

CHAPTER 8

THE CONSUMER/SURVIVOR MOVEMENTS' STRUGGLE FOR RECOGNITION

Democracy is the battle waged by subjects in the context of their culture and their liberty, against the domineering logic of systems (Touraine, 1997: 12).

Give people opportunities to tell their stories privately and really listen and listen and listen. Our experience suggests that when we do genuinely feel heard we will be ready for the next action stage: 'what are we going to do about it' (Wadsworth & Epstein, 1996a: 74).

The consumer/survivor movement's claim that the failure to listen to patients in acute public mental health services is a failure to recognise the patient as a subject is supported by Touraine (1997). This failure has resulted in some governmental and World Health Organisation incentives to improve the institutional organisation of relationships in acute mental health services, the fundamental source of the problem as Touraine (1997) sees it. These incentives and their success are outlined below. The consumer/survivor movements' initiatives and their limitations are also considered. The failure of these incentives to so far transform the ethos of practice demands further inquiry into the reason for the failure to recognise acute psychiatric patients as subjects. This is a problem this thesis has attempted to address. How a reversal of this stigmatising process is to be accomplished, will be considered in the third part of the chapter through the work of Alex Honneth where the importance of recognition in overcoming stigma and facilitating recovery is discussed.

Governmental and World Health Organisation Initiatives for Recognising the Consumer/Survivor Perspective

The consumer/survivor movement makes a claim for a right to democracy and social justice through participation. The World Health Organisation (1978) has supported the claim that people have both the right and duty to be involved in decisions that affect their daily lives.

The consumer/survivor literature argues that consumer/survivors have a unique perspective (Wadsworth & Epstein, 1996a). The World Health Organisation identifies that this perspective provides a critical contribution to service development, because, it argues, if those who use the service are involved in the planning, development and implementation, the service will be more responsive (World Health Organisation, 1993). There is even recognition that this type of participation provides greater efficiency, effectiveness, equity and self-reliance (World Health Organisation 1989). The World Health Organisation recognises that consumer/survivors are more able than any other to:

provide checks and balances in the design, delivery and evaluation of services, which introduces a validity to the system that can be achieved in no other way (WHO, 1993: 3).

In response to the World Health Organisation's (1978) declaration, the need for participation has been recognised as a high priority by governments and mental health services internationally. This has involved a growing recognition of the importance of introducing

consumer/survivor respecting practices (Allen et al., 1999; Kinderman & Cooke, 2000; Mental Health Commission, 2001; Sozomenou, Mitchell, Fitzgerald, Malak & Silove, 2000; Verna, 2000).

For instance, in 2001, The Mental Health Commission in New Zealand published *Recovery Competencies for New Zealand Mental Health Workers* (Mental Health Commission, 2001). This document defined the skills and competencies required to incorporate the perspective of those who use mental health services in the delivery of services. The United Kingdom has also released a report (Kinderman & Cooke, 2000) identifying the central importance of responding at a personal level to the complexity of mental illness. In the United States there is a growing and active consumer/survivor movement with increasing resources allocated for consumer/survivors to establish their own treatment responses supported through the National Empowerment Center (Verna, 2000).

In Australia there has been a number of State and National initiatives to develop consumer/survivor participation in mental health services. The Mental Health Council of Australia (MHCA) was established in 1997-8 under the National Mental Health Strategy to represent and promote the interests of the mental health sector and advise on mental health in Australia. This took over the function of the National Community Advisory Group. The State Community Advisory Group continues to provide input into local and national policy development. Whether these

Community Advisory Groups actually influence decision-making, however, is uncertain. Participants find this uncertainty demoralising.

The *National Mental Health Report 2000*: (Commonwealth Department of Health and Aged Care, 2000) identified the poor resourcing of these advisory groups as an impediment to consumer/survivor participation in them. Adequate training of people for these roles was also identified as lacking although an initiative is underway to address this. The Community Development Project is an initiative that aims to equip consumers (and carers) with the skills and confidence to participate in decision-making forums. The Mental Health Council of Australia is distributing *The Kit*, a resource for this purpose (Commonwealth Department of Health and Aged Care, 2000).

Another concern of the national consumer/survivor movement has been the lack of user involvement at a local service delivery level. Despite the government policy initiatives, twenty-six percent of national services had no consumer participation program in 1998, (an improvement from 47 percent in 1994) (Commonwealth Department of Health and Aged Care, 2000: 124). For those programs that do offer participation, until now this has only involved advisory roles in committees (Commonwealth Department of Health and Aged Care, 2000).

Consumer/survivors also argue that it is not enough to evaluate services that are already established. Consumer/survivors also want to

be involved in developing, evaluating and articulating policy and designing services (Epstein & Shaw, 1997).

The *National Mental Health Report 2000*: (Commonwealth Department of Health and Aged Care, 2000) identified that stigma and discrimination have not improved and that treatment planning has not been collaborative. The participation that has occurred has usually involved an endorsement of pre-determined plans. In the report, participation in decision making has been acknowledged as tokenistic, and a great source of frustration for those involved in the consumer/survivor movement. For government policies of consumer/survivor participation to be substantiated, not only in Australia but internationally, services require participatory practices in line with consumer/survivor perspectives. The real site of transformation, as Foucault has defined it, is 'the subject who acts—the subject of action through which the real is transformed' (Foucault, 1991d: 84).

Initiatives for Recognising the Consumer/Survivor Perspective

The consumer/survivor initiatives to change the culture of acute psychiatric services have focused on advocating for patient participation in the mental health system. Consumer/survivors are not happy with the level of participation facilitated by governmental organisations in

services so far. In response, consumer/survivors argue that for change to occur in mental health practices in the interest of recipients of services, it is necessary that change be user-driven (Wadsworth & Epstein, 1996a: 10-12). Provider-driven changes, they argue (which includes a reference to the influence of Laing), have been only partial. Complete transformation, they continue, needs to be from the patient perspective, involving consumer/survivors as equals (Wadsworth & Epstein, 1996a: 10-12). These activists maintain that it is not that they want to jeopardise the delivery and/or availability of services but that they want a change in the culture of service provision (Epstein & Shaw, 1997: 87-90).

