seen to provide services without which the State could not engage its mission of either care or containment, but which the State is reluctant to pay?

Similarly, this study elicits some internal inconsistencies within structuration theory (Giddens, 1984) when applied to mentally ill persons. Structuration theory is premised around the notion of structure as a performative consolidation of the habitual actions of self conscious individuals. These reproduced social practices have structural properties of rules and resources where implicit and explicit rules operate to sanction modes of social conduct. Giddens (1984) implies that to produce action (rather than reproduce action, or respond), actors need ontological security that is trust between actors in order to reduce anxiety. Further, Giddens (1984) explained that actors operate from a sense of co-presence – a sense that they will not experience 'assaults on their own self' (Giddens, 1984, p.15). If these are the conditions upon which organisations thrive in a dynamic engagement of partnership, then clearly LIMHS has difficulty meeting these qualities which Giddens (1984) argued would enable a 'dialectic of control', through which all organisational constituents at various times would influence organisational behaviours (and therefore structure). Largely, this is because the structure as performance is managed by and through the clinical director who, as a psychiatrist draws upon his power within the organisation and his power arising from societal sanctions, to position himself over other constituents and above the common rules. Thus rules of co-presence do not apply to the clinical director, since he can and does, publicly shame consumers, carers and social workers. This appears to have elicited structures of appeasement, whereby social workers negotiate between consumers and carers and the psychiatrist in ways which protect the psychiatrist from 'assaults on the self', while demonstrating less concern for the ontological assaults on consumers and carers. The data on participation and partnership indicates that the psychiatrist has more agency than any other constituent of LIMHS. He can, 'at any phase in a given sequence of conduct have acted differently' (Giddens, 1993, p.96), and to 'know this to be the case' (Giddens, 1987, p.220). Consumers in this case study demonstrated little agency in this sense. Their 'power to act differently' had such draconian consequences so as not to provide real choice to act other than compliant. Given that consumers especially, but carers also have little choice in

reaching this 'I can' (act differently) position, then in terms of Giddens (1984) structuration theory, they cannot have transformative impact (capacity) on an organisation. It is this lack of agency of people living with schizophrenia which severely curtails their participation within LIMHS.

This study found that LIMHS failed on all 7 criteria of Standard 3. Thus LIMHS did not 'maximise the roles of consumers and carers involvement at every level of mental health services; LIMHS did not support a range of activities which maximises participation including 'consumer/carer networks, consumer/carer evaluation of the MHPs, establishing and maintaining contact with the consumer/carer groups, public meetings, consumer/carer participation in consumer and staff training and the provision of space and equipment for consumers and carers to use'. LIMHS did not assist with 'training and support for consumers and carers and staff…including training in peer support, consulting, staff selection, computing skills and financial management. LIMHS did not reimburse consumers and carers for expenses of their time and expertise', in fact in this study there was evidence that LIMHS withdrew support from a consumer who was a psychiatric unit visitor for other consumers. LIMHS does not 'have a written statement of roles and responsibilities and code of conduct for consumers and carers, which is written and reviewed by consumers and carers'. Neither does LIMHS have this for administrative and professional staff. A finding of this study is that such a statement as desired for consumers and carers needs also to be an expectation of administrative and professional staff. LIMHS did not support consumers and carers to independently and individually determine who would represent their views to LIMHS. As per the final criteria of Standard 3, LIMHS did not 'monitor the performance of Standard 3 and using the data collected improve the performance as part of a quality improvement process'.

Further, this study found that LIMHS failed to engage any of the principles of participation as outlined by Hardy and Hudson (2002). Thus, LIMHS did not administratively or professionally acknowledge the need for a partnership; have clarity and realism of a shared vision and specific aims and objectives for the engagement of participation and partnership building. LIMHS did not demonstrate commitment and ownership, and certainly the highest level of sabotage of participation and partnership emanated from the most powerful player at LIMHS, the clinical director. LIMHS did not display high levels of trust in relation to or between potential partners. Thus there was low level trust between the administrative and professional staff and consumers and carers and low levels of trust demonstrated between social workers and the clinical directors and between some social workers

and other social workers and between one social worker (Thomas) and the community development worker. There were no clearly established robust (or even weak) partnership arrangement to ensure the clear delineation of responsibility, tasks, and accountability. Finally as in Standard 3, there was no process for monitoring, reviewing and sharing organisational learnings about participation.

Results of this study clearly indicate that while the policy environment of Lantana is one which offers lip service to participation and partnerships with its consumers and carers, LIMHS is largely a structure which simultaneously constrains participation and partnership building between itself and its consumers and carers.

Section Two: How is social work structured into and/or out of Lantana mental health service and how do social workers provide a social work service?

Social work's interface with mental health promotion and the treatment of mental illness dates to the earliest roots of the profession. This is particularly so in the Australian context, which tended to follow American based education options for social work training which focused on hospital social work and psychoanalysis (Boas and Crawley, 1976; Weeks, 2000). Thus as for American social work, Australian social workers have been involved from policies and practices of the 'asylum' to the development of community based services counseling clients, supporting families and engaging efforts to prevent mental illness and alleviate its consequences including the development of programmes, and advocating for public policy and funding responsive to the demand for mental health service provision, and they have done so while building firm practices grounded in a bio-psycho-social framework (NASW, 2006). Nonetheless, as in the British context (Jordan, 2002; Kemshall, 2002) and this study has shown, Australian mental health services have made a shift from community based services to third way policies which are reliant on residual welfare frameworks of drawing on family support and which position social workers as part of a generic mental health workforce which risk manages vulnerable populations including those suffering mental health issues (see Kemshall, 2002). While the first section of this chapter presented a dire picture of the engagement of participation and partnerships of consumers and service providers, this section demonstrates that social workers are largely engaging consumers in respectful relationships imbued with the principles of partnership outlined by Jordan (2002). Furthermore this section of this chapter illustrates that the strengths of social work are recognised by administrative and other professional staff and consumers and carers themselves. This gives expression to Jordan's (2002) theory that policies of partnership and participation rely heavily on social work skills of face-face

engagement; brokerage and negotiation between consumers and other service providers both internal and external to the primary site of service provision; family engagement; resources brokerage; and advocacy. Furthermore, partnership and participation practices rely on ethical practices enshrined in social work codes of ethics. While Jordan (2002) recognised the apparent sidelining of social work in practices of third way welfare, he believes this is unsustainable and the findings of the first section of this chapter provide evidence of this sentiment. There is some indication therefore, that far from engaging practices of appeasement as illustrated in the first section of this chapter, the skills and values of social workers are needed as much in the present time as ever they were in ensuring welfare provision.

Table 10.2 below summarises the data collected about social work, social workers and social justice in this study. On the second page of this table, note that consumers and carers were not asked specifically to respond to social justice, rather, data was provided by consumers and carers about their needs being met by LIMHS and this data is presented and analysed in the next section.

Table 10.2 Data summary of social work

Respondent	Role of Social Workers at LIMHS	Strength of Social Work	Social work post grad education	Social Justice
Manager	Clinical case management	Case management	Mental health psychotherapy	Is assured through legislation Constrained by psychiatry
Clinical Director	Integrate social and medical aspects	Empowerment Brokerage of health, welfare, income support and housing sectors	Sophistication and training around DSM IV diagnoses	Is subservient to the diagnosis
Community Development Worker	To comply with the medical model	Competency standards; Empowerment; Social Justice	Promotion of mental health; Prevention of mental ill-health; Parenting skills; Holistic assessments and interventions.	Social justice is constrained by: Compliance of social workers with medical model; the power of the psychiatrist and psychiatry; lack of senior social worker.
Social Workers	Clinical generic practice; Working with families including in treatment plans and discharge planning; Include social factors in assessment and interventions;	Client centred practice; Empowerment; Brokering community resources for consumers and carers; Know about law, family systems and social justice; Understand the links between myriad disciplines of LIMHS	Research; Management; Supervision; Community Development; Consumer participation; Dual diagnosis; Cross-cultural mental health; Use of self; Psychotherapy; Psychiatric diagnoses.	Social justice is constrained by: Lack of trained managers in social justice; Lack of resources in the community as a whole to assure social justice practices and outcomes; Attitudes about consumers held by LIMHS staff and the general community; Separation of social justice from day to day activities;

				The juxtaposition of the medical model with social justice frameworks; Lack of social justice perspective by psychiatrist; Allied health having less power than management and the psychiatrist; Busyness.

Respondent (cont.)	Role of Social Workers at LIMHS (cont.)	Strength of Social Work (cont.)	Social work post grad education (cont.)	Social Justice (cont.)
Consumers		Think like us; Sense of humour; Normalise things through personal engagement; Link consumers to the community; Actively listen; Demonstrate respect; Are kind; have a broader than medical focus; Have consumer interests at heart; Are caring and helpful; Link consumers to other welfare, community sectors; Are tenacious even when the consumer is difficult/ unwell.	Empathy, understanding, love, compassion, hope; Law and its impact on the lives of consumers; Person in environment focus; Human rights; Respect, including respectful communication; Dealing with violent people; Referral processes; non-threatening communication.	
Carers		Link with other agencies /resources; Do not see anything as too much trouble; Link the carer to opportunities at LIMHS; Are kind, polite; empathic and helpful; Do things face to face; Include the carer; Work outside of formal office hours.	Learning from carers; Sensitivity; Offering support; Empathy; Indigenous carers' perspectives; How to put current standards into practice; Basic communication skills like active listening; Different perspectives on mental health.	

Initially all research participants except the consumers and carers who had social workers as their case managers perceived a narrow focus of social work practice in mental health. Each of these stakeholders, however, in the course of their interview were able to explicate wide and unique roles undertaken by social workers in mental

health, and these wider perceptions were consistent with the positive views most consumers and carers had of social work case managers. Consumers and carers, on the whole understood the breadth of work undertaken by social workers.

The manager initially perceived social work to do with clinical case management. In this regard, the manager initially disqualified unique social work knowledges and practices arguing that any other case manager could undertake the tasks of the social worker, yet the social worker was not equipped to undertake all aspects of the work of other professionals (psychologists, psychiatrists, nurses etc.). He was therefore ambivalent about the need for a senior social worker perceiving that the team leaders (most of whom are nurses) were well equipped to guide the practice of social work. As manager, he was also concerned about funding and saw the appointment of senior social workers constrained through budget. During the course of his interview, however, the manager did recognise that case management as the primary means of mental health service delivery, was developed by the social work profession.

The clinical director (psychiatrist) initially talked about the need for social workers to integrate medical aspects of treatment with social aspects. He demonstrated a keenness for social workers to be supervised by him and seemed somewhat exasperated that social workers would query his prescriptions for treatment in empowerment terms. That the clinical director was aware of empowerment theory and principles seemed to derive from his interactions with social workers. Furthermore, the clinical director noted the important role played by social workers in helping clients negotiate the welfare, income support and housing sectors, in order to get their (holistic) needs met. By the end of his interview, the clinical director was in support of employing a senior social worker in mental health.

The community development worker recognised the contribution of social work to mental health in terms of the social work competency standards. She argued that LIMHS had a medical orientation to their practice and that social workers were co-opted to this framework. She largely noted the compliance of social workers in mental health with the medical orientation of the service. The community worker argued strongly for a senior social worker in mental health to give professional direction and supervision and to steer the profession more in line with its empowerment and social justice focus.

One third of social workers in this study knew about the competency standards for social work in mental health. Despite this, most social work participants could see that they operated from their social work perspective of empowerment (inclusive of a holistic focus of client in their environment) and of client centred practice. Social work participants noted that there is a generic focus to their practice which is driven by a medical model and enforced through medical practitioners who guide the work of social workers.

Social workers thought this focus was exacerbated by the lack of senior social work personnel (Carol) and the fact that social workers do not get together to discuss their professional direction and service delivery within LIMHS (Carol, Thomas, Camilla). Globerman, MacKenzie, Davies and Walsh (1996) warn social workers that their lack of a clear, united view of social work creates a lack of understanding about their role amongst other professionals and results in them having a loss over decisions in regard to what would otherwise be seen as the domain of social work. Other constraints on utilising a social work framework for practice included lack of support for this holistic social, emotional, environmental and political focus were that consequences for work practices outside of a medical focus would be borne by the individual social worker rather than the service as a whole or the team (Carol). This is something of a dilemma, since Coglan and Cheers (2002) strongly put the case that engaging practices for which social workers are not licensed will open the social worker to charges of professional misconduct. Consequences for practising in alignment with the medical model are experienced as being regarded by powerful people as worthy of their praise and induce a higher sense of status. Thus Thomas both lambasts the medical model yet uses its terminology and seeks supervision with a psychiatrist. Foucault (1980b) said that 'what makes power hold good, what makes it accepted, is simply the fact that it does not only weigh on us as a force, but that it traverses and produces things (like perceived increased status); it induces pleasure, forms knowledge and produces discourse (p. 119).

There had been examples of public vilification of social work by the clinical director (Thomas). Mugford and Walters (1998) recognised the difficulties social workers have when psychiatrists use their ideology to dismiss other viewpoints and approaches. Sian, however courageously challenged her fellow workers about their collusion with the medical model. Her resistance took up the challenge laid down by Foucault (1989) that, 'if the fight is directed against power, then all those on whom power is exercised to their detriment, who find it intolerable, can begin to struggle on their own terrain and on the basis of their proper activity (p. 81). Continually

reminding MHPs of their individual areas of authority as Sian does, and as urged by Coglan and Cheers (2002), problematises the effects of genericism and continually reminds social workers of their mandate and obligation towards the consumers and carers they serve:

- the development in pharmacological solutions to mental health issue had burgeoned and appeared to be sanctioned by the wider community as *the* response to mental health issues (Wendy, Maria, Joyce);
- a focus on biology had led to a surfeit of pharmacological resources with a dearth of resource provision for other definitions of mental health (Wendy);
- there is more status in assuming medical terminology and less risk for the individual social work practitioner in mental health (thus social workers could recommend increased medication (Wendy, Thomas) and this was accepted by the psychiatrist as legitimate despite this being outside the domain of social workers' professional knowledge;
- supervision of social work practice occurs through medically trained staff.

Five social workers in this study were supervised by medical staff, either nurses or psychiatrists. This is somewhat contrary to the Queensland Health *Mental Health Services Certified Agreement, 1998*, which emphasises that all MHPs should have access to and receive professional supervision from a discipline senior of their own profession. Yet this Agreement concedes that numerous services do not recognise the unique skills of individual disciplines. It is therefore up to individual social workers to maintain a sense of professional self. Social workers who prefer supervision from medical staff demonstrate their acceptance of both the medical model and the genericism of MHPs. They demonstrate the value of supervision that informs them of medication and pharmacological interventions and their side effects. Simultaneously, however, this supervision and this focus, can leave social workers feeling that their own skills are not of value and they are more easily coerced (or seduced) therefore into the medicalisation of their own practice;

- there are no discipline specific evaluations of practice. This means that the evaluation of all MHPs occurs through a single lense of psychiatry and administration;
- results *per se* drive the mental health agenda rather than process (Maria);
- decisions about consumers are largely made by medical staff.

