CHAPTER 1

THE CONSUMER/SURVIVOR MOVEMENT AS A NEW SOCIAL MOVEMENT

> Assume a consumer understands their own experiences better than others do (Wadsworth & Epstein, 1996a: 76).

The purpose of this chapter is to understand the claims of the mental health consumer/survivor movement. The activism of this movement will be analysed in the first part of the chapter through new social movement theory. This provides some context and legitimacy for the demands being made. Recognition of the issues central to new social movements offers a framework to understand the kinds of demands being made by the consumer/survivor movement in mental health, which will be explored in the second half of the chapter. The intent being that understanding the perspective of the consumer/survivor movement, which is made up of patients and ex-patients of acute public mental health services, offers the possibility of new insights into conceptualising and responding to mental health problems in acute public mental health services.

1. The Emergence of New Social Movements

In recent times, the political response to injustices, lack of rights, freedom and inequity has been the emergence of new social movements. The link between democracy, human rights and social movements is evident in the movements that have emerged to demand change in society. These include the women's movement; the black rights movement, the gay and lesbian movement, the indigenous rights movement and more recently, the refugee movement. Burgmann (1993) describes new social movements as a result of the disillusionment with political structures that are unresponsive to the crises that arise. The battle, she claims, is over economic and political decision-making, which deeply effect people who are dependent on these structures. Touraine has written extensively on this topic and argues new social movements respond to such crises with an alternative form of political action which leads to the:

> Deliberate reconstruction of a society based on the very principles of justice, liberty, and respect for human beings—the very principals on which democracy is based (Touraine, 1997: 58).

Other social theorists such as Giddens (1987a; 1987b; 1991), suggest, like Touraine (1974; 1997), that new social movements are political movements particular to post-industrial society. They consider new social movements to be part of a larger crisis over the legitimisation of traditional authority in the public sphere. Such movements, they claim, are a reaction against the systemic imposition of knowledge through instrumental measures of efficiency as a way of understanding human beings' relationships to the world, each other and to themselves. Notably, these relationships have resulted in the destruction of personal and cultural creativity and therefore identity. While it is structural factors within society which confer privilege upon those with power compared to those without, new social movements attempt to bring democracy and visibility to areas of discrimination, inequality and domination.

Typically, new social movements confront the traditions of authority in the public sphere and offer new sites of opportunity for the development of novel sites of social change or, in Gidden's terms, 'detraditionalisation'. New social movements represent the raising of qualitatively new issues about social life. They act as an agent of change in shifting the emphasis from economics, which has emotional costs, to personal growth, which offers new possibilities. Thereby, they bring repressed areas of moral and existential issues into public discourse. These movements value personal identity as opposed to totalising 'truth'. This however, increases political conflict over identity (Giddens, 1987a; 1987b; 1991; Touraine, 1974; 1997). Until now the role of identity has not been operationalised in the political conception of actors. However, the revolution of new social movements has been to focus on the everyday patterns of cultural life, which brings with it the realisation of the right of individuals to choose their own identity.

This shift to moral and existential issues is about strengthening autonomy in sensitive ways to promote personal wellbeing. This alternative approach, as Giddens (1991) identifies it, is tied to a life politics that extends the self-reflexive project beyond modernity's self-referential systems. The impetus of social movements is to generate alternative kinds of practices in society that value human beings over products. Such social transformation is possible through innovative practices. New social movements recognise the role of narrative as central to innovative practices and the creation of a personal identity.

Cohen and Arato (1992: 492) affirm that new social movements make the realisation of the positive potential of modern civil societies possible through a contestation of resource allocation and identity construction. For them, the salient features of new social movements are the involvement of:

> Actors who have become aware of their capacity to create identities and of the power relationships involved in the social construction of those identities (Cohen & Arato, 1992: 511).

It is the realisation of the social construction of identity that initiates a social movement’s push for change. Social movements concern with participation leads to the identification of both the means and the ends as social products.

Cohen and Arato identify the success of these movements as to do with the democratisation of values and institutions in a political culture. The institutionalisation of rights is the catalyst for contemporary struggles and initiatives. The continuation of these initiatives requires the continuing reflexive democratisation of rights and communication. Cohen and Arato (1992: 517) recognise that the stakes of social conflict revolve around institutionalisation of the dominant cultural model, that is the: ‘elite controlled, technologically managed structures permeated by relationships of domination’.

In a similar way Nancy Fraser (1993) describes new social movements as involving two kinds of interrelated struggles: the struggle over institutional versus professional need interpretation. For example, the debate at the heart of the social movement in mental health is the contestation and opposition over the administrative and therapeutic interpretation of need by professionals. Those who oppose and contest the type of service delivered are at the same time also seeking State provision for their needs. The conflict in mental health services is over access to help for problems that those who require those services articulate and identify as what is needed for recovery.

The failure to provide basic respect to acute psychiatric patients according to Rogers and Pilgrim (1991a) is due to the dominance of the medical perspective in mental health. For example, Rogers and Pilgrim (1991a) identify that the dominance of professional discourses means that the British Mental Health Users' Movements perspective and views are excluded. The failure to provide basic respect and or accommodate patient's views in acute psychiatric services is the site of contention, which has generated the mental health movement both here in Australia (Epstein & Olsen, 1999) and elsewhere (Read & Reynolds, 1996) as will be demonstrated.

Language is central to this struggle over need interpretation, as how needs are defined in terms of the language used has implications for the identity of patients and professionals alike. In *The Self-Production of Society* Touraine (Touraine, 1977) describes new social movements as arising due to conflict over the definition of actors by the dominant culture. In the same way the mental health consumer/ survivor movement contests the way patients are defined in acute public mental health services, as it has implications for identity. The challenge to established practices produces conflict both within and between stakeholders in the field of mental health services.

Analysing New Social Movements: Identity, Totality, Opposition

What distinguishes the consumer/survivor movement, as a new social movement will be discussed using Touraine's (1974; 1977; 1978; 1997) work. In *The Voice and the Eye: An Analysis of Social Movements* Touraine (1978) defines the sine qua non of new social movements as conflict over conventions in the relationships of identity. At the same time, these identities are totally interdependent. Thus new social movements always involve 'a double relation, directed at an adversary and at what is at stake' (Touraine, 1978: 80). Furthermore Touraine observes that what is culturally at stake is integral to the ideology of both the social movement and of the adversary (Touraine, 1978: 80).