The consumer/survivor literature insists that the way forward is to change the culture of present practices to one that reflects the recognition of the acute psychiatric patients' right to respect as a person (Epstein & Shaw, 1997; Sozomenou et al., 2000). The movement indicates that patients desire to be treated as persons, whether in a psychiatric crisis or not. This means listening to patients with respect:

If you were treated as a person, they would listen to what your concerns were when you entered and that would become part of your treatment plan (Wadsworth & Epstein, 1996c: 157).

One consumer/survivor put it thus: 'I want to be treated with respect as a human being, not like how the elephant man was treated' (McGuinness & Wadsworth, 1992: 19).

Prevalent in consumer/survivor literature is the view that distress is due to problems that need to be solved. The counsel offered is: 'always take the consumers seriously (that is if the consumer is upset they...have a reason to be upset no matter what anyone else thinks)' (Epstein & Shaw, 1997: 76). The *Developing Effective Consumer Participation in Mental Health Services: The Report of the Lemon Tree Learning Project* (Epstein & Shaw, 1997) holds that patients are the experts on their needs if they are given an opportunity to express them. The *Orientation and Job Manual: Staff-Consumer/survivor Consultants in Mental Health Services* (Wadsworth & Epstein, 1996a), tells that people who have utilised services:

Have important insights, understandings, and assessments of their experiences essential to point services in the direction of improved quality (Wadsworth & Epstein, 1996a: 10).

The Report of the Lemon Tree Learning Project (Epstein & Shaw, 1997: 12) argues that as ex-patients have user experience, these views need to be sought.

Central to the consumer/survivor agenda is that patients:

define their own experiences, defining the questions as well as the answers, having a determining say in the settings, form and design of the efforts and the programs (Epstein & Shaw, 1997: 12).

But it is only when consumer/survivors are recognised as legitimate subjects with a legitimate voice is there a possibility that what the patient defines as needed will be addressed and that practices they identify as needed in the provision of mental health services will be provided. This means building in sites where client's views can be heard

in practice. However, as identified in chapter one, the system itself inadvertently works against hearing from patients about their needs. The *Understanding and Involvement Project* concluded with a recommendation that mechanisms be built in to prevent the ‘tendencies to contradict its fundamental healing purposes’ (Wadsworth & Epstein, 1996b: 213).

The *Developing Effective Consumer Participation in Mental Health Services: The Report of the Lemon Tree Learning Project* (Epstein & Shaw, 1997: 21) discussed how to incorporate the findings of the *Understanding and Involvement Project* in patient participation. Here patient participation is defined as ‘consumers offering to help services improve their practice’ (Epstein & Shaw, 1997: 21). Epstein goes on to argue that quality assurance is the model that could best respond to the expressed needs of users.

It is only when we think of consumer participation in the context of quality assurance activity that we can start to understand that the argument made by consumers, that part of the necessary change is that our participation must be seen as work and therefore respectfully remunerated. The Lemon Tree Project has developed this aspect as a major theme (Epstein & Shaw, 1997: 86).

The Report of the Lemon Tree Learning Project (Epstein & Shaw, 1997) discussed changing the culture of psychiatric service provision through consumer/survivor participation in quality assurance as ‘changing things that are taken for granted in the way services are practiced’ (Epstein & Shaw, 1997: 88). This requires that there be a ‘fundamental change in the way service providers see and are able to be with consumers’ (Epstein & Shaw, 1997: 88). For instance, desirable

services are defined as 'consumer-inclusive' rather than 'consumer-exclusive' and as 'self-confident and inquiring rather than fearful and resistant' (Epstein & Shaw, 1997:89).

Effective patient participation depends on a model of practice that is:

Reflective and self critical, asking questions and searching for answers from consumers rather than guessing, observing through professional perspective eyes or assuming righteous authority simply because of an affiliation with an established professional base (Epstein & Shaw, 1997: 18).

The *Understanding and Involvement Project* (Epstein & Wadsworth, 1994; Wadsworth & Epstein, 1996b; Wadsworth & Epstein, 1996c) showed that, people primarily want services that are responsive to their needs. What consumer/survivors prefer is:

To be asked and listened to ('they communicated about that with me') rather than stating, being told and informed ('they communicated to me'); being invited, included and trusting we can contribute... having things explored with us (iterative, tentative dialogue) rather than commands and being given to conclusive 'discussion' or compelling argument; preferring safe, honest talk and unimposed and offered options, rather than being tested and exposed, or having unwelcome or compulsory courses of action prescribed, often with a hidden and insulting agenda (e.g. to aid 'insight' or 'ventilation'); being respected rather than dismissed or patronised; having connection (eye contact, body language) which is warm rather than distanced and cold (answering a pager, checking a watch or shuffling paper); and being collaborated with, rather than 'managed' or manipulated (Wadsworth & Epstein, 1996a: 69).

Wadsworth and Epstein (1996b) and Epstein and Shaw (1997) found that for such change to occur, there needed to be the presence of some form of ongoing research or evaluation to provide the opportunity for reflective practices, otherwise professional staff maintained a distance from patients.

The result of this research was the introduction of the position of consumer consultants into mental health services (since November 1996) to facilitate the beginning of patient participation in psychiatric services. The role of the consumer consultant according to the *Orientation and Job Manual: Staff-Consumer/survivor Consultants in Mental Health Services* (Wadsworth & Epstein, 1996a), is to provide a feedback mechanism between consumers and staff for reviewing and improving the quality of services. The point being that:

It is their driving interest in the services which is most likely to energise the effort to seek consumer/survivor feedback, promote staff-consumer communication and assist staff to make the subsequent necessary changes to services (Wadsworth & Epstein, 1996a: 10).