While the practices above constrain the social work endeavour, Callum (1999) reminded us that social workers colluding with these practices also threaten the profession and the maintenance of its values, skills and frameworks of practice.

Governmentality in the form of the technologies of surveillance (Deleuze, 1992) as listed above have potentially serious consequences for social work as they impact how social workers see themselves and how they would like to practice (Dean, 1995).

Despite these constraints to the operationalisation of social work values, skills and knowledge, social work participants spoke in ways which evidenced their social work perspective. Thus, social work practitioners said they:

- engaged consumers in holistic ways (Wendy, Natalie, Rowena, Sian, Tilly). While this was acknowledged by consumers as very helpful, and they had previously cited the mono-vision of psychiatry as a severe constraint to their willingness and capacity to participate a third way politics attempts to push people through systems expeditiously despite evidence that this will lead to their relapse (Dominelli, 1996). The tenacity of Tilly in following up with consumers after their immediate mental health needs are met bears testimony to the strength of social workers to persevere in the face of this constraint;

- looked at things from a consumer perspective (Joyce);

- were asked by other MHPs about empowerment and resources (Joyce, Carol);

- put the interests of the consumers at the forefront of their work even when this was at odds with a medical or treatment perspective (Joyce). Sopie Freud (1999) urged social workers to hold on to the moral aspects of their work and have ethical principles as their highest purpose. Clearly client centred work is the epitome of social work values and ethics (AASW, 1999);

- focused on the relationships between consumers and others and consumers and the community (Carol);

- were asked by other MHPs about community resources and processes of obtaining these for the benefit of consumers and carers (Camilla, Carol). The clinical director (psychiatrist) had also recognised this as an enormous contribution of social work to the mental health enterprise. Deakin Human Services Australia (1999) also noted this as a primary bridge between social work and other professionals in mental health multi-disciplinary teams.

- have knowledge about law, family systems and social justice (Conrad);

- hold family meetings and do family interventions which fit with the broad mental health framework (Joyce, Conrad). Pilgrim (1992) and Chapman and Goodwin (1992) noted the importance of social workers engaging families in the ways described by Joyce and Conrad as this is the level of responsibility expected of a state, and which is even more pronounced within a third way politics (Giddens, 1998);

- tone down the medical jargon and/or explain this to consumers and carers (Natalie);

- engage discharge planning which involves family members and carers (Natalie);

- include social issues in their assessments and interventions with consumers (Natalie, Rowena);

- find situations for consumers to tell their stories in ways which aid recovery even if this is at the expense of their own learning. Thus Natalie enabled a consumer to attend a conference in her place at which he told his story and had it listened to with respect. Similarly, Carol organised a psycho-educational group for carers at which carers were urged to share their stories. These forums for sharing and learning about the nature of schizophrenia, pharmacology and problem solving was recognised as needed by carers themselves (see section 3 below) and also shown in literature to be important in maintaining carer support in the helping enterprise (Alexander, 1991; Bland, 1986; Hatfield & Lefley, 1987; Kingwell, 1996; Kirkpatrick, Landeen, Woodside & Byrne, 2001);

- understand the links between nursing, medicine, psychology and social work.

Of the 14 consumer participants, five were unaware of the professional background of their case manager. The other seven consumers who knew they had a social worker as a case manager held largely positive views of social workers and substantiated the things social workers say they do in their mental health practice at LIMHS. Consumers said that social workers:

- think like us (Mary);

- have a sense of humour (Mary);

- ask about other thing in your life, not just mental health (Mary, Roger). Mary's comment that social workers do not concentrate solely on a consumer's diagnosis, upholds the *Competency Standards For Mental Health Social Workers* (AASW, 1999), that the practice of social work in mental health services is that of the social circumstances and social consequences of mental illness. Mary's admission that social workers are more inclined than other MHPs to create an environment conducive to consumer disclosures and continuously listen to consumers when they are unwell, also supports the study of Darlington and Bland (1999) which showed that the most powerful helping skill was simply listening. This skill is recognised as maintaining consumers efforts at maintaining hope;

- tell you about things in their life which makes you think that some things they are confronted with may not just be a symptom of their illness but "normal" (Mary). While the psychiatrist demonstrated his distance from consumers, Mary

articulated this as a powerful device for providing her a 'reality check' and a means for making sense of things in her life which might derive primarily from her schizophrenia or from other facets of her life.

- ask about leisure and community activities and link you into these (Roger);
- listen over and over to the same story, with respect (May);
- are kind (Vera, Rose);
- try to find out what is happening with other family members and feed this back to the consumer (Vera);
- have consumers' interests at heart (Lara);
- are caring and helpful (Lara);
- work out of hours and keep their promises about maintaining contact (Rose);
- work with other welfare organisations and bureaucracies in the interests of the consumer (Lara);
- shrug off the hard times they have with consumers when they are unwell (Roland).

Consumers and carers in the Deakin Human Services Australia (1999) study argued that social workers need expertise in specific psychiatric disorders and the prognosis and treatment of such disorders and that they maintain a non-judgemental attitude in their work with consumers and carers, as articulated by Roland in this study. Bainbridge (1999) argued that this is a core social work attitude and expected as part of their professional training and professional code of conduct (AASW, 1999).

Each of these qualities which consumers highlighted as illustrative of helpful practice, endorses the work of Darlington and Bland (1999), Landeen, Woodside and Byrne (2001) and Moxley and Mowbray (1997) all of whom discussed the importance of active listening, providing hope for consumers at times the schizophrenia and its treatment threatened to engulf their very sense of self and the importance of consumers telling their stories over and over as a means of validating and making sense of their experiences. This active listening also enables social workers to glimpse possibilities for enhancing the ways in which they offer services and for glimpsing and focusing on consumer strengths. Workers like Joyce, who cannot privilege the professional background of social work over case management, run the risk of minimising the importance of their own skills (active listening) in consumers' recovery. Thus SANE Australia (2003) revealed that one third of all mental health clients do not receive any active counselling as part of their treatment plan.

Of 14 carers in this study, six did not know the professional background of their case manager. Those carers who had a social worker as case manager, however, said that social workers:

- intervened on their behalf with Centrelink (Fran). This reflects the same finding in the Deakin Human Services Australia (999) study which was that access to real material resources and other helping bureaucracies was helpful to both the consumer and the carer;
- did not see anything as too much trouble (Fran);
- got the cared for a flat which was close to the carer and the day-centre programme (Rena);
- got the consumer legal aid assistance (Rena);
- linked the carer with psycho-education opportunities (Rena);
- picked a mother up to take her to the lock-up to see her son when he was first incarcerated (Prue);
- were kind (Laura);
- were polite (Laura);
- came out to the house to tell a carer bad news about the cared for, rather than just telephoning (Thelma) ;
- included the carer in discussions, visits to mental health and in the treatment plans (Gloria, Louise). Louise shared an example of working with both a nurse and a social worker. When her son was case managed by a social worker, Louise felt included, appreciated and skilled, whereas when the nurse was case manager, Louis e felt excluded, unsupported and taken for granted as the nurse focused solely on medical intervention;
- responded empathically and helpfully (this was said about a social work student with a specific example given (Gloria).

This data demonstrates that while social workers may not be implementing participation policies as per government expectations, they are strongly engaging principles and practice of partnership – using qualities and skills of openness and mutuality.

Social Justice

A cornerstone of social work is its philosophical framework of social justice. Data from the social justice section of the data chapters for management, community development worker and social workers are discussed below. The responses of

consumers and carers to social justice, however, are used to articulate responses to the third research aim of elucidating the extent to which people diagnosed with schizophrenia and their carers, perceive mental health services in Lantana to be involving them in meeting their needs.

The manager strongly articulated the view that social justice concerns for consumers and carers of mental health services were assured through legislation such as the *Queensland Mental Health Act, 2000.* Further, he argued, social justice is assured since mental health practitioners operate from the principle of "least restrictive care" and the National Standards also protect people's rights. When pressed, however, the manager recognised the propensity for abuse of mental health consumers and carers as elicited through several royal commissions. He seemed puzzled that this should occur, and articulated that this occurs through the trust the system has in psychiatry and psychiatrists and in leadership of mental health services.

The clinical director was much more forthright about human and civil rights necessarily being subservient to the diagnosis of a consumer. He did not problematise this, which possibly supports the manager's view about the power of psychiatry to determine the level of wellness at which human rights could be invoked or rescinded.

Like the manager, the service development coordinator felt that social justice was assured due to measures such as the statement of consumer rights. He did recognise, however, that people are disempowered through regulation and that psychiatry contains subjective elements.

The community development worker responded to the question of social justice in LIMHS personally. She reported what she personally does to ensure social justice in her own practice. She therefore highlighted her autonomy in assuring socially just practice.

Social workers by contrast felt less optimistic about social justice for a number of reasons these were:
- lack of trained case managers in social justice (Wendy);
- lack of resources in the community which would assure social justice practices, outcomes and opportunities (Wendy);
- attitudes about consumers and carers held not only by the wider society, but also by LIMHS personnel (Carol, Joyce, Sian);

- the separation of social justice issues, perspectives and assurances from day to day case management practice (Carol);

- the juxtaposition of social justice principles and practices with a medical focus of practice (Lucy, Natalie);

- social workers taking on the attitudes of the community which are negative as far as mental health is concerned, and the perception that LIMHS has a culture of offensive attitudes (Thomas);

- that participation of all service providers does not occur. Some providers have more power than others and some (psychiatry) have much more power than others. If participation was not happening at this level, then one could assume that participation extended even further away from this power base would be even more problematic (Lucy);

- the perception that other MHPs and the psychiatrist not engaging social justice assessments and interventions impacts the ability of social workers to do so (Thomas, Joyce., Wendy);

- allied health being represented on the executive by one member, who represents all disciplines including social work but not including management and psychiatry who represent themselves (Carol);

- prioritising self over the needs of clients in a busy task focused environment ("I do what I have to do"; Maria);

- services are provided for the good of the greater community rather than for mental health consumers (Camilla).

This data shows similar characteristics to the data about partnership and participation and this analysis will not be duplicated here. Importantly however, this finding itself demonstrates a strong connection in the minds of social work research participants, between participation and social justice. This data reiterates a sense that participation is separate from the day to day operation of LIMHS and that without the lead of key powerful players at LIMHS, social workers are constrained in their practice of social justice (Hudson and Hardy, 2002; Jordan, 2002). It also points to the marginalisation of social work in the face of the more dominant medical profession. This data presents a performative structure which disparages consumers as worthy of a prime practice focus and engagement and instead illustrates the purpose LIMHS plays for the wider society at the expense of mental health consumers.

Social Work: Postgraduate education

The Australian Association of Social Workers, since 2003, has had a policy of Continuing Professional Education (CPE; AASW, 2003). All social workers seeking accredited member status with this professional body must pursue life long learning. Some social workers engage in post graduate education in order to meet this requirement. Case study participants were asked to comment on the type of post-graduate education they thought was important for social workers, except for consumers and carers who were asked what postgraduate education was important for MHPs.

The manager wanted social workers to have postgraduate studies in mental health and in psychotherapy. The clinical director wanted social workers to have training in case management; therapy with greater sophistication and training around DSM –IV diagnoses. The community development worker wanted social workers to have post graduate education in the promotion and prevention of mental health/ill health; developmental growth; parenting skills; and holistic assessment and intervention which accounted for the consumer and carer in their environment. The community development worker in contrast to the manager and the clinical director was adamant that social workers should not have post graduate training in psychiatric, medical frameworks of practice.

Social workers wanted more post graduate training in:

- research (Carol);
- management/health administration (Carol, Joyce, Camilla, Sian);
- community development (Carol);
- consumer participation (Carol, Joyce);
- dual diagnosis – depression; sexual abuse and mental illness; delusional people (Camilla);
- mental health from a cross-cultural perspective (Sian);
- use of self (Tilly);
- alternatives to psychiatry (Conrad);
- psychotherapy (Wendy, Rowena, Lucy, Maria);
- psychiatric diagnoses (Natalie, Lucy).

The preferred types of post graduate education options wanted for social workers by management and social workers themselves contrasted sharply in what consumers and carers wanted MHPs to be educated. Consumers wanted MHPs to have education in:

- study entailing the consumers' views (Mary);

- legislation that guides mental health consumers' lives (Lara);
- relationships with courts, police, Centrelink, Child Safety (Lara);
- getting human rights addressed (Vera, Mary);
- empathy – belonging to the most stigmatised group – learn what it is like getting through the day heavily medicated, walking, not driving (Roland);
- understanding (John, Rose) ;
- love for consumers (Isobel);
- hope and how to give hope (Isobel);
- compassion (Isobel);
- respect – including respectful communication (Jim);
- learning to cope with people when they are violent (Sally);
- keeping people safe in critical incidents – including the consumer (Sally);
- non-threatening engagement with consumers (Sally);
- appropriate referral (Roger).

Carers wanted MHPs to have postgraduate education in:

- learning from carers (Louise, Paula);
- sensitivity (Louise);
- how to offer support (Louise);
- empathy – the carers reality (Louise);
- Indigenous carers' perspectives (Gloria);
- putting current standards into practice (Simone);
- basic communication skills, especially listening and learning to involve carers in programmes (Teresa);
- different perspectives on mental health (Teresa).

Responses to the question about social work post graduate education on the whole, indicate particular allegiances from management and social workers to psychotherapy and more 'sophisticated' education. This contrasts sharply with consumers and carers who wanted MHPs to have more holistic understanding of the lives and issues of consumers and carers and engaging in practice which embraces relationship qualities of empathy, love, caring, kindness and respect demonstrated through skills of active listening, brokering relationships and resources for consumers and carers. In short, data from this question elicited that consumers and carers want MHPs to have more of the education offered in schools and departments of social work (see for example social curriculum of Schools of Social Work on university websites around Australia) than that offered through psychiatry (psychotherapy).

The overall indication from data about social work practice at LIMHS, social work education and the space for social justice practices at LIMHS indicates that social workers overtly collude with the demands of psychiatry, while covertly, social workers operationalise core social work practices in their engagement with consumers and carers. They engage consumers and carers in ways which are consistent with the relationship qualities necessary for developing partnerships and engaging participation (Jordan, 2002). Perhaps as a result of this ongoing wrestle, however, between appeasing psychiatry and being true to their own principles and practices, social workers see themselves in a less favourable light than they are seen by consumers and carers.

This finding must be tempered with an acknowledgement that social workers place themselves in a precarious position by engaging this clandestine relationship with their own profession. Social workers collude with the hegemonic practices of LIMHS by not always identifying their professional 'badge' to the consumers and carers they serve. Professional identification would raise the profile of social work and indicate some roles of engagement since presumably consumers and carers would have expectations of what various professions including social work could offer them. Similarly, four social workers (Thomas, Maria, Joyce, Wendy) justified the dominance of the medical model in their practice and all social workers who had supervision (5) chose supervision by a medical practitioner over social work supervision. Social workers therefore discursively feed into habits and practices which maintain the dominance of psychiatry at LIMHS. Instead of social workers assuming the "I can" position of structuration theory (Giddens, 1984) in the workplace, social workers demonstrate a reflexive monitoring of self (Giddens, 1984) so that they know when they 'cannot', but also when they 'can' act differently from the prescriptions psychiatry has of them. Thus they are restrained through a lack of ontological security (since they are not free of the assaults to self) in the workplace to exercise their skills, knowledges and values of social work, but through the dialectic of control (Giddens, 1984), engage practices with consumers and carers which asserts the power of social work in these more intimate settings of practice, over the power of psychiatry.