The social movement, Touraine (1978: 80-94) explains, is a combination of three totally interdependent principles: identity, opposition, and totality. Touraine explains 'if one is to fight, however, should one not also know in whose name one is fighting, against whom and on what grounds' (Touraine, 1978: 81)? Similarly, in the field of mental health, the principle of identity is the site of conflict over which the consumer/survivor movement has emerged. Stigma, experienced by those who utilise acute psychiatric services, is the principal source of conflict. The opposition against whom the consumer/ survivor movement fights, is psychiatry itself. This is the group with whom consumer/survivors experience the most stigmatisation. The principle of totality is manifest as Goffman outlines later, in the domination of psychiatry in the field of acute public mental health services. What is at stake for consumer/ survivors of acute psychiatric services is the stigma of a *diagnostic-identity*, the consequence of accepting a diagnosis of mental illness.

Touraine (1978: 81-94) identifies a model that represents the interdependence of identity, opposition and totality as particular to the field of relationships. The dimensions of a conflict in the relationships between a social movement and an adversary depend on whether the link between them is between the social movement and the stakes or between the stakes and the adversary. In the instance of the consumer/survivor movement, the stakes and the adversary reinforce each other as the adversary is totally in control of the relationships of identity. So the site of conflict for the consumer/survivor movement involves opposition to both these dimensions. The three principles of social movements: identity, totality and opposition will be outlined further.

Identity, as stated, is central to the analysis of what is at stake for all the stakeholders in a system in conflict. Significantly, the identity of the participants emerges in the midst of the conflict. That is to say, the identity of the participants: 'cannot be defined independently of the real conflict with the adversary and of recognition of the stake of the struggle' (Touraine, 1977: 312). Notably, identity emerges through participants finding a voice to claim what is at stake, and it is this 'self-expression that causes the principal of identity to appear' (Touraine, 1977: 312).

The need 'to claim a voice' emerges in relation to the reliance on a system that has been experienced as inadequate. This contradictory set of relationships characterises new social movements. This concept of 'voice' or 'self-articulation' is the same notion consumer/survivors themselves have come to recognise as needed for their recovery. Touraine (1977) makes clear that a movement does not begin with a need for self-expression, but with an unmet need. Self-identity emerges in the conflict with the adversary over the failure of the system to meet the needs of those dependent on it. The importance of identity for consumer/survivors will be explored further later in this chapter and in chapter seven through the work of Charles Taylor and Paul Ricoeur. Further, the importance of the recognition of one's identity is considered in chapter 8 through the work of Axel Honneth.

According to Touraine (1977), when a system is in conflict an adversary appears. This is the second principal, the principal of opposition. The conflict with the adversary subsequently shapes the consciousness of the actors. Opposition to the adversary is from those who are defined and receive identity from the system in conflict. This is characteristic of the opposition in acute public mental health services. Consumer/survivors receive diagnoses from professionals in the public mental health system. This diagnosis carries a stigma for consumer/survivors. Users of acute mental health services have been marginalised in multiple ways through stigma, cultural, economic and political exclusion, social isolation and disability. This stigma has negative implications for the mental wellbeing of the actors, already consumer/ survivors of mental health services, and so is contested.

Another tension in social movements is the principal of totality. In Touraine's (1977) work, totality refers to a dispute over the adversary's domination of a system. The consumer/survivors' claim is that the perspective of the medical profession in acute public mental health services dominates the system. The consumer/survivor movement is a reaction to the inequality of power in relationships in mental health services. Challenging the totalising power of the mental health professional in the field of acute public mental health services to define patients according to their diagnosis is the central intent of the consumer/survivor movement.

The second part of the chapter will consider the consumer/survivor movement perspective in the field of acute public mental health services around these three principals, whilst the position of psychiatry as adversary will be addressed in chapters two and three. The fourth and fifth chapters will analyse the totality of the 'domination exercised by the adversary over the cultural stakes of the struggle' (Touraine, 1978: 81) by examining the function of psychiatric concepts and practices in the *Mental Health Act 1986* (Victoria, 1998) and in government.

2. The Consumer/Survivor Movement as a New Social Movement

A social movement is only defined as such, according to Touraine (1978: 85), if it matches up to four conditions. The first condition is that a committed population initiates the movement. The second is that it exists in terms of an integrated organisation. Thirdly, it must 'fight against an adversary, which may be represented by a social group' (Touraine, 1978: 85). Fourthly, the conflict with the adversary is a problem that concerns the broader society. Evidence that the consumer/survivor movement fulfills the first two conditions is demonstrated in the following section. Chapters two and three address the third condition, and the fourth condition is addressed in chapters four and five.

The context of recent policy changes has placed the quality of care in acute psychiatric services under further threat. The rising incidence of mental health problems (Australian Bureau of Statistics, 1998), and the crisis of the management of deinstitutionalisation, has precipitated a crisis for governments internationally in the delivery of mental health services. Quirk (2001) has noted that the experience of users is 'bleak' with evidence of violence, sexual harassment and substance misuse. He notes that there has been very little research conducted on acute wards (Quirk & Lelliot, 2001: 1565).

The issue of eliciting true informed consent in this area makes researching in this area very difficult. Draper and Hill (1996) suggest the best way to get information is from research that users themselves have conducted. So, to consider the consumer/survivor experience of acute psychiatric services, a range of locally produced and international consumer generated literature will be considered. For example, ground breaking research, which used ex-patients to research acute inpatient views was conducted in Melbourne and supported by the Victorian Mental Health Awareness Council.

This research began with *Understanding, Anytime: A Consumer Evaluation of an Acute Psychiatric Hospital* (McGuiness & Wadsworth, 1992) and developed into the *Understanding and Involvement Project* (Epstein & Wadsworth, 1994; McGuiness & Wadsworth, 1992; Wadsworth & Epstein, 1996b; Wadsworth & Epstein, 1996c). This led on to the *Orientation and Job Manual: Staff Consumer Consultants in Mental Health Services* (Wadsworth & Epstein, 1996a) and *Developing Effective Consumer Participation in Mental Health Services: The Report of the Lemon Tree Learning Project* (Epstein & Shaw, 1997), and a further report generated by a local group—The Melbourne Consumer Consultant's Group (1997) *Do You Mind? The Ultimate Exit Survey: Survivors of Psychiatric Services Speak Out.*

The Mind charity in the United Kingdom also specialises in the research and publishing of consumer experiences (Pedler, 2001; Read & Reynolds, 1996; Read & Wallcraft, 1992). Examples include *Experiencing Psychiatry: Users' Views of Services* (Rogers, Pilgrim & Lacy, 1993). These authors also produced other publications exploring the consumer perspective: *Pulling Down Churches: Accounting for the British Mental Health Users' Movement* (Rogers & Pilgrim, 1991a); *Experiencing Psychiatry: Users' Views of Services* (Rogers et al., 1993). Other research that explores the consumer/survivor perspective utilised here is: *From the Mental Patient to the Person* (Barham & Haywood, 1991). Research that consumer/survivors have produced in the United States will also be used.