The role of consumer consultants has been designed to provide feedback mechanisms of how people actually experience services. This feedback could be built into everyday practice to 'challenge the assumption service providers make in relating to consumers' (Epstein & Shaw, 1997: 105). The attempt was to involve patients in decision making so that: 'consumer participation is respected, valued and even sought' (Epstein & Shaw, 1997: 23). A further role of the consumer consultant according to the *Orientation and Job Manual: Staff-Consumer Consultants in Mental Health Services* (Wadsworth & Epstein, 1996a: 184), is to provide a 'critical bridge between both staff and consumers to increase consumer feedback and staff communication'. Consumer consultants were also considered to be a mechanism for reviewing and improving the quality of services.

Evaluation of Consumer/Survivor Initiatives

Despite the current policy initiatives that claim to recognise the role and importance of 'consumer' participation; this has not transformed services into what is considered 'consumer' friendly places in acute public psychiatric services. Failure to listen to patients as valuable human beings is a failure to recognise and validate patients' already vulnerable sense of self. For this to occur, as highlighted there needs to be the presence of some form of research or evaluation to provide the opportunity for 'reflecting on practices and making changes' (Epstein & Shaw, 1997: 14).

Self-reflection was found to be vital for change as: 'All new practice involves a pause and conceptual shifting and distancing from old practice' (Epstein & Shaw, 1997: 15). The introduction of consumer consultants was an attempt to provide the opportunity to acknowledge the patient perspective in the hospital culture. This has also been found to offer a positive role model for patients (Sozomenou et al., 2000). And though this initiative has been positive in itself, it has not transformed the ethos to one that respects patients as persons.

Though it is the consumer consultant's role to question the assumptions of the culture of acute psychiatric service by introducing the consumer/survivor perspective, such consultants usually feel 'overwhelmed by the entrenched culture in which they find themselves' (Epstein & Shaw, 1997: 91). According to a review of this role, over-

worked consumer consultants have found themselves subject to practicing the same defensive strategies identified as problematic by medical staff (Kroschel, 2000). This highlights the failure of the system to address the needs of not only the people who it is intended to service, but also those who serve in it. Epstein and Shaw (1997) argue, for culture to change a supportive network of reflective practice involving practitioners would be required.

The aim of *The Lemon Tree Project* (Epstein & Shaw, 1997) was the education of the staff. Though promising, and reputedly effective, such an approach is expensive, time consuming, retrospective, slow and not unproblematic. For instance, patient participation:

should not be a further occasion for consumers to experience abuse... yet these problems are frequently experienced by consumers in such settings (Epstein & Shaw, 1997: 26).

The Lemon Tree Learning Project involved training sessions with service providers in patient participation. Trainers quickly came up against the problem of the conceptualisation of consumers by providers. They found service providers could not make the conceptual leap of going from

seeing patients as objects... dictated by the classifying, therapeutic and limiting language of the medical model to seeing consumers as people... with a range of experiences and opinions to contribute, including their involvement with mental health services (Epstein & Shaw, 1997: 33).

The Department of Human Services Victoria has recently released an independently conducted research report on the *Evaluation of Consumer Participation in Victoria's Public Mental Health Services* (Service Quality

Australia, 1999) to assess the effectiveness of the policy of consumer participation in mental health services. Four hundred and fifty contributions were made to the consultation process. The report did not offer a specific analysis of consumer consultant contribution as such, but an overview of the impact of the effectiveness of the policy from responses received. A problem identified was that the need for patient participation was not clear for some managers and staff in mental health services.

Neither was it clear what constituted consumer participation in the report. Another problem of the report is that it did not distinguish between the distinctly different perspectives of consumers and carers. The significant finding of the report was that it identified that services had no aim or sense of direction in their policies. There was a clear need to clarify 'what constitutes effective consumer/survivor participation in public mental health services and what should be the intended outcomes' (Service Quality Australia, 1999: 15).

The report recognised the purpose of participation as the empowerment of users. But what was found was a failure to listen and to respect the views of service users and that this worked against mental wellbeing. Listening was recognised as facilitating better outcomes by allowing voice, choice and responsibility as aids in recovery. The best outcomes were for those who were involved in service delivery at both an individual and systemic level. For this to occur would require

consumers to participate at both these levels which would require recognition of and respect for the consumer/survivors point of view.

However, participation as a 'consumer' was not unproblematic. In forums where people were invited to participate in a discussion, those who had utilised services were still stigmatised. For instance, though participation 'should not be a further occasion for consumer to experience abuse...these problems are frequently experienced by consumers in such settings' (Epstein & Shaw, 1997: 26). Further, participation as a 'consumer' requires identification as a 'consumer'. This positioning relocates participants as subject to the stigma of psychiatric illness, which works against incorporating the wealth of knowledge and understanding available from the consumer/survivor perspective into practice.

Neither were consumers/survivors happy with the way they are treated at an individual level. The consumer/survivor movement indicates that people desire to be treated as persons, whether in a psychiatric crisis or not. This would mean listening to patients with respect:

If you were treated as a person, they would listen to what your concerns were when you entered and that would become part of your treatment plan (Wadsworth & Epstein, 1996b: 157).

Yet only when patients are recognised as legitimate subjects and listened to as such, will practices identified as problematic in the provision of mental health services be improved. But how is this impasse to be overcome? What will it take for people who use acute

psychiatric services to be engaged with as legitimate human beings? Organisational and/or participatory consultative roles will not be effective until real change in the culture of mental health services takes place. This change requires recognition of the autonomy and equality of all human beings including acute public psychiatric consumer/survivors. This recognition requires building concepts and practices into the system, which are based on mutual respect. To identify practices of respect we will turn to the work of Alex Honneth.