This data therefore demonstrates the resilience and confidence of social work as a discipline, strong enough to survive through its own professional competencies even given the stranglehold of psychiatry in the field of mental health. Deakin Human Services Australia (1999) reminded social workers, through their similar findings of consumer and carer esteem of social workers, to take these results as a way of

rekindling their own value and appreciation of themselves and of social work as a helping profession.

Kovel (1981) reminds social workers, however, that practices of appeasement and an overt collusion with psychiatry could be evidence of the unconscious motivation (Giddens, 1984) of social workers for an underlying bid for power rather than a means for enhancing their care of the needs of consumers and carers. He also warns that this collusion will not result in the power social workers may be seeking, intimating that the habitual performance of psychiatry, uses these even sycophantic forms of collusion for its own purposes.

Section Three: To what extent do people diagnosed with schizophrenia and their carers perceive mental health services at Lantana to be involving them in meeting their needs?

The qualitative data collection of this study did not allow for a direct measure of the perception of consumers and carers of Lantana meeting their needs. To the extent that there was more critique of LIMHS than there was positive valuation is perhaps some indication that many consumer and carer needs are not being met. This, however, is too crude a measure given the results of this study which demonstrate an enormous satisfaction in some programmes (the day-centre programme) and with some service providers (social workers). The power of psychiatry and the attitude of the LIMHS psychiatrist was perceived by consumers and carers as a predominant factor against consumers and carers getting their needs met. Psychiatry was presented as limiting in terms of its focus of assessment and intervention, and in its process of intervention. These findings are analysed further below.

Both groups of consumers and carers noted the enormous positive impact of the day-centre programme in their lives. Of particular import was the transport of consumers to the day-centre programme, the range of activities and outings, the socialisation with other people who have schizophrenia, and the affective components of respect demonstrated at the day-centre programme including across race.

Consumers and carers indicated some satisfaction with MHPs when they helped consumers sort out some of their broader problems; did not award blame at times of relapse; and were encouraging and did not act as if they believed the myths surrounding mental illness.

One consumer (Ray) felt included in his care at the hospital and one quarter of consumers (Rose, Roland and Jim) felt consulted about their treatment. Three carer participants (Laura, Louise and Rena) felt that they had been consulted in relation to the treatment plan of the person for whom they care which included being present at reviews and agreeing to changes in medication. Others (Ada, Prue, Annie and Simone) spoke positively about the psycho-educational programmes in which they had been involved and through which they learned about the side effects of medication and how to cope with the symptoms of schizophrenia. Two carers (Laura and Marion) thought that LIMHS provided a reasonable standard of care and another carer (Tom) found the CATT team helpful, particularly when he utilised the out-of-hours facility of this service.

Consumers and carers were more critical about the parameters of partnership qualities, than they were about the task focus of participation. They felt it was these qualities which hindered their needs being met. Consumers and carers thus said that they:

- are not always comfortable voicing their opinions (Roger, Fran);
- don't always understand what is being said (Roland, Rose);
- don't feel welcome (Annie);
- that sharing is not equal, rather they are expected to share intimate details without this being reciprocated (Laura);
- are not assured that human rights will be guaranteed (Paula, Tom);
- confidentiality is invoked by professionals as the means to exclude carers from involvement with the treatment plan (Teresa, Paula);
- perceive an attitude held by service providers that it is their job to make all the decisions, rather than decision making being a shared process (Laura, Rena);
- experience a sense of workers being rushed and too busy to gain or accommodate consumer perspectives (Sally, Mary, Jim, Paul, Roger, Fran, Marion);
- experience a sense that bureaucracies collude with each other to the detriment of the rights of mental health consumers (Lara, May, Vera).

Consumers and carers identified the emotional distance between themselves and the psychiatrist (see particularly John) as hindering partnerships for meeting their needs. Thus the psychiatrist was identified as lacking in empathy; having a negative attitude towards consumers and carers; lacking in patience and understanding; making fun of consumers; insulting and/or excluding carers; making carers feel inadequate, ashamed and guilty; giving carers a diagnosis without a prognosis and without

support for the carer; rushing a consultation; giving medication without explaining the side effects; and being rough and speaking in a rude manner.

Besides these emotional barriers to partnership building, other factors were raised by consumers and carers as hindering the tasks of participation. These factors were:

- non-engagement of consumers and/or carers in the drawing up of a treatment plan (Vera, May);

- treatment plans which are drawn up despite the consumer not being able to comply (e.g. due to the effects of medication). This indicates the catch-22 of some treatment interventions (Sally, Teresa);

- broader issues outside of a psychiatric definition are not focused upon. Therefore carers and consumers are left alone to deal with real, psycho-socio-material aspects of living with schizophrenia including breakdown; family isolation and stigma; suicidal ideation of the consumer; the behaviour of consumers when they are unwell, including the consequences of this behaviour (Simone, Gloria, Thelma, Prue, Fran, Ada, Tom, Laura);

- a lack of coordination between services, with the treatment plan focusing solely on the psychiatric definition of the problem despite major life events which could be impacting this psychiatric condition (such as the removal of children; May, Vera, Thelma);

- a lack of engagement in a treatment plan, with issues of dual diagnosis (e.g. of drug use and mental illness; Prue);

- no follow through when carers are away, despite the carer and LIMHS agreeing to particular actions (Fran);

- the short term nature of treatment plans – there is no long term planning for the care of a consumer over a life span (especially when this is longer than that of the carer). Thus carers are left to worry about what will happen to the consumer when the carer is sick or dies. In this same sense, budgeting for the care of a consumer is short rather than long term (Paula, Louise, Thelma, Marion, Annie, Tom). Carers therefore expose a weaknesses in third way politics of 'care', given that it cannot account for the responsibility of care once a carer dies or becomes otherwise unable to care for their offspring (see also Finch, 1989; Perring, Twigg & Atkin, 1990; Qureshi & Walker, 1989; Twigg & Atkin, 1994). Similarly, carers are often unable to provide for the long term financial costs (Rena, Laura) of their offspring's care given that they have not been able to build up material wealth themselves as a consequence of their care duties often over many years.

Further, carers said that:

- aspects like depression need to be considered as a result of other life contexts, such as consumers being excluded from seeing their children rather than have all of their behaviours symptomatically linked to schizophrenia (Fran);
- social workers need to engage family work (Thelma, Gloria);
- bizarre behaviour of their offspring can lead to disintegration within the family – mothers can be separated from their other children and grand-children as they take responsibility for this most vulnerable family member they therefore experience feelings of loss. There was a sense that a carers group would help them deal with their losses including that of potential grandchildren and dreams they had for their child/ren. Hockley (1985) called this fantasised loss, while McKissock and McKissock, (1985) talked about the need for carers to work through disenfranchised grief (Ada, Simone, Fran). This indicates that in cases of mental illness, a third way politics may desire a familial response, but this response is likely to become the primary responsibility of one family member (usually the mother), who bears an enormous psychological and social cost for the care they undertake of the afflicted family member;
- intermittent behaviour of violence towards the carer when the person is having a psychotic episode, is frightening yet carers are not provided a debrief after the episode has passed, yet this facility would be offered to 'real' members of staff (Prue);
- carers enormous concern and sadness around the lack of intimacy in the lives of their children with schizophrenia (Teresa, Annie, Rena) and in relation to their offspring threatening suicide (Burdekin, 1993; Cohen, Test & Brown, 1990). This was experienced by 7 of the carers (Prue, Thelma, Tom, Laura, Simone, Gloria, Fran). Suicide is the most common way for people with schizophrenia to die (84% die this way; Pezzullo, 2002; see also Cohen, Test & Brown, 1990; Kaplan & Saddock, 1998; Kosky & Goldney, 1994). For Indigenous consumers this risk is higher, with Indigenous suidicidal rates for Indigenous males in Queensland between the ages of 15 and 29 being four times that of other Australians (Hunter, 1993).

Data in this section revealed that consumers and carers experience remarkably high satisfaction with the day-centre programme, and satisfaction with some aspects of their engagement with LIMHS. Dissatisfaction mainly revolved around the absence of facilitative conditions of respect, active listening, unhurried time with the MHPs and lack of consultation with carers about the treatment plans of their offspring. Carers

elicited many aspects of their material and psychological concerns not dealt with as part of their engagement with LIMHS.

Conclusion

This chapter examined three key questions of enquiry. These focused on the opportunities for and constraints of participation and partnership building between LIMHS and consumers and carers; the structure of social work within LIMHS and the means engaged for providing social work services; and the extent to which people diagnosed with schizophrenia and their carers, perceive mental health services in Lantana to be involving them in meeting their needs. The following and final chapter of this thesis integrates these findings into a proposed model of social work practice at LIMHS. Recommendations arising from this research and the substantive conclusions of the research are also presented through the model in this final chapter.

CHAPTER ELEVEN
A new model of social work service delivery

Critical social workers with a background in academia can offer crucial support to social workers in the field, mainly by voicing their concerns about the impact of government policy and community service provision on marginalised populations (Healy, 2001). This has occurred through the research described in this thesis that culminates in this chapter by outlining a model of social work service delivery within mental health services that prioritises the required partnerships for consumers diagnosed with schizophrenia and their carers: the major enquiry pursued throughout this research. A key shift in new models of mental health service delivery has been the focus of working with people and identifying what they require from their involvement with the mental health service. In accordance with this development, the model under discussion is created from the findings in chapters five, six and seven, and to a greater extent, from chapters eight and nine. It integrates both the generic responsibilities required in current social work practice in mental health services, and also strategies for social workers to incorporate inclusive interventions that embrace principles of social justice.

The model is presented in two parts. Part One describes a modification to existing case management technologies and reveals the key partnerships and research priorities necessary to meet the vision of the research participants. Part Two outlines the roles of the consumer and carer consultative committee and the training needs for both social workers and consumers and carers. It also contains ideas for professional social work supervision. The discussion of the model closes by exploring similarities and differences with other models of mental health service delivery, the present climate at the LIMHS and how the model might work in this climate. It also explores possibilities of why other models haven't been fully implemented.

Rationale for the model

It is increasingly apparent that the government intends to re-shape mental health services in ways that could be detrimental to the interests of consumers and carers (Callum, 1999). Despite this, the government has given mental health services a clear remit that mental health services will not return to or maintain old practices of consumer and carer exclusion, and will embrace strategies to reduce the discrimination and abuse experienced by consumers and carers (Whiteford, 1999; Woolridge, 1999). Nonetheless, the government's own 'socially inclusive' strategy

implies that people experiencing mental ill health are in some way responsible for their problems (Campbell, 1990).

Politicians have distorted the concept of social exclusion, which was originally associated with poverty and inequality (Leviter, 1998). They assume that people experiencing mental ill health are people who live apart from the rest of the community and require assistance to participate in community life. This way of thinking silences any philosophical discussion of the positioning of consumers and carers in the community and ignores the possibility that consumers and carers have a positive identity, for example, as independent thinkers who resist this prevailing discourse, as demonstrated by some of the consumer and carer responses in chapters eight and nine of this study. Some authors (see Pezzullo, 2002; Twigg & Atkins, 1994) believe that the government's socially inclusive strategy is more about getting people with mental ill health to own their illness and for carers to take responsibility for the burden of care, rather than about tackling their very real problems of poverty, discrimination and stigma. Therefore, models of 'help' have tended to revolve around the medicalisation of mental illness. It is important however, that social workers are provided an alternative to the medical model with its emphasis on controlling symptoms with medication and assisting consumers and carers to accept the status quo. Social workers must be unwavering in their conviction that the psycho-social model is crucial to working with consumers and carers in order to both empower consumers and carers, and increase societal awareness of the social and psychological problems that exacerbate their circumstances (AASW NSW, 1993).

A central philosophical question for social workers is whether help is offered according to the consumers' and carers' definition of need, or whether the dominant aim is to reconcile them towards conformist behaviour. There is also the problem of the ambiguity of the concept of 'need' in mental health work and consumers often being unable to express needs in a clear, straightforward way. Many consumers with schizophrenia are accustomed to concealing rather than revealing their problems. Therefore, through the model of social work service delivery outlined in this chapter the consumers and carers have their definition of need applied to social work practice while simultaneously offering social workers a framework for service delivery that incorporates their core professional values (Ife, 1997).

In the current climate where the generic case management model underpins service delivery, social workers have to be creative when finding opportunities that unite the structured, rational world of case management (Coglan & Cheers, 2002) with the often disorganised, chaotic lives of consumers and at times their carers. Social workers must be willing to reach out to consumers and carers and maintain an ongoing relationship even during the hard times. This can go a long way with assisting consumers in their recovery, raising the quality of life for consumers and carers and instilling a sense of hope for a future (Darlington & Bland, 1999; Kirkpatrick, Landeen, Woodside & Byrne, 2001). It is the consistency of the social worker's caring, the human relationship, and a sense of union between equals that are important in this work. Consumers experiencing a psychotic episode are likely to have problems functioning at home and in the community that directly affects themselves and the carer. Social workers are obliged to adopt a critical approach to their work. It is morally bereft to hide behind the medically influenced generic case management model and use it as an excuse to ignore the plight of consumers and carers. In a climate of increasingly bureaucratised and depersonalised services, social workers must provide the human face of the organisation and act as a guide for consumers and carers. In addition, social workers should continually seek out resources and groups within the community where consumers and carers may find ongoing support.

This view is reinforced by the findings of this study that highlights social work as an established, important and necessary discipline within the LIMHS. Social workers are employed in large numbers relative to other disciplines. This privileged circumstance, the compulsory powers invested in the authorised mental health practitioner (social worker) and a training that confers social workers with the power to make independent decisions, reinforces my contention that social workers can challenge medical authority. Social workers can use their *Code of Ethics* (AASW, 1999), the *Competency Standards for Mental Health Social Workers* (AASW, 1999) and the *National Standards for Mental Health Services* (Australian Health Ministers Advisory Committee, 1996), as the rationale informing all decisions towards consumer and carer participation and partnership.

Searching the literature for guidance towards a new model of social work service delivery is pointless. As Foucault, (1991b) cautioned "I will absolutely not play the part of one who supplies solutions" (p. 157):

> "It is true that certain people … are not likely to find advice or instructions in my books that tell them 'what is to be done.' But my project is to precisely bring it about that they 'no longer know what to do.' So that acts, gestures, discourses that up until then seemed to go

The research reported in this study discovered that many of the social work participants have largely co-opted psychiatric discourse as the basis of practice (see chapter seven). It can be argued that by accepting the psychiatric model, mental health social workers construct a limited and dependent role for themselves thereby failing to explore other possibilities for those they serve. The psychiatric construction of schizophrenia regards it as a mental disorder caused by some yet undiscovered, biochemical dysfunction that can be treated only by biochemical intervention authorised by the psychiatrist. If mental health social workers continue to endorse this view it would seem an inevitable consequence that social work interventions continue to consist of facilitating and dispensing medication, controlling the behaviour associated with mental illness until the medication takes effect and helping consumers through psychotherapy to adapt their life to the inevitable disability of a biochemical dysfunction. It is the contention of some social work participants in this study that the social work profession has more to offer than this. It involves skilled interventions to facilitate consumers' and carers' potential to move through their mental illness in an inclusive manner.