The resources accessed to identify the problems users of acute psychiatric services experience are not limited to this published literature. It includes material the movement has generated internally. This internal literature is accessed via a network of collaborations established by the consumer/

survivor movement across the globe. Consumer/survivors of mental health services locally, nationally and globally express their dissatisfaction with services in through a range of fora including conferences, emails, workshops, research literature and political fora. Active consumer groups include Survivors Speak Out (UK), The National Empowerment Centre (USA) and Support Coalition (USA) and The European Alliance. Email groups and Internet websites offer further opportunities for sharing information, research and active networking providing cross fertilisation of ideas.

Burgmann (1993) notes that movements are only able to function with the support of technology, providing contact and support for activists. The organisational methods of these movements are ends in themselves, as the ‘activists within these movements self-consciously practice, in the present, the future social changes they seek’ (Burgmann, 1993: 4). It is important to note that those consumer/survivors that become involved politically do not necessarily represent the views and experiences of all consumer/survivors of mental health services (Epstein & Olsen, 1999) as such activists are self-selected. Even so, the growth of new social movements, Burgmann argues, requires intellectual capital and the ability to understand theories of politics and of change in theoretical ways. She (Burgmann, 1993: 13) claims: ‘new social movement theorists aim on behalf of their class to claim the role of privileged agent in social transformation’, though this would be insufficient without recognition of the experience of oppression.

This formal and informal literature form the bulk of resources from which I draw an understanding of what is referred to in this document as the consumer/survivor movement perspective. This research and the experiences noted by participants and researchers' indicate that not only are patients needs not met, but also that people are damaged by the service. The findings from this research will be discussed in detail in this second part of the chapter. This research provides details of patients' own experiences of acute public mental health services, something that Quirk (2001), as stated earlier considers desperately needed. An issue central to both the consumer/survivor movement and other stakeholders is the issue of terminology.

Terminology Debates

The first and second principal that Touraine (1978: 85) identified as necessary to define a social movement is that it be initiated by a committed population and that it exists in terms of an integrated organisation. Demonstrated here is that the consumer/survivor movement fulfils these conditions. The consumer/survivor movement emerged internationally 30 years ago in response to the conflict over acute public mental health service provision (Support Coalition International, 2000). This world wide liberation movement is working towards setting up and running its own supportive services and advocacy groups (US Department of Health and Human Services, 2001).

Australian activists use the term 'consumer', though there is lack of consensus over its use. In the United States and New Zealand the preference is for the term 'survivors', while in the United Kingdom the term is 'users'.

The term ‘consumer/survivor/ex-patient’ (C/S/X) is often used by activists themselves to encompass the varying positions represented in the debate and the complex relationships of identity around the experience of being a patient in an acute public mental health service. Each of the term’s consumer/survivor/user indicates in one way or another, a person’s attempt to articulate their relation to mental health services. The different relationships to terms in the movement will be discussed further, while the term used here as identified, in the introduction, to refer to the complexity of personal perspectives represented in and by the movement will be ‘consumer/survivor’.

According to activists Epstein and Shaw (Epstein & Shaw, 1997) in *Developing Effective Consumer Participation in Mental Health Services: The Report of the Lemon Tree Learning Project,* the consumer/survivor perspective has grown out of belonging to a group that is discriminated against. The attempt to overcome this discrimination in Victoria has been through identifying with the term ‘consumer’, a term imposed in the context of economic rationalist driven policy. ‘Consumer’ is a term employed by users in an attempt to claim the provision and protection as ‘consumer’, even though patients of general health care have not found this expectation to be fulfilled (Wood, 1994).

The use of the term ‘consumer’ has been problematic from the point of view of service providers as well as consumer/survivors. For example, researchers from the *Orientation and Job Manual: Staff Consumer Consultants in Mental Health Services* (Wadsworth & Epstein, 1996a), reported that the professional staff felt the term made them feel as though they were 'being consumed'. Another limitation of the term is that it is perceived by consumer/survivors to reduce the person in receipt of services to an economic value. This reduces the position of the patient to that of a commodity, which misses the point of the consumer/survivor claims. It also bypasses the question of the right of the patient to participate in their treatment, which is what the movement is in reaction against (Epstein & Shaw, 1997). In addition the term 'consumer' locates and identifies patients as dependent on and in relationship to service providers. This positioning does not support the intention of the movement in the use of the term 'consumer' by these groups.

Neither is there agreement within the movement about the use of the term 'consumer'. Judi Chamberlin (1978) in *On Our Own: Patient Controlled Alternatives to Mental Health Services* rejects the term 'consumer' for its depoliticising implications. It implies that there is freedom and choice in mental health services and creates a 'bogus' of 'co-operation'. She rejects too the co-option of consumer organisations that claim to 'work with' and 'improve' the mental health system as the Australian movement has done. Instead, the National Alliance of Mental Patients, of which she is a member and which formed in 1985, advocates for the abolition of involuntary psychiatric interventions and for the development of user run services as true alternatives to the mental health system (Chamberlin, 1978; US Department of Health and Human Services, 2001).

Even so, the term consumer has re-emerged in the American movement literature in combination with other terms. For instance, a recent issue of: *The Key: National Mental Health Consumers' Self-Help Clearinghouse Newsletter* announces 'Consumer/Survivors Need a Voice in Washington' (Verna, 2000). A contributor to the Ozmad email list where these type of heated discussions take place, considers people who accept the term 'consumers' 'dupes for believing that the mental health system has any value at all' (Heyes, 2000). Amongst the movement, the term 'survivor' is often preferred. Another contributor to the Ozmad email list defines psychiatric survivor as:

> Indicating (a la cancer survivor) we have come through a serious of crises using our skills, guts, knowledge, wisdom, intuition, etc and a whole lot of other strengths and qualities we rarely get credit for. This is the term I like best. Many psychiatrists see it as meaning a survivor of psychiatry, which has the advantage of hopefully getting them to reflect on the quality of their care (Carne, 2000).