Recognising the Subject

As demonstrated in chapters two and three, the institutional organisation of acute psychiatric services depends on the conception of the subject as 'mentally ill', the premise upon which a person's status as an equal is called into question. This premise undermines the legitimacy of the patient as a person. What is required to overcome stigma, it is argued here, is to recognise the patient, though traumatised and distressed, as an equal. Touraine (1997) has highlighted the need for a patient to be recognised as a subject as a democratic necessity. This recognition would require putting into place democratic practices of dialogue and communication where the patient as a person is listened to and engaged with. The concept of the subject identified in chapter seven through Taylor, Ricoeur and Levinas' work provide the basis for this ethos in acute psychiatric services. The question of practices that facilitate the basic human necessity to be

recognised as a subject will be considered here through reference to the work of Alex Honneth.

Alex Honneth (1995) in *The Struggle for Recognition: The Moral Grammar of Social Conflicts* suggests all social struggles are over a struggle for recognition as legal, ethical and social subjects. Morality involves, he suggests, all subjects having their opinions heard equally as individual, autonomous subjects. What is meant by the *ethical* is the ethos of a 'particular lifeworld'. New social movements, such as the mental health consumer/survivor movement contest the devaluation of a particular lifeworld. Ethical problems according to Honneth (1995: 172) are structural, in that they disable 'communicative enabling self-realisation'. Notably what Honneth suggests is required for an ethical approach is that it:

has to contain everything that is subjectively presupposed in order for subjects to know that the conditions for their self-realisation are safeguarded (Honneth, 1995: 172).

Honneth, like Taylor and Ricoeur, identify the patterns of approval and recognition, internal to language, as central to the integrity of human beings. The self-descriptions of those that consider themselves as treated wrongly by others share the failure of recognition as legal, ethical and social subjects at the source of their experience of disrespect. Disrespect is incurred through human beings vulnerability and need for recognition. Intersubjective negativism injures the positively acquired understanding of oneself. This is important because self-image depends on:

the possibility of being continually backed up by others; the experience of being disrespected carries with it the danger of an injury that can bring the identity of the person as a whole to the point of collapse (Honneth, 1995: 131-132).

The diagnosis of mental illness carries a stigma demonstrated through the withdrawal of recognition by others and this denigration of respect has implications for respect for self. Honneth (1995: 172) identifies the negative emotional reaction to the experience of disrespect as typical in driving a new social movement such as the consumer/survivor movement.

Three sites of disrespect

Honneth (1995) identifies three sources of disrespect: physical abuse, denial of rights and social value. This model of disrespect provides a framework in which to understand the ways in which consumer/survivors feel that they have been disrespected. The three sites of disrespect that Honneth identifies are the sites that the consumer/survivor movement identifies as the sites that they experience as disrespectful in acute psychiatric service. Identifying the site of the problem also facilitates providing a way to overcome the problem. Practical examples of these three sources of disrespect, which consumer/survivor's claim both precipitate mental health problems and perpetuate them will be discussed in the following section.

i) Physical abuse

One source of disrespect that people who receive services report as precipitating their 'mental health problems' is physical and sexual

abuse. Physical and sexual abuse is a lasting source of damage to one's sense of self-confidence and undermines one's sense of autonomy. This, along with the accompanying shame about being abused, results in a loss of trust in oneself and the world, which affects relatedness with the world (Honneth, 1995). Herman (1992) identifies traumatic events such as physical and sexual violence as violating autonomy at the level of bodily integrity such that a person considers that their view counts for nothing. 'Traumatic events thus destroy the belief that one can *be oneself* in relation to others' (Herman, 1992: 53). The shame of untold tales and unrepresented traumas are embodied as helplessness. The taboo of abuse means the trauma is not articulated or incorporated in a constructive narrative to provide coherence and meaning. But rather internalised into a negative sense of self shame.

There is established evidence of the high incidence of sexual abuse in acute psychiatric patients (Brier, 1992; Everett & Gallop, 2001; Graham, 1994; Read, 1997; Read, 1998). The prevalence of sexual abuse in clinical samples of acute psychiatric patients ranges from fifty to eighty percent depending on the study (Everett & Gallop, 2001; Hawthorne et al., 1996; Herman, 1992). Research also indicates that those considered unresponsive to treatment for mental illness have a history of sexual abuse (Everett & Gallop, 2001; Read, 1997; Read, 1998; Read & Fraser, 1998; Tooth et al., 1997).

Even though there is acknowledgement in the psychiatric literature of the significant contribution of abuse to psychiatric problems (Geller, 1992; Hawthorne et al., 1996; Herman, 1992; Kleinman, 1988; Mitchell, Grindel & Laurenzano, 1996), these events are rarely addressed or responded to in a way that people feel recognises their plight or responds to their plight (Graham, 1994; Read & Fraser, 1998).

McFarlane states:

Patients with schizophrenia and bipolar disorder who have a history of abuse have high rates of suicide attempts, show more aggressive behaviour and have longer hospitalisations. At this point in time, there is little or no attention to these observations in mental health delivery in Australia. This is perplexing and a matter of concern (McFarlane, 2000: 897).

Consumer/survivor accounts as described in chapters one and three, affirm patients' claims that they have stories to be told that are often traumatic tales of suffering. According to these consumer/survivor accounts, recovery occurs through the telling of these stories. As argued in chapter seven, it is through the telling of these stories that the self is discovered and recovery occurs. Survivors claim they are experts on their own experience and healing. That expertise needs to be acknowledged in a conception of the physical, sexual, emotional, and spiritual damage caused by life events which legitimises survivors' discourses. Legitimation for these experiences springs from the linguistic practices and discourses, communication and critiques of the consumer/survivors themselves (Lyotard, 1979).

But in acute psychiatric services, these stories are not legitimised and remain unheard. The experience of clinicians who work with people who have survived sexual abuse have found that it is not that the memories cannot be retrieved; the problem is finding a safe place to do so where the stories are believed. Survivor speech, as has been demonstrated throughout this thesis, presents a violent confrontation to the dominant conceptions of mental illness in mental health services. Even so, in a preliminary investigation of a therapy that provided acceptance, belief, understanding, confidentiality, a safe environment, honesty, respect, trust, and a stable and available service, had extraordinary success (Smith, 2000).