Part One: Case management, partnerships and research

The model depicted on the following page exhibits the necessary changes to case management according to the consumers and carers in chapters eight and nine of this study. It also highlights the necessary key partnerships and the research foci that are essential to meeting the requirements of the research participants.

Figure 11.1 Case management, partnerships and research

Case management: Full Support Model and Expanded Broker Model (excluding facilitating and dispensing medication)

IMPORTANT
Consumer & carer participation is crucial to the success of the whole process

Crucial additions to case management
Undertake a promotion, prevention and recovery focus
Use of the strengths model
Carers to be conceptualised within a carers' framework
Consumers to be conceptualised within a consumers' framework
Ensure that involuntary consumers are treated with the utmost compassion
Advocate and provide support for consumers and carers with psychiatrists
Advocate and provide support for consumers and carers with key formal partners
Indigenous mental health workers involved with Indigenous consumers & carers
Indigenous mental health workers involved with facilitating psycho-education
Liaison with consumers' GPs imperative

Recovery plan
Agreed to by social worker and consumer & carer
Living document - updated on a three monthly basis
Holistic – covering all aspects of the consumer's life
GPs involved with ongoing care of consumers
Planning for relapse

Key formal partnerships
Department of child safety
Drug and alcohol services
Queensland police department
General practitioners

Research Priorities
The relationship between schizophrenia and suicide
Issues involving mothers with schizophrenia with children in care
Lived experiences of ageing of with schizophrenia
The development of inclusive models of day-centre programme programmes
The relationship between serious mental illness and sexual abuse

Case Management

It is paramount that consumers and cares retain the right to choose or resist the policies of participation and partnership. The findings reported in this thesis reveal that more consumers than carers express an interest with participating in mental health services. This can be understood against a background of historical disadvantage whereby mental health policies have increased the burden of care on families. Clearly, it is essential that consumers and carers are willing to involve themselves with change for the process to be viable. Therefore, it is crucial that social workers embrace the enthusiasm voiced by willing consumers and carers in a bid to ensure these policies do not follow past policies that failed to improve the circumstances of people experiencing mental ill health and their families.

A case management approach for social workers implementing the following model would retain a combination of the full support model and the expanded broker model. However, it is crucial that social workers convince their team leaders that their existing role with facilitating and dispensing medication (Farmer & Bentley, 2002) is not authorised (Coglan & Cheers, 2002). In return social workers can involve themselves with roles that they are authorised to undertake. Many of these roles are documented in this chapter.

Promotion, prevention and recovery focus

The key major themes in the *Second National Mental Health Plan* (AHM, 1998) and the *Third National Mental Health Plan* (AHM, 2003) are promotion, prevention and early intervention for mental health. Consumers place importance on this approach to mental health issues rather than waiting until a situation requires action to be taken. However, the Australian Health Ministers (2003) concede that service planning and delivery across the spectrum of care from promotion and prevention to recovery, has not yet been achieved in Australia. This study is an attempt to provide social workers with an opportunity to hear from consumers and carers and work together with them on projects and issues that assist with the development of initiatives that improve and enhance their mental health and the well-being of their communities. In chapter six of this study, the community development worker encourages social workers to concentrate on the areas of promotion and prevention. She points out that people with schizophrenia are not their mental illness and one of the areas where social workers are so important, and where so much has to be done, is to look at the person holistically. This involves looking at the person across the life-span that includes the school-yard, parenting, the family and community. She believes it is the

role of the social worker to recognise illiteracy, culture, emotional wellbeing, hopelessness and despair. Therefore, it is crucial that social workers minimise the impact of genericism and the medical model on their work and strive to work from a promotion, prevention and recovery perspective. A way forward for social workers willing to adopt this perspective is discussed later in this chapter.

The use of the strengths perspective

The most common themes emerging from the consumer and carer participants' dialogue on their lived experiences with MHPs and mental health services, suggest that the use of a strengths perspective by social workers is the most suitable approach when attempting to create a therapeutic alliance and uncover a consumer's potentiality. The participants in this study do not believe that periods of unwellness justify case managers refusing them opportunities to participate. The present model of service delivery used by social workers at the LIMHS primarily focuses on the identification of weaknesses with a view to assisting consumers to develop proficiencies or competencies that prevail over these deficits. While this kind of assessment remains important, the strengths approach (Saleeby, 1992) takes social workers beyond deficits to consider additional criteria. For example, consideration can be applied to consumers' personal strengths, artistic and creative abilities and interpersonal abilities. It can also be applied to consumers' employment potentiality, their intellectual and spiritual beliefs and their sporting and physical abilities. This type of assessment is lengthy and requires social workers to carefully listen to consumers' and carers' stories and experiences to maximise strengths and minimise weaknesses.

The strengths approach locates case management in the domain of rehabilitation (Macias, Kinney, Garley, Jackson & Vos, 1994). It enables social workers to depart from a medically focused approach to case management, to a psycho-social rehabilitation approach. This empowers consumers and carers as it enables social workers to form a partnership with them. In chapters eight and nine we heard the consumer and carer participants' affirm the strengths of social work case management, as opposed to case management by other MHPs. This offers hope to social workers who are concerned about the erosion of their role in mental health services due to the generic case management model. In turn, social workers must strive to highlight the strengths in the consumers and carers they work with. This approach offers carers recognition of their role in mental health services, and builds hope in consumers that encourages them on their journey to recovery.

Figure 11.2 Principles of a strengths perspective
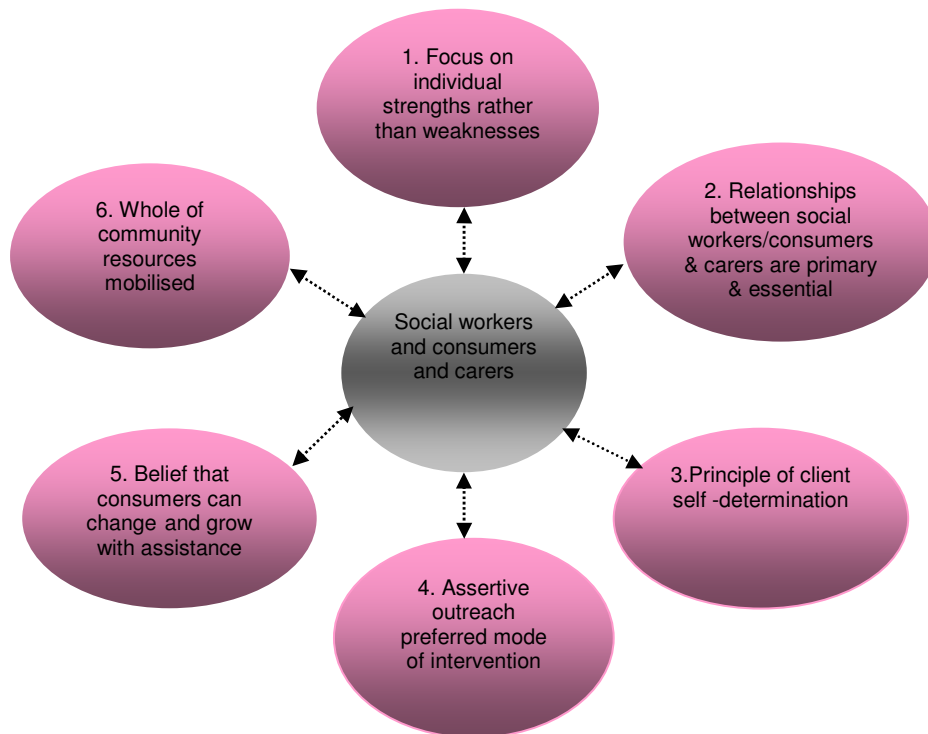
Consumer and carer frameworks

Throughout this research many consumers and carers described negative experiences of their interactions with MHPs and psychiatrists. However, they also reveal instances of good practice whereby MHPs interact with them in a way that leaves them feeling hopeful, supported and understood. The positive experiences of consumers and carers are collated and named consumers' and carers' frameworks. A consumer framework refers to the way we, as social workers, can conceptualise people with schizophrenia and behave towards them. This is a very important concept as it informs the way we work with consumers. The consumer participants in this research define their framework as follows:

1.   Social workers who take an active interest in what consumers are doing in their lives apart from their mental illness.

2   Social workers who demonstrate acceptance and use supportive practices such as active listening and returning phone calls.

3.   Social workers with a good sense of humour who take a holistic approach and advocate for consumers.

4.   Social workers who are willing to extend themselves in crisis situations.

5.   Social workers who demonstrate respect, forgiveness, tolerance, sharing and genuineness.

6.   Social workers who are dedicated enough to research and publish their findings in a bid to improve consumer's lives and the way they are perceived by the general public.

7.   Social workers who do not perceive consumers as 'too sick' to participate both in the service and in life generally.

A carers' framework is equally as important as a consumers' framework. Essentially it entails working with carers of people with schizophrenia in much the same way as carers' of people with a physical or intellectual disability who are often portrayed as heroes. The carer participants in this research define their framework as follows:

1.   Social workers who do not blame the illness on carers and family members.

2.   Social workers who treat carers with respect for the burden of care and offer assistance to ease this burden.

3.   Social workers who explore opportunities for respite and assess carers to see where they can help with some of the duties.

4.   Social workers who include carers in the recovery plan as carers are expected to ensure the plan is carried out after 4.30pm and over weekends and holidays.

5.   Social workers who demonstrate professionalism, empathy, sensitivity, instil hope for the future and work in a collaborative manner with carers.

6   Social workers who recognise and address the grief experienced by carers for their loss, both current and ongoing.

7.   Social workers who do not use the Code of Confidentiality arbitrarily in a bid to keep carers out of decision-making processes related to the cared-for.

Involuntary admission

It is important for social workers to ensure that involuntary consumers are treated with the utmost compassion. According to Foucault (1972) power relations exist only when particular relations exist. Regardless of how unequal, people have to be in a position to choose or resist. A consumer situated within 'total domination' (regulated) cannot exercise choice and possesses no means of resistance; all relations of resistance are cancelled out. It is therefore crucial for social workers to grasp every opportunity to advocate for involuntary consumers' rights and needs.

Advocating for consumers and carers

Not everyone has the confidence or skills to address and enforce their rights. Social workers receive training to advocate for marginalised people and groups. Furthermore, through their employment advocacy skills are enhanced by an awareness of the specific networks and resources that can be mobilised to assist particular groups of people disadvantaged by their disability. Social workers also have a good working knowledge of government policies, *Acts* and the Declarations of Human Rights specific to consumers and carers living with schizophrenia. These documents can be used to argue against discriminatory practices with psychiatrists and with other organisations whose policies discriminate against consumers and carers.

The involvement of Indigenous mental health workers

Indigenous consumers and carers are entitled to receive services from an Indigenous worker. Indeed, an Indigenous carer participant in chapter nine highlighted the benefit of an Indigenous mental health worker who understands her family's unique situation. Indigenous people continue to experience discriminatory practices and many Indigenous people are affected by the memories of historical injustices. Social workers played a central role in facilitating violent government policies that involve the removal of children from their families and communities and their relocation. This situation is recognised in the *Second Mental Health Plan* (AHM, 1998) that recommends targeting Indigenous people for selective preventative measures. Therefore, social workers need to ensure that Indigenous consumers and carers are offered an Indigenous mental health worker either as principal service provider or in partnership with a social worker. Furthermore, Indigenous mental health workers are trained to approach their work with the orientation and expertise to understand mental illness within a cultural context (McGrath, AMHAC, 2000).

Indigenous psycho-education

It is crucial that Indigenous consumers and carers attending psycho-education have an Indigenous mental health worker as co-facilitator. The idea of a psycho-education group exclusive to Indigenous carers is not sustainable as they are few in number compared to non Indigenous carers attending psycho-education. The experiences of non Indigenous carers are both similar and different to those of Indigenous carers. This is another reason for both non Indigenous and Indigenous carers coming together at psycho-education. Schizophrenia crosses all cultures and is a great leveller. Therefore, carers can benefit from hearing the stories and gaining the insights into the ways that both cultures experience caring for people with schizophrenia.

The involvement of an Indigenous mental health worker at psycho-education is essential for ensuring that a clinician is familiar with the nuances of an individual's cultural frame of reference. This minimises the possibility of pathologising normal variations in behaviour, belief or experience that are culturally specific (DSM-IV, 1994). Indigenous mental health workers also understand the devastating effects of the historical and social context that contemporary Australia has on Indigenous carers (Smallwood, 1996). This includes recognising the interface of the 'stolen generation' and displacement with the on-going trauma inflicted on Indigenous families from violent past policies (AHM, 1998).

The involvement of general practitioners

The benefit for MHPs working in partnership with general practitioners in the community was mentioned by both consumers and carers in this study. The value of this partnership will be explored later in this chapter in the sections named a recovery plan and key formal partnerships and not discussed further here.

A recovery plan

The recovery plan incorporated within the model under study is necessarily holistic. It covers all aspects of a consumer's life and incorporates the findings from chapters eight and nine, the consumers and carers respectively. It also features insights that are a necessary part of good evidence-based social work practice from a social justice perspective. The insights are designed to complement and reinforce the consumers' and carers' contribution and are mainly strategies that can assist social workers to operationalise the model. The rationale for bringing my own voice into the

discussion of the recovery plan is based on my professional experience in mental health services and research into contemporary models of service delivery.

Consumer and carer participation in the development of plans for their treatment and care promotes the development of a partnership between the consumer, carer and the MHP. It is essential that all plans are agreed to by the social worker and the consumer and carer, be free of unnecessary jargon and updated on a three monthly basis. Ideally, the plan will be recorded electronically on a central database whereby other MHPs can access the document when individual case managers are on holidays or sick. This will also assist new case managers if the consumer is referred to another team, or moved elsewhere in Queensland Health's Northern Zone network.

Holistic scope of the recovery plan

A mental state assessment is the first review undertaken with consumers when they enter the system. This assessment is often facilitated by a social worker. It involves an appraisal of individual consumers' general appearance, their behaviour, speech, appetite, sleep pattern, orientation to time, place and memory. It also includes a review of impulse control, insight, judgement, thought processes and perception. Finally, the consumer's mood, substance use, psychiatric history, personality issues and personal history are documented.

The mental state assessment is followed by a medical examination. This is necessary to discount any physical factors that may affect a consumer's mental state, for example, thyroid or malignant tumour. This includes recording any history of injury or inherited problems with a particular focus on suicidality. This is followed by an evaluation of the impact of positive and negative symptoms of schizophrenia on the consumer and their families. Problems revealed in the medical assessment can be followed up to ensure that consumers receive optimal treatment. It is also important for social workers to assess a consumer's attitude to health care and the extent to which they can access health services autonomously. The onus is also on social workers to ensure that information on health risks, such as those related to sexuality, drug abuse and preventative screening are understood. General health issues such as sensory, nutrition and mobility problems can be part of a physical health assessment. This includes information on the side effects of psychotropic drugs and other medication, risks to health in physical environments and other major injury or illness, such as head injury or diabetes. Obviously many of these issues

cannot be addressed by a social worker. However, it is their responsibility to ensure referral is timely and effective.