Likewise, Richard Gosden, a New South Wales survivor and activist, attests the term psychiatric survivor is used 'to emphasize the ordeal they have claimed to endure'. Gosden (1999: 143) in 'Coercive Psychiatry, Human Rights and Public Participation' asserts there are two streams of belief regarding participation in mental health services, which are opposing. The dominant group is made up of a powerful coalition of professionals and support groups for carers of the mentally ill who seek to increase the legislative powers of involuntary treatment. The equation of this movement with the voluntary psychiatric consumers' movement, Gosden considers, conceals the involuntary and coercive nature of public acute mental health services. He suggests that the tendency to identify all mental patients as ‘consumers’ implies consent and works against the interests of survivors who attempt to:

> raise the public consciousness about the perceived fraudulent nature of psychiatric diagnosis, the injustice of involuntary incarceration and the dangers of psychiatric treatment (Gosden, 1999: 1).

Nonetheless, as will be demonstrated, the lines between voluntary and involuntary public mental health services are not clearly defined. What happens in practice is that survivors, whether involuntarily admitted or not, are considered to lack credibility, due to the diagnoses they have been given. What has become clear in this discussion is that those who use mental health services are in conflict with providers over the definition of needs and methods of practice.

Hence, the term consumer/survivor is an attempt to refer to a large and divergent movement with a range of perspectives represented in the debates about the use of terms typical of new social movements. The debate around these terms is characteristic of the debate over constructions of identity in new social movements as Touraine (1978) has pointed out. However, as Touraine’s framework of analysis of new social movements makes clear, the issue of terminology is linked with constructions of identity. The struggle over identity, represented in this debate over terms is in response to the failure to take consumer/survivor views seriously.

Though there is dissatisfaction with the use of terms amongst the Australian activists, it is also claimed that debates about terms are a distraction from the more important issues of stigma. [1] Yet the issues are inextricably linked. The claim to the right to participation is tied up with identity, which has implications for stigma. The consumer/survivor movement is also in response to the exclusion of consumer/survivors from social membership and participation in the delivery of acute psychiatric services (Epstein & Wadsworth, 1994; Wadsworth & Epstein, 1996b; Wadsworth & Epstein, 1996c). [2]

3. The Patient's Experience of Acute Public Psychiatric Hospitalisation

As Touraine (1977: 12) attests, 'democracy is the battle waged by subjects in the context of their culture and their liberty, against the domineering logic of systems'. Practices are the site where the attempt to democratise society occurs. The attempt to liberate the oppressed is through a contest over the

---

[1] Stigma and human rights were addressed at the Madpride events in Oregon, Toronto, London, Washington, California and the Congo. This was called an 'internal celebration of psychiatric survivor human rights'. It was an attempt to destigmatise the concept of the 'crazies' similar to the Negro movement, and to invest such terms with strength and empowerment (Carne, 2000).

[2] Turner (1993: 14) suggests 'citizenship as a model of social movements', 'be embraced and developed by such movements'. Turner defines citizenship as a practice of social membership, thereby overcoming the limitations of the concept. He defines citizenship as practices: 'that define a person as a competent member of society', and which 'shape the flow of resources to persons and social groups' (Turner, 1993: 14).

politics of the construction of identity. Touraine claims social movements are created at sites where there is opposition between parties over practices. Opposition is typically from those who are defined and receive identity from the social system, which is the case for consumer/survivors of acute public mental health services.

The consumer/survivor movement opposes the treatment of those diagnosed as mentally ill in acute psychiatric services. This is because the stigma associated with being diagnosed as mentally ill, has implications for a person's identity, and the way a person is treated. The diagnosis or *diagnostic-identity* then has implications for interpersonal relationships and specifically with medical professionals in acute public psychiatric services. It is the associated stigma of being diagnosed as mentally ill, which affects the way consumer/survivors are treated.

The stigma attached to the identity of the 'mental patient' is what consumer/survivors are fighting against in the field of mental health. As this is central to the conflict, the dynamics of this stigmatisation will be examined, drawing on Touraine's notion of totality, identity and opposition. The totality of identity with, and opposition to the experience of stigma by people utilising services will be explored here through examining the consumer/survivor movement literature already referred to. This analysis is an attempt to gain some insight into the problems as consumer/survivors themselves identify them, in order to understand.

Stigma as Totality

Admission to a mental health service is the last resort for acutely distressed persons. But psychiatric hospitalisation comes at a price according to those who have utilised these services. A person from The Melbourne Consumer Consultant's Group claims:

> It costs a personal sense of self, of being prepared to submit to psychiatric constructs of serious mental illness, diagnoses of psychosis, and subjection to psychiatric treatment and practice and the stigma that entails (The Melbourne Consumer Consultant's Group, 1997: 4).

Ex-patients say the experience of psychiatric hospitalisation is like being: 'in a rubbish bin sort of thing… the worst place to be…it makes you low just being in the place and knowing you're in the place' (Barham & Haywood, 1991: 38).

Research on coercion and the law has also found that threats of the loony bin start before admission, which also has a negative effect on recovery (Lidz et al., 1995). Scheff (1984) in *Being Mentally Ill: A Sociological Theory* argues that 'mental illness' acts as a conceptual dustbin or label for deviant behaviour. The negative implication of the bin metaphor makes people feel 'unwanted and neglected' (Jewell & Posner, 1996: 7). For many 'the psychiatric unit or psychiatric hospital will be the ultimate defining metaphor of rejection and abandonment' (Jewell & Posner, 1996: 7).

A person's experience of being devalued for receiving psychiatric services is referred to as stigma. Ex-patients claim stigma is acquired on admission to a psychiatric ward. For instance one person stated 'Once you have been in there is a stigma' (McGuiness & Wadsworth, 1992: 16). For Cath, the most damaging aspect of mental illness is stigma: 'It is about labelling, and it's about ownership and it's about creating other' (The Melbourne Consumer Consultant's Group, 1997:3). To avoid stigma, what is really important according to Jon is: 'To not accept the labels of the psychiatric medical model that they give you, because then you're accepting the stigma that goes with it' (The Melbourne Consumer Consultant's Group, 1997: 4).

Consumer/survivors experience the psychiatric ward as the most stigmatising kind of environment. Cath says, 'I think my experience of a psych hospital is somehow predicated on stigma itself' (The Melbourne Consumer Consultant's Group, 1997: 3-4). The introduction of The National Mental Health Strategy has been reported by The Melbourne Consumer Consultants' Group (1997) to be of some benefit in reducing stigma, though they also argue that it has only made stigma more covert. According to Jon the anti-stigma campaigns have not addressed the stigma inherent in professional services.