The need to be listened to, to process and articulate one's narrative as was demonstrated in chapter seven, is essential for the development of the human subject. This process is required for victims of abuse to overcome their trauma. Even though it is a more complex process in acute psychiatric patients, it is all the more important. An ethic of practice is required to provide acute public psychiatric patients with an opportunity to articulate their narrative. Taylor, Ricoeur and Levinas demonstrated that the telling of the narrative allows for the communication of something more: the human spirit. Listening to people's narratives provides access to a person's subjecthood, personhood and identity. Moreover, the narrative provides for genuine human relatedness between human beings and facilitates through understanding, recognition of the ethical subject.

The failure to provide listening in acute psychiatric services through coercively delivered involuntary treatment, or the threat of such, adds further trauma to the loss of self-confidence and autonomy. Ricoeur identifies the kind of suffering consumer/survivors recount as ‘the reduction, even destruction, of the capacity for acting, of being-able-to-act, experienced as a violation of integrity’ (Ricoeur, 1992: 190). Being able to act he defined in reverse: the attempt to share another’s pain. This ‘suffering-with’ is an alternative response to another’s need.

For from the suffering other there comes a giving that is no longer drawn from the power of acting and existing but precisely from weakness itself (Ricoeur, 1992: 191).

‘Suffering-with’ is what is required in acute psychiatric services in response to people’s distress. However, instead of this ‘suffering-with, what happens in acute psychiatric services is just the opposite.

ii) Denial of Rights

The second form of disrespect Honneth identified was the denial of rights. Involuntary admission or the threat of involuntary admission denies a person their rights as a citizen. Formal or informal admission denies the rights and responsibilities of a person as a functioning participant of the social order. What the denigration of rights signifies is: ‘a violation of the intersubjective expectation to be recognised as a subject capable of forming moral judgements’ (Honneth, 1995: 133-134). This creates an inability to relate to one self and others as equals. Thus the acute admission of someone with a diagnosis of mental illness under the *Mental Health Act 1986* (Victoria, 1998) works to denigrate a

person's sense of self-respect through institutionally imposed discrimination. The authorisation through the *Mental Health Act 1986* (Victoria, 1998) the use of coercive measures against a patient, and the punitive way of relating to patients and their families in acute psychiatric services, is identified as institutionalised discrimination (Campbell, 1994) and is debasing. This physical abuse combined with the 'feeling of not enjoying the status of a full-fledged partner to interaction' (Honneth, 1995: 133), leads to an overwhelming sense of demoralisation.

The failure to recognise patients' rights in a legal sense has at least in part generated the consumer/survivor movement. The consumer/survivor movement's claim for a right to participate at the individual and systemic level is, as has been demonstrated in this chapter central to the attempt to gain back a sense of self-respect for oneself and in the eyes of others. The failure to recognise a person's distress as meaningful and valid but rather as symptomatic by professionals leads to a failure to respond appropriately to consumers of those in acute psychiatric services. The failure to respond with legal means of protection for people, who have experienced a violation of their rights through past abuse, indicates to the person that they do not matter and that what has happened to them does not matter.

Read (1998) showed that appropriate legal support is often needed to protect acute psychiatric patients' interests. Yet rarely is legal or

protective action taken. Traumatic events are rarely asked about, acknowledged, recorded or responded to (Graham, 1994; Hawthorne et al., 1996). Rather, a further denial of rights to a person already traumatised occurs through institutionalised practice in mental health services, which further undermines a person's moral sense of self-respect. This occurs through the mechanism as outlined by Taylor and Ricoeur in the last chapter. The events that happen to people are interpreted and given a moral value and these values inform one's own sense of value and worth. Negative events, such as trauma and abuse, impute a negative value toward the self.

Everett and Gallop (2001) have demonstrated that nursing staff feel ill equipped to respond to peoples' accounts of abuse. The failure to act on the reports of abuse and domestic violence in an appropriate way is central to the continuation of abuse in the system (Read, 1997; Read, 1998; Read & Fraser, 1998). Learning to respond appropriately is a skill that needs to be learnt. The failure to respond appropriately to patients' accounts of abuse is a further denial of a person's rights. To live without rights, according to Honneth, is to have no chance of developing self-respect. Recovery of a sense of self-respect involves responding appropriately to people's accounts of abuse.

Read (1998) considers the failure to take the appropriate action and report these crimes against clients to the police as a failure of the system. The problem is not only that peoples traumas are not listened

to, but also those problems are decontextualised, pathologised and stigmatised as symptoms in a system that re-traumatises. Conversely, the recognition of the trauma that people have suffered, offered through listening to peoples' narratives, offers healing through understanding. Symptoms then become understandable as meaning is revealed through appreciation of the context as Laing (1965a; 1965b) identified.

iii) Social Value

The third type of disrespect refers to the denigration of the social value of an individual or of a group. Honneth relates that a person's sense of their unique value and worth is established in community. Community, he suggests, provides the site for self-realisation, a process whereby one can be convinced of one's value. Self-assurance comes from internalising a shared concept of value. Value is intersubjectively established by the ethical convictions of a community.

One cannot conceive of oneself as a unique and irreplaceable person until one's own manner of self realisation is recognised by all the interaction partners to be a positive contribution to the community (Honneth, 1995: 89-90).

The difficulty of achieving recognition consists in recognising in the other 'a common good that puts everyone in the same position to understand his or her value for the community' (Honneth, 1995: 90).

Human subjects: 'always need a form of social esteem that allows them to relate positively to their abilities and traits' (Honneth, 1995: 121).

The denigration of the value of a person, identified as stigma in the first

chapter, has been shown to be a pervasive form of denigration and personal disrespect for people relying on psychiatric services.