It is essential that a consumer's individual potential for identifying strategies for dealing with symptoms and their recognition of early warning signs are evaluated. This includes their capacity to identify more and less effective strategies for dealing with stressful events. This can include attitudes to seeking help, judgement and decision making. It is the role of the social worker to discover a consumer's ability to use positive strategies for dealing with stressful situations and the identification of problematic coping mechanisms, such as, alcohol and drug use. It is crucial that a consumer experiencing negative effects of past events such as, sexual abuse is referred to the appropriate services for therapeutic intervention.

To ensure an optimal outcome from serious mental ill health, it is necessary for social workers to unearth a consumer's confidence in, or confusion with their identity. This may involve personal turmoil and distress related to mental illness and the loss of their previous self and their dreams of a healthy and productive future. It can also involve the resolution of trauma related to illness and treatment experiences, such as embarrassing behaviour, loss of children or estrangement from loved ones. A consumer's self-esteem is affected by the diagnosis and prognosis of schizophrenia. Feelings of distress, anxiety and sadness are commonplace and are often compounded by the lack of control consumers experience over their life and the availability of appropriate support. Social workers can assess consumers in regard to their strengths, which may involve coping skills, humour, hopeful attitude and a strong sense of self. A consumer's personal explanatory model of mental illness requires exploration and how it fits with the service and family cultures.

It is paramount that the safety of a consumers' physical and emotional environment is investigated. This can include any current or previous experience of physical or sexual abuse by others. In the words of a social work participant in chapter seven "why are mental health consumers being sexually abused? There seems to be so much sexual abuse in their background". This section of the recovery plan can also address potential high risk behaviours, such as wandering in traffic, intentional self-harm, suicidality and the risk of violence towards others, particularly family members. Several carers in chapter nine voiced their fear of physical violence from the cared-for when unwell, or using illegal substances. Finally, if the consumer has children, it is crucial that the children's physical and emotional security is explored.

The diagnosis of schizophrenia has an enormous affect on families as described in literature and the experiences of the consumer and carer participants in this study. Social workers can assess the family's attitude towards the illness and their cultural perspective on seeking help and response to the cared-for's illness. A sensitive assessment can reveal tensions in family relationships, and pinpoint feelings of guilt and blame harboured by family members. It can also discover the resources and strengths within the family. Special consideration should be given to the family's economic position and any existing health problems that may impact on the degree of support offered to the cared-for. It is also important to reveal the degree of isolation or connectedness the family experiences with the community and the special needs of any children of the cared-for. If children are undertaking the role of primary carer, their needs require assessment as a matter of urgency. Social workers are also obliged to discover if the consumer has any children in the care of the Department of Child Safety. A major finding of this study is the plight of consumer mothers and grandmothers regarding their inability to access their children and grandchildren. If a consumer has children in care, an immediate, collaborative relationship must be forged with the case-worker at Child Safety, to ensure that consumers and carers are receiving fair and equitable access to children.

Consumers and carers deserve every available support option in the formal and informal networks. To enable this, social workers are obliged to assess the skills training that are necessary to support consumers and carers in their unique daily living situations. This may involve an assessment of the level of concern or distress regarding performance of daily living skills. It can also involve the needs of children and elderly parents that depend on the consumer for personal care and survival. It is also important to evaluate the consumer's cognitive abilities, their social versus task issues and the impact on other family members of caring for a consumer.

Living with schizophrenia affects social relationships. This is mainly due to the myths, misunderstandings, negative stereotypes and attitudes directed at both consumers and carers that often result in isolating them (Buckland, 2005; Clayer, McFarlane, Czechowicz, & Wright, 1991). Therefore, mapping consumer's and carer's support systems offers social workers insight into the extent and quality of their friendship network and the level of enjoyment and satisfaction they gain from existing relationships. It is also important to investigate the levels of comfort or anxieties gained from existing relationships and identify any practical barriers to friendships, such as previous experiences of trauma with relationships. Another important aspect of exploring social relationships is to ascertain the level of support offered to

consumers and carers within their family relationships. This is useful information for predicting future requirements for increased services and the need for respite.

The use of illegal substances in conjunction with psycho-tropic medication is well documented (Piatkowska & Visitona, 1989; Rosenhan & Seligman, 1989) and consumers with a dual diagnosis are notoriously difficult to work with. Furthermore, the historic and present difficulty encountered when attempting to get consumers co-casemanaged by mental health services and drug and alcohol services compounds the problem. Often the illegal drug abuse becomes the primary focus for intervention for MHPs. Therefore, when working with dual diagnosis, it is important for social workers to discover the type of substance/s used; the amount ingested or injected and the consumer's tolerance levels. It is also crucial that social workers investigate the withdrawal symptoms of individual consumers. This investigation can be followed by charting the time spent by the consumer obtaining, using and recovering from the use and their attempts to cease using the substance. It is also important to ascertain the social, occupational or recreational activities associated with use and the effects of use psychologically and/or physically. A non judgemental attitude should be maintained by social workers attempting to instil a desire or willingness to change the drug habits of consumers. It is also necessary to ensure that consumers gain the confidence to change use and for social workers to ensure that consumers receive education on harm minimisation by adopting safe practices when using illegal drugs.

Social workers should ensure that the availability of housing options matches the preference of the consumer as far as possible, including their financial circumstances. If agreed to by the carer and family, housing should be in close proximity to the family home. This is particularly pertinent if difficulties with transport are a problem for both consumers and carers. Specific support needs influenced by symptoms, gender or cultural issues may need to be considered as part of the assessment. If alterations to housing are necessary for physically disabled consumers then referral for an occupational therapy assessment is required.

If a consumer is living with their family it is important to assess the impact of the arrangement on other members of the household. Other factors involved with consumer housing is the consumer's ability to live with other people. For example, pacing, hallucinations, delusions, specific behavioural problems and insomnia tend to escalate conflict in shared housing. Consumers require a review of their ability to live with other people and share the responsibility for household tasks.

People with schizophrenia often live in poverty (Burdekin, 1993). They depend on their Disability Support Pension and often receive additional funds from other family members, friends and particularly from their carers. Social workers, as part of the overall assessment can assist consumers and carers to work out the financial requirements necessary to meet lifestyle needs. Potential sources of additional income should be assessed and the consumer offered assistance to access the skills demanded by specific employment opportunities.

Consumers who budget well should be offered a high level of autonomy over their finances by enabling them to take charge of spending for major purchases and everyday living. However, in particular circumstances it may be deemed necessary to have a consumer's pension managed by the Public Trustee. This decision should not be taken lightly by social workers or in isolation from other family members. Unfortunately, many consumers fall prey to exploitation by others, or experience problem spending directly related to drug addiction or hyper-manic episodes. Under these conditions, consumers' funds require protection to ensure enough money for food, rent and the associated costs for basic daily living. Placing consumers under the administration of the Public Trustee should not be viewed as a permanent arrangement. If a consumer recovers from drug addiction or their problem spending is alleviated by medication and therapy, social workers can recommend a review by the Guardianship Review Tribunal.

A consumer who has debt or unpaid fines will require advocacy by a social worker. This can involve approaching financial institutions to arrange the debt to be paid back in smaller payments. If unpaid fines are the problem, social workers can write to the Clerk of Courts and arrange for the outstanding fines to be converted to fine option community service hours. Further advocacy with the Department of Corrections can assist consumers by ensuring the nominated place of work is accessible to their home and the type of work is achievable within the parameters of their illness.

For social workers to provide high-quality psycho-education, it is important for consumers and carers to acquire written and verbal information on the diagnosis, options for treatment and possible prognosis. They also require information on the potential benefits, adverse effects, costs and choices with regard to medication use and other technologies. Social workers need to ensure that consumers and carers are fully conversant with the stages and range of care available and how they pertain to them. This includes an overview of assessment, case review and how the *Mental Health Act* 2000 guides and informs case management. Social workers need to be

cognisant of consumers' and carers' levels of education and their literacy skills and where necessary address any deficits in this area.

Psycho-education is not only about information giving. It is a therapeutic intervention whereby skilled social workers pick up expressions of grief and loss and address these within the group, or later at individual consultations. Carers in this study are both aware of the problems encountered when psycho-education is inadequate and grateful when it meets their unique needs. It is crucial that social workers remember that a psycho-education group that is attended by one or more Indigenous people must have an Indigenous mental health worker as co-facilitator. This is not negotiable, as social workers with grounding in cross cultural training are no substitute for the role of an Indigenous mental health worker (McGrath, AMHCA, 2000).

It is essential that the effects of poverty on consumers and carers living with schizophrenia are not over looked. Assisting consumers into employment does not receive the priority or resources required. Describing the affects of poverty Beresford (2001) stated "In terms of loss of choice and hope, sense of fear and worthlessness and sheer wretchedness I would not wish it on anyone…" (p. 2). Paid employment is a goal cited by some consumers in this study. To maximise the chance of gaining employment it is essential that consumers set their own objectives. Social workers can contribute to the success of consumers gaining employment by documenting a consumer's previous work, leisure, educational experiences, personal interests, motivation levels and current skills. It is also important to assess a consumer's capacity for new learning, problem-solving, concentration and memory.

It is crucial that consumers are not encouraged to go for job interviews until their illness is stabilised. The impact of negative and positive symptoms on consumers can interfere with them holding down paid employment and failure in the workplace can deter consumers from trying again. A good starting point for social workers is to get consumers interested in opportunities for staged involvement in activities that are meaningful to them.

Through therapeutic alliance, social workers become aware of the unique features of consumers' and carers' cultural, religious and spiritual beliefs, and the values and practices that underpin their beliefs. This enables an evaluation of ways that particular values relate to or affect treatment and support. Historical factors such as the 'stolen generation' may affect current circumstances. For example, Indigenous

consumers and carers may exhibit anxiety if a social worker has to assess the welfare of children living with a parent who has schizophrenia. Indigenous consumers and carers and those from overseas that may have been exposed to warfare or persecution should be encouraged by social workers to talk about historical factors, if any, that are relevant to their current circumstances.

It is also important for social workers to explore the role of the family and community in regard to treatment and support. This includes communication issues and access to local resources. If possible, consumers and carers should be linked into services that are culturally appropriate. Social workers should also exhibit sensitivity to consumers' and carers' religious and spiritual affiliations by validating the consumers' and carers' belief system. This requires a non judgemental attitude and may involve assistance with transport to enable consumers and carers to access places of worship or fellowship.

In common with other people in society, many consumers and carers are turning away from mainstream religions, but they are still searching for spirituality, meaning, or connectedness through different approaches. For example, for many it is a more philosophical and questioning exploration. Others search for meaning through creative and artistic expression, love of environment and ecology, or acts of altruism. Consumers and carers should be encouraged to explore spirituality in ways that are personally and culturally relevant to them. Social workers can incorporate a spiritual history of consumers and carers and discuss issues of hope and forgiveness in their recovery, and train them in meditation techniques. For some consumers and carers it is the first time they have tried anything like meditation, but the opportunity offers a way of making sense of their illness and feelings of hopelessness.

People with schizophrenia are vulnerable to abuse of their human rights (Burdekin, 1993). In the opinion of Clarke (1994), a lack of education results in only a small percentage of consumers having an awareness of basic human rights and fewer still have knowledge of specific rights relating to services. Therefore, it is crucial for social workers to ensure consumers and carers have the ability to understand their rights. They are also obliged to inform consumers and carers about advocacy groups and their rights in relation to mental health care, tenancy, health care and income security. Consumers are entitled to choose an Allied Person who acts as a support person and advocates for them independent of the mental health service.

Consumers without family or those abandoned by family should be informed about the role of the Adult Legal Guardian. This person has different powers than those enshrined in the *Queensland Mental Health Act* 2000. An Adult Guardian can assist social workers with advocacy when the guardian recognises and agrees with the solution to specific problems. A guardian also has the power to make decisions that ensures a consumer's safety. When informing consumers and carers of their rights it is important to fully explain the role of the Public Trustee as some consumers voluntarily place themselves under their administration after hearing that they manage funds by paying rent, electricity, telephone and pharmacy bills direct, and also offer consumers enough money for their daily living needs whilst holding a nominated amount for savings.

Consumers experiencing outstanding legal issues should be offered assistance with accessing legal services and specialised mental health services, such as forensic services. Social workers must ensure good partnerships with other services in the court system so that consumers' unique circumstances are understood and opportunities for positive discrimination pursued.

General practitioners

The general practitioners that consumers attend in the community should be invited to be part of the recovery plan. Several consumer and carer participants in chapters eight and nine expressed their concern that mental health services fail to involve their doctor by keeping them informed about individual consumers' progress. Psychiatrists also fail to refer consumers back to their doctors once stabilised on medication. Consumers in this study experienced feelings of normality when attending their doctor's surgery in the community. However, after entering the mental health system they are case managed by MHPs and their files remain open after they have reached an optimal level of mental health recovery. Therefore it is important for social workers to ensure that a consumer's doctor is invited to case reviews and kept informed about their mental health state. Social workers must advocate with the psychiatrist on behalf of consumers who are willing to return to the care of their doctor and have their file closed at mental health services. In the event of relapse, and the doctor refers a consumer back to mental health services, it is simple to re-open the file. Consumers deserve to be mainstreamed back to their doctor and social workers must facilitate this.

Planning for relapse

The experience of relapse is part of the recovery process. It is paramount that social workers view regression by consumers as a normal part of recovery and not penalise consumers when they reach this part of the recovery cycle. The relapse section of the plan should clearly document consumer and carer objectives and priorities. Plans should present negotiated solutions to difficult issues such as unrealistic objectives, concerns about risk and tensions between consumers and carer priorities. Solutions are not always forthcoming. Therefore, when reciprocal satisfactory solutions between the social worker and consumer are impossible, the points of divergence should be clearly presented.

Key formal partnerships

To enable social workers to address the human rights abuses of consumers and carers reported in this study, it is crucial that partnerships are formed with specific government departments. This is challenging because both clinical and social profiles of persons with severe mental illness focus on characteristics that make service delivery difficult. Besides suffering from serious mental ill health which is often compounded by drug and alcohol abuse, consumers often lack family and social supports, have frequent encounters with the criminal justice system, exhibit serious medical problems, and live in extreme poverty. The key formal partnerships identified by the consumer and carer participants in this study involve the Department of Child Safety, Drug and Alcohol Services, the Police Department and General Practitioners.

Department of Child Safety

The most urgent area of need occurs between the Department of Child Safety and Community Mental Health Services. Reports by consumers involving the removal of their children by this department and the permission received by their husbands to remove children interstate without regard to the feelings of the mother is inhumane treatment. In addition, consumer mothers report the lack of access they receive regardless of the visits being supervised by child support workers. Social workers in mental health services have to approach this department and together draw up a formal partnership agreement that immediately addresses these issues.