> In spite of the latest $8 million government campaign for combating stigma, my own personal experience is that it is still rife everywhere - from the Federal Industrial Relationships Court all the way down to the staff in the psychiatric hospitals or in a hospital psych ward (The Melbourne Consumer Consultant's Group, 1997: 1).

The biggest problem, consumer/survivors claim, is stigma from the medical profession. This claim was supported by the recent *Attitudes of Health Professionals Project* (Commonwealth Department of Health and Family Services, 1998) which demonstrated people experience more stigma and discrimination from professionals in mental health services than from anywhere else in society.

Jewell and Posner (1996: 7) identify the lack of understanding for the consumer/survivor perspective and the lack of recognition of the social context of 'illness' as the source of stigma. They say the negative judgement or stigma involved in the diagnosis of mental illness seems to justify treating someone as less than human. These serious negative effects call for further investigation about the roots of stigma: what it is, its effects on a person experiencing mental illness, how it is to be managed and how it can be overcome. These questions will be discussed next.

Stigma is defined as a mark or brand of disgrace associated with a particular circumstance, quality or person (Pearsall, 1999: 1410). In Goffman's (1963) classic text *Stigma,* it is described as the disqualification of an individual from social acceptance. Furthermore he argues that stigma is a reference to a person's negative moral status. He outlines how attributes that are different to the stereotype expected of an individual, mark, reduce, discount or stigmatise a person, rendering him/her less than human. This results in discriminatory treatment. Goffman (1963: 15) explains, stigma is: 'an ideology to explain his inferiority and accounts for the danger he represents'.

Yet stigma is created in and varies with the social context. What is judged normal in one context may not be so in another depending on the social circumstances. For instance, depression is not considered depression in the context of bereavement. The International Pilot Study of Schizophrenia (World Health Organisation, 1973) showed that though the incidence of schizophrenia was found to be similar across different cultures, developing countries had 'significantly better clinical and social outcomes than patients in the developed world' (Janca & Saxena, 2000: 2). The improved outcome for developing countries is considered to be due to a lack of stigma associated with mental health problems in these areas.

Warner (1996) demonstrates that those working in the third world found that mental disorder does not carry the same stigma as it does in Western societies. For instance, in Dakar, Senegal, those experiencing delusion and hallucination were not rejected or stigmatised as their experiences were considered culturally relevant, and this impacted on outcome: ninety percent of the psychosis did not last. Conversely, the stigma associated with psychosis in the west carries a significant emotional burden, which may account for the ongoing problems. In contrast, a supernatural explanation consistent with eastern views means that derogatory labels (crazy or insane) are not used. In some places psychosis may even improve status.

Another contrasting view of stigma in the east is in Sri Lanka, where tuberculosis is more stigmatising than mental illness. The high level of tolerance for the symptoms of mental disorder means that people so affected have an opportunity to readjust (World Health Organisation, 1978) without the added burden of social degradation. Warner also found that people who did not experience stigma did not experience ongoing problems. The point is that stigma actually influences the outcome and the course of mental illness and has important implications for prognosis.

The experience of stigma according to Fulford [1994; 1996] is a product of the judgement involved in a psychiatric diagnosis. The process of diagnosis, according to Victoria's Chief Psychiatrist (2000: 5), 'involves a judgement about what is normal', though 'it is subject to changing social norms'. And though the Chief Psychiatrist (2000: 5) argues 'their illness is not them', Fulford recognises the role of diagnoses as value judgement at two levels. At one level, the evaluation of symptoms according to the description of symptoms in the Diagnostic and Statistical Manual in the terms of a mental disorder, is a negative judgement of symptoms. That is, to judge a condition as a mental disorder is to import a negative value.

At another level, the descriptive criteria, established according to convention by an 'evaluating community', carries the connotations of a negative judgement. Even though it is argued that the utilisation of the medical model in mental health has been an attempt to remove negative notions of badness and/or evil, this has not removed the connotations of a negative judgement. Negative connotations of descriptive terms emerge in a social context. Thus, Fulford considers diagnoses as negative value judgements with implications for the person being diagnosed. This challenges the notion of the supposedly descriptive, scientific approach of psychiatry as an objective medicine. Critics such as Szasz (2000) go so far as to argue that the evaluative nature of diagnostic criteria disqualifies mental disorders from the status of illness.

The effect of stigma was discussed by the Melbourne Consumer Consultants' Group (1997: 2) in the first chapter *Do you mind?… The Ultimate Exit Survey: Survivors of Psychiatric Services Speak Out*. Joshua identified the negativity associated with stigma as preoccupying: 'It sort of pre-empts whatever you do, even if there's actually nobody else there, it's something that's in your mind all the time' (The Melbourne Consumer Consultant's Group, 1997: 2). Marina said the negative value judgement of the diagnosis was internalised in her identity:

> You end up thinking of yourself as a less worthwhile person simply because you've got a psychiatric disability. It just colours the whole way you go about your life because you're constantly thinking of yourself as a lesser person, and not a worthy person (The Melbourne Consumer Consultant's Group, 1997: 2).

Trying to avoid admitting one's history of admission to a psychiatric ward did not reduce the sense of stigma, and to deny one's history also caused stress. For instance, Cath found herself thinking 'ooh did I let something inadvertently slip which is going to identify me' (The Melbourne Consumer Consultant's Group, 1997: 11).

The Melbourne Consumer Consultant's Group (1997) then went on to discuss how stigma added a further burden to the issues that had precipitated admission. The stigma involved in admission determined the type of treatment received and how it was delivered. That is, consumer/ survivors found that admission to an acute public psychiatric service involved being stigmatised. The consumer/survivor movement literature has highlighted the role of stigma in exacerbating the effects of 'mental illness'. This theme was present in the consumer/survivor's accounts recorded throughout Burdekin's report.

> The horrendous consequences of my illness have been a result of public attitudes of ignorance, fear, discrimination and professional indifference (Human Rights and Equal Opportunity Commission, 1993: 443).