Honneth goes on to say that such social devaluing 'robs the subjects in question of every opportunity to attribute social value to their own abilities' (Honneth, 1995: 134). Thus:

The result of this evaluative degradation of certain patterns of self-realisation is that these persons cannot relate to their mode of life as something of positive significance within their community (Honneth, 1995: 134).

This sense of demoralisation is embodied, and entails the loss of a sense of personal self-esteem. Social approval requires recognition within a group context for self-realisation. Failure of recognition accounts for the lack of social approval. Forms of disrespect are historically mediated through institutionally established patterns of valuing.

The institutionalised totality of medicine in acute psychiatric services constitutes disregard for acute psychiatric patients' perspectives. The denial of a person's perspective, is a failure to recognise a person's integrity. This shame carries the metaphor of 'social death' for the person, manifest in the symptoms people present to psychiatric services with (Johnstone, 1996). The need to be recognised as a subject is integral to the human being, such that Honneth (1995: 135) attests: 'The experience of being socially denigrated or humiliated endangers the identity of a human being'.

This highlights how a person is constitutively dependent on the recognition of others' (Honneth, 1995: 138) such that the converse is also true—that relationships of recognition are able to protect subjects from suffering disrespect. The dependence of humans on social recognition for a successful relation-to-oneseff makes interpersonal relationships central: 'one is dependent on the intersubjective recognition of ones' abilities and accomplishments' (Honneth, 1995: 136). What results for the person whose experience is denied recognition is that the individual fails to validate his or her own experience. From this lack or gap, the negative emotions of shame or rage emerge. These feelings then further lower one's feeling of a sense of self-worth.

The shame that accompanies participating in, or being subject to, another's violation of norms, also violates one's own sense of self-respect. As Taylor, Ricoeur and Honneth ascertain, actions that violate moral norms affect a subject's moral sense of self. As human subjects, social injuries result in emotional responses. The disrespect entailed in the withholding of recognition causes an affective reaction, resulting in the impetus for social actions to reclaim self-respect such as that evident in the consumer/survivor movement.

According to Casement (1985), psychosis is the attempt to avoid reliving the shame of previous events triggered in the present. However, Casement suggests that the failure to process these events maintains

them intact. This means that the unnarrated or unexpressed experiences of past traumas are re-experienced in the present as real and immediate. To process painful memories means reliving them and this requires having supportive personal resources. Although there is some recognition of these processes in acute psychiatric services, providing support services needs to be facilitated through conceptual and practical resources not currently available.

Casement (1985) identifies relationship as the source of that which triggers this overlap from past to present. This occurs to different degrees for both staff and patients in acute public psychiatric wards. The objectification of the other as identified in chapter two, is to some degree, an attempt by staff to avoid this experience (Main, 1977).

Everett and Gallop (2001) supported this claim in their research which showed that nurses resist hearing accounts of abuse due to their own sense of vulnerability. Casement (1985) in response to mental health professionals' tendency to this distortion, raised the question whether the patient individuality was being respected and preserved, or overlooked and intruded upon (Casement, 1985: 25)?

There is another dimension to this self/other relationship that Casement noted, which was not communicated through narrative, but through affect. This affective communication refers to what is beyond words and relates to unspeakable and/or pre-verbal experiences. Affective communication is a form of projective identification that

particularly applies to psychotic states as a form of unconscious communication. This explanation accounts for why providers experience distress in dealing with acutely ill clients. Projective identification is a powerful form of affective communication where a patient has unarticulated or unconscious feelings that need to be expressed. The person's unconscious desire is for these overwhelming feelings to be contained, by them being responded to.

The sequence unfolds as follows: the patient has unmanageable, uncontrollable or uncontainable feelings; the patient has a fantasy of these being contained, listened or responded to; there is a desire that the other has these feelings instead of him/herself; this is communicated by projective identification (this is where the professional's feelings take on the same quality as the client's based on affective identification); this sameness is established projectively by the patient and experienced by the mental health professional to whom the projection is directed, which they experience as intolerable.

What is projected is any feeling that might be experienced as unmanageable by the client: acute distress, helplessness, fear, rage, or a contemptuous attack upon the self (Casement, 1985: 82). These feelings are projected in order for them to be expressed. The client requires that these feelings be acknowledged. Affective communication is achieved if the one to whom it is transferred identifies the emotion in this projection. When this happens, previously unmanageable and

terrifying feelings become less terrifying and more manageable because there has been an acknowledgement and social recognition and validation of the person and their feelings.

The client can then take back the feelings along with the recipient's capacity to tolerate being with such previously intolerable feelings.

Projective identification as a means of communication requires a therapeutic response. Casement identifies a number of possible results to this unconscious projection. If the projection is not met with an acknowledgement, there is no therapeutic response and the patient continues to experience the feelings as unmanageable. If mental health professional experienced the patient's projected emotions as intolerable, the patient's feelings are traumatically confirmed as unmanageable: the hope to overcome these 'demons' is lost and there is a new state of hopelessness and despair (Casement, 1985: 82). When acute psychiatric patient's attempt to communicate distress is misunderstood or punished, the distress is recreated as present in current relationships.

Distressed and distraught patients who cannot manage the excesses of their emotions end up in acute psychiatric services as a last resort, often in response to those around them feeling overwhelmed by this process of projected feelings. Yet this distress is rarely responded to therapeutically in acute public psychiatric services. The failure to understand this process partly explains why acute public psychiatric

patients do not find the help they are looking for. It is a further missed opportunity to understand and respond to the patient's distress. This failure may well explain the high incidence of suicide of people using psychiatric services both here (Victorian Task Force Report, 1997) and overseas (Whiteford, 2000) as well as the high rate of calls to life/crisis lines of those in recent contact with psychiatric services (Hocking, 1998).