Drug and alcohol services

Many carers reported in this research have concerns regarding the cared-for's use of illegal drugs. The difficulty encounter when attempting to get drug and alcohol services working together with mental health services was mentioned previously in this chapter. If an attempt by social workers in mental health services to form a partnership with the social workers at drug and alcohol services fails, one way forward is for the social workers at mental health services to approach their counterparts at drug and alcohol services and arrange for on-going in-service training. The propensity for consumers to fall through the net due to the inability of both services to form partnerships and work together must be addressed by social workers.

Queensland Police Department

In chapter nine several carers had concerns regarding the cared-for's involvement with the police and in particular their experiences at the local police watch houses. The LIMHS has a memorandum of understanding between the State of Queensland through Queensland Health and the State of Queensland through the Queensland Police. It is agreed to and signed by the Director-General and the Police Commissioner in May of 2001. The memorandum of understanding commits both agencies to work in full cooperation to promote a coordinated system of care to ensure effective and efficient delivery of services to meet the needs of people with a mental illness, who may from time to time, require assistance from both services. Both agencies agreed to develop formal arrangements at the system level to identify respective responsibilities and to resolve issues which may impede effective interventions. It promotes best practice in the care of people with a mental illness in situations which involve both services. Social workers can use this memorandum of understanding as a basis for advocating for consumers and carers with their local police.

General practitioners – shared care

Social workers need to forge good relationships with each individual consumer's doctor and offer them shared care. Often the doctor has worked with the whole family over many years and is aware of the family dynamics. Perhaps consumers and carers prefer treatment by their family doctor over a psychiatrist, as the doctors may conduct themselves in a polite and respectful manner, compared to the offensive approach by some psychiatrists reported throughout this study. Social workers can ensure that consumers have a general practitioner in the community. If not, they can

be asked to nominate one. Once the psychiatric assessment has been completed all findings and the treatment plan should be forwarded to their doctor. General practitioners can also be invited to be part of the treatment plan if consumers consent. Once the consumer's management is stable and on completion of the specialised treatment plan, consumers should be discharged back to their nominated doctor. Further consultation and discussion of needs or advice from LIMHS should be available to the doctor through the case manager over the phone, or by making an appointment to review the case in more detail.

Future research activity

The AASW (1999) reminds social work researchers of their duty to "bring research results that indicate or demonstrate social inequalities or injustices to the attention of the relevant bodies … [and] where feasible, inform research participants or their representatives of research results that are relevant to them" (p. 20). Social work practitioners should be active in influencing research agendas to ensure that everything they learn of the intolerable conditions through their daily practice is exposed and understood. The distinction that separated social work theory from practice is unhelpful. Therefore, it is crucial that social workers are able to demonstrate to individual consumers, carers and other service providers that the work undertaken contributed to better outcomes for the consumers and carers who use the service. Consumers and carers need to be consulted about what research questions they want answered and participate in the research process. For example, they might have input into service design or assist in conducting the research carried out from within the mental health service.

Suicide and schizophrenia

One of the major research priorities unearthed from discussions with consumer and carer participants in this study, focuses on the fear both consumers and carers harbour regarding people with schizophrenia dying from suicide. Consumers are fearful when a peer successfully takes their own life. This is due to both the loss of a friend and the reality that it may also happen to them. Carers are preoccupied with the possibility that the cared-for can die from suicidal activity. This finding suggests that an important research focus for social workers is in the area of schizophrenia and suicide. Research into suicidality and the services set up as a result of that research have clearly failed. This may be due to a focus of suicide as a symptom of schizophrenia. Therefore, future research activity may need to focus on appropriate hospital discharge planning processes and the community resources necessary to

adequately resettle the consumer in the community after leaving hospital. It may also need to focus on the relationship between the impact of forced involuntary treatment and the consumer's hope for a quality future.

Issues with children

Studies that focus on mothers with schizophrenia's plight over custody and access to their children in the care of the Department of Child Safety is another area that requires urgent research activity. Several mothers reported in this study had their children removed and access limited solely due to the perceptions held by officers from Child Safety towards people with schizophrenia. Their perceptions are largely based on the myths that surround the illness. It is paramount that social workers use the research skills gained through their training to discover models of service delivery that enable the Department of Child Safety to work with these mothers and address this major breach of their human rights.

Ageing with schizophrenia

Another area that requires research according to the participants in this study is the plight of people ageing with schizophrenia. This concerns both consumers and carers alike. Consumers are aware of the current one size fits all approach to activities at the day-centre programme. Indeed, a consumer participant in chapter eight stated that to her, participation means the ability for MHPs to recognise that consumers require continual review as they grow old. Issues that hold significance when consumers are young change over time. Research in this area could focus on the changing needs of consumers through their life journey. This includes developing strategies to assist them to better cope with the death of elderly carers. It may also assist consumers that currently do not have satisfactory solutions for aged care placement. They are predominantly placed in facilities that cater for people with dementia.

Day-centre programmes

Through the literature search for this study it was evident that there is a dearth of information relating to inclusive, innovative day-centre programmes. Most of the literature focuses on drop-in centres that offer limited activities to consumers. Other literature focuses on the Clubhouse Model (Glickman, 1993), which is more appropriate for larger centres than Lantana with its population of 120,000 people. The importance of developing new models of day-centre programmes is one of the major findings from chapters eight and nine. Consumers and carers cite this resource

as central to their lives and wellbeing. A study that takes into consideration the demography, geography and the unique needs of the population of people with schizophrenia can identify the future direction for workable day-centre programmes in Lantana.

Incidences of sexual abuse

The prevalence of past episodes of sexual abuse endured by consumers with schizophrenia troubled a social work participant in chapter seven. She considers it serious enough to warrant further investigation. My professional encounters with consumers and those of my colleagues have also exposed many accounts of sexual abuse both prior to and during the onset of schizophrenia. At times psychiatrists sweep consumers' claims of sexual abuse under the carpet preferring to view their disclosures as delusional. The potential for sexual abuse to trigger an enduring, serious mental ill health is an area of research so far neglected by academics. The incidence of sexual abuse on people who develop schizophrenia and its relationship with the onset of serious mental ill health is an important focus of enquiry.

Part Two: a model for committee, participation and training

The model described on the following page outlines the roles of the consumer and carer consultative committee and the training needs for both social workers and consumers and carers. It also contains ideas for professional social work supervision.

Figure 11.3: Committees and training

IMPORTANT
Consumers & Carers are entitled to decline an offer to participate in service delivery, planning and evaluation of mental health services without penalty

Consumer and carer consultative committee
Consumer and carer sits on the Executive
Consumer and carer sits on all clinical staff selection panels
Provides advice on social and clinical matters
Provides input into policy and planning
Involved in all aspects of service evaluation
Plays a surveillance role
Provides training for case managers
Assists with psycho-education

Social Workers   -   EDUCATION AND TRAINING NEEDS   -   Consumer and Carers

National Standards for Mental Health Services
Competency Standards for Mental Health Social Workers
Carer's framework
Consumer's framework
Writing skills for publishing mental health issues
Research skills
Community development
Cross-cultural training

Professional Supervision

Social Work Director

Psycho-education
Micro-skills
Cross-cultural training
Group skills
Qld Mental Health Act 2000
Public speaking
Participation & partnerships
Processes of recovery

One of the major findings of this study is that the majority of consumer and carer participants report a lack of interest in forming partnerships and participating in the mental health service. Indeed, some carer participants feel it is absurd to expect them to take on further burden in addition to the myriad duties they already perform (service delivery). Therefore, it is fair to assume that not all consumers and carers will take up the governments' invitation to form partnerships and participate in service planning, delivery and evaluation. Obviously this is their right and they require respect for their decision. This said, however, the indifference exhibited by particular consumers and carers should not to be used as an excuse for social workers and other MHPs to ignore the right of willing consumers and carers to participate in the process. In addition, social workers need to keep the invitation to participate open for unwilling consumers and carers, as the decision not to participate according to the participants of this study, is based on a diversity of long-term disillusionments with mental health services. Over time consumers and carers may come to realise that these policies, if implemented diligently by social workers and other MHPs, are an improvement on the past and may actually assist them. This is particularly so, when social workers adhere to a model of service delivery that incorporates a promotion, prevention and recovery focus.

Consumer and carer consultative committee

Committees responsible for decision-making about how the mental health service operates and for making decisions about the future directions of service delivery need to have mechanisms in place to ensure that the consumer and carer voice is represented. Therefore, a consumer and a carer consultant must attend the executive committee with consumer and carer feedback as a regular agenda item. An important aspect of the role is to provide advice on social and clinical matters. Although only one carer and one consumer is necessary for representation on the executive committee, a consumer and carer consultative committee is important to enable other consumer and carer members who are immersed in the concerns of consumers and carers through their committee, to sit on the executive when others are busy or experiencing a period of unwellness.

Staff selection panels

In chapter seven, a social work participant highlighted the value of consumers and carers sitting on staff selection panels. However, management, a number of social workers and consumers were ambivalent about this important role. Whilst the social workers' resistance is based on fear, the consumers' resistance may stem from a

lack of knowledge about the importance of the role. Consumers and carers do not have to hold insider knowledge of each discipline in mental health services (AMHAC, 2000). The role of consumers and carers is to offer feedback to the panel on their perception and intuition of how caring and passionate the applicant is about working with people with schizophrenia.

Policy, planning and service evaluation

The LIMHS is obliged to pay consumers and carers for input into policy, planning and evaluation. Membership on the executive committee allows consumers and carers to become involved in discussions around the implementation of new policies and planning for future services, or major changes to existing services. When new policies have been formulated consumers and carers must receive monetary reward for reviewing the policies before they are ratified. Consumers and carers must also be involved in facilitating surveys focusing on consumer and carer satisfaction with service delivery. Consumers and carers are also entitled to a private audience with the surveyors when the mental health service enters an accreditation cycle. Feedback to the accreditation committee must involve consumers and carers as well as the LCAG. This will ensure the accreditation committee receives a balanced view of the services on offer at the LIMHS due a conflict of interest when the LCAG is the only source of consumer and carer information.

Surveillance

In chapter seven a social work participant considered that consumers and carers could be more politically active, whereby they assume a watchdog role and report anything they are dissatisfied with to management. The consumer and carer consultative committee are in a central position to ensure that consumers and carers are not discriminated against. Incidences of abuse by MHPs and psychiatrists can be reported to the committee and in turn they can offer support to consumers and carers and practical assistance if they decide to formalise the complaint. In turn, If MHPs and psychiatrists are aware that the committee functions as a surveillance mechanism, it may assist with minimising the frequency of abusive treatment.

Training for case managers

It was suggested by many consumer and carer participants that MHPs must acquire knowledge of their lived experience. This includes the Indigenous experience. An important role for the consumer and carer consultative committee can be the facilitation of formal in-services for MHPs in the work-place. The in-services will cover the area of communication and explore ways that MHPs can involve consumers and

carers in activities that will decrease MHPs load and allow them to focus on clinical matters. MHPs will also learn that consumers and carers prefer talking therapies as an adjunct to pharmacological solutions. They will also learn of the dangers encountered when MHPs view consumers and carers from a personal frame of reference; a common practice in mental health services.

The consumer and carer consultative committee can contact the local university and offer input with curriculum design and their involvement with the delivery of lectures and tutorials. This will assist MHPs entering the field to gain first-hand knowledge of the lived experience and service delivery needs of consumers and carers. The presence of consumers and carers at lectures and tutorials will also assist new graduates to learn about the myths surrounding mental illness and the importance of dispelling such myths. At a more structural level, consumers and carers can highlight their powerlessness when dealing with government services that discriminate against them.

Involvement with psycho-education

A few of the carer participants in chapter nine were not satisfied with the way that some MHPs delivered psycho-education. One participant discussed the inability of a particular MHP to pick up on her feelings of grief at the loss at her son's future that could have been. Therefore, it is essential that psycho-education groups are facilitated by specific disciplines that are fully trained in the different strands of psycho-education. For example, it is necessary to have representation from social workers, nurses, occupational therapists and Indigenous mental health workers. Each discipline offers its own area of expertise and is not interchangeable. The onus is on each MHP to ensure they have sufficient training to work with this vulnerable group of carers.

The practice wisdom required from social workers

For a partnership model of participation to be effective a capacity for reciprocity is required. Social workers are required to move outside of themselves and practice trust, caring, empathy and compassion. Paulo Freire (1973) pointed out that "knowledge is not extended from those who consider that they know to those who consider that they do not know; knowledge is built up in the relations between human beings" (p. 109). Social workers are required to deconstruct old myths and assumptions and construct new meanings and understandings from these reciprocal processes. As new ideas and planning approaches emerge through conversations

with consumers and carers, the social workers' actions need to be purposefully framed by these processes.

Standards and competencies

Social workers are obliged to develop a good working knowledge of the *National Standards for Mental Health Services* (AHMA, 1996) and the *Competency Standards for Mental Health Social Workers* (AASW, 1999). These documents spell out the way social workers are to work with consumers and carers. Social workers and other MHPs working with consumers with schizophrenia need to adopt a practice framework that is defined by official documents and the people they work with. Previously in this chapter, a framework for working with consumers and carers was described and documented from the findings of chapters eight and nine. According to the consumers and carers, they want courteous behaviour from MHPs and psychiatrists. This requires active listening and returning phone calls, respect, forgiveness, tolerance, sharing and genuineness. Consumers refuse to be viewed as 'too sick' to participate both in the service and in life generally, and carers do not want confidentiality to prevent them from assisting the cared-for. They appreciate humour and a case manager who views them as more than a mental illness. They want case managers to advocate for them and extend themselves in crisis situations.

Research and writing skills

Social work researchers with an interest in mental illness are obliged to undertake studies and publish their findings. Although there is an extensive growth in excellent consumer research, social workers are in a position to undertake research from the 'inside'. The consumers and carers in this study described the importance of social workers developing the skills that will enable serious breaches to their human rights to be exposed and addressed through research and advocacy. They also expressed a wish to have research commissioned that will improve their lives and the way they are perceived by the general public. Research methodologies do not have to be complex. Case managers have the training to undertake simple surveys in the work-place that will expose bad work practices and assist the development of more user friendly techniques.

Community development

Although working from a community development model was referred to in chapter six, as a perspective that social workers should adopt at the LIMHS, it is not part of the generic case management position description. Community development is a

strand of social work that is most important when working with communities such as people living with schizophrenia. However, this study involves social workers as generic case managers. Therefore, whilst acknowledging the benefit of community development to consumers and carers, it will not be discussed any further in this chapter.

Cross-cultural training

This study did not include participants from a culturally and linguistically diverse (CALD) population. This is solely due to the absence of people from a CALD background applying to become part of the research. It concentrates on mainstream Australian and Australian Indigenous cultures. Therefore, any need for social workers to gain cross-cultural skills is confined to Indigenous cross-cultural training.