The consequence of stigma is that people receiving services do not experience being understood but judged. One person reported: 'you wouldn't believe how many professional people don't understand the illness' (Human Rights and Equal Opportunity Commission, 1993: 440). The failure to understand people with mental health problems results in stigmatising and avoiding people, which further compounds problems. As Burdekin's report identified:

> Lack of understanding of what is happening to a mentally ill person can make up for difficult situations. Many people prefer to avoid relationships with others whose behaviour is not seen as normal. This is not good for the mentally ill person. People need social interaction to improve health (Human Rights and Equal Opportunity Commission, 1993: 444).

A consequence of the stigmatised conception of mental illness is that under the *Mental Health Act 1986* (Victoria, 1998) professionals are not required to get patients' consent in participating in treatment once admitted to an acute psychiatric service. This is regardless of the added trauma the patients themselves experience by this failure. This is not to dismiss the complexity of the problems these people face, but an attempt to embrace them. This is discussed further in chapters four and eight. The failure to consider the patient's symptoms as meaningful or to involve the patient in their own care adds to the powerlessness of the patient. A person in Barham's study says, 'You do feel terrible because there's nothing you can do …they make decisions and say, 'Well, he's out of his mind' (Barham & Haywood, 1991: 17).

Stigma as identity

The totally stigmatising experience of acute psychiatric hospitalisation has implications for the consumer/survivor's self-concept. Consumer/survivors are very aware of the social stigma that is associated with their diagnosis. This negative evaluation of people with mental illness is a central concern in the consumer/survivor discourse, literature and other fora. The stigma of diagnosis has implications for identity in terms of a person's self-conception of their status as a person.

Merinda Epstein's (Epstein & Shaw, 1997: 38-39) account of her experience as a patient highlights the centrality of the issue of identity, and the potential for damage to self-identity in the patient's experience of mental health services. Merinda (Epstein & Shaw, 1997: 38-39) stated: 'I would not survive if I succumbed to naming myself as a psychiatric patient'. She also said that 'I made a very important decision when I decided that I couldn't really afford to define myself as pathetic or as a victim, or as any other of the things that were so tempting at the time'. Merinda (Epstein & Shaw, 1997: 38-39) said that after hospital was the worst time 'I felt unclean as though the words 'been sectioned' [that is involuntarily committed] were written across my brow for everyone to read'.

Sandy Jeffs (2000: 8) states 'mental illness systemically strips you of your identity'. 'To have no identity' she states 'is to move in the shadow of others and cast none of one's own'. Conversely, mental health or wellness is 'a state of being in which I can make connections' (Jeffs, 2000: 8). Burdekin's report also identified diagnosis as a process whereby the person's identity, rights and status as an equal human being were removed. He noted that:

> Many witnesses recounted the loss of their identity once a diagnosis had been made. They felt that society only saw their label and with this they ceased to have the same needs, emotions and rights to

> make decisions about their lives (Human Rights and Equal Opportunity Commission, 1993: 445).

Thus, the stigma of mental illness was found to result in an ongoing denial of a person's identity as a person, beyond that of the occurrence of the problem itself. As one patient recounted:

> It is important to note that my illness is episodic, but the label is continuous. So, the minute your mental illness is perceived you vanish. All they see is that (Human Rights and Equal Opportunity Commission, 1993: 444).

Further stigma means that complaints about mistreatment in mental health services are not taken seriously.

> One of the worst things that can be done is to have a psychiatric label put on you... because it discredits you for the rest of your life. And people use that to discredit what you want to say, when you want to complain about abuses in psychiatric hospitals and the abuses in hospitals today (Human Rights and Equal Opportunity Commission, 1993: 444).

This theme was also apparent in Rogers and Pilgrims research (Rogers & Pilgrim, 1991a; Rogers & Pilgrim, 1991b; Rogers et al., 1993) and Barham and Hayward's (1991) research. Barham and Haywood (1991) interviewed 24 people who had schizophrenia and lived alone in Northtown, England. They explored the social side of what it is to live with schizophrenia. One of those interviewed identified the stigma of a psychiatric label as a problem as it meant being considered 'useless'. As one consumer/survivor said 'it's that feeling of being useless that bugs me more than anything, I think people brand me as useless' (Barham & Haywood, 1991: 40].

This sensitivity to how one is regarded is also revealed in *Perceval's Narrative: A Patient's Account of His Psychosis, 1830-1932* (Bateson, 1974). Perceval, in his account of his experience of 'lunacy' states:

> That many lunatics are extremely sensitive to ridicule, this sensitiveness is indeed one of the phenomena of an unsound mind and I know that many lunatics are very much pained and embarrassed by exposure under their misfortune (Bateson, 1974: 278-279).

Consumer/survivors report that what this means is that disclosure of a history of mental illness results in being made to feel 'less of a person' (Barham & Haywood, 1991: 16). Barham and Haywood (1991) found consumer/survivors experience the diagnosis of schizophrenia as an identity trap. It was not that the diagnosis was problematic, but the burden of a cultural devaluation that accompanied it, as the regard for a person as an individual was lost.

What has been indicated in this chapter, is that being diagnosed as mentally ill disrupts people's self-definition and wellbeing in two ways. Firstly the experience that had precipitated the person's distress is not considered meaningful, legitimate, or worth listening to. Secondly, a psychiatric diagnosis jeopardises a person's civic standing, civil liberties and civil rights. Even if civil liberties and rights have not formally been removed, the person experiences a failure to be respected as a person. Those who utilise services consider the failure of mental health providers to be aware of the negative impact of the way patients are treated, to indicate a serious lack of self-reflective practices (Wadsworth & Epstein, 1996b). Professionals, on the other hand, do not consider mental health patients capable of self-reflection.

Refusal to accept a diagnosis and treatment for mental illness is one of the criteria for involuntary admission in the *Mental Health Act 1986* (Victoria, 1998). This failure to recognise the need for treatment is considered by mental health professionals as a lack of insight and one of the diagnostic criteria for psychosis. Paradoxically, what Barham's (1991) study and other research such as the *Understanding and Involvement Project* identified, was that what undermined a person's sense of wellbeing was the erosion of their identity as the status of being 'mentally ill' was accepted. This is because the acceptance of a diagnosis of 'mental illness' requires renegotiating one's status as a devalued person with the world.

This conflict over need interpretation between patients and providers is central to the emergence of the consumer/survivor movement in acute mental health services. The medical profession in acute public mental health services demand that patients accept their diagnosis, which as stated above, undermines a person's sense of worth and value as a person. The power and dominance ascribed to medicine and consequently mental health services, results in the overriding of the patients' need to resist the degrading and damaging effects of being diagnosed. The failure to accommodate the patient's perspective in the professional's response to a patient's problem is paradoxically, a failure to support the patient as a person and therefore their sense of wellbeing.