Patients' experience of receiving psychiatric services as one of disrespect is due to the failure of those services to take their experiences seriously. Patients' expression of emotion and behaviour are not given credibility. This lack of recognition works to further undermine their sense of wellbeing. The three sources of disrespect Honneth has identified are central to the issues that consumer/survivors raise in relation to acute psychiatric services. This indicates that what is required for wellbeing is that the three dimensions of respect be offered to acute psychiatric patients.

Even when there is an apparent absence of an ability to communicate in a meaningful way this still applies. The possibility of relatedness between equals is paramount. This model of respect is not dependent or reliant on narration, but is recognised as a precondition for relatedness. This respectful approach recognises the person as valid even where the art of narration is not possible due to the unarticulated and damaging effects of trauma. In these instances, the use of creative art such as:

music, art, movement, and dance may facilitate relatedness when through the conditions of relatedness—an acknowledgement of and recognition of a patient as a person—is re-established. Establishment of listening in the face-to-face relationship, consumer/survivors claim and as discussed here and in chapter seven, is critical for healing.

Respect for patients narratives require being prepared to forfeit established concepts of knowing in preference for understanding. This requires professionals being willing not to know, but to learn from the patient, in the moment, what is needed for healing. This practice would require providing a supportive working environment for staff.

Understanding requires allowing participants to identify for themselves through listening to their own experience as expressed in narrative and other expressive, creative or artistic forms. Allowing patients to identify their own needs provides understanding of what they consider is needed provides an opportunity of responding respectfully to this.

The failure to provide recognition for a person results in a failure of self-realisation, which gives rise to a sense of disenfranchisement and a lack of self-respect. The failure to be recognised as a valuable and worthwhile human being—stigma—is often associated with the experience of receiving acute public psychiatric services, as this thesis has outlined. Users of these services have responded to the failure of respect with political mobilisation as a social movement to regain respect. The logic of such movements Honneth (1995) argues can only

be explained by an analysis of social conflict on the basis of moral experiences. The moral neglect of those most vulnerable is demonstrated in the *People Living with Psychotic Illness* (Jablensky et al., 1999a), is demonstrated in the failure to provide community-based rehabilitation services such as: behavioural and psychosocial treatment, management modalities (such as occupational therapy) cognitive remediation, social skills training, psychoeducation and supportive therapies.

The current government and consumer initiatives have failed to transform the moral culture of acute psychiatric services. This culture functions on the premise of the inequality of those receiving services. Honneth's (1995) analysis of the three dimensions of recognition addressed these shortcomings through identifying the importance of recognition through intersubjective respectful relationships. Acute psychiatric services require the provision of intersubjective conditions whereby both patients and staff find new ways to relate positively to each other and themselves. A positive relationship to oneself depends on others' recognition of one's own abilities, which one can then internalise. The experience of recognition intersubjectively constructs a relationship to one's self.

The only way in which individuals are constituted as persons is by learning to refer to themselves from the perspective of an approving or encouraging other (Honneth, 1995: 173).

A positive experience of recognition is the source of self-confidence, self-respect and self-esteem, but this is not autonomously established; rather it is dependent on others. For self-realisation, a 'lack of coercion' (for both patients and staff) is required. This is so as not to sabotage the need for individuals to internalise a sense of trust so that their own needs can be articulated and abilities exercised. Psychiatric clients and staff alike have this need for recognition.

What would provide this recognition in acute psychiatric wards is structures that facilitate an ethos of practice that all patients and staff are recognised for their particular abilities. As Honneth (1995) has indicated, each relationship potentially offers affirmation for a different aspect of the self and different relationships confirm different aspects of self-realisation. The indication of whether one has successfully developed a sense of self-recognition is the degree to which 'subjects mutually experience themselves to be loved in their individuality only in so far as they are not afraid of being alone' (Honneth, 1995: 176). As Laing stated, acute psychiatric patients do not have an established sense of being loved; consequently they find being alone a source of terror. Counterproductively, isolation is used as a form of 'treatment' in acute psychiatric services. This is despite reports of patients 'head banging' (in some instances to a degree that causes facial swelling), but this does not seem to bring the practice of isolating distressed clients into question.

The experience of love is a basic prerequisite for the development of the self-confidence necessary to articulate needs. The experience of love, free of coercion, is the basis of an ethical life. Legal relationships, which protect civil rights, are the central conditions for the development of self-realisation. Self-realisation is dependent on legally guaranteed autonomy. Only then, Honneth contends, can subjects conceive of their own desires. This highlights the need for the legal provision of an adequate structure of rights for acute psychiatric patients, while accommodating the particular circumstances of individuals and their families.

The *Mental Health Act 1986* (Victoria, 1998) needs to protect individuals subject to an authority from abuse, not authorise it. Intersubjective conditions need to be protected to facilitate personal growth. It is the failure to provide for these basic needs that has united consumer/survivors in an attempt to reclaim self-respect. It is only through community recognition that consumer/survivors can gain self-realisation, self-confidence and self-esteem.

An ethical practice requires commitment to a set of values to provide the intersubjective conditions for self-realisation. This pattern of recognition must include social solidarity, which can only come from 'collectively shared goals' subject to legally sanctioned autonomy. These goals coexist with the need for other forms of recognition: love and rights. The consumer/survivor movement is a response to the

experience of all three forms of demoralisation as identified by Honneth (1995). The reversal of stigma involves the recognition of the patient as an ethical, legal and social subject.

The recognition of the ethical subject involves the need for the person to articulate narratives of trauma. The recognition of the legal subject involves respect for a patient's rights to protection from harm. The recognition of the social subject entails the support of a community of people so that the person can be reassured of their own sense of value and worth. These three sites of recognition—the ethical, legal and social—are available through listening to the narrative.