The Indigenous participants in this study do not have any major problems with MHPs at the LIMHS treating them 'differently'. Two consumer participants stated that they do not feel any racism at the day-centre programme and they are treated the same as everyone else. Although the carers have problems with dislocation and missing the extended family, they are mainly positive with the services they receive from MHPs. However, MHPs need to keep abreast of cross-cultural training as Smallwood (1996) reminded us of the culturally inappropriate methods of assessment that leads to Indigenous people being diagnosed with serious mental ill health in disproportionate numbers to non Indigenous people. She also warned us of the danger with working from an Anglo-Celtic culture that dominates the Australian Health Care System and will not allow cultural safety unless MHPs have a keen awareness of the need for cultural competence. Social workers with skills in Indigenous cross-culture must note that they are no substitute for an Indigenous mental health worker.

The skills consumers and carers require

It is essential that consumers and carers are empowered. This involves shifting the balance of power from service providers to consumers and carers who have traditionally been powerless (Freire, 1973; Honey, 1996). This can occur when MHPs provide opportunities for consumers and carers to gain control over their personal lives by ensuring they have the information, knowledge and skills to participate and make choices about the processes they wish to involve themselves with. Empowered consumers and carers can also contribute to government policy development, the management of mental health services, non-government organisations, and peer

organisations (Meagher, 1996). It involves the recognition that people with a mental illness are valued members of the community who have influence over all things that affect their lives (Deegan, 1997).

Psycho-education

In chapter nine, a carer participant pointed out the value of psycho-education for the whole family. The family needs to know about specific disorders and their side-effects and the different drugs used to treat them. They also require education on the early warning triggers that precede an episode of unwellness and how to lower stress levels in the home that will assist both the consumer and their family members. Carers were keen to know how to lower their expectations of the cared-for during periods of relapse and strategies to adopt that will take the fear out of dealing with the cared-for when experiencing an acute episode. Carers wish to learn these skills as a matter of urgency, as they require the support network of friends and family to assist them through the bad times. Consumers and carers do not want skills in psycho-education to be the sole domain of MHPs. They also want to have the proficiency required to facilitate psycho-education groups.

Cross-cultural training

Indigenous carers should be trained with holistic approaches to psycho-education by an Indigenous mental health worker. Their needs are similar and different. In addition to the experiences they share with their non Indigenous counterparts, Indigenous carers experience location and environmental factors and the legacy of past practices such as removal from land, cultural dislocation, family separation and racial discrimination. The Indigenous carers in this study expressed a wish to learn about psycho-education in a bid to join with other Indigenous carers.

Group and communication skills

It is essential that consumers and carers gain group skills. Some of the carer participants in this study expressed an interest in setting up their own self-help groups. They also want to learn about psycho-education, in particular, issues of grief and loss that they can use to support other carers. The carers also want to learn how to set up a buddy system. Any training in groupwork by social workers must include teaching the consultative committee about committee dynamics and how to chair meetings. Consumers and carers must not be set up to fail. The most common request from carers is for training in assertiveness skills that will assist consumers and carers to communicate more stridently with the psychiatrist and some MHPs.

Social workers are obliged to find the time to teach consumers and carers' communication skills as a way of narrowing the gap in knowledge between MHPs and service users.

Queensland Mental Health Act 2000

It is crucial that consumers and carers gain insight into the *Queensland Mental Health Act* 2000. This includes processes of other government organisations that work closely with the *Act*.

It must not be underestimated how difficult it is for consumers and carers to gain information on important decisions made on their behalf. For example, the Public Trustee administers an involuntary consumer's finances. When a consumer demands to know exactly who the person is that decides whether they can purchase a particular item or not, the question becomes exceedingly difficult. The case-worker at the Public Trustee may tell a consumer to consult their case manager at mental health services and in some instances their Adult Guardian, then make a judgement based on either or both of their recommendations. If the consumer approaches the latter two players, they are often offered a similar response implicating the absent player.

This type of scenario is also played out in mental health services regarding decisions made by the Mental Health Review Tribunal. The case manager compiles the six monthly review of the involuntary treatment order and makes a recommendation to extend or revoke the order. However, the psychiatrist is also signatory to the review. The Mental Health Review Tribunal makes the final decision based on the case manager's report signed by both the psychiatrist and case manager. If a consumer wants to hold a particular person or committee responsible for the decision, it is impossible to identify one single person.

This is one of the most important of Foucault's insights with regard to power. That is, it is more effective when it (power) is obscure. In other words, although knowledge and technologies are employed to control and regulate consumers and carers, the official version of things is that they are working in their best interests and looking after them for their own good.

Public speaking

Speaking at public forums or meetings is a scary business for most people. However, it presents particular difficulties for consumers and carers living with schizophrenia

due to their marginalisation within society. Throughout this research personal stories of abuse and manipulation have been revealed. From this basis, it is fair to assume that this abuse has seriously eroded consumers' and carers' self-esteem and feelings of self-worth. Training consumers and carers to speak in public requires compassion and patience from MHPs. A safe environment such as, talking at consumer and carer meetings, is a good starting point. MHPs must be mindful not to use jargon and encourage consumers and carers to progress to speaking about their lived experiences at schools and universities if they wish. Consumers and carers who want to progress to speaking at conferences, should be encouraged and offered monetary assistance to present at conferences such as the annual THEMHS conference. This forum encourages consumers and carers to present papers on their personal experiences and experiences and opinions of service delivery.

Participation and partnerships

The consumers and carers in this research are clearly located at the lowest level of the ladder of participation as defined by Arnstein (1969). They experience non participation thus support the belief of Croft and Beresford (1992) that most of the current initiatives focusing on marginalised groups fall into Arnstein's first category namely manipulation. This concept is non-participative.

For participation and partnerships to be effective, consumers and carers need to understand what it means. Social workers and other MHPs need to explain Standard 3 of the NSMHS (AHMAC, 1996) to consumers and carers and analyse each individual's response to the concepts. Drawing from the inspiration of Paulo Freire (1973), individuals do not gain critical awareness by being "empty vessels" to be filled with knowledge or ideas from government's policies and standards. They can come to accurately understand themselves within the context of participation and partnerships by a process of praxis. By employing Freire's techniques of problem-posing, and of analysing problems from a position of personal, cultural and institutional perspectives, MHPs can work with consumers to facilitate their individual and collective empowerment through participation and partnerships. Consumers and carers must be offered this opportunity of personal understanding as a response to genuine service delivery.

Processes of recovery

The idea of recovery is an emerging paradigm (Anthony, 1993). Recovery is a key standard of the *National Mental Health Plan 2003-2008* (AHM, 2003). For consumers and carers to reach optimal levels of recovery, it is necessary for MHPs to teach

them that recovery does not mean absolute cure. Recovery is an individual journey that consists of a process of empowering individual consumers and carers to find new meaning and purpose in their lives. Previously in this chapter, a recovery plan was outlined. It was an attempt to pull together the needs of the participants in this study with a workable framework focusing on recovery. MHPs can train consumers and carers on processes of recovery through in-depth discussion on how such a plan would benefit them to reach their own individual recovery.

Professional social work supervision

The director of social work is located at the Lantana Base Hospital and represents all social workers in the LIMHS. Her substantive position is "the social worker in charge" at the Lantana Base Hospital; therefore she does not necessarily have experience working in mental health services. This lack of specialised mental health knowledge deters mental health social workers seeking her out for supervision. This is understandable as far as practice content is concerned. However, this situation also means that mental health social workers' issues are not fully represented on the executive committee of the LIMHS. Obviously this disadvantages the social workers in the long-term. It is proposed that mental health social workers strike an alliance with the director in a bid to get their issues on the agenda of the executive and her support for professional development opportunities.

Through this research it was revealed that mental health social workers are receiving supervision from medical staff. This is not acceptable as it promotes an unquestioned acceptance of the medical model and support for the genericism of MHPs. The manager was clear that professional seniors would not be funded. In conjunction with the social work director, mental health social workers can set up peer supervision. There are several social workers at LIMHS that have over 20 years practice experience in mental health services. Sharing their experience in a group peer supervision setting is a powerful tool. If the mental health social workers are committed to meeting as a collective, issues such as professional development and the training of consumers and carers can be discussed and planned. Inviting consumers and carers to join them will assist mental health social workers to hear their unique perspective. The director of social work can advocate with the manager to provide time for social workers to meet on a monthly basis. The social work director can also assist with the training of both the social workers at the LIMHS and the consumers and carers, in the areas of need described by them in this study.

How is this model similar to other models and how is it different?

The model discussed in this chapter is unique to one organisation. However, as documented in chapter four, it can be transferred to other organisations if the reader chooses to implement it at a compatible location. It is similar to other models of mental health services as it retains the Expanded Broker Model and the Full Support Model (assertive outreach) that dominates mental health service delivery in Australia. The difference is that the model described in this study excludes the facilitation of medication and encourages social workers to engage with consumers and carers in a different way. This model is also different as it is informed by consumers and carers who live with schizophrenia. It is what they want.

Why other models have not been fully implemented

Other models of service delivery have not attempted an in-depth analysis between the needs of all stakeholders that integrates the requirements of government and a specific organisational management culture with consumer and carer needs. Traditionally, models of mental health service delivery have mainly adopted a symptom management approach to service delivery that often results in the person being treated as an illness and not as a person. Models of service delivery that focuses on partnerships between social workers at the LIMHS and local consumers and carers has not previously been implemented in Lantana because there has not been a uniformed approach to implementing the policies across the organisation.

Existing attitudes in Lantana include resentment from the process being viewed as too much work, insufficient time to work in this mode and not enough funding to implement the policies (see chapters five, six and seven). This culture makes it difficult to focus on empowerment, strengths, consumer-focused care, participation and recovery. For many people, these are new concepts and are hard to adopt. Furthermore, psychiatrists continue to demand consumers, carers and MHPs worship them as revered experts, dominating a hierarchical system that reinforces their privileges and distances them from the people with which they work. The model described in this chapter challenges old constructs. Government policy now makes it very clear that mental health services need to adopt a consumer-focused service delivery model. It requires MHPs to explore personal concerns over shifts in control, in boundaries, and in the therapeutic use of self.

Present climate and how the model might work in this climate

In 2004, LIMHS received funding to set up rehabilitation services in the community. The development of the rehabilitation service has been a gradual process hindered by the difficulties encountered with acquiring suitable buildings and the stringent approval processes determined by the Department of Public Works who oversee the purchasing, or leasing of government buildings. The project has also been delayed through a backlash by community groups against setting up psychiatric rehabilitation services in their neighbourhood. Unfortunately their concerns were upheld by the Lantana City Council on several occasions.

The team referred to in chapter one as the Mobile Intensive Treatment Team has been expanded, transformed and renamed. The team retains its original aims of maintaining people in the community with chronic schizophrenia who do not respond to anti-psychotic medication. However, the expanded team has received in-depth training in psychiatric rehabilitation services in readiness to receive consumers exhibiting signs of, or expressing a desire to be rehabilitated. The rehabilitation services will also focus on consumers experiencing symptoms of early psychosis. It is envisaged that the new psychiatric rehabilitation service in Lantana will be ready to accept consumers at the beginning of 2008. This new development at the LIMHS presents an opportunity for social workers and other MHPs to adopt a different model of service delivery.

Recommendations arising from this study for LIMHS programmes

1. That management is restructured to either be comprised solely of administration exclusive of any professional discipline being represented (including psychiatry) or, and preferably, that management is represented by administration and each discipline of LIMHS including social work, occupational therapy, psychology and nursing and further, that meetings embrace wider than psychiatric considerations. Note that the psychiatrist must not be made the representative of other disciplines. A multidisciplinary focus will enable both a psychiatric assessment and plan of action and an assessment that incorporates diverse circumstances –social, physical, material and political – whole "messy lives". This recommendation is made directly from the data of consumers and carers.

2. That a support group comprising carers and administered by carers is funded and strongly supported through the resources of LIMHS. This body must be comprised separate from the LCAG. This recommendation arises strongly from carer data.

3. That LIMHS supports the LCAG more fully in providing resources and forums for the LCAG to truly represent carers and consumers in an 'advisory' capacity.

4. That social workers be commended for interfacing the intersections of medicine, psychiatry and social-political-material aspects of consumers and carers lives and that social workers be given increased overt license from LIMHS to continue to interface consumers and cares and wider systems in ways that advocate the rights of consumers and carers.

5. That a senior social worker be appointed to LIMHS to drive the 4. above and to represent social work at management level as per recommendation 1.

6. that an education programme on schizophrenia be developed and offered to all consumers and carers at intake or at another suitable time, which focuses on: diagnosis, future implications for consumers and their families; drug treatments including side-effects; coping with a loved one during a psychotic episode; international examples of best practice, of and with, carers and consumers and other issues important to consumers and carers.

7. That family engagement occurs as a matter of course upon a person, who relies in some way on their family, being admitted to a psychiatric facility.

8. That a protocol be developed for debriefing carers and/or families after their loved one has experienced a psychotic episode.

9. That a protocol be developed for engaging members of the day-centre programme in a debriefing session upon the suicide of a peer.

10. That a protocol is established for ensuring that the human rights of both voluntary and involuntary consumers are accounted for in any procedure with them.

11. That the day-centre programme be commended for its importance in the lives of both consumers and carers. This programme needs to be strengthened and provide opportunities for its administration by consumers themselves.

12. That LIMHS begins to demonstrate adherence to all criteria of Standard 3 of the NSMHS (1996) and has a monitoring procedure to account for this adherence. This must be conducted with a view to both the tasks of Standard 3 and the spirit of Standard 3, which demands facilitative conditions of empathy, trust, respect, reciprocity and openness.

Conclusion

To change the system social workers have to understand it. An attempt was made in this research to use the works of Anthony Giddens and Michel Foucault to assist in understanding how we as social workers and how consumers and carers are constituted by and through institutions, practices and ideologies of power. This insight may empower social workers to understand their positioning within their organisations and the way that power influences and informs their daily practice and decision-making. Social workers may then throw off the 'blinkers' and see both the way ahead and consumers and carers through a different lens.

This final chapter has drawn conclusions from each of the results and analysis sections in chapter's five to ten respectively. Strategies for a new model of social work service delivery from a social justice perspective were elucidated in this chapter. The predominant aim of this research was to describe what model of social work service delivery within mental health prioritises the required partnerships for consumers diagnosed with schizophrenia and their carers. Strategies for the new model were therefore drawn from what these participants believe to be "true". Given that a primary focus of a social justice perspective is to hear clearly from persons who are in a dispossessed or disadvantaged position (Ife, 1995), and that "truth" is experienced uniquely and is more important to unravel than acceptance of dominating discourses (Foucault, 1972), then the voice of the participants must be heard in terms of the model of service delivery drawn from this study. No other "universal truth" is being credited above the "truth" of the participants within this study.

This study has substantial implications for the practice and teaching of social work with people who experience serious mental ill health. It is a tribute to those participants who gave so honestly and freely of themselves to make this study possible. Many of the participants expressed the desire to make the world a better place for people with schizophrenia. It is my heartfelt hope that the insights gained through this study will make a contribution towards that aim.

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Appendix One: Standard 3 – Consumer and Carer Participation

Consumers and carers are involved in the planning, implementation and evaluation of the MHS.