The patient's experience of the medical professional's disregard of their needs, through failure to consider their perspective is demonstrated in two examples from Barham's (1991: 102) study. Sidney went to hospital and 'asked to be admitted because I was aware I was ill, I knew things weren't right with my family' [102]. He wasn't admitted but was told he was merely fantasising. The result was, 'the next day I had more or less a total breakdown' [102]. Another example is from Ben. Ben ended up in hospital again after a spell of four years. He was having trouble sleeping, which had got him into trouble before but felt that the situation could have been managed differently. 'The sleep problems come from the worry and the work …In other words, it's not just in my chemistry, it's to do with the life that I lead' [128].

Even though Ben did not think it necessary to seek mental health treatment, as all he felt he needed was a good night's sleep, he was denied being able to make a decision about his own well being. He found this created a lot more problems in getting on with people as they were 'thinking that you're mad because you've been in a mental hospital' [130]. The depression he experienced facing these kinds of difficulties was then considered further evidence of his 'illness', rather than of internalising the effects of stigma, and he was put back on sick leave. This kind of vicious cycle is intractable.

For people experiencing 'mental health problems', the identity incurred through the stigma of diagnosis with a mental illness becomes a greater problem than the original problem. People with a history of mental illness reported experiencing stigma in every aspect of their lives. For people subject to acute public mental health services, being labelled as mentally ill was reported as involving being exposed to many abuses in mental health services. These problems were then re-interpreted as illness. For example Epstein (1997: 18) says she was described in her case notes as 'manipulative' for saying what treatment she preferred.

This overview of consumer/survivor perspectives in research indicates that the stigma associated with admission and diagnosis in acute mental health services devalues the patient as a person. The imposed diagnosis undermines a person's own narrative based identity and results in a diminished sense of value and worth. A personal sense of value and worth depends to some degree on social recognition. This is discussed further in chapter eight through reference to Honneth's work. Denial of this recognition has implications for social membership, which means for consumer/survivors, social marginalisation and diminished access to resources. The marginalisation and diminished access to resources induced by stigma requires management.

Managing Stigma

Managing the burden of social stigma is a skill in itself. People with a diagnosis of schizophrenia feel that their credibility is constantly in question. The dilemma over how to manage a contradiction in their sense of self is discussed by The Melbourne Consumer Consultant's Group [1997]. They reported their credibility as being constantly on probation, and that there was a need to constantly demonstrate normality while being denied their capabilities. Even those ex-patients who are well, experience others as wary of them, because once diagnosed, credibility as a person is jeopardised. This discussion of Goffman's (1963) *Stigma* identified this as a fundamental self-contradiction. He states that the stigmatised person considers him/herself as 'no different from any other human being, while at the same time he and those around him define him as someone set apart' [132].

Goffman (1963) recognised the code to coping as a process of revealing the stigma to some and concealing it from others. Complete concealment is not acceptable; neither is accepting the negative attitudes of others. Goffman (1963) explained that the skill involved in what is expected of people with 'mental illness' is an example of a contradiction of the reputation associated with people considered to be sufferers. These codes are very important, as they provide 'recipes for an appropriate attitude regarding the self' (Goffman, 1963: 135).

> To fail to adhere to the code is to be a self deluded, misguided person; to succeed is to be both real and worthy, two spiritual qualities that combine to produce what is called authenticity (Goffman, 1963: 135).

Negotiating the complexities of when to and when not to reveal such stigma is taxing.

Goffman (1963) indicated that those who are stigmatised become 'situation conscious'. That is, become conscious of a whole array of contingencies of acceptance and disclosure. In other words, the stigmatised are aware of and conscious of the codes that those not stigmatised are unaware of. Interaction then is a very different experience for the consumer/ survivor and the professional. Both are alert to and conscious of very different social codes and cues. Goffman (1963) identified how the awareness of these social codes by the stigmatised may result in them becoming social critics of these scenes of human relationships. This has been formalised in recent times with the introduction of consumer consultants: ex-patients employed in acute public hospital wards on a part-time basis to provide a systemic evaluation of the service from the consumer/survivor perspective (Epstein & Olsen, 1999).

Goffman (1963) pointed out the stigmatised position of a person diagnosed with a mental illness constitutes the discrediting of an entire category of persons. It is the social positioning of the individual within a stigmatised group that continues to deny this group a legitimate voice as their contribution is devalued, rejected and discredited. It is not that this group do not have a valid contribution to make, but that the perspective from which they speak is denied validity. These processes as described by Goffman and consumer/survivors themselves have been identified in the consumer/ survivor movement literature. However, as Goffman (1963) and others such as Scull (1983:118-119) have discerned, the attempt to draw attention to the stigma involved, enigmatically confirms the problem, with the advocate considered an adversary to both the movement and the adversary. [3]

Humanity is denied those labelled 'mentally ill'. Goffman (1963) noted that it is up to those most stigmatised to provide evidence of their humanness. This requires providing evidence of the possession of their subjective self to others, even while this is what is constantly being denied. This paradox is continually renegotiated. Yet, the stigmatised individual needs to accept him/herself as normal to be well adjusted, while acknowledging others may not consider him/her so. The onus is put on the stigmatised person to not

---

[3] Scull (1983: 119) likens the territory to that of a combat zone between husband and wife, where those intervening receiving 'an assault from both forces simultaneously.' He states 'the best I can hope to look forward to is matching lumps on each side of my head' (Scull, 1983: 119).

present to others what would invoke their intolerance for the stigmatised. The ability to maintain this level of containment is the mark of adjustment. The irony as Goffman (1963: 148) identified it is that the demands made of the stigmatised person are not offered to back to them in return.

Thus, Goffman (1963) concluded that the stigmatised and the normal are not different persons but different perspectives, played by the same people at different times. This is highlighted by the changing capacity of an attribute to be stigmatising. That is, stigmatisation is historically located and socially changeable.

> The painfulness then of sudden stigmatisation can come not from the individual's confusion about his identity, but from his knowing too well what he has become (Goffman, 1963: 158).

To interrupt the process of stigmatisation, Goffman (1963) suggests separation from the stigmatising community. That is because a break in exposure to the normative expectations of social life facilitates disregarding the stigmatising norms of identity. Alternatively, he suggests training in maintaining impression management to strategically control the image presented. Instruction in the roles of the 'normal-deviant drama' highlights how individuals can participate in both roles at different times.