The inability of a patient to articulate a narrative does not mean there is not a narrative or that respect is not demanded. What has to be provided is listening. Laing showed that understanding is possible if the time is taken to hear the biography. Access to recognition and understanding is through the narrative of lived experience. To abstract the person out of their context is a violation of the humanity of the person, for, as Ricoeur has established, the recognition of humanity resides in a narrative account. For people receiving mental health services, these accounts are often of victims of sexual, physical and mental abuse and/or emotional neglect, which has been denied a voice and narrative, and therefore identity as an ethical subject.

Several experimental attempts have been made to provide a more therapeutic milieu than the traditional hospital environment. For

example, Harry Stack Sullivan established a small ward for schizophrenic men that was staffed with hand-picked attendants, set apart from the rest of the Sheppard Pratt Hospital in the 1920s (Barton Evans III, 1996). He gave his staff autonomy to operate on their own with patients. As Sullivan (1962) stated:

[W]e found intimacy between the patient and the employee blossomed unexpectedly, that things I cannot distinguish from genuine human friendship sprang up between patient and employee, that any signs of the alleged apathy of the schizophrenic faded, to put it mildly, and that the institutional recovery rate became high (Barton Evans III 1996).

Sullivan's experimental ward could be seen as a precursor of the therapeutic community movement, whose influence came to be integrated with mainstream psychiatry (Jones 1952, van Putten 1973). This emphasis on the social aspects of treatment, though, is much less obvious in the current climate of risk assessment and psychotropic drug management (Clark 1974). RD Laing recognised that all forms of behaviour are understandable if we are willing to go to the trouble of taking a biography. Laing's (1965a) case study of Julie in *The Divided Self*, and others in *Sanity Madness and the Family* (Laing, 1965b) highlighted that a person experiencing psychosis is understandable, if we make an effort to understand them.

Practical implications

The failure to conceptualise the consumer/survivor as equal is embedded in a complex social, political and economic organisational structure around acute mental health services. Institutional

organisations impose limitations on the recognition of the subject, through limitations in resources for communicative relationships between subjects. These constraints include inadequate resources to identify and respond to the social, structural, personal and traumatic precipitants of mental health problems. To amend this inadequacy would require providing adequate and appropriate training of and support for the subjective needs of patients and staff alike. The failure to do so results in as has been seen, professionals, ill-equipped for any other response, discounting consumer/survivor accounts of their needs as illegitimate.

Providing services that consumer/survivors deem as necessary for recovery has the potential to legitimise and destigmatise the delivery and treatment and diagnosis of people with mental health problems. However, what is needed for this ethical practice is 'know how, knowing how to speak and knowing how to hear' (Lyotard, 1979), that is, practices that recognise the consumer/survivor narratives and knowledge's as a legitimate perspective. The consumer/survivor movement as a new social movement argues for equality and respect for mental health consumers through the recognition of the patient as a person. In Australia, this push for innovative practices has been established collaboratively with governmental organisations. This is because as activists such as Wadsworth (1996a) argue, it only when staff do not feel defensive will there be support for consumer/survivors' participation both at an individual and institutional level.

Incorporating the consumer/survivor perspective into a conceptual and practical framework within acute psychiatric services has the potential to transform services to be efficient, effective, equitable, self-reliant and responsive to consumer/survivor needs as they define them. A consumer/survivor perspective-orientated practice would involve 'listening to' the consumer/survivor narrative and 'being with' consumer/survivors as an authentic response to distress. This would also involve consumer/survivors participating in defining their own needs, and being involved in the design and evaluation of those same services.

So far, consumer/survivor and government initiatives have been unsuccessful in transforming the culture and ethics of practice in acute psychiatric services. What this thesis has identified as problematic is the premise that someone who is mentally ill does not deserve equal respect as a person. This premise, built into the institutional organisation of the relationships between subjects, undermines the regard for the patient as a person. What is required to address this institutional discrimination, is a shift in the institutional organisation of relationships from that which punishes people for their distress, to one that responds to people in respectful ways. As discussed above, Honneth's (1995) multidimensional model of respect addresses this need.

The concept of the subject as a *narrative-identity* as opposed to the concept of the subject constructed in relation to a *diagnostic-identity*, allows for all the dimensions of respect to be met through endorsing the practice of listening. The importance of providing listening is not to do with listening to the narrative as such, but in providing the opportunity for recognition of the 'other', which is the means by which a person develops a sense of self-respect. This involves listening (for presence), as explained by Levinas in the previous chapter, which offers the narrator an opportunity for self-discovery and self-identity. The autonomous role of meaning-making, that Taylor identified as central to the respect due to a person will not be discovered if it is not presupposed, as both Laing in chapter six and Ricoeur in chapter seven attest. This requires facilitating the time, space and opportunity for listening, which is a respectful practice because it acknowledges a person's autonomy and value. In other words, the recognition of the value of a person is achieved through listening to the narrative only if this value is assumed.

In sum, recovery from acute 'mental illness' requires providing the means of recognition for a patient's value and worth as an ethical subject which further implies recognition of a person's value as a legal and social subject. Recognising acute psychiatric patients as equals requires supporting patients as people; this would require innovations in the institutional organisation of relationships. It is *in relationship*

that provisions for recognition for a person's identity, rights and social value occurs.

Narrative is a powerful means through which to pursue the recognition of the ethical subject in a context where the strengths of people in the face of extreme suffering can be realised. The very practice of listening provides recognition for a person's value as an ethical, legal and social subject. Recognition of acute psychiatric patients on grounds of equality is the key to the problem of stigma, and this recognition of equality is provided through listening and responding appropriately to people's needs and through the provision of adequate socio-cultural supports. Empowering a person through providing a sense of their own social value and worth:

leads to a dramatically different means of helping people through their emotional distress. Instead of a heavy emphasis on maintenance-oriented medication compliance, the Empowerment Model is oriented towards finding ways to help the person achieve a significant role in society independent of the mental health system (Fisher & Ahern, 1999).

The model of recognition proposed in this thesis, is offered in response to the current domination of the medical approach and the current crisis facing the delivery of acute public psychiatric services in Australia and throughout the world today.