Criteria

3.1 *The MHS has policies and procedures related to consumer and carer participation which are used to maximise their roles and involvement in the MHS.*
Notes and Examples: The policy acknowledges that consumers and carers should be involved at every level of the MHS, the different expertise and interests that each group may have, identifies the requirements of each group in terms of information, equipment, space and budget, and whether consumers and carers want collective or separate representation.

3.2 *The MHS undertakes and supports a range of activities which maximise both consumer and carer participation in the service.*
Notes and Examples: Establishment of advisory committees, consumer carer networks, consumer/carer evaluations of the MHS, establishing and maintaining contact with consumer/ carer groups, public meetings, consumer/carer participation on staff recruitment processes, consumer/carer participation in peer and staff education & training, provision of space and equipment for consumers and carers to use.

3.3 *The MHS assists with training and support for consumers, carers and staff which maximise consumer and carer participation in the service.*
Notes and Examples: Training in peer support, consulting, staff selection, computer skills and financial management.

3.4 *A process and methods exist for consumers and carers to be reimbursed for expenses and/or paid for their time and expertise where appropriate.*
Notes and Examples: Advice is sought from State/Territory Consumer Advisory Group (CAG) to determine rates of payment, a budget (which may be separate for each group) is managed by the consumer and carer representatives.

3.5 *The MHS has a written statement of roles and responsibilities (code of conduct) for consumers and carers participating in the service which is developed and reviewed with consumers and carers.*
Notes and Examples: Advice sought from State/Territory CAG, covers areas such as confidentiality, accountability, responsibilities, rights and conflict of interest.

3.6 *Consumer and carers are supported to independently and individually determine who will represent the views of each group to the MHS.*
Notes and Examples: MHS supports a confidential mail-out to current clients which enables elections for representative positions.

3.7 *The MHS monitors its performance in regard to the above criteria and utilises data collected to improve performance as part of a quality improvement process.*
Notes and Examples: The MHS continually monitors and reviews consumer and carer satisfaction with opportunities to participate in the MHS.

Sourced: National Mental Health Standards (1996)

Appendix Two: Consent Form – Management
<u>INFORMED CONSENT FORM</u>

I…………………………agree to be a participant in the research study Catherine Flanagan is conducting on the unique experiences of social workers, consumers diagnosed with schizophrenia and their carers. I understand that the themes emerging from the interviews of all members of management will be used for topics for discussion with consumers and carers. I understand that my experiences will be published as a Phd thesis in the School of Social Work and Community Welfare at the James Cook University, Lantana and that Professor Rosamund Thorpe is the supervisor of the thesis.

I have been advised and understand that interviews will be audiotaped and transcribed. The tapes will then be destroyed in a manner acceptable to me. Some of the issues that I discuss will be personally sensitive to me and I understand that I may halt the interviews at any time I choose.

I also understand that my name will not be used and that I may use any name I choose to protect my identity and anonymity.

signed………………..
Dated / / 2000

Witnessed……………
Dated / / 2000

Appendix Three: Consent Form – Community Development Worker
<u>INFORMED CONSENT FORM</u>

I…………………………agree to be a participant in the research study Catherine Flanagan is conducting on the unique experiences of social workers, consumers diagnosed with schizophrenia and their carers. I understand that my experiences will be published as a Phd thesis in the School of Social Work and Community Welfare at the James Cook University, Lantana and that Professor Rosamund Thorpe is the supervisor of the thesis.

I have been advised and understand that interviews will be audiotaped and transcribed. The tapes will then be destroyed in a manner acceptable to me. Some of the issues that I discuss will be personally sensitive to me and I understand that I may halt the interviews at any time I choose.

I also understand that my name will not be used and that I may use any name I choose to protect my identity and anonymity.

signed………………..
Dated / / 2000

Witnessed……………
Dated / / 2000

Appendix Four: Consent Form – Social Workers
<u>INFORMED CONSENT FORM</u>

I………………………agree to be a participant in the research study Catherine Flanagan is conducting on the unique experiences of social workers, consumers diagnosed with schizophrenia and their carers. I understand that the themes emerging from the interviews of all social work participants will be used for topics for discussion with consumers and carers. I understand that my experiences will be published as a Phd thesis in the School of Social Work and Community Welfare at the James Cook University, Lantana and that Professor Rosamund Thorpe is the supervisor of the thesis.

I have been advised and understand that interviews will be audiotaped and transcribed. The tapes will then be destroyed in a manner acceptable to me. Some of the issues that I discuss will be personally sensitive to me and I understand that I may halt the interviews at any time I choose.

I also understand that my name will not be used and that I may use any name I choose to protect my identity and anonymity.

signed………………..
Dated / / 2000

Witnessed……………
Dated / / 2000

Appendix Five: Consent Form – Consumers and Carers
<u>INFORMED CONSENT FORM</u>

I…………………………agree to be a participant in the research study Catherine Flanagan is conducting on the unique experiences of social workers, consumers diagnosed with schizophrenia and their carers. I understand that my experiences will be published as a Phd thesis in the School of Social Work and Community Welfare at the James Cook University, Lantana and that Professor Rosamund Thorpe is the supervisor of the thesis.

I have been advised and understand that interviews will be audiotaped and transcribed. The tapes will then be destroyed in a manner acceptable to me. Some of the issues that I discuss will be personally sensitive to me and I understand that I may halt the interviews at any time I choose.

Confidentiality towards other group member's disclosures will be required of me and I also understand that my name will not be used and that I may use any name I choose to protect my identity and anonymity.

signed………………..
Dated / / 2000

Witnessed……………
Dated / / 2000

Appendix Six: Letter of Introduction – Management

Dear Participant,

We have discussed doing a research study on service provision for people diagnosed with schizophrenia and their carers. You may not have read very much regarding people in this situation. This is because very little has ever been documented about the experience.

I can understand there could be some issues you would prefer not to share, and there is no obligation on you to proceed with the study or to continue talking at the interview if you feel uncomfortable. You can stop the interview at any time you like. To guarantee confidentiality no names will be used during this study. You may also decide where the interviews are to take place.

Many of the things that you say will be written down and fed back to you for confirmation. They will also be combined with things that social workers say on the same topic. Later it will be published as a Phd thesis in the School of Social Work and Community Welfare at the James Cook University, Lantana. A model of social work service delivery will then be compiled and presented to the Lantana Integrated Mental Health Service, offering you another perspective when considering the needs of consumers and carers in future social work service provision.

Considering that it is your experiences that we discuss you will be able to have a say in the final draft, and can correct anything you do not agree with which relates to you.

You will be able to share your knowledge at an interview that will be held at the end of 2000. It will last for approximately one hour.

This research study will have the Ethics Committee's approval of the James Cook University prior to the discussions.

If you require any further information please feel free to call me at the university on 40421372. If I am not in my office, please leave a message and I will return your call as soon as possible.

Regards

Catherine Flanagan
SOCIAL WORKER

Appendix Seven: Letter of Introduction – Community Development Worker

Dear Participant,

We have discussed doing a research study on service provision for people diagnosed with schizophrenia and their carers. You may not have read very much regarding people in this situation. This is because very little has ever been documented about their experience.

I can understand there could be some issues you would prefer not to share, and there is no obligation on you to proceed with the study or to continue talking at an individual or group interview if you feel uncomfortable. You can stop the interview at any time you like. To guarantee confidentiality no names will be used during this study. You may also decide where the interview is to take place.

Many of the things that you say will be written down and fed back to you for confirmation. They will also be combined with things that social workers say on the same topic. Later it will be published as a Phd thesis in the School of Social Work and Community Welfare at the James Cook University, Lantana. A model of social work service delivery will then be compiled and presented to the Lantana Integrated Mental Health Service, offering them another perspective when considering the needs of consumers and carers in their future social work service provision.

Considering that it is your experiences that we discuss you will be able to have a say in the final draft, and can correct anything you do not agree with which relates to you.

You will be able to share your knowledge at an interview or discussion group that will be held at the end of 2000. They will last for approximately one hour.

This research study will have the Ethics Committee's approval of the James Cook University prior to the discussions.

If you require any further information please feel free to call me at the university on 40421372. If I am not in my office, please leave a message and I will return your call as soon as possible.

Regards

Catherine Flanagan
SOCIAL WORKER

Appendix Eight: Letter of Introduction – Social Workers

Dear Participant,

We have discussed doing a research study on service provision for people diagnosed with schizophrenia and their carers and I have received written permission from management to interview you during working hours. You may not have read very much regarding people diagnosed with schizophrenia and their carers. This is because very little has ever been documented about the experience.

I can understand there could be some issues you would prefer not to share, and there is no obligation on you to proceed with the study or to continue talking during the interview if you feel uncomfortable. You can stop the interview at any time you like. To guarantee confidentiality no names will be used during this study. You may also decide where the interview is to take place.

Many of the things that you say will be written down and fed back to you for confirmation. They will also be combined with things that other participants say on the same topic. Later it will be published as a Phd thesis in the School of Social Work and Community Welfare at the James Cook University, Lantana. A model of social work service delivery will then be compiled and presented to the Lantana Integrated Mental Health Service, offering them another perspective when considering the needs of consumers and carers in future planning for service provision.

Considering that it is your experience that we discuss you will be able to have a say in the final draft, and can correct anything you do not agree with which relates to you.

You will be able to share your knowledge at an interview that will be held at the end of 2000. They will last for approximately one hour.

This research study will have the Ethics Committee's approval of the James Cook University prior to the discussions.

If you require any further information please feel free to call me at the university on 40421372. If I am not in my office, please leave a message and I will return your call as soon as possible.

Regards

Catherine Flanagan
SOCIAL WORKER

Appendix Nine: Letter of Introduction – Consumers and Carers

Dear Participant,

We have discussed doing a research study on service provision for people diagnosed with schizophrenia and their carers. You may not have read very much regarding people in your situation. This is because very little has ever been documented about the experience.

I can understand there could be some issues you would prefer not to share, and there is no obligation on you to proceed with the study or to continue talking at an individual or group interview if you feel uncomfortable. You can stop the interview at any time you like. To guarantee confidentiality no names will be used during this study. You may also decide where the interviews are to take place.

Many of the things that you say will be written down and fed back to you for confirmation. They will also be combined with things that social workers and other participants say on the same topic. Later it will be published as a Phd thesis in the School of Social Work and Community Welfare at the James Cook University, Lantana. A model of social work service delivery will then be compiled and presented to the Lantana Integrated Mental Health Service, offering them another perspective when considering your needs as consumers and carers in their future social work service provision.

Considering that it is your experiences that we discuss you will be able to have a say in the final draft, and can correct anything you do not agree with which relates to you.

You will be able to share your knowledge at interviews or discussion groups that will be held at the end of 2000. They will last for approximately one hour.

This research study will have the Ethics Committee's approval of the James Cook University prior to the discussions.

If you require any further information please feel free to call me at the university on 40421372. If I am not in my office, please leave a message and I will return your call as soon as possible.

Regards

Catherine Flanagan
SOCIAL WORKER

Appendix Ten: Interview Schedule – Management

1. What is your understanding of Standard 3 of the National Standards for Mental Health Services?

2. What is your understanding of the AASW, Competency Standards (1999) for Mental Health social workers?

3. How do you feel about consumers and carers participating in areas such as planning and policy development in the mental health service?

4. How is consumer and carer participation encouraged within the mental health service?

5. What constraints or obstacles exist within the service which hinders social work involvement in consumer participation?

6. What are you doing to support consumer and carer participation?

7. What model of service delivery do the social workers employ at LIMHS?

8. Do you evaluate social workers' practice? If so, how?

9. Do you think there is a need for a senior social worker at LIMHS?

10. What roles do you consider to be unique to social workers within LIMHS

11. Are you aware of any constraints preventing social workers from incorporating social justice principles in their practice?

12. If postgraduate education and training were available locally for social workers employed in the area of mental health, what would be helpful from your perspective in terms of course content?

Appendix Eleven: Interview Schedule – Community Development Worker

1.   What is your understanding of Standard 3 of the National Standards for Mental Health Services?

2.   What is your understanding of the AASW, Competency Standards for Mental Health Social Workers, 1999?

3.   How are consumers and carers encouraged to participate in areas such as planning and policy development in the mental health service?

4.   What roles do consumers and carers currently hold within the mental health service?

5.   What roles could consumers and carers engage with in the mental health service?

6.   What model of service delivery do the social workers employ at the mental health service?

7.   Are you aware of any constraints preventing social workers from incorporating social justice principles in their practice?

8.   What model of service delivery do you employ?

9.   Is your practice evaluated. If so, how?

10.   If postgraduate education and training were available locally for social workers employed in the area of mental health, what would be helpful from your perspective?

Appendix Twelve: Interview Schedule – Social Workers

1.   What is your understanding of Standard 3 of the National Standards for Mental Health Services?

2.   What is your understanding of the AASW, Competency Standards for Mental Health Social Workers, 1999?

3.   How do you feel about consumers and carers participating in areas such as planning and policy development in the mental health service?

4.   How is consumer and carer participation encouraged within the mental health service?

5.   What are you as a social worker doing to support consumer and carer participation?

6.   What model of service delivery do you employ at the LIMHS?

7.   Is your practice evaluated? If so, how?

8.   Do you think there is a need for a senior social worker at LIMHS?

9.   What roles do you consider to be unique to social workers within LIMHS

10.   Are you aware of any constraints preventing you from incorporating social justice principles in your practice?

11.   If postgraduate education and training were available locally for social workers employed in the area of mental health, what would be helpful from your perspective in terms of course content and delivery?

Appendix Thirteen: Interview Schedule – Consumers

1. Recently there has been a lot of discussion within mental health services regarding consumer and carer participation. What does consumer participation mean to you?

2. What roles do you currently have within the mental health service?

3. What ideas do you have for roles you could have within the mental health service?

4. Mental health workers sometimes feel that consumers are too 'unwell' to participate in a meaningful way. What is your response to this?

5. What disciplines have you been involved with at community mental health? (E.g. nurse, occupational therapist, social worker or psychologist).

6. Have you ever accessed a social worker? If so, how would you describe the service provided by the social worker?

7. What is the best aspect/s of your involvement with the mental health service?

8. What is the worst aspect/s of your involvement with the mental health service?

9. What would your vision of an ideal mental health service look like?

10. What type of training would enable you to participate more fully in the mental health service envisaged?

11. What type of training would enable mental health workers to meet the requirements of your vision for a better service?

Appendix Fourteen: Interview Schedule – Carers

1. Recently there has been a lot of discussion within mental health services regarding consumer and carer participation. What does carer participation mean to you?

2. What roles do you currently have within the mental health service?

3. What roles could you have within the mental health service?

4. What disciplines have you been involved with at community mental health? (E.g. nurse, occupational therapist, social worker or psychologist).

5. Have you ever accessed a social worker? If so, how would you describe the service provided by the social worker?

6. What is the best aspect/s of your involvement with the mental health service?

7. What is the worst aspect/s of your involvement with the mental health service?

8. What are your major concerns regarding your role as a carer?

9. What are your major concerns regarding the person you care for?

10. What would your vision of an ideal mental health service look like?

11. What type of training would enable you to participate more fully in the mental health service envisaged?

12. What type of training would enable mental health workers to meet the requirements of your vision for a better service?