Stigma as opposition

Service providers and recipients conceptualise problems in fundamentally different ways, which explains the failure of service providers to meet needs as defined by those who use services. The consumer/survivor movement as a new social movement challenges the total domination of the medical profession in the determination of needs. This is ultimately a contest over the power to define needs, which has implications for the identity of the stakeholders. The opposition by the consumer/survivor movement to the total domination of need interpretation by medical professions is a struggle internal to the system itself.

The consumer/survivor movement research literature makes clear that established acute public mental health services do not respond to patient's accounts of problems as 'not coping with living'. Paradoxically, professional 'treatments' are reported as precipitating further problems. What the consumer/survivor research has identified is that the conceptualisation of problems in terms of 'mental illness' carries a stigma that precipitates inhumane treatment by staff: 'the heavies came and dragged me off' (McGuiness & Wadsworth, 1992: 13-14). This was found to create further problems for person's sense of self.

The stigma associated with mental health problems has created a culture of professionals avoiding interpersonal relationships with patients. For instance, patients said: 'There was not enough contact with staff—they just didn't talk to you' (McGuiness & Wadsworth, 1992: 13); 'There is no feedback from doctors and there is no human level of relationship' (McGuiness & Wadsworth, 1992: 16). Central to the consumer/survivors' accounts of professionals' style of relationship was that respect for patients' personhood was missing: 'I was not treated like a sick person but as a criminal' (McGuiness & Wadsworth, 1992: 23). The way that people are treated in mental health services indicates that patients are not treated with respect as persons. As is evident from the consumer/survivor movement literature considered here, failure to acknowledge consumer/survivor views works against a person's sense of wellbeing.

The problem that stigma has created for patients' identity is a negative feedback system about their identity as a person. One consumer/survivor said: 'It is very difficult when people don't acknowledge you' (McGuiness & Wadsworth, 1992: 39). Researchers in the *Understanding and Involvement Project* (Epstein & Wadsworth, 1994; Wadsworth & Epstein, 1996b; Wadsworth & Epstein, 1996c) and in the precursor study (McGuiness & Wadsworth, 1992) said that they were consistently told by consumer/survivors that they wished to be treated as individuals: 'I wish to be talked to as a person' (McGuiness & Wadsworth, 1992: 23); 'The main problem seems to be that… you're not treated as a person, you're treated as part of a group or you're treated as a disease' (McGuiness & Wadsworth, 1992: 54). Patients also said they didn't like being treated as a group in psychiatric hospitals and felt stripped of their identity, which was reported as taking a long time to recover (McGuiness & Wadsworth, 1992: 54).

The question is: can this fundamental difference in conceptualisation of the problem and treatment be addressed? Even though the National Mental Health Strategy has initiated changes, clearly these changes have not gone far enough. The recent consumer/ survivor movement literature indicates the consumer/survivor perspective is still not heard or responded to.

Beyond Stigma: Voicing the Madness

New social movement theory offers a framework for understanding the conflict in mental health services. Touraine (1974) states it is the absence of correspondence between the different stakeholders located in the historical field of action that generates the force for social transformation. A social movement is an attempt to intervene in the replication of a future that reflects a past of professional domination. Contestation is over the battle to create a new future: a new identity. This is only possible where many factors have intersected to recognise the constructed and political nature of identity.

Rogers and Pilgrim (1991a) question whether British mental health users would be able to establish their own discourse in the light of the interdependence of user and provider identity. Lyotard (1994) suggests the failure of a profession to address the needs of those dependants on it, reduces that perspective to one of no superior knowledge of theory or praxis over other discourses. What may overcome these limitations Lyotard (1994) suggests, is the linguistic practices, discourses, communication and critiques of survivors. As Gray & Alcoff [1993] highlight, survivor discourses are in violent confrontation with dominant conceptions. This is especially the case in the field of mental health problems (Johnstone, 1996; Johnstone, 1998).

Though the consumer/survivor movement is making a claim for the recognition of the voice and identity of patients in acute public psychiatric services, this is not what is happening in acute psychiatric services. The experience of consumer/survivors in acute psychiatric services is that personal identity is unrecognised. This denial of a patient's account or voice or story, is a denial of the legitimacy of the patient as a human being. This legitimacy is unmade through the medical practice of imposing a *diagnostic-identity*. This medicalisation also lends authority to coercive practices. This is a function of the stigma associated with diagnosis.

Thus: the consumer/survivor movement is a response to the way consumer/survivors are treated in institutionalised mental health services. Patients expect to be treated with respect as persons and not as they report being treated, impersonally, and coercively as objects. Mental health patients, who have been denied respect, are making a claim for such. The conflict is over access for people to define their own experience and to access respectful help for problems that they themselves define.

The consumer/survivor movement demands that patients be allowed to participate in defining mental health services. By claiming a voice, recipients of psychiatric services are contesting their exclusion from access to social membership and thereby cultural resources. The conflict in mental health services is over the right for social participation. Hence, the central question that emerges in this analysis of the claims consumer/survivor movement literature is to do with the status of the mental health patient as a subject. [4]

---

[4] The term 'subject' is used in a political sense, to refer to a democratic actor, attempting to make meaning out of his/her own lived experience by transforming 'events and experience into a life-project,' in Touraine's (1997: 12) terms. This is in line with new social movements' attempts to improve their participation in their own lives. It is about letting people produce

What consumer/survivor's argued they want is to be treated with respect as a person: 'I want to be treated with respect as a human being, not like how the elephant man was treated' (McGuiness & Wadsworth, 1992: 19)! And though professionals in acute psychiatric services claim this is the case, this is not what consumer/survivors experience. One consumer/survivor's experience of mental health professionals was:

> They say: 'We treat people as individuals' I'd like to know what kind of individuals they mean cause they don't treat people here like human beings (McGuiness & Wadsworth, 1992: 39).

Patients in the consumer/survivor research said that it is in the time spent listening that enables recovery of sanity. But what is reported as happening is that 'they ignore you and that's very frightening' (McGuiness & Wadsworth, 1992: 55).

What patients claimed they want is to be treated as whole persons, as self aware, thinking, feeling and needing subjects (Wadsworth & Epstein, 1996b). What might have prevented this from happening will be analysed in the next four chapters, before going on to explore what other attempts have been made to address this problem in chapter six. The last two chapters go on to explore alternatives possibilities.

---

their own history, reconciling the universalism and particularism of their own identity (Touraine, 1997).